Developing an intervention to promote shared decision making in child and youth mental health: Integrating theory, research and practice

Daniel Paul Hayes

University College London

PhD thesis submitted in fulfillment for the degree of Doctor of Philosophy in Psychology
Declaration

I, Daniel Hayes, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, this has been indicated.

Signature:
Abstract

There is growing national and international interest around the process of shared decision making (SDM) between patients and clinicians. However, research in this area specific to child and youth mental health is still in its infancy. Whilst interventions to improve SDM are being developed in this area, many of them target parents rather than the young people affected. The five studies in this thesis contribute to the understanding of SDM and the development of a theory-led, evidence-based intervention to facilitate SDM with young people, parents and clinicians.

Study 1 examined the theory, intervention functions (IFs) and behaviour change techniques (BCTs) that are being used in interventions designed to improve SDM. Across all of these studies, a lack of explicit theory was found. However, five possible IFs and fifteen BCTs that may facilitate SDM were identified. Study 2 explored predictors of SDM from the perspective of young people and parents. For young people, the severity of internalising difficulties and age were found to be predictors of gold standard SDM. For parents, both the severity of internalising and externalising difficulties, as well as ethnicity were predictors of gold standard SDM. Additionally, high levels of service variation were found in reported gold standard SDM for parents and young people.

To better understand service variation and predictors of SDM, Studies 3 and 4 explored barriers and facilitators to SDM with clinicians, young people and parents using the Theoretical Domains Framework. For clinicians, 21 barriers and facilitators across ten domains were identified, whilst for young people and parents, 16 barriers and facilitators across eight domains were discovered.

To guide intervention development, the Behaviour Change Wheel (BCW) was employed. Following this process, two decision aids (DAs) and a clinician
educational and training package were developed. Both were co-produced in conjunction with the stakeholders at whom the interventions were aimed. Study 5 describes the process of testing the intervention in a London clinic for acceptability and usefulness. For DAs, changes were made to side effects and the diagnostic language on them. Clinicians interviewed after the DAs were embedded in the clinic found them to be both useful and acceptable. However feedback on the educational and training package received a more mixed response regarding its usefulness and acceptability.
Acknowledgements

There are many people throughout my PhD journey I would like to thank. First, the individuals who took part in this research project, without whom this thesis would not have been possible. I am also indebted to University College London and the Anna Freud National Centre for Children and Families (AFNCCF) who provided me with a scholarship for this research.

Special thanks to my supervisors, Dr Nick Midgley and Dr Julian Edbrooke-Childs for their support and guidance throughout this project. Both have provided sage advice and insight, which has not only enriched this research but also has enabled me to develop as a researcher.

Thank you to the EBPU, who have allowed me to immerse myself in the ‘swampy lowlands’ of applied child and youth mental health research. I am lucky to have a Unit Director, Professor Miranda Wolpert, who supported this research by providing me with data for one empirical study as well as ample opportunities to present my findings. I am also fortunate to have had EBPU researchers and colleagues, past and present, provide me with insight and support throughout the PhD process. In this instance, special thanks go to Dr Praveetha Patalay, Dr Ana Calderon, Dr Tanya Leyera, Dr Emily Stapley and Amy MacDougall.

I also would like to thank the i-THRIVE team for allowing me to take on the lead role of developing the DAs which formed the latter part of this thesis. Dr Anna Moore, Dr Emilios Lemoniatis, Dr Rachel James, Rosa Town, and Emma Louisy-Scott have been incredibly supportive of me, and their belief, encouragement and input allowed me to produce a product of which I am proud.
Lastly, but not least, the writing of this thesis would not have been possible without the support of my friends and family. Alessandro Lirio and Steven Giddings have provided a sympathetic ear during times of crisis whilst putting things in perspective. Similarly, my family, mum (Catherine Hayes), dad (Steven Hayes), and sister (Jessica Hayes) have provided me with copious amounts of love, support and reassurance, for which I am very grateful.

Funding

This thesis presents independent research undertaken as part of an IMPACT scholarship. Funding for this research was generously provided by University College London (UCL) and AFNCCF. The views expressed in this thesis are the author’s own and may not be representative of the views of UCL or AFNCCF.
Papers and conference presentations associated with this thesis


Hayes, D., Edbrooke-Childs, J., & Midgely, N. Using the Theoretical Domains Framework (TDF) to understand factors that affect clinicians shared decision making in child and youth mental health. Oral Presentation. 9th International Shared Decision Making conference. Lyon, France. July 2017


Hayes, D., Town, R., Edbrooke-Childs, J., & Midgely, N. Behaviour Change Techniques (BCTs), Shared Decision Making and Outcomes in Child and Youth


Declaration of the PhD candidate’s role in each of the studies

Chapter 1

All work is the PhD candidate’s own.

Chapter 2

All work is the PhD candidate’s own.

Chapter 3

All work is the PhD candidate’s own.

Chapter 4

The candidate drew on the search strategy in Cheng et al. (2017) scoping review, which was co-developed by Helen Cheng (HC), the PhD candidate (DH), and Julian Edbrooke-Childs (JEC), who is the candidates supervisor. Rosa Town (RT), a researcher who is familiar with SDM, contributed to quality checking and data extraction as a second independent researcher.

Chapter 5

Data were provided by the Child Outcomes Research Consortium (CORC). The data received by the PhD candidate was previously cleaned by CORC researchers and was ready to use. Advice on mixed effects logistic regression was sought from Amy MacDougall (AMc) a statistician. The PhD candidate conducted all data analysis and interpretation.

Chapter 6

All work is the PhD candidate’s own.
Chapter 7
All work is the PhD candidate’s own.

Chapter 8
This work formed part of the i-THRIVE project. The PhD candidate was the Project Manager and was responsible for the development of the DAs and the educational and training package. Rosa Town (RT), Emilios Lemoniatis (EL) and Anna Moore (AM) and the Dartmouth Institute for Health Policy and Clinical Practice provided input into the content of the DAs. Rosa Town (RT), Emilios Lemoniatis (EL) and Anna Moore (AM) provided input into the educational and training package.

Chapter 9
This work formed part of the i-THRIVE project. The PhD candidate was the Project Manager. Funding decisions meant the design, methods for data collection, and DA format had already decided prior to the PhD candidate joining. Data collection was split between the PhD candidate (50%) and the Research Assistant (RT) (50%). Analysis and interpretation of results was undertaken by the PhD candidate.

Chapter 10
All work is the PhD candidate’s own.
# Table of Contents

**Chapter 1**  
An overview of SDM ................................................................. 26

1.1  
Introduction ............................................................................ 27

1.1.1  
Search strategy ................................................................. 27

1.2  
History, policy and developments: Moving from paternalism to SDM...28

1.2.1  
Historical context ................................................................ 28

1.2.2  
Law and policy ................................................................... 30

1.2.3  
Drivers behind the rise in SDM ........................................ 32

1.3  
Definitions and models of SDM ............................................. 35

1.3.1  
What is SDM? .................................................................. 35

1.3.2  
Models and frameworks for SDM ..................................... 38

1.4  
Shared decision making in healthcare contexts: Comparing physical  
and mental health ........................................................................ 49

1.4.1  
Capacity to be involved in decisions .................................. 49

1.4.2  
Process of decision making and types of decisions made ..........51

1.5  
Shared decision making in adult mental health – what is the evidence?  
52

1.5.1  
Decision aids ................................................................... 53

1.5.2  
Mobilising patients to engage .......................................... 57

1.5.3  
Models and therapeutic approaches .................................... 59
1.5.4 Discussion prompts ........................................................................................................60
1.5.5 Summary of the evidence for SDM in mental health ..............................................60

1.6 Conclusion .......................................................................................................................62

Chapter 2 Shared decision making with children and young people .... 65
2.1 Introduction .....................................................................................................................66
  2.1.1 Search strategy ........................................................................................................66

2.2 History, policy and developments: Moving from paternalism to SDM with young people .................................................................................................................67
  2.2.1 Historical context .....................................................................................................67
  2.2.2 Law and policy related to SDM ..............................................................................70
  2.2.3 Drivers behind the rise in SDM for children and young people .........................73

2.3 Critical considerations of including young people in care and treatment decisions .........................................................................................................................74
  2.3.1 Capacity of young people to be involved in decisions..........................................75
  2.3.2 The role of the young person’s family in SDM .....................................................79

2.4 Models and frameworks for facilitating SDM in child and youth mental health 81
  2.4.1 Crickard, O’Brien, Rapp and Holmes (2010): SDM for psychotropic medication.........................................................................................................................82
  2.4.2 Simmons, Rice, Hetrick, Bailey and Parker (2012): SDM steps in child and youth mental health ........................................................................................................83
2.4.3 Westermann, Verheij, Winkens, Verhulst and Van Oort (2013): Counselling in Dialogue ..........................................................86

2.4.4 Wolpert et al. (2014): SDM in Child and Adolescent Mental Health Services (CAMHS) ..................................................................................87

2.4.5 Langer and Jensen-Doss (2016): SDM in youth psychotherapy ..........88

2.4.6 Common Room Consulting (2017): The ‘Open Talk’ model ............90

2.4.7 Comparing different models of SDM ............................................91

2.4.8 Summary ......................................................................................97

2.5 Shared decision making in child and youth mental health: What is the evidence? .................................................................98

2.5.1 Decision aids ...............................................................................99

2.5.2 Mobilising young people and parents to engage .........................103

2.5.3 Models or therapeutic approaches ..............................................104

2.5.4 Discussion prompts ..................................................................104

2.5.5 Psychoeducational information intended to facilitate SDM ..........105

2.5.6 Action Planning and goal setting to facilitate SDM ....................106

2.5.7 Summary of interventions .........................................................107

2.6 Barriers and facilitators to including young people in care .............108

2.7 Conclusion ....................................................................................110

Chapter 3 Intervention development and thesis methodology .............114

3.1 Introduction ..................................................................................115
3.2 Developing an intervention ................................................................. 116

3.3 Use of theory in SDM interventions ....................................................... 118

3.3.1 SDM theories: A closer examination ............................................. 119

3.4 The BCW ........................................................................................... 127

3.4.1 Behaviour Change Techniques ...................................................... 130

3.4.2 Research on IFs .............................................................................. 132

3.4.3 Critical evaluation of the BCW ...................................................... 132

3.4.4 Summary ....................................................................................... 134

3.5 A working definition of SDM in child and youth mental health .......... 135

3.6 Methodology ...................................................................................... 138

3.6.1 Study 1 (Chapter 4) ................................................................. 139

3.6.2 Study 2 (Chapter 5) ................................................................. 139

3.6.3 Studies 3 and 4 (Chapter 6 and 7) .............................................. 140

3.6.4 Study 5 (Chapter 9) ................................................................. 141

3.7 Research paradigms in this thesis ...................................................... 142

Chapter 4 A systematic review of SDM interventions in child and youth mental health: Theories, IFs and BCTs ................................................................. 144

4.1 Introduction ....................................................................................... 145

4.1.1 Aims of the present research ...................................................... 146

4.1.2 Research questions ................................................................. 146
4.2 Method ................................................................................................................. 147

4.2.1 Protocol and registration .................................................................................. 147

4.2.2 Eligibility criteria and rationale ........................................................................ 147

4.2.3 Information sources and search ........................................................................ 148

4.2.4 Study selection .................................................................................................... 149

4.2.5 Data collection process ...................................................................................... 149

4.2.6 Risk of bias within studies ................................................................................ 151

4.2.7 Ethical approval .................................................................................................. 151

4.3 Results .................................................................................................................. 153

4.3.1 Modality of SDM interventions ......................................................................... 153

4.3.2 Behaviour Change Techniques used in SDM interventions .............................. 154

4.3.3 Intervention functions used in SDM interventions ............................................ 161

4.3.4 The theory used in interventions to facilitate SDM in child and youth health 161

4.3.5 Relationships between IFs, BCTs and Process and Outcome Measures 162

4.3.6 Exploring relationships between BCTs, IFs and process and outcome measures across interventions ................................................................. 166

4.3.7 Quality assessment for risk of bias ................................................................. 169

4.4 Discussion ............................................................................................................ 170

4.4.1 Use of theory in interventions ......................................................................... 171

15
5.4.2 Conclusions and clinical implications .............................................. 203

Chapter 6 Barriers and facilitators to SDM in child and youth mental health: A qualitative study with clinicians .................................................. 205

6.1 Introduction ..................................................................................... 206

6.1.1 Aims of the present study ............................................................. 207

6.1.2 Research question ....................................................................... 207

6.2 Methods ............................................................................................ 208

6.2.1 Setting of the study .................................................................... 208

6.2.2 Recruitment ............................................................................... 208

6.2.3 Participants ............................................................................... 208

6.2.4 Procedure ................................................................................. 209

6.2.5 Data analysis ............................................................................. 210

6.2.6 Ethical considerations ................................................................. 214

6.2.7 Trustworthiness of the research findings ..................................... 214

6.3 Results ............................................................................................. 216

6.3.1 Capability .................................................................................. 219

6.3.2 Opportunity ............................................................................... 227

6.3.3 Motivation ................................................................................. 233

6.4 Discussion ....................................................................................... 241

6.4.1 ‘Behavioural diagnosis’ ............................................................... 241
### 6.4.2 Situating the findings within the literature ........................................ 244

### 6.4.3 Strengths and limitations ................................................................. 247

### 6.4.4 Reflexivity ......................................................................................... 249

### 6.4.5 Conclusion ......................................................................................... 251

### Chapter 7 Barriers and facilitators to SDM in child and youth mental health: A qualitative study with young people and their parents .......... 253

#### 7.1 Introduction ....................................................................................... 254

- **7.1.1 Aims of the present study .............................................................. 256**

- **7.1.2 Research question ........................................................................ 256**

#### 7.2 Methods ............................................................................................ 256

- **7.2.1 Recruitment ................................................................................... 256**

- **7.2.2 Participants ................................................................................... 257**

- **7.2.3 Procedure .................................................................................... 257**

- **7.2.4 Data analysis ................................................................................ 259**

- **7.2.5 Ethical considerations .................................................................. 259**

- **7.2.6 Trustworthiness of the findings .................................................. 259**

#### 7.3 Results .............................................................................................. 260

- **7.3.1 Capability ..................................................................................... 262**

- **7.3.2 Opportunity .................................................................................. 267**

- **7.3.3 Motivation ..................................................................................... 273**
7.4 Discussion ..................................................................................................................280

7.4.1 ‘Behavioural diagnosis’ .........................................................................................280

7.4.2 Situating findings within the literature .................................................................282

7.4.3 Strengths and limitations .......................................................................................289

7.4.4 Reflexivity ..............................................................................................................291

7.4.5 Conclusion .............................................................................................................293

Chapter 8 Developing an intervention to facilitate SDM in child and youth mental health .................................................................................................................. 295

8.1 Introduction ..............................................................................................................296

8.1.1 Aims of the present chapter ..................................................................................298

8.2 Developing the intervention to facilitate SDM in child and youth mental health 298

8.2.1 Change of sites ......................................................................................................298

8.2.2 Selecting IFs (Step 1) ..........................................................................................298

8.2.3 Applying IFs to the identified barriers and facilitators (Step 2) .........................301

8.2.4 Selecting BCTs and approaches (Step 3) ............................................................302

8.3 The inclusion of THRIVE and i-THRIVE ..............................................................306

8.3.1 THRIVE and i-THRIVE ......................................................................................306

8.3.2 The i-THRIVE team for improving SDM ............................................................308

8.4 Specific considerations for the DA as well as the educational and training package ..................................................................................................................308
8.4.1 What is the target age for the DA? ................................................................. 308
8.4.2 Should the DA be designed for specific presenting difficulties, and if so, which ones? .................................................................................................................. 309
8.4.3 How should the DA be designed? .................................................................. 310
8.4.4 How should the joint educational and training package be structured? .. 311

8.5 Developing the intervention content ................................................................. 314
8.5.1 The DA ........................................................................................................... 314
8.5.2 The educational and training package ............................................................ 322

8.6 Discussion ......................................................................................................... 324
8.6.1 Conclusion ..................................................................................................... 327

Chapter 9 Testing of the DAs and educational and training package to facilitate SDM in child and youth mental health ................................................. 328

9.1 Introduction ........................................................................................................ 329
9.1.1 Aims .............................................................................................................. 329
9.1.2 Research questions ......................................................................................... 329

9.2 Methods ............................................................................................................. 330
9.2.1 Setting .......................................................................................................... 330
9.2.2 Participants .................................................................................................. 330
9.2.3 Procedure .................................................................................................... 330
9.2.4 Ethical considerations .................................................................................. 332
9.2.5 Analysis ........................................................................................................ 332
9.3 Results........................................................................................................333

9.3.1 Refining the DAs using the PDSA cycles ............................................333

9.3.2 Interviews to explore the usefulness and acceptability of the DAs ....339

9.3.3 Examining feedback from clinicians on the educational and training
package .............................................................................................................346

9.4 Discussion ..................................................................................................348

9.4.1 Strengths and limitations .................................................................350

9.4.2 Conclusion ...........................................................................................353

Chapter 10 General Discussion ................................................................. 355

10.1 Introduction ..............................................................................................356

10.2 Chapter summaries and exploration of their contribution to knowledge
about SDM .........................................................................................................356

10.3 Strengths and limitations of these studies ..............................................368

10.3.1 Limitations ..........................................................................................368

10.3.2 Strengths .............................................................................................369

10.4 Revisiting the working model of SDM for child and youth mental health
370

10.5 Reflection ..................................................................................................376

10.6 Implications ..............................................................................................377

10.7 Future directions .........................................................................................380

10.8 Overall conclusion ....................................................................................382
### Table of Tables

Table 1-1: Towle and Godolphin’s model .......................................................... 39

Table 1-2: The Elywn et al. (1999) model .......................................................... 43

Table 1-3: Makoul and Clayman’s (2006) model ............................................. 45

Table 2-1 SDM models in child and youth mental health compared with Makoul and Clayman’s (2006) essential elements ................................................. 94

Table 3-1: A working model of SDM in child and youth mental health .......... 136

Table 4-1 An outline of eligibility criteria for this review and the rationale for each point ............................................................................................................. 147

Table 4-2 Characteristics of interventions included in the final review ........ 155

Table 4-3 EPHPP Quality Assessment Method (Thomas et al., 2004) for risk of bias .............................................................................................................. 160

Table 4-4. Intervention functions present and whether the study findings indicated an increase in SDM ................................................................. 163

Table 4-5. Behaviour change techniques present in studies and whether the study found increased SDM ................................................................. 164

Table 5-1 Characteristics of young people in the sample who reported on experiences of SDM ..................................................................................... 184

Table 5-2 Characteristics of children in the sample whose parents reported on experiences of SDM ............................................................................. 185
Table 5-3 Correlation matrix for predictor variables included in young person-reported experiences of SDM ................................................................. 191

Table 5-4 Correlation matrix for predictor variables included in parent-reported experiences of SDM .................................................................................. 191

Table 5-5 Mixed effect logistic regressions with demographic and case characteristics predicting young-person-reported experiences of SDM ........ 193

Table 5-6 Mixed effect logistic regressions with demographic and case characteristics predicting parent-reported experiences of SDM .......... 194

Table 6-1: Clinician barriers and facilitators to SDM using the TDF (Cane et al., 2012) ................................................................................................. 217

Table 7-1: Parental and young person barriers and facilitators to SDM using the TDF (Cane et al., 2012) ................................................................. 261

Table 8-1 APEASE criteria (Michie et al., 2014) ............................................. 299

Table 8-2 IFs aimed at increasing SDM .......................................................... 301

Table 8-3 Breakdown of the proposed intervention into IFs and their component parts ................................................................................................. 304
Table of Figures

Figure 1-1: The SDM continuum................................................................. 36

Figure 3-1 MRC guidelines for developing and evaluating complex interventions (Craig et al., 2008)................................................................. 116

Figure 4-1 Search flowchart........................................................................ 152

Figure 8-1 A logic model outlining the proposed intervention for SDM........ 305

Figure 8-2 The THRIVE conceptual framework (Wolpert, Harris et al., 2016) 307

Figure 8-3 Description of the DA ERGs and editorial team ......................... 314

Figure 8-4 Early example of a mock-up DA................................................ 317

Figure 8-5 Decision aid for depression/low mood ‘inside the NHS’ version 1 320

Figure 8-6 Decision for depression/low mood, ‘outside the NHS’ version 1 ... 321

Figure 8-7 Outline of the ERG and the editorial team for the training and educational package................................................................. 322

Figure 9-1 Decision aid for low mood, ‘inside the NHS’, after the final PDSA cycle......................................................................................... 337

Figure 9-2 Decision aid for low mood, ‘outside the NHS’, after the final PDSA cycle......................................................................................... 338
Abbreviations

AFNCCF – Anna Freud National Centre for Children and Families

BCT – Behaviour Change Technique

BCW – Behaviour Change Wheel

CYP IAPT – Children and Young People’s Improving Access to Psychological Therapies Programme

CORC – Child Outcomes Research Consortium

DA – Decision Aid

EBPU – Evidence Based Practice Unit

ERG – Expert Reference Group

IF – Intervention Function

MIP – Medication Integration Protocol

QPL – Question Prompt List

RCT – Randomised Control Trial

SDM – Shared Decision Making

SDQ – Strengths and Difficulties Questionnaire

TDF – Theoretical Domains Framework

US – United States

UK – United Kingdom
Chapter 1 An overview of SDM
1.1 Introduction

This chapter provides an overview of SDM in healthcare. It begins by outlining early contributions from researchers and exploring how these have influenced existing policy. It then examines what is meant by the term ‘SDM’, and explores the prominent models which have been developed. Following this, the application of SDM to healthcare is reviewed with a focus on the differences between adult physical and mental health. Finally, this chapter concludes with a review of the evidence related to SDM in adult mental health.

1.1.1 Search strategy

The search strategy for this chapter covered two concepts: shared decision making and mental health. The first concept was investigated using the following terms: shared decision making, decision aids, self determination, client choice, informed choice, patient choice, client participation, decision-aids, client/patient centred care, therapeutic alliance, collaborative practice, recovery oriented care, shared care, user empowerment, shared agreements, goals, value oriented care, and personalisation/personalization. The second concept was investigated using the following terms: mental health (the term ‘mental health’ as well as individual diagnoses), mental illness, mental disorder, chronic mental illness, community mental health, community mental health centers/centres, and community mental health services. These key terms were combined (see syntax below) and six research databases were searched (PsycINFO, EMBASE, Medline, PubMed, Web of Science and Cochrane Libraries) until Jan 2018.

The syntax for the search was as follows: (“Shared decision making” OR “Decision aid**” OR “Self determination” OR “Client choice” OR “Informed choice” OR “Patient choice” OR “Client participation” OR Decision-aids OR (“Client cent* care” OR “patient cent* care”) OR “Therapeutic alliance” OR...
“Collaborative practice” OR “Recovery oriented care” OR “Shared care” OR “User empowerment” OR “Shared agreements” OR “Common goals” OR “Value oriented care” OR “Personalisation).

AND (“Mental health” OR “Mental illness” OR “Mental disorder*” OR “Chronic mental illness” OR “Community mental health” OR “Community mental health cent*” OR “Community mental health service*” OR “Primary mental health prevention” OR “Anxiety disorder*” OR “Anxiety management” OR “Emotional problem*” OR “Emotional adjustment” OR “Affective disorder*” OR “Behaviour disorders” OR “Behaviour problem*” OR “Affective disorder*” OR “child psychopathology*” OR Psychosis OR (Neurosis or neuroses) OR “Cognitive behaviour therapy” OR depression OR Psychology OR Therapy OR Counselling).

1.2 History, policy and developments: Moving from paternalism to SDM

1.2.1 Historical context

The concept of the clinician as the expert in diagnosis and treatment has been at the heart of healthcare for most of history (Komrad, 1983). Examples of this paternalistic style date back as far as Hippocrates. In fact, it is enshrined in the Hippocratic Oath, which emphasises the clinician’s role as that of possessing knowledge and doing everything within one’s power to ‘benefit the sick patient…using all methods required’ (Dong, 2011, pp. 5–6). More recent historical records show that this style of thinking and working remained prevalent throughout the 19th century, and official medical bodies stipulated that clinicians should not seek input from their patients (American Medical Association, 1848).

Over the last 60 years, however, there has been a gradual shift towards the inclusion of patients in healthcare decisions. The earliest cited example was by Szasz and Hollender (1956), who suggested three models of the patient-
clinician relationship: active passivity, guidance-cooperation and mutual participation. The first two approaches rely on a paternalistic, ‘parent-like’ approach in which the clinician advises on, or performs actions, such as tests or treatment, on the patient (Szasz & Hollender, 1956). Conversely, ‘mutual participation’ involved the clinician working alongside the patient (Szasz & Hollender, 1956). The clinical application for each model was also posited to be different. Active passivity was regarded as useful for anaesthesia and delirium, guidance-cooperation for acute infections, and mutual participation for chronic illness and psychoanalysis (Szasz & Hollender, 1956).

Balint’s (1957) work on doctor-patient relationships also contributed to the evolution of patient involvement. He examined the emotional relationship between patients and clinicians and found that there was a need for the clinician to engage in ‘active listening’ in order to understand the patient’s perspective. A further contribution was the identification of the need to gather information outside of the biomedical model in order to assist and address patient concerns (Balint, 1957). This move towards ‘illness-centred care’ contributed to the gradual shift of the role of the patient from the passive outskirts of care and treatment to a more centralised position (Deegan & Drake, 2006).

The development of the biopsychosocial approach (Engel, 1977) helped to advance the role of the patient further with regard to treatment and care planning. Within this approach, the clinician was not only required to assess the biological aspects of illness, such as chemical imbalances, but also needed to acknowledge the psychological components such as how the patient felt, along with the social and cultural components (Engel, 1977). Through this process, clinicians were able to construct the illness narrative with the patient in order to arrive at the correct diagnosis and treatment plan (Borrell-Carrió, Suchman, & Epstein, 2004). The psychological and social aspects of illness, which are
subjective to the patient, were particularly important to informing the plan as treatment proceeded (Scambler, 2008).

Ultimately, the movement away from paternalism and the focus on patient involvement led to the coining of the term, ‘informed consent’ in the 1950s’ (Faden, Beauchamp, & King, 1986; Hall, Prochazka, & Fink, 2012). This is the process by which a patient obtains information about their illness and treatment plan which enables them to make a decision about whether to proceed with treatment (Jones, McCullough, & Richman, 2005). Whilst clinicians were still considered to be experts in diagnosing patients and drawing up treatment plans, the patient could, in most circumstances, choose to reject treatment if they did not agree with the diagnosis or course of action (Langer, Mooney, & Wills, 2015). As patients now had the right to request more information from healthcare professionals and could overtly refuse treatment, the concept of the ‘empowered patient’ came into existence (Langer et al., 2015).

1.2.2 Law and policy

A study that formed part of the 1982 United States (US) President’s Commission Report on patient involvement found that 56% of clinicians and 64% of patients felt that increasing patient involvement would improve the quality of care (President’s Commission for the Study of Ethical Problems in Medicine Biomedical & Behavioral Research, 1982). This report recommended SDM as an appropriate ideal for patient–professional relationships, and stated that these relationships should be supported by the doctrine of informed consent (Abram, Ballantine, & Punlop, 1982).

However, the President’s Commission Report (1982) also noted that although SDM was not appropriate for all cases, care should be taken that it was not limited to use with only well-educated, articulate and self-aware individuals. The report recommended that those who were incapacitated should still be
consulted and included. However, it also stated that families and clinicians could play a more active role when the patient decided on an option that was not in their own best interests. Barriers to achieving patient involvement and SDM were also outlined in this report. These included clinicians’ attitudes, complex rather than simple language, and the increasing complexity of medicine. Nonetheless, the President’s Commission Report (1982) concluded that informed consent and SDM should be “a measuring stick…to which all participants in healthcare decision making can strive” (p. 6).

Subsequently, an article by Eddy discussed the idea of including patients in choosing their treatment (1990). Central to this proposition was that treatment should only be considered 'standard' if there was 'virtual unanimity among patients about the overall desirability... of the outcomes’ (Eddy, 1990, p. 3081). As desirability of outcomes is, in most cases, idiosyncratic to the patient, patients need to be involved in developing a management strategy consistent with their own preferences. In this proposition, the clinician’s role is to help the patient make decisions while exploring possible treatments in light of outcomes and preferences, rather than advocating for the specific option that they think may be best (Eddy, 1990).

The 1998 Salzburg Global Seminar *Through the Patient’s Eyes* (Billingham, 1998) brought SDM to the forefront of healthcare. It posited that significant improvements could be made in healthcare if patients became equal partners in their care and treatment (Delbanco et al., 2001). With the coining of the term, ‘nothing about me, without me’, the message was that illness and treatment needed to be understood through the experience and needs of the patient (Barry & Edgman-Levitan, 2012). Whilst this concept was not new, this was the first time that international experts had collaborated in outlining how healthcare should look and to begin formulating how to implement SDM on a larger scale.
Over the last 20 years, there has been a rapid rise in the number of publications on SDM (Makoul & Clayman, 2006). Internationally, patient involvement in care and treatment has become the focus of research and policy in many countries, such as Australia (McCaffery et al., 2011), Chile (Bravo, Cabises, Bustamante, Campos, & Stacey, 2011), Israel (Miron-Shatz, Golan, Brezis, Siegal, & Doniger, 2011), Germany (Härter et al., 2011) and the Netherlands (van der Weijden et al., 2011). In the United Kingdom, the involvement of patients in care and treatment is now a cornerstone of healthcare policy, with the terms ‘SDM’ and ‘no decision about me, without me’ featuring in government reports such as ‘Equity and Excellence: Liberating the NHS’ (Department of Health, 2010) and in the Health and Care Social Act (2012 sections 23 and 26). Moreover, think tanks such as the King’s Fund and charities such as the Health Foundation further endorse the practice of SDM (Coulter & Collins, 2011; Da Silva, 2012, 2014).

1.2.3 Drivers behind the rise in SDM

The increasing emphasis placed on SDM both politically and clinically has been justified by two different approaches. These are the ethical and clinical imperatives for SDM (Coulter & Collins, 2011; Slade, 2017). However, a third driver may also be related to resources and cost (Coulter & Collins, 2011).

1.2.3.1 The ethical imperative for SDM

Many scholars have argued that SDM should occur as it is an essential human right (Coulter & Collins, 2011; Slade, 2017). This argument asserts that patients have the right to have their autonomy respected, that is, both the right to be informed about and involved in decisions that affect them (Coulter, 2017).

Legally, these views may be supported. The Human Rights Act (1998), under which all public bodies, including healthcare providers, must operate, contains a
number of articles which can be interpreted in relation to decision making between healthcare professionals and patients (Haggett, 2001). For example, Article 3, which states that ‘No one shall be subjected to torture or to inhuman or degrading treatment or punishment’, could be viewed in the context of treatment decisions. Withholding treatment from a patient who requests it, or alternatively forcing treatment on a patient who does not consent to it, may violate Article 3. Indeed, this has been supported by the European Court in the case of Herczegfalvy v Austria (Herczegfalvy v Austria, 1993), in which a mentally ill patient was forcibly administered food without his permission. However, United Kingdom (UK) law allows other individuals to act in their ‘best interests’ when the patient lacks capacity (Committee on Medical Ethics, 2000).

A number of other factors related to moral and ethical perspectives can also be attributed to the rise of SDM. From the late 1960s, the civil rights movement, the second wave of feminism, the disability rights movements, and greater public awareness of medical experimentation undertaken without consent all contributed to the advocation of greater autonomy over decisions related to an individual’s body, life and liberty (Igel & Lerner, 2016). Other influences, such as the move away from inpatient care towards more community-based services for mental health patients, and the development of technology providing individuals with more access to information (Morrison & Starks, 2014), may also have contributed to the rise of SDM and patient empowerment.

1.2.3.2 The clinical imperative for SDM

Another contributor to the rise of SDM may have been the greater emphasis placed upon evidence-based practice. Beginning in the early 1990s, this movement shifted treatment approaches from relying on clinical experience to a process which incorporated research evidence as well as patient values and preferences (McKibbon, 1998). As this shift valued other elements in addition to
clinical expertise, it may have helped to expand the possibilities of meaningful patient involvement within the clinical encounter. It has been posited that when used correctly, SDM may be a vehicle that strengthens evidence-based practice by incorporating all elements of evidence into the clinical session (Barratt, 2008).

Shared decision making may also lead to improved clinical outcomes, as patients have better adherence to and engagement with the treatment they are receiving if it is congruent with their values and preferences (Coulter & Collins, 2011; Slade, 2017). This is particularly important when it is the patient’s responsibility to begin or continue treatment outside of the clinical setting (Priebe, 2017; Wagner, Austin, & Von, 1996). Findings regarding improved clinical outcomes have been mixed, however, with two recent reviews suggesting that SDM was associated with at least one positive outcome in around half the studies examined (Clayman, Bylund, Chewning, & Makoul, 2016; Shay & Lafata, 2015).

1.2.3.3 Service and cost savings

As clinical outcomes suggest a mixed picture that is composed of virtually no documented negative effects and the potential for positive effects, SDM may seem attractive to commissioners and service leads who are trying to ensure care is appropriately, equitably and efficiently distributed (Coulter & Collins, 2011). Shared decision making has the potential to reduce service variation as it ensures that it is not only the clinicians who are responsible for administering a specific treatment (Andersen, Mooney, & McPherson, 1990; Wennberg & Gittelsohn, 1975). It may also help commissioners understand which services patients want to use and which ones they do not (Coulter & Collins, 2011). There is some theoretical and empirical support for reductions in service variation and potential cost savings due to SDM. A cost analysis carried out in
the US suggested that incorporating the use of DAs in treatment options in 11 health conditions would lead to approximately £9.2 billion in savings over a 10 year period, as patients chose less expensive or invasive options (The Lewin Group, 2008). Empirically, the Healthcare Group in Washington reported reduced costs of up to 21% in six months, as fewer surgeries were taking place when DAs were used (Arterburn et al., 2012). However, a review of DAs and cost effectiveness suggests inconclusive results from the seven incorporated studies (Walsh et al., 2014).

A further potential cost saving related to SDM may be reduced litigation against clinicians by patients. A lack of communication with patients around treatment risks and side effects, as well as clinicians’ failure to answer patients’ questions, appear to be predictors of negligence claims (Levinson, Roter, Mullooly, Dull, & Frankel, 1997). Thus, SDM, with its emphasis on communicating and sharing information about care and treatment with patients, could help to combat such claims by taking the onus off physicians in terms of liability (King & Moulton, 2006). A review of the literature around litigation and SDM found a lack of evidence within the included studies and was unable to form any firm conclusions (Durand, Moulton, Cockle, Mann, & Elwyn, 2015). However, the review included simulated scenarios that suggested that failure to communicate did increase the perceived risk of litigation.

1.3 Definitions and models of SDM

1.3.1 What is SDM?

Shared decision making in healthcare is still relatively loosely defined in conceptual terms (Charles, Gafni, & Whelan, 1997; Makoul & Clayman, 2006). This has led to multiple definitions, and many still question what is specifically being described and measured in SDM (Moumjid, Gafni, Bremond, & Carrere,
There is a general consensus that SDM lies on a continuum between consumer choice and paternalism (Charles et al., 1997; Charles, Gafni, & Whelan, 1999; Elwyn, Edwards, Gwyn, & Grol, 1999). This is illustrated in Figure 1-1 below.

Figure 1-1: The SDM continuum

Paternalism, or clinician choice, indicates that a healthcare professional should have sole responsibility for a patient's healthcare and treatment (Sandman & Munthe, 2010). This has been the dominant model within healthcare for much of history (Komrad, 1983). Central to this idea is that the clinician makes a decision with the intention of 'doing good' or 'avoiding harm' to the patient, and that the decision can be made without consent, or in some instances even when it is against the patient’s wishes (Beauchamp & Childress, 2001). Within this paradigm, emphasis is placed on the clinician’s professional expertise, scientific knowledge and duty of care which ‘authorise’ the clinician to make decisions (Da Silva, 2012; Sandman & Munthe, 2010). Patient factors, including lived experience, values and preferences, are not taken into account, as paternalism assumes that patients lack the knowledge or capacity to make decisions (Da Silva, 2012; Sandman & Munthe, 2010). It is argued that there are a few exceptions within which paternalism in healthcare is ethically appropriate (Kopelman, 2004). This includes situations in which the patient is truly incapacitated and lacks the insight to make a decision, when the patient
may do harm to others, or when the patient’s behaviour or responses are deemed out-of-character at that time and a paternalistic stance is necessary to understand whether the patient’s decisions are autonomous and informed.

Conversely, informed choice (or consumer choice) indicates that patients are responsible for and held accountable for all decisions made within the healthcare context (Sandman & Munthe, 2010). According to this approach, patients are seen as having the capacity to make rational choices between their healthcare and treatment options, provided that they possess the necessary information (Da Silva, 2012; Sandman & Munthe, 2010). However, for a patient to take on this role, the clinician needs to act as a facilitator by using their specialist medical knowledge to outline the necessary information regarding treatment options (Da Silva, 2012; Sandman & Munthe, 2010). It is noted by some that clinicians may still retain overarching control, as they may choose to present only the options which they deem to be appropriate or consistent with their healthcare provider’s offer (Sandman & Munthe, 2010). This, the authors argue, differs from a ‘free market’ model where all options would be outlined (Sandman & Munthe, 2010).

Accordingly, SDM lies between the two constructs of paternalism and informed choice. Central to this premise is that SDM should involve communication between the clinician and the patient that emphasises the roles both parties have in care and treatment (Coulter & Collins, 2011; Da Silva, 2012). The clinician brings their medical knowledge and clinical experience from training and practice to the encounter, whilst the patient brings a lived knowledge of their illness, their self and what would fit with their lifestyle (Coulter, 2009). Conversations may be around (but not limited to) tests for screening, undergoing procedures, participating in self-help or psychological interventions, whether or not to take medication and whether to make lifestyle changes (Coulter & Collins, 2011). Elaborating on how this may be realised in practice
requires a closer inspection of the individual models of SDM.

1.3.2 Models and frameworks for SDM

There are many models for SDM in healthcare, however, four models are prominent within the literature. Three are outlined by Makoul and Clayman (2006), who found in a systematic review of conceptualisations of SDM that they constituted almost 50% of the citations in this field. The fourth one is Makoul and Clayman’s (2006) own model. These are outlined below with a focus on the similarities and differences in their underlying constructs.

1.3.2.1 Charles, Gafni and Wheelan’s model(s)

The earliest model of SDM, which was developed by Charles et al. (1997), examines SDM through the physician-patient encounter. The authors drafted their own model focusing on three characteristics: information exchange, deliberation and deciding on a treatment plan (Charles et al., 1997). For the decision to be shared rather than guided by paternalism or informed choice, the patient and clinician must share information, deliberate together, and conclude by making a jointly agreed decision (Charles et al., 1997).

This model was subsequently updated with the recognition of a need for a more dynamic and complex approach to SDM (Charles et al., 1999). Information exchange was expanded to include flow, direction, type and style. In this model, SDM consists of a two-way flow of information in both directions. The type of information exchanged focuses on both medical and personal information, whilst the amount of information exchanged is dependent on the decision in question (Charles et al., 1999). New aspects of this model delineated that involvement may differ over time – both within and between consultations. Sometimes the patient may take more of a lead depending on their expertise, whilst at other times the clinician will take the lead (Charles et al., 1999).
Although the updated model by Charles et al. (1999) describes a more dynamic and complex relationship than their original model, it has received criticism. Wirtz, Cribb and Barber (2006) note there is no mention of who develops the list of possible choices from which to choose, nor any outline of accountability for the patient or clinician. Kaminskiy (2014) states that this model suggests a decision is only shared if a joint decision is agreed upon, regardless of whether there was any collaboration beforehand. Additionally, the model does not elaborate on how a partnership may work in a clinical setting, nor how to appropriately address power imbalances (Kaminskiy, 2014).

1.3.2.2 Towle and Godolphin’s model

An alternative model, which examines SDM in light of competencies, has been suggested by Towle and Godolphin (1999). Following a review of the literature and semi-structured interviews with clinicians and patients, Towle and Godolphin (1999) propose eight competencies required by clinicians, as well as seven competencies needed by patients, in order to engage in SDM. These are outlined in Table 1-1 below (Towle & Godolphin, 1999)

Table 1-1: Towle and Godolphin’s model

<table>
<thead>
<tr>
<th>Physician competencies</th>
<th>Patient competencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Develop a partnership with the patient.</td>
<td>1. Define (for oneself) the doctor-patient relationship.</td>
</tr>
<tr>
<td>2. Establish or review the patient’s preferences for information (such as amount or format).</td>
<td>2. Find a physician and establish, develop and adapt a partnership.</td>
</tr>
<tr>
<td>3. Establish or review the patient’s preferences for their role in decision making (such as risk taking and degree of involvement of self and others) and the existence and nature of any uncertainty about the course of action to take.</td>
<td>3. Articulate (for oneself) health problems, feelings, beliefs, and expectations in an objective systematic manner.</td>
</tr>
<tr>
<td>4.</td>
<td>Ascertain and respond to patient’s ideas, concerns, and expectations (such as disease management options).</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>5.</td>
<td>Identify choices (including ideas and information that the patient may have) and evaluate the research evidence in relation to the individual patient.</td>
</tr>
<tr>
<td>6.</td>
<td>Present (or direct patient to) evidence, taking into account Competencies 2 and 3, and framing effects. Help the patient to reflect on and assess the impact of alternative decisions with regard to his or her values and lifestyle.</td>
</tr>
<tr>
<td>7.</td>
<td>Make or negotiate a decision in partnership with the patient and resolve conflict.</td>
</tr>
<tr>
<td>8.</td>
<td>Agree on an action plan and complete arrangements for follow up. Informed SDM may also: a. Involve a team of health professionals. b. Involve others (partners, family). c. Differ across cultural, social, and age group.</td>
</tr>
</tbody>
</table>

A model based on competencies allows for the specification of the skills that are needed for SDM to occur in clinical practice. This focus on competencies contrasts with previous models (Charles et al., 1997, 1999), which focused more on the process of SDM. Moreover, breaking down competencies by stakeholder allows for a better understanding of the skills needed by each party if SDM is to be successful.

A focus on patient competencies highlights the importance of the patient’s sense of agency from the beginning of the decision-making process. Towle and Godolphin (1999) state that the patient is responsible for defining the
relationship; finding a clinician; and establishing, developing and adapting a partnership. This may help to create a more equal partnership and increase patient empowerment. A further strength of this approach is that it allows for the patient to outline their health difficulties within their own terms using language that they understand and with which they feel comfortable, which the clinician needs to take into account (see Competency 6). This allows for a conversation containing less jargon, which is a noted barrier to including patients in their own care (Joseph-Williams, Elwyn, & Edwards, 2013).

In relation to clinician competencies, this model highlights the need to present evidence in a non-biased way and to acknowledge that the way in which this is performed may affect the outcome. A subsequent study by Towle, Godolphin, Grams and Lamarre (2006) examining competencies within general practice suggests that the presentation of evidence is rarely done, and when it is, it ranges from clinician anecdotal experience to actual research evidence. A further strength of this model is that it affirms a range of other individuals who may be involved in and affect the SDM process. For the patient this may include family members, whilst for the clinician it may be other healthcare professionals. Acknowledging the presence and influence of others in SDM is important in order to take into account the complexity of the decisions that are being made in healthcare, such as referring on to specialists or involving family members when working with vulnerable individuals or people with chronic conditions.

Whilst this model makes important contributions to the area of SDM through examining competencies, limitations do exist. In particular, the purpose of Towle and Godolphin’s (1999) research was to develop competencies which may be used for teaching, learning, research and practice. Whilst patient competencies are present, they are underdeveloped due to a lack of literature (Towle & Godolphin, 1999). This means that clinicians’ competencies, which are more clearly defined, lend themselves better to testing and application. Moreover, the
teaching of these competencies may be better suited to clinicians than patients, as clinicians may receive additional support during medical school and residential training. Other limitations of this model are that some concepts are ethnocentric, as patients in many countries may not have the option of choosing their clinician unless they have private healthcare. Limitations related to who has the final say when there is disagreement and around patient capacity have also not been addressed.

1.3.2.3 Elwyn and colleagues model

Building on the competencies suggested by Towle and Godolphin (1999), Elwyn et al. (1999) worked to adapt and develop these competencies from ‘abstract notions’ to ones which could be used in general practice. To do this, focus groups were conducted with 39 general practitioner (GP) registrars after they had observed a simulated doctor-patient encounter. Findings suggested that GPs were not being trained in SDM, that their skills related to this area were often poor, and that their attitudes varied with regard to when and how to involve patients in decisions (Elwyn et al., 1999). Patients’ contextual factors such as age and education were implied to have an influence on SDM, as GP registrars highlighted that some individuals would have trouble understanding more complex information (Elwyn et al., 1999). Moreover, corresponding to suggestions by Charles, et al. (1999), Elwyn et al. (1999) also highlighted the possibility that the preference for SDM may differ throughout the course of the interaction. Based on their findings, these authors developed their own version of the eight clinician competencies for involving patients in healthcare decisions (Elwyn et al., 1999) which are highlighted below in Table 1-2.
Table 1-2: The Elywn et al. (1999) model

<table>
<thead>
<tr>
<th>Stages and competencies of involving patients in healthcare decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implicit or explicit involvement of patients in the decision-making process</td>
</tr>
<tr>
<td>Explore ideas, fears and expectations of the problem and possible treatments</td>
</tr>
<tr>
<td>Portrayal of options</td>
</tr>
<tr>
<td>Identify preferred format and provide tailor-made information</td>
</tr>
<tr>
<td>Checking process: understanding of information and reactions — for example, ideas, fears and expectations of possible options</td>
</tr>
<tr>
<td>Acceptance of process and preferred role in decision making</td>
</tr>
<tr>
<td>Make, discuss or defer decisions</td>
</tr>
<tr>
<td>Arrange follow-up</td>
</tr>
</tbody>
</table>

An important difference between the model by Elwyn et al. (1999) and the model by Towle and Godolphin (1999) is the need to explore the presenting problem and options prior to establishing the patient’s preferred role for involvement. Elwyn et al. (1999) posit that some steps, particularly in discussing the risks, benefits and associated probabilities, need to be undertaken prior to a patient deciding their ‘role’ in decision making, and that role-setting from the outset is related to an insurance-based, consumerist approach to healthcare (Elwyn, Edwards, Kinnersley, & Grol, 2000). The outlining of the potential for the deferral of a decision may also be considered an important step which previous models have neglected, as it acknowledges that the patient may need more time to consider the information prior to making a decision. Some strengths of this model, which are similar to Towle and Godolphin’s (1999) model, are that it provides clinicians with a model to work against and through which they can review their skills in relation to the outlined competencies.

There are, however, limitations to this model. Due to its focus on GP registrars, the model may not be generalisable to other settings or healthcare providers in which different competencies may be needed. Moreover, unlike Towle and
Godolphin’s model (1999), no attempt is made to explore patient competencies. Whilst clinician competencies may be important to target as the consultation may be weighted in favour of clinicians (Abram et al., 1982), Elwyn et al. (2000) highlight that patient competencies also need to be explored further. This is particularly important as patients play a role in the decision-making process and there may be substantial gains when patients are employed to assist with their long-term conditions. A further limitation specifically related to this model may be the climate in which current general practice operates. With recent funding cuts and increased patient pressure, whether it is possible for GPs to engage in effective SDM within short appointment sessions should also be considered.

1.3.2.4 Makoul and Clayman’s model

An integrative model proposed by Makoul and Clayman (2006) incorporates concepts used across the field of SDM. A systematic review conducted by Makoul and Clayman (2006) identified 23 key characteristics of SDM. This list consists of 13 ‘elements’ which are defined as ‘observable behaviours’ within a SDM interaction. They are then divided into ‘essential elements’, defined as tasks that need to take place for SDM to occur, and ‘ideal elements’, which are not mandatory but have the potential to further enhance the experience and process of SDM (Makoul & Clayman, 2006). Ten general qualities are also outlined that were discussed in models but do not lend themselves to testing as easily in research or clinical settings (Makoul & Clayman, 2006). The elements and qualities are outlined below in Table 1-3 (Makoul & Clayman, 2006).
Despite a comprehensive list of elements, only two (‘patient values/preferences’ and ‘options’) appear in over half of the reviewed articles, which demonstrates the large variability in conceptualisation when it comes to defining SDM (Makoul & Clayman, 2006).

An additional element included by the authors is patient self-efficacy (Makoul & Clayman, 2006). They define this as an ‘essential element’, which suggests that the ability of the patient to carry out a decision is as important as what the patient wants or values (Makoul & Clayman, 2006). Within their model, Makoul and Clayman (2006) suggest that whilst professional knowledge and recommendations are seen as ‘essential elements’, the presentation of evidence and the providing of unbiased information are seen as ‘ideal
elements’. This places emphasis upon the clinician’s knowledge and recommendations which may be biased, subject to framing effects (Towle & Godolphin, 1999), or based on anecdotal experience rather than evidence-based options (Towle et al., 2006).

A strength of this model is that it integrates concepts used to define SDM across healthcare settings. As such, this model may be used by clinicians across different settings in order to improve their practice. Furthermore, the clear definition of elements, rather than more general characteristics as outlined in previous models (Charles et al., 1997; Charles et al., 1999; Elwyn et al., 1999; Towle & Godolphin, 1999), means that SDM can be tested and observed across research and clinical environments. It may also lead to the development and testing of interventions.

Whilst this model is purported to be integrative and encompassing of all the concepts and behaviours associated with SDM, it may only be applicable to a subset of healthcare contexts. Notably, the majority of papers included came from physical rather than mental health settings and adult rather than child health. In these contexts, where issues such as capacity, management of illness over longer periods of time, and potential input from caregivers, the concept of SDM may require additional elements or alterations in terms of what is regarded as essential and ideal.

1.3.2.5 Critical considerations of the SDM models

Entwistle and Watt (2006, 2016) state that the majority of decision making models focus solely on treatment. This narrow definition arises from early work in acute healthcare. As SDM moves into non-acute healthcare contexts, a broader, more pragmatic approach is needed within which relationships become longer term, decisions can be revisited, and the patient is responsible for daily
administration and the review of treatment (Entwistle & Watt, 2006, 2016). This can occur through a holistic approach to decision making, which would not only focus on what the problem is and the possible options for treatment or care, but also examine how decisions are reached, implemented and evaluated (Entwistle & Watt, 2006, 2016).

This broader view also incorporates how situations and other people influence SDM. Similar to Towle and Godolphin (1999), Entwistle and Watt (2006, 2016) highlight the role that others may play in the decision making process. For patients, this may be friends or family members, whilst for clinicians, this may be colleagues in their multidisciplinary team or other professionals and services with whom they liaise. Entwistle and Watt (2006, 2016) also outline the need to take into account the situation and broader context. For patients, this may refer to their socio-economic situations, which may have predisposed them to, precipitated or perpetuated the health difficulty. For clinicians, this may be the organisational influences pertaining to what is available, and when and to whom it is offered.

The supportive role of the clinician is also highlighted as important in SDM (Entwistle & Watt, 2006, 2016). Within this broader conceptualisation, different types of support are needed. For example, the clinician may support the patient in exploring their views and preferences which may not be stable or fully-formed (Entwistle & Watt, 2006, 2016). This helps the clinician to understand the patient’s beliefs regarding suitable care and positive outcomes (Cribb & Entwistle, 2011). The length and duration of contact can also affect the relationship, with long-term contact resulting in deeper relationships. An outcome of this is that personal and deeply-rooted values are discussed more openly, and the clinician’s contribution of expertise ‘evens out’ as the patient takes on responsibility for their illness management (Cribb & Entwistle, 2011).
A further consideration is the need for the feelings and views of stakeholders to be discussed (Entwistle & Watt, 2006). Entwistle and Watt (2006) highlight that whilst effort and contribution have received substantial focus, feelings and views have received less attention. Yet, the clinician’s and patient’s feelings and views towards the relationship, as well as towards each other’s efforts, contributions and roles, may play an important role in decision making (Entwistle & Watt, 2006). For example, patients may be unlikely to engage in decision making if they feel the clinician has ulterior motives or if they are not happy with their clinician’s effort, role or contribution.

1.3.2.6 Summary of models and frameworks of SDM

The four most prominent models (Charles et al., 1999; Elwyn et al., 1999; Makoul & Clayman, 2006; Towle & Godolphin, 1999) related to SDM have been outlined, reviewed and critically considered. These models move away from the earlier paternalistic model of care which has formed the dominant paradigm for most of history (Komrad, 1983). Whilst all models have attempted to define SDM, they have done so in different ways. Despite these differing conceptualisations, some commonalities are present across all the models. These include pros and cons, options, preferences, role definition, making (or in some cases, deferring) a decision, and the process/stages (Makoul & Clayman, 2006).

Models like those of Charles et al. (1997, 1999) and Makoul and Clayman (2006) outline the key characteristics of SDM. The latter model separates the characteristics of SDM into elements which can be observed and measured within research and clinical settings. Conversely, models by Towle and Godolphin (1999) and Elwyn et al. (1999) focus on the competencies and skills required for SDM to occur. All of the models are aimed at clinicians as the intended audience, with an emphasis on the role of the clinician in the decision-making process.
making process and ways in which the clinician can include the patient. As other authors have stated, this may reflect the inherent power imbalance weighted towards the clinician that is present within the doctor-patient relationship (Sandman & Munthe, 2010).

Most models of SDM are aimed at any practitioners working in healthcare, with the exception of Elwyn et al. (1999) whose model is specifically aimed at GPs. However, the development of SDM models in acute settings with a narrow focus may limit their generalisability to other contexts (Entwistle & Watt, 2006, 2016). This may be particularly true when there are more stakeholders than the traditional doctor-patient dyad, when patients are seen for a longer period of time, and when the evidence base or treatment options are unclear (Entwistle & Watt, 2006, 2016). Shared decision making in mental health fulfils such criteria. Accordingly, the next section examines SDM in physical and mental health settings.

1.4 Shared decision making in healthcare contexts: Comparing physical and mental health

The translation of SDM from acute settings into other settings warrants further investigation, particularly with regard to how this may affect treatment decisions and patient involvement. This section examines the key differences that occur in SDM when it is applied to physical and mental healthcare. The focus is upon capacity as well as the process and types of decisions being made in each setting.

1.4.1 Capacity to be involved in decisions

In both mental and physical healthcare, patients express a desire to be involved in treatment decisions (Adams, Drake, & Wolford, 2007; Chewning et al., 2012; Kiesler & Auerbach, 2006; O’Neal et al., 2008). Yet, for patients to be fully
involved in decision making, mental capacity is required. The Mental Capacity Act (2005) states that an individual is able to make decisions when they understand the information given to them, they are able to retain that information long enough to be able to make a decision, they are able to weigh up the available information to make a decision, and they are able to communicate that decision (Department for Constitutional Affairs, 2007, section 4.14). Importantly, capacity should be assumed for adults unless otherwise proven (Department for Constitutional Affairs, 2007).

However, for patients with mental health difficulties, clinicians have identified incapacity as a barrier to decision making, particularly in the case of more severe presenting difficulties (Hamann et al., 2009, 2016; Seale, Chaplin, Lelliott, & Quirk, 2006). This also fits with reports from patients who have identified their passive role in decision making in mental health settings (Deegan, 2007; O’Neal et al., 2008). The view that people with mental illness are unable to take part in decisions due to incapacity may be unwarranted, as studies have found that individuals with psychosis and severe mental illness are still able to be involved in decisions about care and treatment (Hamann, Cohen, Leucht, Busch, & Kissling, 2005; Puschner et al., 2010). Additionally, there is some research suggesting that educational interventions may help to increase capacity in such cases (Carpenter, 2000). This fits with the Mental Capacity Act (2005) which states that clinicians should take all reasonable steps to assist an individual in being involved in decision making.

The process of determining whether or not an individual has the capacity to be involved in decision making is often subjective and inconsistent (Howe, 2009). Typically, capacity is not usually assessed when a patient accepts the clinician’s recommendations for treatment or a course of action. Yet when a patient refuses treatment, incapacity is considered and SDM is seen as risky (Drake & Deegan, 2009; Howe, 2009). This may conflict with the third principle of the
Mental Capacity Act (2005) which states that making an unwise choice does not equate to being unable to make that decision.

1.4.2 Process of decision making and types of decisions made

The 'profile' of SDM may differ depending on the healthcare setting. In the only study examining SDM across physical and mental health settings, De las Cuevas (2013) found that overall SDM scores did not differ between patients from a physical health sample and a mental health sample when using the SDM-Q-9 (Kriston et al., 2010). However, when viewing the scores item-by-item, differences between the two samples were observed. Shared decision making between patients and clinicians in psychiatric settings placed emphasis on the first stages of SDM (i.e. helping the patient understand the illness and that a decision needs to be made), whilst emphasis was placed on the middle steps of SDM in primary care (i.e. sharing the decision and negotiation). Patients in psychiatric settings were more likely to disagree that they were involved in certain aspects of SDM, whilst patients in primary care felt that they were involved across all stages. Analysis using regression demonstrated that the type of medical care (psychiatric or primary) was the strongest predictor of patient involvement in the different aspects of SDM when examining the different stages within it (De las Cuevas et al., 2013).

It also appears that the types of decisions being made by patients and clinicians may also differ between some physical and mental health settings (Slade, 2017). Within physical health settings, decisions tend to focus solely on the illness or potential illness including different types of treatments, lifestyle changes, or whether to have screening or diagnostic tests (Coulter & Collins, 2011). Conversely, within mental health, a wider range of decisions have been observed. This includes treatment-related decisions such as medical or psychological interventions, as well as social decisions related to housing,
leisure, friends or family, and financial decisions related to work or benefits (Freidl et al., 2016; Hamann et al., 2008).

One study reporting on inpatient settings found that factors outside of treatment were not as commonly discussed by clinician and patients (Hamann et al., 2008). Conversely, clinicians and patients in the outpatient study tended to focus more on social or financial decisions rather than treatment-related decisions (Freidl et al., 2016). Whilst these studies are not directly comparable, they may suggest possible differences within different mental health settings. In inpatient mental health, decisions are akin to physical health treatment decisions, in that there is an emphasis on getting ‘well’. However, outpatient mental health treatment focuses more on other decisions (social and financial), which may help in keeping the individual ‘well’.

1.5 Shared decision making in adult mental health – what is the evidence?

There is a small but growing body of evidence examining the impact of SDM in adult mental health. Studies conducted in naturalistic settings have observed that higher levels of SDM and participation are linked with higher patient satisfaction (Clarke et al., 2015; Swanson, Bastani, Rubenstein, Meredith, & Ford, 2007; Tambuyzer & Audenhove, 2013), greater patient empowerment (Tambuyzer & Audenhove, 2013), and better patient treatment adherence (Loh, Leonhart, Wills, Simon, & Härter, 2007).

The last Cochrane Review examining SDM interventions found that only two studies met inclusion criteria (Duncan, Best, & Hagen, 2010). Both interventions were DAs developed in Germany (Hamann et al., 2006; Loh, Simon, et al., 2007). One DA, designed for inpatients with schizophrenia, outlined psychoeducational and medication options for treatment (Hamann et al., 2006). Findings from this randomised control trial (RCT) indicated that individuals in
the intervention group had a higher level of knowledge, higher satisfaction and an increased uptake of psychoeducational information resources (Hamann et al., 2006). However, longer-term follow-up at six and eighteen months did not support these initial findings (Hamann, Cohen, Leucht, Busch, & Kissling, 2007).

The other DA was for depressed patients in primary care (Loh, Simon, et al., 2007). This DA outlined information about the presenting problem, treatment options, the advantages and disadvantages of each option and a section for patient values. Evaluation of this DA with an RCT found that, when compared to the control group, those in the intervention arm had higher rates of patient satisfaction (Loh, Simon, et al., 2007).

The authors of the Cochrane Review summarised that no concrete conclusions could be formed from these studies due to small sample sizes with different populations, different measures and conflicting results (Duncan et al., 2010). The next section examines SDM interventions in adult mental health that have occurred since this review.

1.5.1 Decision aids

A number of DAs have been developed and tested within the context of adult mental health, the majority of which focus on depression (Aljumah & Hassali, 2015; LeBlanc et al., 2016; Perestelo-Perez et al., 2017; Simon et al., 2012) and psychosis (van der Krieke et al., 2013; Woltmann, Wilkniss, Teachout, McHugo, & Drake, 2011). The underlying rationale of DAs is that they present options for treatment or care, include the evidence base and risks and benefits, and are presented in a comprehensible way which patients can assess in light of their preferences and values (BMJ, 2013). Decision aids may be paper- or card-based (Aljumah & Hassali, 2015; LeBlanc et al., 2016) or electronic (Perestelo-Perez et al., 2017; Simon et al., 2012; van der Krieke et al., 2013;
Woltmann et al., 2011).

One paper-based DA developed in the US focuses on helping depressed individuals make decisions around medication (LeBlanc et al., 2016). The content of the DA centres upon efficacy, side effects, discontinuation and cost. Results from an RCT conducted with this DA found that patients who received the intervention had better knowledge and were more involved in decision making compared with the control group. Both patients and clinicians who used the DA reported improved decisional comfort and satisfaction with the decision-making process (LeBlanc et al., 2016). No differences were found on other measures, such as adherence to medication, improvements in depression or the duration of the encounter. As this large-scale cluster RCT was conducted across a number of settings, contexts and patient demographics, the findings may lend themselves to real-world settings. However, whilst promising, there are several methodological limitations, including no blinding for participants or assessors and a high rate of dropout, which indicates that the findings should be considered cautiously.

Another similar DA for antidepressant medication, consisting of a series of cards detailing side effects, cost, and general information, has been developed in Saudi Arabia (Aljumah & Hassali, 2015). In the evaluation of this DA, significant differences were found between participants in the control and intervention groups related to satisfaction, beliefs about treatment, and adherence, with the control group scoring lower in each measure. Metrics collected on depression severity and quality of life showed no differences between the groups (Aljumah & Hassali, 2015). A particular strength of this study is that it was conducted in a non-Western country and demonstrates that SDM can work in other cultural settings. It also, as with previous studies, utilised an RCT design which minimised biases. However, this study was limited to only one clinic, which places into question the generalisability of the results and
whether the findings could be replicated elsewhere.

The four electronic DAs which have been developed compare a wide array of different treatments. Two of the DAs are for depression (Perestelo-Perez et al., 2017; Simon et al., 2012), one is for psychosis (van der Krieke et al., 2013), and one is for general mental illness (Woltmann et al., 2011). One of the depression DAs, which were developed in Spain, provides information on medication, psychotherapeutic interventions, or combination treatment. It also includes information on response and relapse, side effects, psychoeducational information on symptoms and further support information (Perestelo-Perez et al., 2017). A trial comparing patients who had used the DA with a control group found that patients who used the DA had higher levels of knowledge and lower levels of decisional conflict. No difference was found between groups for treatment concordance, treatment initiation or preference for participation. The limitations of this study involve flawed measure collection and uneven characteristics between the groups. Firstly, rather than collecting the measures before and after the intervention, all measures were collected post-intervention. This may have meant that the participants were aware of the research question or study aims and tailored their responses in light of this. While randomisation could mitigate this, groups were also uneven with regards to levels of education, as the individuals in the intervention arm were more educated (Perestelo-Perez et al., 2017). This could have amplified the finding related to knowledge, which means that the findings should be regarded with caution.

Two electronic DAs, one for depression and one for back pain, have been developed and evaluated in Germany (Simon et al., 2012). Both DAs were developed to provide tailored options for treatment based on an initial assessment completed by patients. Patients that used the DAs had significantly lower decisional conflict at follow-up compared to those that did not. However, no differences were found related to involvement, decisional regret or
adherence at follow-up. Further analysis between the presenting problems indicated that individuals with depression had higher levels of knowledge regarding their condition at the start of the treatment than those with back pain. Individuals with depression also scored higher on the measure of desiring to make the decision alone. High rates of dropout were found within this study, which calls into question whether the follow-up group was representative of the original group. However, a strength of this study is that the authors employed an intention to treat analysis which yielded similar results. However, as there was no validated instrument used in this study for participation or patient adherence, these results should be interpreted with caution.

An electronic DA has been developed in the Netherlands for outpatients with psychosis (van der Krieke et al., 2013). This tool provides tailored feedback on care and treatment options following an initial assessment. No differences between the intervention and control groups were found related to involvement with decision making, satisfaction or confidence in the decision made. High levels of patient dropouts in the trial were observed, and a process evaluation found that the intervention did not fit well within the setting (van der Krieke et al., 2013). Deviations from the intervention protocol were also reported, meaning that it is not clear whether outcome effects were due to the DA or to other factors. However, a strength of this study is that it indicates that individuals with psychosis are able to use and operate electronic DAs, which may help to dispel the belief that they are unable to contribute to decision making in a meaningful way. Moreover, this is the only study to include a process evaluation. This allowed the authors to be critical and to decipher what did not work in the trial and intervention; they were also able to provide information on what needed to change or be altered. This information may be used to support others who are developing DAs in the future.

The final electronic DA was aimed at individuals with a mental health difficulty
without one specific diagnosis or presenting problem (Woltmann et al., 2011). Developed in the US, this DA required patients and clinicians to respond to questions regarding their priorities with regard to treatment and services. It then visually collated the responses for discussion in the pending treatment session. The findings indicated that clinicians in the intervention group were more satisfied with the care-planning process when compared to the control group. Patients in the intervention group also had better recall of treatment plans after treatment than those who did not use the DA. Whilst the findings from this study are promising and potentially generalisable given that the intervention did not focus on one presenting difficulty, both measures used in this study were developed by the study authors and were not validated instruments. This means that it is not certain that these measures measured the constructs they intended to.

1.5.2 Mobilising patients to engage

Training for patients has been considered as an alternative approach to SDM and a means to increasing patient competence and motivation (Hamann et al., 2015). Initiated in Germany, workshops were developed for inpatients with psychosis and taught by a clinician. They contained sessions on participation, motivation and practical roleplay exercises. A small-scale pilot, which compared patients who received the intervention with a control group that received cognitive training, found that the intervention group sought higher levels of participation and increased involvement in the decision-making responsibility. Interestingly, psychiatrists who saw patients in the intervention group reported that the patients were ‘difficult’ during sessions, whilst the patients reported higher levels of perceived distrust regarding treatment. No differences in satisfaction were observed between groups.

Similar to other research (e.g. Aljumah & Hassali, 2015), this study was based
in a single centre, which means that the results may not be transferrable outside of this setting. Differences relating to severity at baseline, though not significant, may also have impacted the findings. Higher levels of symptom severity were found in the intervention condition, which could have possibly had a cumulative or moderating effect along with the DA that resulted in the increased patient difficulty reported by psychiatrists. However, a strength of this study is that it shows individuals with severe mental illness in an inpatient setting are able to be trained in how to participate in decision making. It may also validate patients’ views if they are seen as ‘difficult’ or not compliant with recommendations by their psychiatrist. Consequently, a recommendation arising from the observation that patients were seen as more difficult in the intervention condition caused the authors to suggest that mental health professionals may also need training in SDM (Hamann et al., 2015).

Another training programme, DECIDE, was also developed in the US. This programme aimed to help patients with mental health difficulties increase their participation and involvement in decision making (Alegria et al., 2014). Training sessions and workshops with patients helped participants to identify the decisions being made, the roles for involvement, and sources of information and support. An RCT of DECIDE found that patients in the intervention group reported higher levels of activation and self-management compared with those in the control group. However, no differences were found related to attendance rates or whether patients continued to remain in care. Deviations from the training protocol, as well as more time spent with individuals in the intervention group, call into question whether the findings of the study can be attributed to the intervention or to other factors. However, a strength of this study is that it was able to increase the activation and self-management of ethnic minorities. This is particularly important as such groups are less likely to initiate and engage with services (de Haan, Boon, Vermeiren, Hoeve, & de Jong, 2015;
Malek & Joughlin, 2004). Moreover, as this intervention did not focus on one health condition alone, it may be beneficial to a number of individuals.

1.5.3 Models and therapeutic approaches

One approach underpinned by SDM principles, REORDER, has been developed and tested in the US for military personnel with serious mental illness (Dixon et al., 2015). The approach consists of a series of steps whereby clinicians, along with patients, define goals for recovery, determine whether the patient wishes relatives to be part of the treatment process, and examines the evidence base to help reach decisions regarding treatment. Patients who were assigned to REORDER experienced more family participation, reported feeling less trapped with treatment, and had lower paranoid ideation than those in the control condition. Whilst these results are promising, this study is limited in its applicability to other settings due to the participants being predominantly American male military personnel. However, a strength is that this intervention appeared to be useful in helping to retain the family involvement in the treatment. Whilst not tested in this study, the involvement of family could potentially help with self-management and care outside of the appointment.

Another approach, which is underpinned by SDM and motivational interviewing (SDMI), has been developed with patients diagnosed with substance misuse in the Netherlands (Joosten, De Jong, De Weert-Van Oene, Sensky, & Van Der Staak, 2009). This intervention consists of five sessions which allow patients and clinicians to set goals and to explore and negotiate their different perspectives and treatments. These were then reviewed throughout the treatment using motivational interviewing. Compared to patients who received the usual care, those who received the SDMI intervention reported increased autonomy and extrovert behaviour (Joosten et al., 2009). Similarly, to other studies, high dropout rates limit the generalisability of these results. Moreover,
follow-up was limited to three months, which means that longer-term outcomes were not subject to investigation. However, incorporating SDM and motivational interviewing into an intervention may allow for personalised care, decision making and behaviour change to occur in tandem, particularly when a patient is ambivalent about all the options including the option to do nothing (Elwyn et al., 2014). As such, this technique may allow clinicians to initiate SDM with hard-to-engage patients.

1.5.4 Discussion prompts

Lastly, a one-page question prompt list (QPL) for patients with depression has been developed and trialled in Germany (Hamann et al., 2014). Question prompt lists are designed to support patients in asking clinicians questions in order to help them to understand their illness and to make decisions about care and treatment (Hamann et al., 2014). A comparison between patients who used the QPL and those who did not found no differences in the number of topics raised by patients, nor any differences in ratings related to who made the decision at the end of the appointment (Hamann et al., 2014). The authors concluded that a more complex intervention might be needed for patients to become more active. They also highlighted that this may be more challenging with a depressed group due to their symptomology. This study was only trialled in one setting with one clinician seeing patients, and therefore it is limited in its generalisability to other settings. The use of some non-validated measures related to involvement also means that it cannot be compared to results from other studies.

1.5.5 Summary of the evidence for SDM in mental health

Since the last Cochrane Review of SDM (Duncan et al., 2010), a greater number of interventions have been developed and trialled in the field of adult mental health. Interventions tend to focus on DAs and are more prominent
within the diagnoses of depression and psychosis. In line with the wider literature (Clayman et al., 2016), it appears that increased participation in decision making can be associated with some positive outcomes. However, these outcomes vary between studies. Satisfaction is the most commonly measured outcome across interventions, though this does not always demonstrate consistent findings when examining interventions between groups. Other outcomes, such as the severity of symptoms, indicate a less clear picture as the majority of studies found no effect of the intervention on symptomology.

These mixed findings could be the result of intervention differences or methodological and design limitations. Whilst DAs are the most common form of intervention, differences within this group regarding content, modality and target groups could contribute to some of the variance found in the literature. These interventions can vary substantially with regard to their specific components, and the length, intensity and amount of participation required by stakeholders. A more complex and convoluted picture emerges when comparing these studies to the wider array of interventions designed to facilitate SDM.

The methodological limitations of the included studies may also affect their results. Whilst a strength of all of the studies was the use of an RCT design, other methodological limitations, such as high levels of participant dropout, mean that some findings should be treated with caution. In addition, a number of studies have not employed validated or standardised measures, which means that it is uncertain whether these measures tested what the authors believed they were testing. Even when such measures are implemented within a range of methods examining similar concepts (e.g. decisional conflict and comfort), results are not always comparable.
1.6 Conclusion

Shared decision making has gained prominence in healthcare, policy and academia over the last 60 years (e.g. Billingham, 1998; Coulter & Collins, 2011; Da Silva, 2012; Makoul & Clayman, 2006). The re-conceptualisation of mental illness from a biomedical approach (Engel, 1977) to the idea that patients have the right to be heard (Balint, 1957) and that outcomes are often idiosyncratic to patients (Eddy, 1990) has paved the way for patient involvement. This movement has been driven forward by clinical, ethical and service/resource use perspectives (Coulter, 2017; Coulter & Collins, 2011; Slade, 2017).

Despite these drivers, research in the field of SDM has produced mixed results. The research is inconclusive with regard to the ways in which it impacts the use of resources (Walsh et al., 2014), but outcome research has produced some positive results in particular circumstances (e.g. Joosten et al., 2009). No negative outcomes compared with usual care have yet been established (Duncan et al., 2010). Accordingly, there may be enough perceived clinical and service/resource benefits to create an agenda for the inclusion of patients in care and treatment decisions. The rise of civil rights movements and The Human Rights Act (2005) have also provided a powerful impetus toward patient inclusion.

The mixed results may also be due to the loose existing definition of SDM (Charles et al., 1997; Jansen, 2001; Makoul & Clayman, 2006; Thornton, Edwards, & Elwyn, 2003). Four prominent models exist in the literature (Charles et al., 1997; Elwyn et al., 1999; Makoul & Clayman, 2006; Towle & Godolphin, 1999), with some models focusing on observable characteristics (Charles et al., 1997, 1999; Makoul & Clayman, 2006) and others focusing on skills and competencies (Elwyn et al., 1999; Towle & Godolphin, 1999). Despite these differences, commonalities across all the models include discussing pros and cons, options, preferences, role definition, making (or in some cases deferring)
a decision, and the process/stages (Makoul & Clayman, 2006). The application of such models to mental health settings may be limited as they were all developed in acute or general settings. This means that patients who are seen for longer periods of time, or for whom the evidence base is not clear, may struggle with clinicians with regard to how and when they want to be involved (Entwistle & Watt, 2006, 2016).

Further considerations of SDM in mental health relate to capacity and the types of decisions in which a patient can be involved. Compared to physical health, individuals with mental health difficulties may not be assumed to have capacity (Hamann et al., 2009, 2016; Seale et al., 2006). This occurs despite the fact that capacity should be assumed until proven otherwise (Mental Capacity Act, 2005). Moreover, there is emerging evidence that the process of SDM may differ between physical and mental health consultations, as more emphasis is placed on the initial steps within the consultation in mental health than in physical health. There is also greater variation in whether psychiatric patients feel involved at all stages of SDM (De las Cuevas et al., 2013). The types of decisions between the settings also appear to differ, as with psychiatric patients decisions are related to treatment and also the financial or social decisions which affect the patient’s life.

The involvement of young people in decision making, including young people with mental health difficulties, is a more recent development. It is unclear how the aforementioned findings apply to child and youth mental health. For example, in youth mental health there may be challenges related to capacity issues due to age and mental health diagnosis. It may also be challenging to manage the roles of the multiple stakeholders that are usually present in youth mental health. These areas, along with other considerations relating to this setting, are explored in Chapter 2.
Chapter 2 Shared decision making with children and young people
2.1 Introduction

This chapter focuses on the use of SDM with children and young people with an emphasis on the context of mental health. It begins by outlining the development of SDM in this area, including the historical context, law and policy, and drivers. Next, it explores the similarities and differences between paediatric medicine and youth mental health with a specific focus on the young person’s capacity and the role of the family. This is followed by an examination of the different models of SDM in child and youth mental health as well as a review of the evidence around SDM interventions. Lastly, barriers and facilitators to SDM are discussed.

2.1.1 Search strategy

The search strategy for this chapter covered three concepts: shared decision making, children and young people, and mental health. The first and second concepts are fully outlined in Chapter One (see 1.1.1). The third concept covered the following terms: youth, child/children, childhood, young people, tweens, teen/teenagers/teens, infant/infants/infancy, young adults, juvenile, adolescent/adolescence/adolescents, high school, secondary school, primary school, elementary school, student/students, middle school, nursery school, and pre-school.

Key search terms were combined (see syntax below) and six research databases were searched (PsycINFO, EMBASE, Medline, PubMed, Web of Science and Cochrane Libraries) until Jan 2018.

The syntax for the search was as follows: (“Shared decision making” OR “Decision aid*” OR “Self determination” OR “Client choice” OR “Informed choice” OR “Patient choice” OR “Client participation” OR Decision-aids OR (“Client cent* care” OR “patient cent* care”) OR “Therapeutic alliance” OR...
“Collaborative practice” OR “Recovery oriented care” OR “Shared care” OR “User empowerment” OR “Shared agreements” OR “Common goals” OR “Value oriented care” OR “Personalisation”.

AND (“Mental health” OR “Mental illness” OR “Mental disorder” OR “Chronic mental illness” OR “Community mental health” OR “Community mental health service” OR “Primary mental health prevention” OR “Anxiety disorder” OR “Anxiety management” OR “Emotional problem” OR “Emotional adjustment” OR “Affective disorder” OR “Behaviour disorders” OR “Behaviour problem” OR “child psychopathology” OR “Psychosis OR (Neurosis or neuroses)” OR “Cognitive behaviour therapy” OR “depression OR Psychology OR Therapy OR Counselling”.

AND (Child* OR “young person” OR “teen” OR “adolescent” OR “tween” OR “high school” OR “secondary school” OR “primary school” OR juvenile OR “Elementary school” OR Student* OR “Middle school” OR “Nursery school” OR Pre-school).

2.2 History, policy and developments: Moving from paternalism to SDM with young people

2.2.1 Historical context

‘Children should be seen but not heard’ summarises the predominant thinking in Western society with regard to young people for most of history (Cobb, 2015; Heywood, 2001). Children were viewed as possessions owned by adults with no rights of their own and no voice (Young-Bruehl, 2012). The rationale for this was the belief that young people were incomplete versions of adults and their parents, guardians and society had to shape them into functional adults (Heywood, 2001). In fact, children could be viewed as ‘savages’ lacking the capacity to contribute to society in meaningful ways. It was also believed that
children possessed flawed reasoning and were poor assessors of their own needs (Archard, 2015; White, 2001).

Over the last 50 years, there has been a shift in thinking concerning children and young people as deserving of their own rights (Alderson & Montgomery, 1996; Heywood, 2001). Specific developments have included the legal and moral rights attained by traditionally marginalised groups (Farson, 1974; Gottlieb, 1973); shifts in sociological research that view the young person as a ‘social actor’ (James & Prout, 1990); and psychological advances in our understanding of moral reasoning, ethics and child development (Kohlberg, 1981; Nucci, 2001).

Early developments in the movement to include young people in care and treatment decisions have been attributed to other rights movements. These movements were led by various groups including black people and other ethnic minorities, people with disabilities, women, and LGBT populations (Farson, 1974; Goldstein & Drotman, 1977; Gottlieb, 1973). The increased interest in children and young people’s legal and moral rights may have ‘piggy backed’ off other movements which proposed that all individuals, regardless of their circumstances, should be afforded basic human rights (Farson, 1974; Gottlieb, 1973). This was bolstered by discoveries in the US and UK of abuse and neglect by some parents, guardians and institutions who had been entrusted with caring for and protecting children and young people (Goldstein & Drotman, 1977). In an effort to advance children and young people’s rights, the Youth Liberation Movement was established, and factions developed in the US, UK and other Western countries. They aimed to advance and protect the rights of young people in various areas such as natural or human rights, educational rights and legal rights (Goldstein & Drotman, 1977).
From a scientific and academic perspective, one development was a sociological shift in thinking related to children and their agency (James & Prout, 1990). Until the 1980s, research within sociology focused on how broader social factors, such as families, schools or religious organisations, affected the agency of individuals, with little concern for children and young people (Morrow & Pells, 2016). A seminal book by Allison James and Alan Prout (1990) suggested that, instead of children being static persons who were only affected by social structures, they were ‘social actors’ within the world. This meant that children and young people had voices and were able to influence society through their thoughts, behaviours and actions. These assertions allowed for the sociology of childhood to emerge as a discipline (Brannen & O’Brien, 1995). With this development came research on how children experience life in society (Morrow & Richards, 1996), as well as how children and society both impact upon and influence each other (Mayall, Bendelow, Storey, & Veltman, 1996; Pells, 2012). Such findings opened dialogues around how children and young people should be viewed as ‘human beings’ with a place in society, and that they should be afforded certain rights (Quennerstedt & Quennerstedt, 2014).

Psychological advances in our understanding of moral reasoning, ethics and child development have also contributed to the establishment of rights for young people. This work began with Piaget (1932), who proposed a two-tiered model of moral reasoning. In this model, young people under nine years of age were governed by moral realism and were dependant on external forces, that is, laws and rules, which could not be altered. Conversely, young people aged nine and older could display moral relativism. This meant they could understand that right and wrong were not absolutes and that intentions and consequences were important. Building on Piaget’s (1932) work, Kohlberg (1958, 1981, 1984) extended these ideas in his model consisting of six stages of morality across three levels. This model assumed that morality develops in a linear, age-based
trajectory until adulthood, when concepts then become fully formed. Rights in this model were tied to moral reasoning and the ways in which participants approached moral dilemmas. For example, an understanding of human rights, justice and equality was thought to demonstrate higher moral reasoning. However, as moral reasoning was its main focus, it has been suggested that this model has limited use in the understanding and development of rights (Helwig & Turiel, 2016). Despite this, Kohlberg’s work (1958, 1981, 1984) has acted as a catalyst for other research on this topic (Helwig & Turiel, 2016).

Research on how young people understand and develop rights was first conducted by Gary Melton in 1980. Findings from interviews with children and young people identified three levels in the development of rights, which bore similarities to Kohlberg’s work (1958, 1981, 1984). The findings from this work indicated that children around six years of age conceptualised rights and morality in terms of power and order, whilst adolescents over thirteen years understood natural rights and ethics (Melton, 1980). This work suggested that some adolescents have a concrete understanding of rights, and thus it opened the conversation around whether adolescents should be allowed to invoke such rights when it came to treatment (Melton, 1983). Further research has demonstrated that children and young people can develop a more complex understanding of rights before the age of thirteen. In fact, young people have demonstrated an awareness that they have personal rights, distinct from moral and ethical rights, the latter of which have been the primary focus of study (Nucci, 2001).

2.2.2 Law and policy related to SDM

There is key policy and legal documentation that describes the inclusion of children and young people in decisions about care and treatment. Early policy work to secure these rights for children and young people took the form of
declarations by the Geneva Convention (1924) and the United Nations (1959). In the latter, a set of ten principles were proposed that mandated the right of children to ‘physical, mental, societal, spiritual and moral development’ (United Nations, 1959). This was followed by the United Nations Convention on the Rights of the Child (CRC) (1989), which detailed 41 rights that should be guaranteed to children and young people. To date, all countries apart from the US and South Sudan have signed or ratified the CRC (UN News, 2015).

With regard to treatment decision making, particular attention has been paid to Articles 12 and 13 in the CRC. These highlight that children and young people should have their views taken seriously and that their views should be given consideration consistent with their age and maturity (United Nations, 1989). These articles highlight that all children and young people have the right to express their views regardless of any other factors or circumstances (Alderson & Montgomery, 1996). However, as these authors acknowledge, it is often left to the parents or adults responsible for the young person to decide to what degree the young person’s views are actually taken into account.

In the UK, children and young people’s healthcare rights have legislative backing. The ruling in Gillick vs West Norfolk and Wiscech Area Health Authority (1985) established a precedent that young people should have some control over their healthcare decisions. The case, filed by ‘Mrs Gillick’, debated whether her daughter, a young person aged under 16, could access contraception and contraceptive advice without parental knowledge and consent. It was ruled that young people aged under 16 did not need parental consent providing that two conditions were met. First, the child must have sufficient intelligence and understanding to recognise what is being proposed. Second, the child must have the discretion to make a wise choice in accordance with their own interests. Young people that meet these criteria are deemed to be ‘Gillick competent’ and able to consent to treatment alone. Whilst regarded
as a step forward, this ruling meant that many young people, such as those with learning difficulties, were excluded from being able to consent to treatment as they were unlikely to be considered to have the intellectual capacity to understand what was being proposed.

Four years later, the UK parliament passed the Children Act (1989), which aimed to protect the welfare of children and young people. Within this document, it was stated that children and young people must be listened to and heard. This document also stated that young people should have their wishes and feelings taken into account according to how practical this was, their age and their level of understanding. Two years later, this was followed by the ratification of the CRC (1989), which contained similar proposals related to the rights of young people.

Subsequent guidance from governmental departments and professional bodies has been issued. Notably, the Department of Health (1991) outlined that children with disabilities, including severe learning disabilities, should not be assumed to be incapable of partaking in decisions, and that professionals should make a point of establishing the views, values and preferences of individuals with disabilities. In keeping with this trend, the British Psychological Society affirmed in 2001 that children should be given enough information to decide whether to consent to an intervention. Subsequently, the National Service Framework for Children, Young People and Maternity Services proposed a shift towards SDM and services based on need (Department for Health, 2003).

In youth mental health, developments have occurred with regard to the services offered and policy documentation. In 2011, the Children and Young People’s Improving Access to Psychological Therapies Programme (CYP IAPT) was established. A guiding principle of this service transformation programme is that
there should be an emphasis on SDM with young people and their families (NHS England, 2016). In 2012, the Chief Medical Officer for England called for ‘child-friendly’ personalised care in child and youth mental health (Chief Medical Officer’s Annual Report, 2012; Chapter Ten). Most recently, the Department of Health published its report ‘Future in Mind’ (2015) which states that young people with mental health difficulties and their families should be at the heart of decision making.

2.2.3 Drivers behind the rise in SDM for children and young people

The ethical, clinical and resource drivers for SDM (Coulter & Collins, 2011; Slade, 2017) outlined in Chapter 1 are equally as applicable to children and young people as they are to other patient groups. For example, it has been suggested that there are clinical benefits to SDM, as young people are more likely to adhere to treatment if that treatment is congruent with their values (Simmons, Elmes, Mckenzie, Trevena, & Hetrick, 2016). Similarly, researchers in the field of SDM are increasingly incorporating patient values into evidence-based practice (Williams & Fulford, 2007). However, these clinical drivers are complicated by multiple stakeholders, each of whom has their own values and preferences (Lipstein et al., 2016). Two reviews have been conducted in order to examine the effect of SDM on outcomes. The findings from a meta-analysis of 15 paediatric interventions indicated that SDM interventions significantly improved knowledge and reduced decisional conflict for parents (Wyatt et al., 2015). On the other hand, a systematic review of five interventions to improve SDM with young people, all of which were conducted in physical health settings, produced mixed findings with regard to outcomes (Feenstra et al., 2014).

Shared decision making has also been suggested as a means of reducing the variation in the quality of services and treatment for children and young people (NHS Confederation, 2011). In general, there is high variation in the quality of
services and treatment available for young people (Kennedy, 2010; Rightcare, 2012, 2016). As with other areas of healthcare, a reduction in variation may result in cost savings, as young people may be more likely to continue with treatment rather than discontinuing, or they may be more likely to choose less costly treatments. This may also result in lower litigation costs, although no data is available on this. However, many young people and parents do not feel adequately informed about treatment (Edbrooke-Childs, Calderon, Wolpert, & Fonagy, 2015), and a lack of information can be a significant factor in negligence claims (Levinson et al., 1997).

From an ethical perspective, children and young people have rights under the CRC (1989). Articles 12 and 13 of the CRC are most applicable to decisions about treatment or care, as they address the issue of respecting the views of the young person and freedom of expression. However, whilst these rights are afforded to children and young people, both policy and legislative documentation contain caveats. These allow for the minimisation of, or overriding of young people’s wishes if they are not deemed to have sufficient understanding due to age or maturity (CRC 1989; Department of Health 1989).

### 2.3 Critical considerations of including young people in care and treatment decisions

Shared decision making with children and young people presents unique challenges when compared to other settings. This includes considerations around a young person’s developmental capacity for decision making, as well as the role of the family in decision making (Lipstein et al., 2016). Each of these challenges is explored below.
2.3.1 Capacity of young people to be involved in decisions

The concept of a young person’s capacity to make decisions is not well-defined in the literature (Ruhe, Wangmo, Badarau, Elger, & Niggli, 2015). One of the most frequently used definitions outlines four components which must be established before capacity can be determined (Appelbaum, 2007). This includes: The patient must understand the information provided, show an understanding of the illness and its consequences and outcomes, be able to deliberate between different treatment options, and be able to make a choice about treatment.

Current understanding regarding the capacity of children without mental health difficulties is limited, with most research focusing solely on the area of ‘understanding’ (Ruhe et al., 2015). However, one study involving young people and adults examined their capacity across the domains of reasoning ability, having a choice or preference, and understanding (Weithorn & Campbell, 1982). Within this research, no differences were found between young people aged 14 and adults in terms of their decision-making capacity. Moreover, although younger children (aged nine) showed less capacity for reasoning and understanding than their 14-year-old counterparts, they were still able to express preferences that were considered ‘reasonable’ by experts.

In relation to young people’s involvement in treatment, research has investigated consent to surgery and the capacity of young people to be involved in treatment decisions related to diabetes (Alderson, 1993; Sutcliffe, Alderson, Curtis, & Tyler, 2004). In the former study, both parents and young people were asked what they thought the age of a young person should be in order for them to be able to decide whether to have surgery. Both groups had similar responses, with young people giving a mean age of 13.9 and parents giving a mean age of 14.0. This lends some credence to the assertion that adults believe young people can also be active decision makers.
In the latter study, interviews were conducted with young people who had a diagnosis of Type 1 diabetes and were aged three to 12. Findings suggested that some young people had an excellent understanding of their illness, including how to manage it with blood tests. Young people also displayed insight regarding the outcomes and consequences of eating particular foods, and they knew how to make appropriate choices based on this information (Alderson, Sutcliffe, & Curtis, 2006). Importantly, it was noted that not all children and young people wanted to, or in some cases, could be actively involved. However, these findings challenged the belief that age and ability were barriers to involvement in decisions about care and treatment (Alderson, 2017).

Both of these studies involved young people who were experiencing long-term physical health difficulties. Thus, rather than just age and maturity, it has been posited that other factors such as experience, confidence, relationships and values affect children and young people’s involvement in decision making (Alderson & Montgomery, 1996). These authors also assert that all children and young people can be included in decisions, and that their participation is a stepped process. This process consists of four levels, including being informed of a decision, expressing an informed view, influencing the decision-making process and being the decision maker (Alderson & Montgomery, 1996). Importantly, the authors highlight that the first three steps do not have specific barriers related to age, which allows for all children and young people to be involved.

The capacity to be involved in treatment decisions may be a greater challenge for young people with mental health difficulties, as they have been described as ‘doubly incapacitated’ due to their developmental age and their mental health difficulties (Coppock, 2005; LeFrançois, 2008). Indeed, LeFrançois (2008) has commented on how legislation and policy documentation in child and youth
mental health is restrictive, as discretion is left to competent adults who may subscribe to the view that young people are ‘doubly incapacitated’. This opinion is supported by Moli Paul (2004), who discusses examples in which ‘Gillick competence’ have been overruled or subject to different paternalistic interpretations. This favours parental views over the young person’s views, and it can result in psychiatric treatment being administered without the young person’s consent.

Research related to capacity and decision making has focused mainly on whether young people with mental health difficulties are able to consent to compulsory treatment and admission to services. For example, a Finnish study found that individuals who did not consent to inpatient treatment were more likely to have greater symptom severity or psychotic illness, and that this was not associated with family or sociodemographic factors (Kaltiala-Heino, 2010). Conversely, a US study examining adolescents who had consented to inpatient admission found that 83% did not have a good understanding of their illness or their need for treatment. This suggests that the majority were unable to provide informed consent in the first place (Casimir & Billick, 1994). Alternatively, other research has found that a reading age of US grade five or above is associated with the competency to consent to inpatient treatment, whilst other variables such as diagnosis were not found to be significant (Billick, Edwards, Burgert, Serlen, & Bruni, 1998).

When adolescents’ and adults’ understanding and knowledge of their treatment are compared, it contradicts the assumption that young people are ‘doubly incapacitated’. A study found that there was no difference between adolescent and adult knowledge and understanding in relation to psychotropic medication or general hospitalisation (Lurie et al., 2009). Moreover, adolescents in this study scored better than adults on knowledge related to the side effects and general knowledge about their illness. From this, it was concluded that
adolescents with mental health difficulties must not be viewed as any less competent than adults with mental health difficulties, and that they should be partners in decisions about their care and treatment.

The aforementioned cases are some of the most extreme examples related to young people and their ability to be involved in care and treatment. Most young people attending child and youth mental health services have less severe presenting difficulties and do not require forced inpatient treatment. Research examining capacity in these settings is less common. However, one study, involving adolescents with ADHD, explored their ability to consent to medication and found that their understanding and knowledge around medication was similar to their parents’ (Schachter, Tharmalingam, & Kleinman, 2011). Researchers involved in this study concluded that involving young people in consenting to treatment should be actively encouraged, but that numeracy and literacy levels should be taken into account when considering their ability to consent.

From a broader perspective in relation to consenting to treatment, Batten (1996) suggests that inflexible and arbitrary cut-off points related to the ‘inability to consent’ are unnecessary and unhelpful. Instead, there should be a consideration of factors such as the young person’s developmental cognition and rationalisation, their prior experience, their relationships to both the clinician and family members, their social environment and their understanding of the treatment options. Shaw (1999) takes this further and outlines that in all but the most severe cases, young people should be included in care and treatment decisions regardless of their competency.

Batten’s (1996) thinking is aligned with suggestions by Alderson and Montgomery (1996) that decision making lies on a continuum ranging from being informed of what will happen to being the ultimate decision maker. This
method is favoured by Paul (2004), who suggests that the best approach is to be open and honest about how and when young people with mental health difficulties can be involved. For example, it is important that young people’s views and opinions are listened to, but they should also be informed that a preference for an option that could result in significant harm or death will likely be overruled by those who have a legal obligation to protect the young person (Paul, 2004).

2.3.2 The role of the young person’s family in SDM

Unlike other decision-making scenarios, SDM with children and young people almost always includes multiple stakeholders (Lipstein et al., 2016). This can include parents or guardians, but it may also extend to other family members as well as organisations such as schools (Brinkman et al., 2009). Parents and guardians are often the main decision-makers, as they are seen as being emotionally close to the young person, having a personal knowledge of them and having a stake in ensuring that the young person has the best possible future (Rachels, 1989).

Balancing the role of multiple stakeholders can be difficult when both children or young people and their parents are involved in SDM. With regard to physical health, young people and parents may see the presenting problems, risks and side effects differently (Hughes, Jones, Feemster, & Fiks, 2011; Lipstein, Muething, Dodds, & Britto, 2013). Additionally, various factors can influence individuals’ roles in the family decision-making process (Lipstein et al., 2016). These factors include the dominant voice in the room, the cultural expectations of the family, and the parental distress involved in looking after a young person who may be acutely unwell.

Similarly to paediatrics, multiple stakeholders also play a role in decision making in child and youth mental health. However, given the wider range of
decisions in mental health than physical health, (Freidl et al., 2016; Hamann et al., 2008) and the fact that diagnosis is often based on stakeholder accounts (De Los Reyes, 2013), there may be a greater likelihood of disagreement in this context than in paediatrics. It is well documented that there are often disagreements between young people and their parents over the nature of the presenting problems, their severity and how they affect the young person (e.g. Achenbach, McConaughy, & Howell, 1987; Rey, Schrader, & Morris-Yates, 1992). One study found that 36% of parents and young people were unable to agree about the broad mental health grouping under which the young person’s difficulties should be categorised, whilst 63% of young people and parents could not agree on which aspect of the presenting difficulty should be the focus of treatment (Yeh & Weisz, 2001). Discordant views such as these have been found to impact treatment, as high levels of disagreement have been associated with poorer outcomes (e.g. Becker-Haimes, Jensen-Doss, Birmaher, Kendall, & Ginsburg, 2017; Ferdinand, van der Ende, & Verhulst, 2004).

Even when young people have the option of making a choice about their own treatment or care, parental influence may still affect treatment decisions. In one study where mental and physical health case vignettes were presented to 14 and 15 year olds, young people were more likely to attribute less credence to their own decision if they had experienced heightened parental coercion (Scherer & Reppuci, 1988). Decision conviction was partially negotiated by the severity of the outcome and consequences, with increased severity linked to the increased reluctance of the young person to change their own conviction. The depression vignette revealed moderate changes in the young person’s conviction when parental coercion was applied, and a similar trajectory occurred with tonsillitis. This theoretical example demonstrates that the dominance asserted by a parent during an appointment can affect their child’s conviction,
and suggests that young people may benefit from being seen separately from their parents for at least part of their assessment.

The perspective of the clinician in the clinical encounter with a young person complicates this situation further. In one study examining agreement between therapists, young people and parents, 44% of all participants could not agree on the broad mental health grouping under which the difficulties should fall. In addition, 76% of all participants could not agree on which aspect of the presenting problem should be the focus of treatment (Hawley & Weisz, 2003). Owing to discord between all the stakeholders, therapists typically agreed with the parental views. However, this was reversed when family or systemic issues influenced the presenting difficulty (Hawley & Weisz, 2003).

In both paediatric and mental health settings, when a clinician sides with one stakeholder it may cause tension or lead to further difficulties (Hawley & Weisz, 2003; Lipstein et al., 2016). For example, giving more weight to the child’s views and preferences risks alienating the parents who are usually responsible for bringing the child to treatment. Conversely, aligning with parents may cause children or young people to disengage from treatment (Hawley & Weisz, 2003). One way of solving this is to try to incorporate both views or concentrate on areas of shared interest. However, this includes the possibility of compromising the focus of the intervention (Hawley & Weisz, 2003).

### 2.4 Models and frameworks for facilitating SDM in child and youth mental health

Six models and frameworks have been identified that aim to facilitate SDM in child and youth mental health. Each model is explored in terms of its definition of SDM along with its strengths and limitations. Following this, the models are compared and contrasted in order to build an integrative account of SDM.
2.4.1 Crickard, O’Brien, Rapp and Holmes (2010): SDM for psychotropic medication

The earliest framework for applying SDM to child and youth mental health was developed in the context of psychotropic medication (Crickard et al., 2010). This model was based on a review of the literature as well as work with clinicians, parents and young people. Three broad areas for SDM related to psychotropic medication were identified, including ‘setting the stage’, ‘facilitating SDM’ and ‘supporting SDM’.

During ‘setting the stage’, healthcare services should train clinicians in SDM to help them effectively collaborate with young people. Clinicians should also help young people and parents to define their preferences for involvement during appointments, while remaining aware that these preferences could change over the course of treatment. Lastly, clinicians and young people should set medication goals that are reviewed in order to monitor progress.

To support SDM, information should be comprehensible and accessible, with an emphasis on the side effects and outcomes related to the treatment. Peer support should also be offered to parents and young people, ideally before prescription appointments. Peer support can take on both formal and informal guises, such as a peer support worker or an internet chat room. Lastly, for successful SDM in clinics, buy-in and leadership are needed across all levels of the organisation.

The service’s support of the agenda and help with setting the scene are precursors for facilitating SDM. During appointments, clinicians should work to elicit any decisional conflict related to medications, as this may affect adherence to the treatment. An important step in this process is acknowledging that each stakeholder has expertise to contribute. Other important steps are documenting decisions and tracking progress against set goals. Clinicians should also work
with young people to establish tasks that will occur outside of the clinical setting. This includes identifying activities which will keep the young person well and helping the young person to think about monitoring and tracking their progress and side effects.

A strength of this model is that it incorporates both parents’ and young people’s views with regard to decision making about medication. It also examines goals in relation to medication, rather than focusing on medication as a way of reducing symptomology. Clinician training is also acknowledged as important for SDM, and workshops are suggested as a way of facilitating this. Additionally, this model emphasises that young people and parents need to take an active role in medication management outside of clinical sessions, which may enhance self-efficacy.

Limitations to this approach relate to resource issues. Within a UK setting, peer mentors are unlikely to be present in clinical settings to aid with decision making as a result of funding cuts. More informal sources of support may be biased toward particular medication options or less evidence-based interventions, which means that they would not necessarily present a balanced view to help a young person make an informed, preference-sensitive decision. Additionally, this model fails to account for disagreement between young people and parents and how to navigate this, and it is limited to the context of psychotropic medication. However, this model could be adapted to include other types of treatment.

2.4.2 Simmons, Rice, Hetrick, Bailey and Parker (2012): SDM steps in child and youth mental health

A model for SDM has been developed in Australia by Headspace, which is an organisation that provides early intervention services to young people and promotes mental health and wellbeing (Simmons et al., 2012). Aimed at
clinicians, but developed in conjunction with young people, this model outlines ten steps for ‘good’ SDM in youth mental health. First, the clinician should set the scene. This involves telling the young person and family that they can be involved and that they are experts in themselves. Second, the clinician should elicit the young person and family’s preferences on how they want to be involved. Third, the clinician should introduce psychoeducation to help the young person and their family understand the causes and symptoms of their presenting difficulty. Fourth, the clinician should outline the different options that are available for treatment. Fifth, the clinician should ask the young person and family how they would like to receive additional information about the presenting difficulty and inform them about options for treatment or support. Sixth, the clinician should discuss the risks and benefits related to the different treatments according to the available research evidence. Seventh, the clinician should explore the young person’s and family’s fears, expectations of treatment and their understanding of the presenting difficulty. Eighth, the clinician should ‘check in’ with the young person and family to ensure they have understood everything that has been discussed. Ninth, the clinician, young person and family should either make or defer making a decision. If a decision is not made during the appointment, a follow-up time to further discuss the decision should be arranged. Tenth, once a decision is made, the clinician should arrange a time to review the treatment and the presenting difficulty with the young person and family.

These authors also outline additional important factors which should be considered when working with children and young people (Simmons et al., 2012). One of these relates to the parents’ role in decision making, with the model stating that parents are likely to play an increased role in this process as the young person’s age decreases. Another is that clinicians should be flexible when using SDM, and they should adapt it as necessary to suit the young
person’s needs. Lastly, the authors highlight that the option of ‘watchful waiting’ should be explored, as it may enable the young person to seek help in the future if they are not yet ready for active treatment.

One strength of this model is the inclusion of watchful waiting as an option, as it is currently not mentioned in any other models of SDM. Research indicates that a proportion of young people with mental health difficulties recover without receiving treatment (e.g. Richardson et al., 2012), and the presentation of all the options, including not having treatment and monitoring symptoms, fits with the ethos of SDM. A further strength of this model is its emphasis upon adopting flexibility in approaching SDM and its acknowledgement of the particular challenges clinicians face when working with young people, including capacity and reading age. Another strength is that this model puts young people at the heart of decision making, and asks young people about their preferred level of involvement and what they would like their caregivers’ level of involvement to be. This empowering stance suggests that significance should be accorded to the young person’s views, which fits with the premise that most young people can and should be involved in decision making (Shaw, 1999). Lastly, explicit prompts are provided for ‘checking in’ with the young person and family. These prompts are likely to be useful in practice, as the way in which questions are asked can affect how and whether patients respond to them (McCabe, 2017). For example, the phrase ‘any questions?’ when used by clinicians may not open further dialogue, whilst ‘do you have any worries or questions about what was discussed today?’ is much more likely to elicit a response (McCabe, 2017).

There are some limitations to this model. While comprehensive in the number of steps that are provided, the detail provided for each step other than ‘checking in’ is sparse. It would be beneficial for this model to provide example quotes on how to present treatment options in neutral ways that avoid framing effects. While this model focuses on SDM for treatment decisions, it neglects other
decision-making topics, such as what the focus of the decision should be (e.g. treatment versus which presenting problem to focus on). The model also fails to acknowledge that preferences can change within a clinical session, and this is an aspect that has been included in more general models of decision making (Charles et al., 1999).

2.4.3 Westermann, Verheij, Winkens, Verhulst and Van Oort (2013): Counselling in Dialogue

‘Counselling in Dialogue’ (Westermann et al., 2013) is an approach developed in the Netherlands aimed at the parents of young people with mental health difficulties. It consists of three sections, including retrospection, discussion and treatment planning/policy. Retrospection aims to empower parents by tailoring the session to their needs. During discussion, results from tests and treatment options are discussed and parents’ values and preferences are established. Additionally, in order to facilitate understanding and a shared narrative between stakeholders, a visual aid is used in this approach to map the individual, social and environmental influences on the presenting difficulties. Lastly, in treatment policy/planning, treatment options are decided upon, any decisions or conflicts are recorded, subsequent appointments are arranged, and an agreement is made about who will inform the young person about the decision(s) reached.

A strength of this approach is that its developers explicitly followed the Ottawa Decision Support Framework (ODSF) (O’Connor, 2006). The ODSF (O’Connor, 2006) is a step-by-step approach to designing decision support interventions. It is underpinned by theories which have been agreed on by experts as factors which affect SDM (see Chapter 3 for a full account). This approach may be preferable to the conceptual models which have not incorporated factors that are known to influence decision making. An additional strength of this approach is that it has been rigorously evaluated. An RCT of ‘Counselling in Dialogue’ reported that parents who received the intervention were significantly more
likely to have reduced decisional conflict after their appointment and were more likely to accept the treatment recommended by the clinician (Westermann et al., 2013). Parents commented that they liked the visual aid and that it helped with information, and therapists found ‘Counselling in Dialogue’ convenient to use.

However, a limitation of this approach is that due to its focus on decision making between the parent and the clinician, it neglects the young person’s views, preferences and values. Instead, a decision is made by the parent and clinician about who should inform the child of the decision, which by that point has already been finalised (Westermann et al., 2013). Although the ages of the young people who participated in this evaluation ranged from two to 12 years and this could affect their participation in decisions, not including young people at all in the decision making process may violate their right to be involved as outlined in the CRC (1989).

2.4.4 Wolpert et al. (2014): SDM in Child and Adolescent Mental Health Services (CAMHS)

As part of a wider project aimed at improving SDM in CAMHS in England (Wolpert et al., 2014), a steering group of young people, parents, researchers and clinicians developed a model for SDM. This model was adapted from another model used in long-term conditions in which decisions may take place over a longer period of time, should be altered as needed, and where greater emphasis should be placed on patient self-management (Montori, Gafni, & Charles, 2006). In the original model, four steps were outlined for SDM. These included ongoing partnership, information exchange, deliberating on options and deciding/acting on a decision (Montori et al., 2006). The model that was adapted for child and youth mental health consisted of five steps. First, key problems and goals should be agreed between the clinician, young person and caregiver(s). Second, there should be an understanding of the options that are available. Third, there should be agreement on which option to try. Fourth,
progress related to goals and outcomes should be reviewed. The fifth step, if necessary, should involve making changes to the treatment or goals.

One strength of this model is that it considers decision making from a broad perspective focusing on different options rather than specific treatment decisions. This may be particularly important because of the wide range of decisions that often need to be considered in mental health (Freidl et al., 2016; Hamann et al., 2008; Slade, 2017). Moreover, although it was adapted from a chronic model for care, it highlights that mental health treatment is not the same as acute decisions faced in other settings. In this way, this model implicitly acknowledges how decisions and goals may change over time. Lastly, this model highlights the need for a consensus between the stakeholders on what to focus on before exploring options. However, it does not provide any detail on how to reach this consensus, nor what to do if a consensus cannot be reached.

Like the Simmons (2012) model, this model lacks detailed information on each step. However, unlike the Simmons’ model (2012), it does not include other salient aspects of SDM. These include the process of outlining the young person’s preference for involvement or the importance of psychoeducation in understanding the difficulty prior to the options being discussed.

2.4.5 Langer and Jensen-Doss (2016): SDM in youth psychotherapy

A six-step model for SDM in psychotherapy was developed in consultation with clinicians, parents and young people in the US by David Langer and Amanda Jensen-Doss (2016). The first step involves identifying the stakeholders who will be involved in the decision, how much influence each stakeholder will have and whether agreement needs to be reached before treatment is administered.

Next, the decision that needs to be made should be specified. This is divided into understanding the presenting difficulties that will be focused on, which stakeholders will be involved in psychotherapy and what type of psychotherapy
may be appropriate. This step is followed by exploring the available options, with a focus on a few ‘top’ options which the clinician should present to the young person and parents. This may include watchful waiting and investigating other options which may be available elsewhere. A discussion of the advantages and disadvantages of each option is the next step. This involves exploring each option in relation to the evidence base and in light of the young person and family’s values and preferences. Following this discussion, a preliminary treatment plan is assembled. When no clear preference is highlighted, the treatment plan should begin with the therapy option with the strongest evidence base. If the evidence base is lacking, the treatment plan should begin with the therapy the clinician feels most comfortable practicing, provided that there are no documented adverse effects. The last step involves monitoring the young person’s treatment progress and reviewing this throughout the therapy.

A strength of this model is the detail it provides within each step of the decision-making process. It also provides possible solutions to the challenges which may be faced in SDM. For example, it advocates using ‘the collaborative and proactive solutions approach’ (Ollendick et al., 2016) when stakeholder agreement cannot be reached (Langer & Jensen-Doss, 2016). Similarly to previously mentioned models and frameworks, this model also includes the option of watchful waiting.

However, a potential limitation of this model is that it directs clinicians to only reveal a few ‘top options’ for treatment. Whilst this may cause less anxiety and stress for young people and parents, it is grounded within a paternalistic model of care as it indicates that clinicians can make assumptions about what may be best for the patient without consulting them. The model also is limited to decisions related to psychotherapy. However, similar to the model by Crickard
et al. (2010), this model could be adapted or expanded to include other types of decisions.

2.4.6 Common Room Consulting (2017): The ‘Open Talk’ model¹

Another model for including young people with mental health difficulties in decision making is the ‘Open Talk’ model (Common Room Consulting, 2017). This model was developed from a review of the literature related to SDM in child and youth mental health and refined in collaboration with young people who are ‘experts by experience’. Its seven steps are outlined below.

The first step of this model involves a discussion with young people about how much influence they have over the decision that is to be made. This involves identifying whether the decision can be shared or whether it should be led by the professional or young person. The next step involves exploring the available options, including what may have been tried before along with the option of doing nothing. Following this, there should be a discussion of the pros and cons of options in relation to the evidence base. Then, there should be a discussion about values and preferences in light of the options, how these may impact on decisions and any worries or concerns the young person has. Following this, the clinician should express what they think would be best, outline any options that they cannot support and provide their justification for this.

Once a potential decision is reached, the clinician should determine the young person’s self-efficacy and whether any further support will be needed. If the young person does not feel able to proceed with the option, this model

¹ The PhD candidate (DH) is contributing to the ongoing evaluation of Open Talk.
highlights the need to reconsider and explore previous steps until an option is identified that works for both parties. The last step is to revisit the decision and decide how it can be put into practice. Before ending the appointment, a date should be set to review the decision.

A strength of this model is that it acknowledges that SDM is not a binary process, and that decisions may be led more by patients or professionals. Importantly, this model outlines the need to be explicit about whom, if anyone, will be leading the decision making process and the reasons for this. Moreover, similarly to Makoul and Clayman’s model (2006), this approach also highlights the importance of self-efficacy. It explains that without it or the necessary support structures, the ‘best options’ may not work. Lastly, this model does not approach decision making in a linear fashion and acknowledges that the topics of conversation in each step can impact upon each other. For example, if a decision cannot be reached, these steps need to be repeated.

This approach is limited by the lack of involvement of parents and guardians in decision making. These key stakeholders are only briefly mentioned during the discussion of influences on the young person’s difficulties. This may make this model less accessible for children and young people who want their parents or guardians to be involved in decisions about their care and treatment. Additionally, whilst the model allows for decisions to be led by patients or professionals, it does not provide criteria related to what should constitute a professionally led decision. This leaves this process open to tokenistic decision making, which runs the risk of professionals only involving young people on a superficial level or when they feel it to be appropriate.

2.4.7 Comparing different models of SDM

Six models with the aim of facilitating SDM in child and youth mental health have been outlined above. The term SDM appears to be fluid, as different
models target different decisions and stakeholders. To gain a conceptual understanding of the different approaches, the models are compared against Makoul and Clayman’s (2006) integrative framework (see Table 2-1). Similarities and differences between the models are also explored.

Two elements were present in most models. These were ‘values and preferences’ and ‘making or deferring a decision’. Five models explicitly outlined the importance of discussing patients’ values when making or deferring a decision (Common Room Consulting, 2017; Crickard et al., 2010; Langer & Jensen-Doss, 2016; Simmons et al., 2012; Westermann et al., 2013), while one did not mention this aspect (Wolpert et al., 2014). Five models explicitly outlined the need to make or defer a decision (Common Room Consulting, 2017; Langer & Jensen-Doss, 2016; Simmons et al., 2012; Westermann et al., 2013; Wolpert, et al., 2014), while one model did not include this (Crickard et al., 2010).

The prevalence of these elements differs from the findings of a systematic review which produced the integrative model of SDM (Makoul & Clayman, 2006). The original review focused mainly on adult physical health studies and identified the most common essential elements as being: eliciting patient values/preferences, presenting options, discussing pros/cons, and doctors providing knowledge/recommendations. Conversely, the most common essential elements for SDM identified in child and youth mental health were: presenting options, arranging follow up, eliciting patient values/preferences and making or deferring a decision. These differences in elements may be due to the presenting problems and context. For example, arranging follow up, along with making or deferring a decision, fits with the idea that mental illness is not acute and that decisions can be reviewed or amended during future appointments.
An existing similarity across the models and approaches is that they have all been developed in Western societies, including the US (Crickard et al., 2010; Langer & Jensen-Doss, 2016), Australia (Simmons et al., 2012), the UK (Common Room Consulting, 2017; Wolpert, et al., 2014) and the Netherlands (Westermann et al., 2013). This may account for why models of SDM tend to align with the emphasis in Western cultures upon liberty and autonomy (Markus & Kitayama, 1991; Oishi, 2000; Shweder, Mahapatra, & Miller, 1987). However, the prominence of models from the US is surprising given that it is one of only two countries that has not signed or ratified the CRC (1989) (UN News, 2015), which has been instrumental in shaping children and young people’s rights in other countries (Alderson & Montgomery, 1996).
## Table 2-1 SDM models in child and youth mental health compared with Makoul and Clayman’s (2006) essential elements

<table>
<thead>
<tr>
<th>Model</th>
<th>Values/preferences</th>
<th>Options</th>
<th>Knowledge or recommendations</th>
<th>Make/defer decision</th>
<th>Define/explain problem</th>
<th>Check understanding</th>
<th>Pros/cons</th>
<th>Self-efficacy</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crickard et al. (2010)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Simmons et al. (2012)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Westermann et al. (2013)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Wolpert et al. (2014)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Langer et al. (2016)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Common Room Consulting (2017)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>
One difference between the models is the varying emphasis on the particular stakeholders and their roles in decision making. Four models highlight that young people, parents and clinicians are all stakeholders in SDM (Crickard et al., 2010; Langer & Jensen-Doss, 2016; Simmons et al., 2012; Wolpert, et al., 2014). One model suggests that parents and clinicians are stakeholders (Westermann et al., 2013), and another suggests that young people and clinicians are stakeholders (Common Room Consulting, 2017).

Having multiple stakeholders leads to the challenge of balancing potentially contradictory values and preferences (Lipstein et al., 2016). This is not a problem when there is agreement between all parties; however, research suggests that the majority of young people, parents and clinicians do not agree on what should be addressed during treatment (Hawley & Weisz, 2003). Two models of SDM address whether or not agreement should be reached between stakeholders prior to proceeding with a given option. One of these models implies that agreement is needed before proceeding (Wolpert et al., 2014) whilst the other suggests that a conversation should take place about whether or not agreement is needed prior to proceeding with the treatment (Langer & Jensen-Doss, 2016).

Closely aligned with this is the influence of each stakeholder on the decision-making process. Two models explicitly acknowledge the influence of the various stakeholders. The Langer and Jensen-Doss approach to youth psychotherapy highlights the need to be explicit about stakeholder influence from the outset of the decision-making process (Langer & Jensen-Doss, 2016), as does the Open Talk model (Common Room Consulting, 2017). Exploring or being explicit about the degree of influence a young person has over a decision is important, as it allows young people to know how and when they can be involved (Paul, 2004). However, care should be taken to ensure that decisions are not being made
based solely on what the parent or clinician wants, but rather on what is in the child’s best interests.

Notably, self-efficacy is neglected in the majority of the models. Only Open Talk (Common Room Consulting, 2017) outlines the need for a conversation about whether or not the young person feels able to go ahead with treatment. As self-efficacy has been shown to mediate and predict outcomes in psychotherapy (Brown et al., 2014; Maric, Heyne, Mackinnon, Van Widenfelt, & Westenberg, 2013), it is an important consideration in SDM. Not including this element within the decision-making process may cause a young person or family to decline a particular option or drop out of treatment because they do not feel that they have self-efficacy.

Similarly, capacity has been described by clinicians as a potential barrier to including young people in decisions about care and treatment (Abrines-Jaume et al., 2016; Simmons, Hetrick, & Jorm, 2013; Tam-Seto & Versnel, 2015). Thus, it is of interest that the majority of models do not refer to the young person’s capacity to participate in SDM. Only Simmons et al. (2012) outline that clinicians should consider cognitive capacity when engaging young people in care and treatment decisions. That capacity is not cited in most models could be perceived as positive, as it is possible that the model developers do not view capacity as a barrier to SDM. This fits with previous assertions that most young people should be able to be involved in care and treatment decisions regardless of capacity (Alderson & Montgomery, 1996; Paul, 2004; Shaw, 1999). However, without formally mentioning capacity or ways in which it can be addressed, these models may lead clinicians to assume incapacity and omit the young person from the decision-making process.
2.4.8 Summary

Six models of SDM in child and youth mental health have been investigated. Each model conceptualises SDM differently in terms of what is involved and how to undergo the process. A comparison of these models with Makoul and Clayman’s (2006) integrative model resulted in the identification of differences with regard to the clinician’s knowledge and recommendations, pros/cons, arranging follow-up and making or deferring decisions. These differences could reflect the unique considerations of SDM within child and youth mental health. The pertinent differences across models included who the decision makers were, the influence of multiple stakeholders, the types of decisions made, the role of capacity and the young person and exploration of the young person’s self-efficacy.

One similarity across all the models was that they were developed within a Western cultural setting. This corresponds with assertions that Western societies value individualism and prioritise liberty, autonomy and choice. Specifically, it has been suggested that children and young people learn about the rights and values associated with their culture early on. For example, in Western society, values related to choice are subtly afforded to young people when they are allowed to make choices including what to wear, eat and when their parents knock on the door before entering the child’s room (Shweder et al., 1987). This contrasts with Eastern society, whose collectivist values place importance on interdependence, community, and honour (Shweder et al., 1987). This may mean that the current models do not fit with those from Eastern backgrounds and cultures.

The role of options and arranging follow up were also present across all the models, which suggests that these may be particularly important for SDM in child and youth mental health. Additionally, patient/parent values and making or
deferring a decision were also found in the majority of the models, which implies that these constructs could also be an important feature of SDM. Identifying the most prevalent essential elements across all of the models provides a useful working definition for SDM which will be applied to this thesis (see section 3.5).

2.5 Shared decision making in child and youth mental health: What is the evidence?

The recent application of SDM to child and youth mental health has resulted in a smaller body of research in this area compared to other domains. Findings from observational studies indicate that high levels of SDM are associated with lower levels of symptomology or impairment in young people (Butler, 2014; Butler, Weller, & Titus, 2015; Fiks, Localio, Alessandrini, Asch, & Guevara, 2010), a lower perceived sense of stigma in receiving a mental health diagnosis (Butler, 2014), a greater likelihood of having all mental health needs met (Golnik, Scal, Wey, & Gaillard, 2012), a greater likelihood of no school or extracurricular impairments (Butler et al., 2015) and higher levels of satisfaction (Golnik et al., 2012). However, these studies rely on parental reports of SDM which may not accurately reflect the opinions or lived experiences of young people. This may be particularly likely if there is any disagreement with regard to presenting difficulties or treatment prior to the treatment decision being made (Hawley & Weisz, 2003; Yeh & Weisz, 2001).

In the only observational study to investigate both parent- and child-reported SDM, findings indicated that higher reported SDM from both stakeholders was associated with higher levels of child- and parent-reported improvement with psychosocial difficulties (Edbrooke-Childs et al., 2015). Further analysis indicated that child-reported experiences of SDM were only associated with improvements in psychosocial difficulties when parents also reported higher levels of SDM. This led the authors to conclude that both young people and
their caregivers should be involved in decision making in order for treatment outcomes to improve (Edbrooke-Childs et al., 2015).

Other studies have focused on the effect of interventions designed to improve SDM. A recent scoping review identified 22 different SDM interventions in child and youth mental health that fell under six overarching approaches (Cheng et al., 2017)\(^2\). These included DAs, mobilising young people and parents to engage, models and therapeutic approaches, discussion prompts, psychoeducational information, and action planning and goal setting. The research evidence for each, where available, is explored below.

### 2.5.1 Decision aids

Seven DAs were evaluated in the review by Cheng et al. (2017). Two were for depression (Simmons, 2011; Simmons et al., 2016), two were for autism (Anixt, Meinzer-Derr, Estridge, Smith, & Brinkman, 2015; Grant, 2016), two were for ADHD (Brinkman et al., 2013; Ossebaard, van Gemert-Pijnen, Sorbi, & Seydel, 2010), and one was not specific to a presenting difficulty (Evidence Based Practice Unit, 2015).\(^3\)

The two DAs for young people with depression were both developed in Australia. They were electronic and followed the same format. This involved outlining the treatment options, the probabilities of getting better, the side effects, discussion points for deciding what matters most and the process of

---

\(^2\) The PhD candidate (DH) is joint first author on this scoping review.

\(^3\) This decision aid was developed by the unit in which the PhD candidate (DH) works. However, the PhD candidate played no part in its development or evaluation.
getting ready to make a decision. One was for young people with mild-moderate depression (Simmons, 2011), while the other extended to young people with severe depression (Simmons et al., 2016).

The acceptability and usability of the DA for mild-to-moderate depression was evaluated as part of a doctoral dissertation thesis. All clinicians (n = 3) and young people (n = 5) found the DA to be acceptable. Most clinicians and young people also found the DA to be usable, and one suggestion for improvement was to make the side effects section more concise as it was felt that there was too much information (Simmons, 2011). The other DA for severe depression was evaluated using an uncontrolled pre-post cohort study (Simmons et al., 2016). The findings indicated that after using the DA, young people were more likely to make a guideline-concordant decision, felt more able to make a decision, were satisfied with the decision they made and scored lower on decisional conflict.

There are several strengths to these studies. Most importantly, this was the first time a DA was used and evaluated with young people with a mental health difficulty. Moreover, the authors highlighted that young people were involved in the design and content of the DA, which may have aided its acceptability and usability (Simmons, 2011; Simmons et al., 2016). However, the lack of a control group in the second study means that it is difficult to attribute the changes to this DA as opposed to other factors (Simmons et al., 2016).

Both of the DAs developed for autism were aimed at the parents of young people. One of these DAs, developed in Australia, outlines psychotherapeutic and behavioural interventions for difficulties related to autism (Grant, 2016). The other DA, developed in the US, outlines medication options for challenging behaviour related to autism (Autism Speaks, 2011).
For the psychotherapeutic and behavioural interventions DA, parents were presented with a series of questions on a computer screen related to various areas of their young person’s life and asked to rate the importance of each area. The results of the ten best-fitting interventions based on their answers were then displayed after the questions were completed (Grant, 2016). An evaluation of this DA using a cluster RCT design found no difference in the scores between the intervention and control groups related to decisional conflict (Grant, 2016). A strength of this study was its methodological design which used an RCT as well as validated measures. However, as the authors note, the small sample size means that the study was likely to be underpowered, which makes it difficult to detect subtle effects in the use of the DA.

The medication for challenging behaviour DA provides parents with information on autism and medication, a decision table examining what is involved and the pros and cons of each medication (Autism Speaks, 2011). To use this DA, parents first supply information related to their personal values, risks and benefits. Then, they state a preference for treatment and indicate how certain they are about this preference. Findings from an RCT of this DA, which were first presented at a conference, indicated that parents who received the intervention were more likely to be involved in SDM, to have less decisional conflict and to feel that areas they considered to be important were addressed within the treatment plan (Anixt et al., 2015). However, these findings should be treated cautiously as the trial was ongoing at the time these data were collected and the study has yet to be published. Moreover, it has been noted elsewhere that there can be differences in findings between conference papers and published articles on the same study (Balshem et al., 2013).

Two DAs for ADHD have also been developed and evaluated. One involves choosing between medication options for ADHD (Brinkman et al., 2013). The
The medication for ADHD DA, developed in the US, consists of a series of choice cards. These cards detail medication information related to daily routine, how often medication needs to be taken, the cost of medication, the probability of improvement, and the side effects of the medication (Brinkman et al., 2013). A clinical control trial found that parents who used the medication choice cards felt more involved in SDM, had more knowledge about treatment options and experienced less decisional conflict than the control group (Brinkman et al., 2013). This study was methodologically strong in some respects as it used validated measures and had a control group. However, sampling for the study relied on the self-selection of clinicians to take part, which may indicate that only those who were keen to implement SDM participated in this study. It is also unclear which cards were most useful and whether any of the cards could be adapted or omitted for a UK population (e.g. the ‘cost’ card).

The second DA was available online (Ossebaard et al., 2010). Findings from a pre-post survey associated with the DA found no differences in decisional conflict (Ossebaard et al., 2010). However, findings from this study were limited by extremely high dropout rates (94%) at follow-up, the self-selection of parents who accessed the DA and questionnaires, and the lack of a control group.

The last DA was not designed for a specific presenting difficulty (Evidence Based Practice Unit, 2015). Developed in the UK, this DA formed part of a suite of shared-decision-making tools available online and in paper-based form. The DA allows the young person to define or identify a problem and write in the pros and cons related to any decision they choose to focus on during the appointment. The findings from a questionnaire that was administered after
young people used the DA indicated that the young people felt the DA encouraged their communication with clinicians (Ellis, Wolpert, Kay, & White, 2016). A strength of this tool is that it is not limited to one presenting difficulty, which may make it more accessible to a wider range of young people. However, this means that it scores poorly on quality assessment criteria for DAs due to its lack of specificity (The Ottawa Hospital Research Institute, 2016). As this DA formed part of a larger suite of tools, it is not possible to unpick from the report which specific tools helped young people’s communication and which did not. Moreover, this report was produced internally by developers, was not subject to peer review, and used a small convenience sample, which means that findings should be treated with caution and may not be transferrable.

2.5.2 Mobilising young people and parents to engage

Two approaches to shared decision making aimed to mobilise young people and parents to engage in SDM (Cheng et al., 2017). These were a pre-conference workshop in the US designed to increase young people’s motivation to make decisions (Adelman, MacDonald, Nelson, Smith, & Taylor, 1990) and an approach, also from the US, in which parents were explicitly told that they could choose the option they wanted (He, Gewirtz, Lee, Morrell, & August, 2016).

The pre-conference workshop aimed to provide young people with learning disabilities with strategies to help them to talk to adults and express their opinions (Adelman et al., 1990). An RCT found no differences between the intervention, comparison and control groups in their participation in decision making (Adelman et al., 1990). The use of an RCT, as well as an active comparison and control group, could be considered a strength of this study as it allowed researchers to compare whether the provision of any type of additional support affected findings. However, validated measures for participation in
decision making were not used and confounding variables were not examined, both of which may have affected the results of this study.

The parental preference choice study, conducted in the US, outlined four different options for the treatment of young people’s challenging behaviour and allowed parents to choose their preferred treatment (He et al., 2016). In an RCT of this intervention, findings indicated that parents who were given their preferred choice were significantly more likely to remain in treatment (He et al., 2016). A strength of this study is that it used a double-randomised preference trial. This increased external validity compared to an RCT, whilst it also allowed for comparison between choice, engagement and outcomes (He et al., 2016). However, given the multiple interventions and small sample size within each arm, the trial may have been underpowered. This reduces the likelihood that a statistically significant result reflects a true effect.

2.5.3 Models or therapeutic approaches

The only therapeutic approach to SDM with an evaluation component is Counselling in Dialogue (Westermann et al., 2013), which has been described above (see section 2.4.3).

2.5.4 Discussion prompts

The resource in which discussion prompts form a central feature is the QPL (Ahmed, McCaffery, & Aslani, 2015). Developed in Australia, this discussion prompt consists of 88 potential questions, which were provided before the appointment, for parents of young people with ADHD to ask clinicians. Questions fell under the domains of understanding ADHD, diagnosis, types of treatment, types of support, the healthcare team, managing and monitoring ADHD, future expectations and support and information. A pre-post evaluation
of the QPL found a parent-reported decrease in anxiety, an increase in parent-reported satisfaction with their decision-making role, and an increase in parent-reported satisfaction with the information that was elicited using the QPL. Moreover, clinicians viewed the QPL as acceptable and thought that it was helpful for parents, as they seemed better able to manage and navigate the conversation (Ahmed et al., 2017). However, as the QPL was trialled in a private clinic and the evaluation sample size was small, the findings are not likely to be representative of the wider population.

2.5.5 Psychoeducational information intended to facilitate SDM

Two approaches used psychoeducational information to facilitate SDM (Cheng et al., 2017). One approach was a website, ‘My CAMHS Choices’, which detailed what service users could expect from CAMHS and emphasised collaboration and decision making (Evidence Based Practice Unit, 2014). The other was a medication passport which aimed to increase SDM in relation to psychotropic medication (Murphy, Gardner, Kutcher, Davidson, & Manion, 2010). Both were designed for young people.

The ‘My CAMHS Choices’4 website contained information about services, as well as a set of videos for young people detailing what happens during sessions, different types of help and support available, having choices and what good and bad appointments in CAMHS look like (Evidence Based Practice Unit, 2014). Findings from a small-scale evaluation of ‘My CAMHS Choices’ suggested that young people felt the website encouraged them to attend

4 This web portal was developed by the unit in which the PhD candidate (DH) works. However, the PhD candidate played no part in the web portal’s development or evaluation.
appointments, to express their own opinions, and to ask questions. Clinicians reported that they felt this resource could directly support informed choice (Kyrke-Smith & Edbrooke-Childs, 2014). Similarly to the previous EBPU SDM tool report (Evidence Based Practice Unit, 2015), this report was also produced internally and subject to a small sample size.

The other approach was the ‘Med Ed’ passport (Murphy et al., 2010). This was a paper-based booklet that provided information about different types of medication for presenting difficulties and frequently asked questions. It also contained a section on discussion prompts for young people to ask clinicians and a tool tracker for medication management. An independent evaluation of the ‘Med Ed’ passport found that young people thought it could be useful when discussing medication options with a clinician (Sundar & Wilson, 2009). Whilst independently evaluated, the ‘Med Ed’ passport sample was, like the other tools outlined here, small. This means that findings should be treated with caution.

2.5.6 Action Planning and goal setting to facilitate SDM

One resource, entitled ‘goal-based outcomes’ (GBOs), evaluated goal setting and action planning as a way to facilitate SDM in child and youth mental health (Law & Jacob, 2015). Goal-based outcomes are a technique which aims to facilitate collaboration with young people and families. They are not attributable to any one model or approach, but instead advocate the setting and reviewing of goals as a central part of therapeutic work. This facilitates SDM, as it allows for the connection of the young person’s goals with the clinician’s skillset and clarifies with which areas the service can help (Law & Jacob, 2015). These authors also assert that it allows for discussion concerning what the young person and clinician can achieve together. The APA psychotherapy taskforce found that goal consensus is likely to be an effective element of the working relationship (Norcross & Wampold, 2011).
Whilst GBOs can facilitate SDM, there is little evidence of their impact in youth clinical populations. To date, research on GBOs and young people has tended to focus on the goals young people set as part of treatment (Pender, Tinwell, Marsh, & Cowell, 2013; Rupani et al., 2014; Troupp, 2013) or how goals may link to measures (Jacob, Edbrooke-Childs, Law, & Wolpert, 2015). There is some research to suggest that GBOs may be more relevant to young people’s changes in daily functioning and satisfaction with care at follow-up than other factors such as difficulties or their impact (Edbrooke-Childs, Jacob, Law, Deighton, & Wolpert, 2015). In adult clinical populations, a meta-analysis found that goals help to form a collaboration between individuals to undertake work together, and that outcomes improve the more these goals are agreed upon (Tryon & Winograd, 2011). However, as this latter study was conducted with adult individuals in psychotherapy, the perspectives of stakeholder triads or people with limited capacities remain unclear.

### 2.5.7 Summary of interventions

Whilst a number of interventions to improve SDM have been developed and evaluated, most are not within a UK setting and many suffer from poor methodological design. Moreover, measures aimed at young people have not been validated or tested, which means that findings should be regarded tentatively (Cheng et al., 2017). These findings contrast with studies exploring SDM interventions in adult mental health (see section 1.5), where validated measures were used in the majority of studies and the methodological design was generally more robust.

It appears that there are a number of interventions and tools that are currently being used to facilitate SDM in child and youth mental health. There are clusters of interventions focused around ADHD and, to a lesser degree, autism and depression. The use of DAs appears to be more prominent than other
interventions that promote SDM. Across the majority of approaches and interventions, research and evaluations indicate that these methods are associated with at least one positive outcome. However, the particular outcomes vary across the studies.

Grouping interventions by approach, whilst useful for conceptualisation, may not be the best way to understand the connection between intervention and outcome. Within each approach there is considerable variation with regards to mechanisms for change and content. Understanding what these mechanisms and content are and how these may affect the outcome could help to explain the differences between the effectiveness of each intervention. Similarly, the underlying theories of interventions should also be examined, given the possible links between theory and intervention effectiveness (Albada, Ausems, Bensing, & van Dulmen, 2009; Noar, Benac, & Harris, 2007).

2.6 Barriers and facilitators to including young people in care

Despite studies showing that there are some potential benefits of SDM, implementation still remains a challenge. A recent qualitative review exploring barriers and facilitators to person-centred care in child and youth mental health identified multiple factors that affect person-centred care across the healthcare system (Gondek et al., 2016). This included professional factors, patient/carer factors, relationship factors, service-level factors and contextual factors. However, as person-centred care is broader in scope and covers other concepts such as empowerment, self-management and personalised budgets

5 The PhD candidate (DH) is an author on this paper.
Prominent professional-level factors that were barriers to SDM included a lack of information sharing with young people and parents (Iachini, Hock, Thomas, & Clone, 2015; Simmons, Hetrick, & Jorm, 2011; Simmons et al., 2013), and the professional failing to listen to, validate or respect the young person and family (Offord, Turner, & Cooper, 2006; Pelto-Piri, Engström, & Engström, 2013; Pycroft, Wallis, Bigg, & Webster, 2013; Simmons et al., 2011). Both of these could also be facilitators to SDM. Another professional factor was related to the amount of effort, trust and flexibility the clinician was willing to invest in the session, which facilitated SDM when it occurred (Abrines-Jaume et al., 2016).

Regarding patient/carer factors, a barrier to involvement was the young person lacking the capacity to make a shared decision (Simmons et al., 2011, 2013; Tam-Seto & Versnel, 2015). Conversely, parental involvement in decision making was often seen as a facilitator, with young people trusting parental judgement when they were unable to make decisions themselves (Iachini et al., 2015; Kovshoff et al., 2012; Oruche, Downs, Holloway, Draucker, & Aalsma, 2014; Tam-Seto & Versnel, 2015). However, some young people outlined that parents could become too involved, which could result in the young person feeling left out of the conversation (Simmons et al., 2011).

The quality of the relationships between young people, parents and clinicians was frequently mentioned as a factor influencing involvement. When young people and families reported having a strong relationship with their clinician, this was seen as a facilitator to SDM (Oruche et al., 2014; Pelto-Piri et al., 2013; Pycroft et al., 2013; Tam-Seto & Versnel, 2015). However, the same studies highlighted that a poor relationship could be a barrier, particularly when young people and parents did not feel supported. In a similar vein, communication
between the clinician and other stakeholders was seen as both a barrier and facilitator, which depended on the presence of communication and its quality (Pycroft et al., 2013; Simmons et al., 2011).

For service-level factors, a lack of resources was commonly highlighted by clinicians as a barrier to SDM (Oruche et al., 2014; Pelto-Piri et al., 2013; Pycroft et al., 2013; Simmons et al., 2011, 2013), as well as a lack of flexibility from the service regarding treatment choice and provision (Simmons et al., 2011, 2013). Few contextual factors emerged; however, an underdeveloped evidence base for some options was seen as a barrier by clinicians (Simmons et al., 2013). Another potential barrier was the limited scope of what services could offer parents and guardians due to how funds were allocated (Simmons et al., 2013).

Whilst providing insight into barriers and facilitators for SDM, these studies are not without their limitations. The majority were conducted outside of a UK setting, which means that differences related to healthcare systems may have influenced findings. Moreover, many did not specifically intend to examine barriers and facilitators, but rather experiences, which means that some may have been missed. The paucity of research on this topic warrants further investigation if a tool to facilitate SDM is to be successfully implemented. Notwithstanding this, these qualitative studies do provide some preliminary understanding into the process of SDM and the factors which may affect it.

2.7 Conclusion

Shared decision making in children and young people’s healthcare is a more recent development than in adult settings. However, it is underpinned by similar clinical, ethical and resource drivers. Developments in this field have relied on other marginalised adult groups gaining rights (Farson, 1974; Goldstein &
Drotman, 1977; Gottlieb, 1973), scientific advances related to how young people interact with the world (James & Prout, 1990) and developments in thinking and research regarding how young people develop rights and morality (Melton, 1983). Legal and policy documentation have subsequently given children and young people greater influence over their treatment, with young people now able to consent to treatment, in certain circumstances, without parental consent (Gillick vs West Norfolk and Wisbech Area Health Authority, 1985). Moreover, policy and legal documentation outlines that all children and young people have a right to be heard and to be included in care and treatment decisions (e.g. Chief Medical Officer’s Annual Report, 2012; Department of Health, 2015).

As with adults with mental health difficulties, whether young people have the capacity to be involved in decision making has been questioned. This may be particularly challenging in the case of young people with mental health difficulties, who are considered by some to be ‘doubly incapacitated’ (Coppock, 2005, p. 150; LeFrançois, 2008). The research on capacity has mainly focused on consent to inpatient treatment, resulting in mixed findings with regard to whether and when young people can give informed consent (Billick et al., 1998; Casimir & Billick, 1994; Kaltiala-Heino, 2010; Lurie et al., 2009). It has been posited that different factors may affect this. However, there is research to suggest that in outpatient settings, young people with ADHD and parents may have similar levels of understanding when it comes to medication (Schachter et al., 2011). Importantly, there is growing recognition that factors other than capacity, such as experience, understanding, social environment and relationships, need to be examined in relation to young people’s decision making (Alderson, 2017; Alderson & Montgomery, 1996). Additionally, the role of the family is important (Lipstein et al., 2016). However, balancing multiple
stakeholder beliefs and possible divergent views, can lead to tensions regarding how to proceed (Hawley & Weisz, 2003; Lipstein et al., 2016).

Models of SDM specific to child and youth mental health have increased in quantity over the last eight years. Models differ in terms of who the decision maker is, the types of decisions being made, the young person’s capacity and whether self-efficacy is mentioned. All of these models come from Western countries and place prominence on the following elements: the importance of options, arranging follow up, patient/parent values and making or deferring a decision. Interestingly, models in child and youth mental healthcare differ from the integrative model of SDM that was outlined in Chapter 1 (see 1.3.2.4), which was based on studies with adult populations. This may highlight key differences in how decision making occurs in child and youth mental health settings when compared to adult settings due to issues such as capacity or the presence of multiple stakeholders.

A number of interventions have also been developed to facilitate SDM in child and youth mental healthcare. There appears to be a trend towards developing DAs as well as a focus on externalising difficulties. Compared to adult mental healthcare, there are a lack of studies that robustly evaluate these interventions. However, as in adult mental health, evaluations of youth mental health SDM interventions demonstrate that in some instances, approaches can be associated with at least one positive outcome. However, what this outcome is varies according to the study under examination.

Whilst SDM in the UK is gaining momentum, the majority of interventions, as well as research into outcomes, barriers and facilitators, have been conducted abroad where there are stark differences in healthcare settings (e.g. Simmons et al., 2011, 2013). Moreover, interventions and research tend to focus on parents rather than young people (e.g. Butler, 2014; Butler, Elkins,
Kowalkowski, & Raphael, 2014; Butler et al., 2015; Westermann et al., 2013). Consequently, through a series of studies, this thesis aims to contribute to the understanding of SDM in the UK by including perspectives from young people and parents. Through this work, an intervention for promoting SDM will be developed. The next chapter outlines the intervention development framework and the methodology employed within this thesis.
Chapter 3 Intervention development and thesis methodology
3.1 Introduction

This chapter details the process of developing the intervention and methodology for this thesis. It begins by outlining the MRC guidelines (Craig et al., 2008, 2013) which are frequently used to design and develop interventions. The limitations of the MRC guidelines are discussed with a focus on theory and the process of choosing intervention content. Following this, theories used in SDM interventions are explored. The chapter then describes the BCW (Michie, Atkins, & West, 2014) and explains how its application to MRC guidelines is a potential solution to the limitations cited above. Next, a working definition of SDM is proposed and the epistemological stance taken by the PhD candidate is stated. Finally, an outline of each empirical study is provided referencing how each fits within the framework of this thesis and contributes to the development of an intervention to facilitate SDM.
3.2 Developing an intervention

There is no set distinction between what makes an intervention ‘simple’ or ‘complex’ (Craig et al., 2008). ‘Complex’ interventions tend to have a number of interacting components and potentially target multiple behaviours, outcomes, groups or organisations (Craig et al., 2008). Therefore, few interventions are ever truly simple, but instead differ in levels of complexity.

The process of designing and evaluating complex interventions within healthcare research is fraught with difficulties. The inadequate use of theory, a lack of feasibility or pilot studies and difficulty implementing interventions in real-world settings have all hindered this process (Craig et al., 2008; Medical Research Council, 2000). To counteract some of these challenges, the Medical Research Council proposed a framework for developing and evaluating complex interventions consisting of four segments, which are detailed below in Figure 3-1.

![Figure 3-1 MRC guidelines for developing and evaluating complex interventions (Craig et al., 2008).](image)

Early versions of these guidelines assumed that this process proceeds in a series of sequential steps, starting with development and progressing to
feasibility and piloting, and finally, evaluation (Medical Research Council, 2000). However, subsequent guidelines have amended this by outlining the need for a more integrated and versatile approach. In this model, some steps may occur simultaneously and learning from one step may lead developers to revisit and refine other steps (Craig et al., 2008, 2013). An important consideration in the updated guidelines is that interventions may not function without taking into account the context in which it is implemented.

Whilst MRC guidelines help developers consider key elements during the design, implementation and evaluation of interventions (Craig & Petticrew, 2013), more guidance within this process may be needed (Correy, Clarke, While, & Lalor, 2013). One area where this is apparent is in the application of theory to interventions. Despite the emphasis in the MRC guidelines on the importance of theory, it is still being omitted or inadequately incorporated into interventions (Painter, Borba, Hynes, Mays, & Glanz, 2008; Prestwich et al., 2014). Moreover, even when theory is used, developers tend to employ one of four main theories (Davis, Campbell, Hildon, Hobbs, & Michie, 2015). These authors state that one theory on its own may not be appropriate to address key mechanisms of change; particularly in the case of complex interventions within which there are multiple components (Davis et al., 2015).

The use of theory is important as it not only allows for the identification of causal determinants of change and mediators, but it also allows a space in which theories can be tested, evaluated, refined or discarded in relation to the phenomena studied (Davis et al., 2015). Multiple reviews indicate that the use of theory can lead to more effective intervention outcomes (e.g. Albada et al., 2009; Noar et al., 2007). However, other studies have not found this (Gardner, Wardle, Poston, & Croker, 2011). Beyond the incorporation of theory, there is little information in the MRC guidelines about how to model appropriate
intervention content, nor is there one common framework for identifying intervention content within the literature (Correy et al., 2013).

3.3 Use of theory in SDM interventions

Theory in relation to SDM interventions has been examined in multiple reviews (Bowen et al., 2006; Durand, Stiel, Boivin, & Elwyn, 2008; Sheehan & Sherman, 2012), however, all these are situated in adult health. One review, which focused on cancer screening interventions, identified fourteen decision support interventions, of which only five had an explicit theoretical underpinning (Bowen et al., 2006). Most interventions employed more than one theory, and the most frequently applied theory across interventions (n = 3) was the Transtheoretical Model of Change (Prochaska & Velicer, 1997). These authors found no difference in relation to intervention efficacy between studies that had used an explicit theoretical framework and those that had not. This may suggest that some of the theories examined may not make a difference when it comes to some decision making interventions. However, in this review the degree to which theory was rigorously applied in individual studies was unclear, particularly when there was more than one theory.

Another review across different healthcare settings found that 17 out of 55 decision support interventions referenced theory as part of their design or development process (Durand et al., 2008). Of the interventions that explicitly referenced theory, five referred to Expected Utility Theory (Bernoulli, 1954), whilst four outlined the ODSF (ODSF; O’Connor, 2006) as the basis for their intervention. Whilst effectiveness was not investigated here, the authors noted that the application of explicit theory to interventions was often poor (Durand et al., 2008). This calls into question whether most interventions can actually be described as being theoretically derived. The review also highlighted that
interventions were often not subject to field testing prior to RCTs, meaning that acceptability and usefulness could not have been ascertained beforehand.

A review of computer-based DAs also found that the majority of these tools were not underpinned by explicit theory (Sheehan & Sherman, 2012). The computer-based DAs that were developed from theory mainly utilised Expected Utility Theory (Bernoulli, 1954) or the ODSF (O’Connor, 2006). When DAs underpinned by explicit theory were compared to those that were not, there was tentative support that the application of the ODSF (O’Connor, 2006) increased the accuracy of DAs in comparison to those that did not use this framework. However, as noted by Durand et al. (2008), the degree to which theory was specifically followed and implemented in an intervention was unknown.

3.3.1 SDM theories: A closer examination

Within the field of SDM, a few key theories have been used in the design and development of interventions (Bowen et al., 2006; Durand et al., 2008; Sheehan & Sherman, 2012). Some theories have been used on their own to develop SDM interventions, whilst in other cases, one theory is combined with other theories. The next section explores the theories used in SDM interventions, provides examples of when these are used, and supplies a critique of them.

3.3.1.1 Expected Utility Theory and Decision Analysis

Expected Utility Theory (Bernoulli, 1954) is a normative theory of rational choice that attempts to explain how people make choices under conditions of uncertainty. This theory states that individuals assign values to both the probability of an event occurring and the outcome of that event. Afterward, individuals choose the option with the highest expected utility, which can be expressed as the sum of the products of probability and utility over all possible
outcomes. Expected Utility Theory (Bernoulli, 1954) has been used by clinicians in clinical practice for some time, mainly in the form of decisional analysis (Howard & Matheson, 1984). In this context, doctors rate the importance of the outcomes, the risks and the effectiveness of treatments. From these ratings, they can then calculate the ‘optimal choice’ based on the expected maximum utility (Ledley & Lusted, 1959). Decision making interventions underpinned by this theory usually include decision trees, in which each option is assigned utility based on information provided by the patient. An example of the application of this theory occurred with hypertensive adults deciding whether or not to receive treatment. In an evaluation of this intervention, the patients who used decision analysis were found to have reduced decisional conflict and increased patient knowledge (Montgomery, Fahey, & Peters, 2003).

Critics of normative theories of SDM point out that this theory applies a ‘top-down approach’ to how SDM should take place under ideal circumstances. In the context of real-world settings, individuals may not have the cognitive or intellectual capacity to process all the necessary information, and instead may employ other cognitive processing mechanisms such as heuristics (Simon, 1955). Moreover, critics also highlight that this theory fails to take into account patient values and preferences (Bekker, 2009; Fagerlin et al., 2013). Despite its limited application to real world settings, this theory may have endured in interventions due to its simplicity (Bekker, 2009).

3.3.1.2 Prospect Theory

Prospect Theory (Kahneman & Tversky, 1979) was developed as an explanation for why individuals do not always choose the option associated with the greatest expected utility. Building on Expected Utility Theory (Bernoulli, 1954), Prospect Theory outlines that an individual’s reference point must first be
considered in relation to decision making, as the individual scaffolds probabilities and outcomes around this. It also states that individuals will take greater steps to avoid loss than to increase gains (i.e. they are more risk-averse when it comes to loss) (Kahneman & Tversky, 1979), and that the way information is framed can affect an individual’s ultimate decision (Kahneman & Tversky, 1979).

A strength of this theory is that it is more adaptable than its predecessor, as it addresses how people make decisions in real world settings rather than solely under ideal circumstances (Reyna, Nelson, Han, & Pignone, 2015). Its contribution regarding framing effects has been highly influential in understanding how language affects decisions, and it has since been incorporated into decision support guidelines (Elwyn, Durand, & Blaine, 2015; O'Connor, 2006). However, it appears that this theory only appears in decision making interventions in the context of referencing framing effects, rather than appearing as a singular theory underpinning a SDM intervention (Durand et al., 2008).

Critics argue that Prospect Theory fails to take emotion into account during the decision-making process, which has been found to influence which options are chosen (Loewenstein, Weber, Hsee, & Welch, 2001). Moreover, other critics suggest that individuals may use multiple reference points when making decisions, yet very little research has been conducted on how reference points are used and combined to make decisions (Koop & Johnson, 2012; Schwartz, Goldberg, & Hazen, 2008). This may warrant further exploration, particularly when multiple stakeholders are involved, in order to examine where there are similarities and differences between different reference points and the emphasis stakeholders place on each.
3.3.1.3 The Transtheoretical Stages of Change Model

The Transtheoretical Stages of Change model outlines how behaviour can be modified or acquired over five steps (Prochaska & Velicer, 1997). The first step is pre-contemplation, in which an individual does not want to change their behaviour in the foreseeable future. The second step is contemplation, in which the individual begins to think about behaviour change but is not yet ready to make the desired change. The next step is preparation, in which an individual is ready for change and is beginning to try to limit the negative, or increase the positive, behaviours associated with the target behaviour. The penultimate stage is action, in which behaviour change has been tried and sustained over a target period. Lastly, the final stage is maintenance, in which behaviour change has been continued for an extended period of time.

An example in which this theory was incorporated into a SDM intervention was in the development of a patient DA for colon cancer screening (Pignone, Harris, & Kinsinger, 2000). Here, each stage of change appeared in one section of a booklet along with the corresponding information tailored to that stage for the patient. Results from a study evaluating this intervention indicated that patients who used the DA were more likely to undergo screening tests than those who did not (Pignone et al., 2000).

A strength of this model in relation to SDM is that it emphasises that individuals need to be ready to engage in decision making, and that people in the initial stages require further tailored support before they are ready to make a decision (Levesque, Cummins, Prochaska, & Prochaska, 2006; Prochaska, 2012). It also maps well onto interventions that can be used in decision making, such as motivational interviewing in the pre-contemplation and contemplation stages, and DAs in the preparation stage (Prochaska, 2012).
However, it could be suggested that this theory fits better within an informed decision making or health promotion approach, in which patients are given information and decide on their own what they want to do with it. Indeed, most of the research conducted using this model focuses on reducing unhealthy behaviours (e.g. smoking cessation), which is different from choosing between treatment options. Coupled with this, there is a paucity of information regarding how professionals should facilitate decision making, as the focus in this area is upon getting the patient ready for the decision. Lastly, in the context of child and youth mental health, questions remain regarding whether both the parent and the young person need be at the same stage for SDM to occur, or whether it is acceptable for different stakeholders to be at different stages.

3.3.1.4 Theory of Planned Behaviour

The Theory of Planned Behaviour (Ajzen, 1985) is an updated version of the Theory of Reasoned Action (Fishbein & Ajzen, 1975). The original theory focused on the role of intention in behaviour change. It defined intention as composed of the following two components: attitude and perceived subjective norms (Fishbein & Ajzen, 1975). Subsequently, it was recognised that individuals did not always perform behaviours based only on intentions, and another component, perceived behaviour control, was incorporated into the updated and renamed theory (Ajzen, 1985). Behaviour control is affected by internal factors, such as knowledge and skills, as well as external factors, such as help from clinicians or family members.

These approaches have particular strengths when applied to the field of decision making. The Theory of Planned Behaviour (Ajzen, 1985) is potentially useful for developing decision support tools for SDM, as it includes many different elements considered to affect SDM (Krones et al., 2010). Socio-
cognitive theories may also be a useful framework for examining clinicians’ intentions to facilitate SDM (Thompson-Leduc, Clayman, Turcotte, & Légaré, 2015). A review examining socio-cognitive theories, including the Theory of Planned Behaviour (Ajzen, 1985) and Reasoned Action (Fishbein & Ajzen, 1975), found that clinicians’ intentions to engage in SDM was significantly associated with the perceived subjective norm⁶ (Thompson-Leduc et al., 2015).

The role of perceived behavioural control may be particularly pertinent to the child and family context when a young person’s capacity is called into question and parents are likely to have a greater influence over the decision than the young person has. However, the application of this theory in the context of SDM within child and youth mental health still requires further exploration. Moreover, the role of emotion is neglected within this theory (Hale, 2002).

3.3.1.5 Ottawa Decision Support Framework (O’Connor, 2006)

The ODSF incorporates multiple theories into its guidance for developing SDM interventions. These include the Expectancy Utility Model (Bernoulli, 1954), Decision Analysis (Howard & Matheson, 1984), Prospect Theory (Kahneman & Tversky, 1979), the Conflict Theory Model of Decision-making (Janis & Mann, 1968), the Theory of Reasoned Action (Fishbein & Ajzen, 1975), self-efficacy (Bandura, 1986) and factors related to social support (Norbek, 1988; Orem, 1985).

---

⁶ The subjective norm refers to the ‘influence of the immediate social environment of the professional, that is, the opinions of ‘people important to you’ (Thompson-Leduc et al., 2015).
1995). The ODSF is comprised of three sections. The first section is ‘decisional need’, which focuses on decisional conflict, values, knowledge, and decisional and personal characteristics. Secondly, ‘decisional quality’ focuses on the values and information received, the decisional actions and decisional impact. Lastly, ‘decisional support’ focuses on clarifying the decision and needs.

A strength of this framework is that it incorporates multiple theories rather than relying on one theory, which ultimately allows it to target different aspects of the decision-making process. For example, the decision needs section draws on the Transtheoretical Stages of Change Model (Prochaska & Velicer, 1997) to identify where the patient currently is with regard to the decision in order to affect change (O'Connor, 2006), while the support and resources section draws on the theory around self-efficacy (Bandura, 1986).

Approaches and tools developed within this framework could be time-intensive within clinical appointments, as there is emphasis on patient stories and individually tailored risk information (O'Connor, Stacey, & Boland, 2015). Indeed, use of this framework has resulted in new models for SDM (Westermann et al., 2013) or DAs in which a substantial amount of information must be filled in by the clinician and patient within the session (O'Connor, Stacey, & Jacobsen, 2015). As a result, clinicians may view approaches underpinned by this framework as not conducive to SDM, as this added time pressure is often described as a barrier to including patients (Gondek et al., 2016; Gravel, Légaré, & Graham, 2006; Joseph-Williams et al., 2013). Despite the popularity of the ODSF in designing decision support tools, the latest documentation from the joint meeting of developers concluded that future work should focus on implementation in routine clinical care, examining how the framework applies to young people, and assessing the decisional needs of patients in chronic or long-term conditions (Stacey et al., 2010). These are all
relevant to the field of child and youth mental health, in which this framework has yet to become established.

3.3.1.6 Summary of SDM theories

The application of theory to interventions intended to facilitate SDM in child and youth mental health has yet to be explored. Currently, there appears to be a set of core theories that are being used to guide SDM interventions. Reviews suggest that the most used theory in interventions is Expected Utility Theory (Bernoulli, 1954). Whilst not a theory in its own right but an amalgamation of multiple theories, the ODSF (O’Connor, 2006) also appears to be a dominant approach in designing SDM interventions. Interestingly, when multiple theories are used to develop SDM interventions, they tend to draw from different areas of psychology and behaviour change. This suggests that each may have an important role in developing SDM interventions. Along these lines, it has been noted that some theories may be more applicable to content design (e.g. prospect theory), whilst others are better applied to the process of decision making (e.g. decisional analysis) (Elwyn, Stiel, Durand, & Boivin, 2011).

Despite this, even when theory is applied to SDM interventions, it is often done poorly (Bowen et al., 2006; Durand et al., 2008; Sheehan & Sherman, 2012). This makes comparisons between theoretical and atheoretical decision support tools difficult. Subsequent work related to theory and SDM interventions has noted two reasons focused around a theory-practice gap (Elwyn et al., 2011). Firstly, that singular theories are unlikely to be sufficient, as they omit key characteristics related to design or content. Secondly, that the majority of theories currently used in decision support interventions focus on how individuals cognitively make decisions, rather than how decision support tools and other factors, such as the environment, influence decision making (Elwyn et
Whilst cognition is one important aspect to be considered, the authors propose the need for the consideration of additional theories around these other factors (Elwyn et al., 2011). The Theoretical Domains Framework (TDF) (Cane, O’Connor, & Michie, 2012), which forms part of the BCW (Michie et al., 2014), could be a solution to these challenges.

3.4 The BCW

To try and address the aforementioned issues, such as selecting interventions, choosing theory and modelling outcomes, Susan Michie, an author of the MRC guidelines, developed the BCW (Michie et al., 2014). The BCW maps well onto the MRC guidelines for developing complex interventions (Sinnott et al., 2015), as it provides step-by-step guidance to developing an intervention grounded in theory and research (Michie et al., 2014). Figure 3-2 outlines the different components of the BCW which are described below.

Figure 3-2 The BCW

The hub of the wheel, highlighted in green, includes the sources of intention for
behaviour change. These are capability, opportunity, and motivation. Capability refers to having the necessary capacity to engage in the behaviour concerned. Opportunity is defined as all the external factors that make the behaviour possible or prompt it to occur. Motivation is defined as all the brain processes that energise and direct behaviour. Importantly, capability, opportunity, and motivation may interact and influence one another. This process can cause changes to the wider components of the system and to the behaviour that is being targeted.

When designing an intervention to change behaviour, the BCW can be used to clarify the aspects of capability, opportunity, and motivation which should be targeted. Each of these aspects maps onto one of fourteen key theoretical domains; the Theoretical Domains Framework (TDF) which is highlighted in yellow on the BCW. Capability consists of four domains. This includes skills (which fall under both physical and psychological skills), knowledge, behavioural regulation, as well as memory, cognition and decision making (which all fall under psychological skills). Opportunity consists of two domains. This includes social influences (social opportunity) and environmental context and resources (physical opportunity). Motivation is composed of eight domains, which are reinforcement, emotion (automatic motivation), identity, beliefs about capabilities, beliefs about consequences, goals, optimism, and intention (reflective motivation). To tailor a behavioural intervention for its intended audience, the authors of the BCW suggest that interviews or surveys around the barriers and facilitators of each domain should be conducted for the behaviour which is being targeted.

Utilising the TDF (Cane et al., 2012), could address the challenges involved in incorporating theory into SDM interventions. The TDF (Cane et al., 2012) is a consolidation of 33 psychological theories and 128 behaviour change
constructs which has resulted in 14 key domains related to influencing behaviour. These domains are mapped onto the three overarching constructs of capability, opportunity, and motivation. Importantly, the TDF is inclusive of many theories used within SDM interventions, including decision theories (both motivationally and organisationally focused), the Transtheoretical Stages of Change, socio-cognitive theories, goal theories (both motivational and action-focused) and theories related to reasoned action and behaviour (Michie et al., 2005). The TDF (Cane et al., 2012) can be used both qualitatively and quantitatively to examine barriers and facilitators to behavioural phenomena. Therefore, it could serve as a pragmatic approach to addressing the theory-practice gap outlined by Elwyn et al, (2011).

The next concentric circle within the BCW consists of intervention functions (IFs). These terms describe the underlying causal mechanisms used in an intervention to change behaviour (Colquhoun et al., 2014). The BCW consists of nine different IFs. These are ‘education’, ‘persuasion’, ‘incentivisation’, ‘coercion’, ‘training’, ‘restriction’, ‘environmental restructuring’, ‘modelling’, and ‘enablement’ (Michie et al., 2014). Importantly, more than one IF can be used per intervention (Michie et al., 2014). Guidance on how to select IFs is provided in the BCW, with different IFs suggested depending on which barriers and facilitators are identified from interviews and surveys. For example, a lack of knowledge suggests the need for an individual to be educated so that they are able to perform the target behaviour, and not having the resources to perform the behaviour suggests the need for the environment to be adjusted.

The outer concentric circle of the BCW refers to the policy categories. These refer to the areas or channels in which the intervention can be delivered (Michie et al., 2014). The BCW consists of seven different policy categories: ‘communications/marketing’, ‘guidelines’, ‘fiscal’, ‘regulation’, ‘legislation’,
'environmental/social planning', and ‘service provision’. Like IFs, these policy categories build on the previous circle within the wheel, and the BCW provides advice about which IFs map onto which policy categories. For example, the IF ‘modelling’ maps onto the policy categories ‘communication/marketing’ and ‘service provision’, whilst the IF ‘restriction’ maps onto ‘guidelines’, ‘regulation’, and ‘legislation’.

3.4.1 Behaviour Change Techniques

As well as serving as a guide on how to develop interventions, the BCW (Michie et al., 2014) is useful in providing a standardised language to approach intervention development. Behaviour change techniques are defined as the smallest components of behaviour change interventions that, on their own and in favourable circumstances, can bring about change (Michie et al., 2013). Currently, 96 BCTs have been identified which have been separated into 16 taxonomy groups (Michie et al., 2014). When designing and delivering effective healthcare interventions, it is important to use the correct BCTs which map onto corresponding mechanisms of change (Michie, Johnston, Francis, Hardeman, & Eccles, 2008).

Research on BCTs has traditionally occurred with patients in the context of health promotion and risk reduction behaviours. Within these domains, specific BCTs have been identified as useful in child weight management (Golley, Hendrie, Slater, & Corsini, 2011; van der Kruk, Kortekaas, Lucas, & Jager-Wittenaar, 2013), smoking cessation (Bartlett, Sheeran, & Hawley, 2014) and for targeting physical activity and self-efficacy (Williams & French, 2011). However, these studies are limited in their applicability to SDM in child and youth mental health. This is due to the focus of these studies on increasing healthy or reducing unhealthy behaviours, rather than focusing on increasing patient participation in decision making.
The role of BCTs in interventions intended to change clinicians’ behaviour is underdeveloped when compared to patient research. However, there have been multiple qualitative studies related to intervention development that have identified particular BCTs that could be useful for changing clinician behaviour in specific contexts. This extends to improving low fidelity to a sepsis care bundle (Steinmo et al., 2016; Steinmo, Fuller, Stone, & Michie, 2015), triage, the treatment and transfer of stroke patients (Craig et al., 2017), polypharmacy management by clinicians (Cadogan et al., 2016), sexual counselling for cardiac patients (McSharry, Murphy, & Byrne, 2016) and the medication management by clinicians of patients with multi-morbidity (Sinnott et al., 2015). Only the latter researchers published results in relation to intervention implementation, in which the intervention was piloted and found to be acceptable by clinicians (Sinnott, Byrne, & Bradley, 2017).

The application of BCTs to interventions has the potential to combine well when designing and evaluating SDM interventions. There is an overlap between BCTs and the essential and ideal elements outlined in the integrative framework for SDM (Makoul & Clayman, 2006), given that both are ‘measurable behaviours’ (e.g. pros/cons). It could be argued that interventions developed to facilitate SDM are modifying stakeholders’ behaviours by increasing patient involvement, decreasing clinicians’ paternalism, or both. These interventions to improve SDM have been delivered in a variety of formats, including the use of QPLs (e.g. Ahmed et al., 2017), DAs (e.g. Simmons et al., 2016), workshops aiming to prepare patients to engage in SDM (e.g. Adelman et al., 1990) and training for clinicians (e.g. Hoffman, Bennett, & Del Mar, 2014). The process of understanding the BCTs that are present within each intervention and knowing whether there are particular BCTs which contribute to increased participation by patients in decision making still needs to be explored (Cheng et al., 2017).
3.4.2 Research on IFs

Similar to BCTs, IFs have been used mainly in the context of health promotion and risk behaviour reduction. A meta-analysis of 69 patient interventions on this topic found that 96% (n = 66) focused on patient ‘education’, 57% (n = 39) included ‘training’, 56% (n = 37) included ‘enablement’, and 30% (n = 21) focused on ‘persuasion’ (Meader et al., 2017). ‘Coercion’ and ‘restriction’ did not form part of any intervention, whilst ‘environmental restructuring’ was used in 10% (n = 7) of interventions and ‘incentivisation’ in 4% (n = 3). Interventions that contained ‘education’, ‘training’ and ‘enablement’ were associated with an increased uptake in patients’ physical activity, whilst ‘enablement’ alone was associated with a reduction in patients’ smoking (Meader et al., 2017). However, how these findings link to behaviours such as SDM is still unclear.

For health professionals, a recent review of 141 studies examining behaviour interventions in clinical practice found that ‘education’ and ‘training’, as well as ‘enablement’, were the most useful IFs for changing clinicians’ behaviour (Chauhan et al., 2017). ‘Environmental restructuring’ and ‘modelling’ were also found to be useful. However, as there were fewer studies in these areas (n = 18 and n = 2 respectively), these findings should be treated as tentative. Other IFs, such as the use of ‘incentives’, were not found to support behaviour change (Chauhan et al., 2017).

3.4.3 Critical evaluation of the BCW

The BCW (Michie et al., 2014) has received both positive and negative feedback from academics. Positive feedback has focused around using the BCW to develop a common language to describe and code interventions (Abraham, 2016; Peters & Kok, 2016). This makes the process of establishing and testing key components of interventions easier for researchers. A further
benefit of the BCW is that it provides a systematic approach to intervention development (Johnston, 2016). Unlike frameworks like the MRC, which has been criticised for its lack of specificity in certain areas (Correy et al., 2013), the BCW provides individuals with a detailed framework for understanding and selecting the necessary components for behaviour change.

However, others have viewed the BCW critically. In particular, Jane Ogden suggest that the BCW neglects theory specificity and individual variability in its attempt to systemize behaviour change science (Ogden, 2016a).

Ogden (2016a), as well as Peters and Kok (2016), suggest that the BCW sacrifices theory specificity in its attempt to be all-inclusive and all-encompassing. Individuals theories, which are specific in nature, lend themselves easily to testing but only function in specific, limited scenarios. Theories, which are less specific, are applicable to a wider range of domains, but they are often difficult to test and operationalise. Ogden (2016b) argues that combining theories in the manner of the BCW results in a ‘theory of everything’. This leads to an extremely broad and inclusive theory which is difficult to test. Despite this, leaders in the field of SDM highlight that singular theories are unlikely to be effective (Elwyn et al., 2011), and combinations of theories of theories are preferable. This has been highlighted in frameworks such as the ODSF (O’Connor, 2006).

Critiques around individual variability highlight that use of the BCW results in generic interventions which are not specifically tailored for individuals (Ogden 2016a). The prevailing concern is that use of the BCW will result in the application of the same BCTs to change the behaviour of different groups of individuals (Ogden 2016b). This results in clinicians, researchers, and intervention developers becoming technicians (Gagnon, 2017) which do not take into account the individual, their experiences, and what may work for them.
A solution to this could be to separate BCTs into those which are ‘essential’, ‘optional’, or ‘recommended’. Such ideas are emerging from research in the field (Keogh, Matthews, & Hurley, 2018). This may be said to draw parallels with the integrative model of SDM (Makoul & Clayman, 2006) which unpicks what elements must happen when it comes to SDM, as well as what other elements ‘ideal elements’ could enhance it further.

### 3.4.4 Summary

The BCW (Michie et al., 2014) may provide a useful framework for intervention development, and it supplements areas in the MRC guidelines where guidance is lacking (Correy et al., 2013). It may also provide a pragmatic approach to developing SDM interventions, as it combines theory with research to address the theory-practice gap (Elwyn et al., 2011).

The application of aspects of the BCW (Michie et al., 2014) has mainly taken place in the context of patient health promotion or risk reduction behaviours. Specific BCTs have been associated with increased desirable behaviour in patients (e.g. Bartlett et al., 2014). However, the potential impact of BCTs on clinician behaviour has only been discussed in qualitative studies and not tested quantitatively (e.g. Sinnott et al., 2015, 2017). Intervention functions have also mainly been applied in the context of patient health promotion or risk reduction behaviours. The IFs ‘education’, ‘training’ and ‘enablement’ has been associated with patient behaviour change (Meader et al., 2017). For changing clinician behaviour, the IFs of ‘education’, ‘training’, ‘environmental restructuring’, ‘modelling’ and ‘enablement’ all have demonstrated some effect on behaviour (Chauhan et al., 2017).

The application of the BCW (Michie et al., 2014) to SDM has not yet been studied. There is a paucity of research relating to the BCW outside of the
contexts of health promotion and risk reduction, as well as a lack of research involving multiple stakeholders, young people and mental health settings. In addition to helping to address the theory-practice gap (Elwyn et al., 2011), through the TDF (Cane et al., 2012), BCTs within the BCW (Michie et al., 2014) have the potential to map onto the integrative model of SDM, as both concepts describe small measurable units of behaviour.

Approaches to SDM in child and youth mental health have been investigated (Cheng et al., 2017). However, these approaches have been grouped according to the Health Foundation (Da Silva, 2012) based on the type of ‘tool’ they are, rather than being understood by their IFs. Aspects of the BCW (Michie et al., 2014), which can be used to examine IFs and BCTs, could help to uncover the reasons for the variations in the outcomes of different SDM interventions. This could be particularly useful when interventions fall under the same ‘tool or approach’ but consist of IFs targeting different mechanisms of change.

Before progressing to developing SDM interventions using the BCW (Michie et al., 2014), a conceptual working definition of SDM is needed, as the concept has been ill-defined to date in the literature (Charles et al., 1997; Charles et al., 1999; Jansen, 2001; Makoul & Clayman, 2006; Thornton et al., 2003). Consequently, the next section outlines a working definition of SDM based on the current literature.

3.5 A working definition of SDM in child and youth mental health

A comparison of SDM models (see 2.4.7) highlights the two elements that are present across all the models, which are the presentation of options and the need for follow-up. An additional two elements are also present across most models: discussing values and preferences and making or deferring a decision. These form the basis of the working definition outlined in Table 3-1.
Table 3-1: A working model of SDM in child and youth mental health

| 1. | Young people (and parents) are involved in care and treatment decisions |
| 2. | Options are presented around care and treatment |
| 3. | Young people (and parents) examine these options in light of their values and preferences |
| 4. | Decisions are made or deferred, and follow-up appointments are arranged |

Further details regarding this working model are provided below.

1) Young people (and parents) are involved in care and treatment decisions

The inclusion of young people with mental health difficulties, as well as their parents, in decisions about their treatment or care is central to policy documentation in the UK (Department of Health, 2015). Research suggests that young people are able to be involved in decision making (e.g. Schachter et al., 2011). Importantly, this should not be seen as a binary choice between involvement or no involvement (Alderson & Montgomery, 1996; Batten, 1996). Young people can be involved in decisions in various ways, ranging through a continuum of helping to inform the overall decision to being the primary decision maker (Alderson & Montgomery, 1996). However, a recent rapid internal audit in the UK has suggested that the majority of young people report not feeling involved in care and treatment decisions (Edbrooke-Childs, Calderon, et al., 2015). This also appears to be supported by a recent scoping review of tools intended to support SDM, which highlighted that many tools focus only on
2) Options are presented around care and treatment

Shared decision making models in child and youth mental health refer to care and treatment options (see 2.4.7), though specific treatment options vary by model. Some models focus on different medications (Crickard et al., 2010) or on different types of psychotherapy (Langer & Jensen-Doss, 2016). However, other models are less concrete and leave potential treatment options open for discussion (e.g. Common Room Consulting, 2017). As research suggests that decision making in mental healthcare can encapsulate a wide range of decisions including social decisions (Freidl et al., 2016; Hamann et al., 2008), options should be kept deliberately broad.

3) Young people (and parents) examine these options in light of their values and preferences

Values and preferences include an individual’s ideas and concerns about the different options that are presented to them (Makoul & Clayman, 2006). It is important that individuals examine options while considering their values and preferences, as patients and associated family members are experts in themselves and often know what would work best for them (Coulter, 2009). Moreover, as outcomes are often unique to the patient, it is important that clinicians allow patients to weigh the presented options in terms of their personal preferences and values (Eddy, 1990). Whilst the discussion of values and preferences is considered important in SDM, it may be even more important when there are multiple stakeholders in the room whose individual views can be considered together (Lipstein et al., 2016).

4) Decisions are made or deferred and follow-up appointments are
Coming to a decision about which option(s) to choose may take time and may also require the involved parties to leave and consult with others not present at the time of consultation, such as other family members or healthcare professionals (Makoul & Clayman, 2006). This may also mean that more time is needed to overcome stakeholder differences, which are a frequent concern in child and youth mental health (Hawley & Weisz, 2003). In such circumstances, a follow-up is needed to discuss the decision further. Arranging a follow-up also corresponds with the idea that mental distress is often not acute and cannot always be resolved by a one-off decision (Entwistle & Watt, 2006, 2016). Thus, decisions should be reviewed and/or amended during future appointments (Entwistle & Watt, 2006, 2016).

3.6 Methodology

To develop an intervention to facilitate SDM, five studies were undertaken. Firstly, an updated review of SDM interventions was conducted, exploring BCTs, IFs and existing theory (Study 1; Chapter 4). Next, the existing practice of SDM in England was examined using a national dataset (Study 2; Chapter 5). Following this, two studies using the TDF (Cane et al., 2012) to understand the barriers and facilitators to SDM were conducted. This included perspectives from clinicians (Study 3: Chapter 6) as well as young people and their parents (Study 4; Chapter 7). Findings from these studies were then used to develop an intervention to facilitate SDM in child and youth mental health, which is detailed in Chapter 8. A final study described changes made to the intervention based on testing and user feedback in a London service (Study 5; Chapter 9). Further information on each empirical study is provided below.
3.6.1 Study 1 (Chapter 4)

Study 1 explores the BCTs, IFs and theories that are being used in SDM interventions in child and youth mental health. Previous research to date has only examined interventions in terms of what ‘tool’ they are (Cheng et al., 2017), rather than how they change behaviour. Moreover, the same research has not examined the use of theory in interventions. As such, the research questions for this chapter are: First, which theories and/or frameworks are being used in SDM interventions in child and youth mental health? Second, which IFs are being used to facilitate SDM in child and youth mental health? Third, which BCTs are being used to facilitate SDM in child and youth mental health? Finally, is it possible to draw any links between theories, IFs, BCTs, SDM and outcomes?

The study expands upon the existing review of SDM interventions (Cheng et al., 2017) by conducting an updated search to allow for the inclusion of more recent studies and utilising enhanced screening criteria. The PhD candidate conducted this updated search, whilst data extraction was completed independently by both the PhD candidate and another researcher working in the field of SDM (RT). The findings from this chapter highlight key theories, and IFs or BCTs that could enhance the development of the proposed SDM intervention.

3.6.2 Study 2 (Chapter 5)

Study 2 examines the existing practice of SDM in England. This stems from gaps in the literature which indicate that there is a paucity of research examining the factors that affect SDM which includes the perspectives of young people. Additionally, research to date is mainly concentrated in the US and fails to take into account service-level variation (Butler, 2014; Butler et al., 2014, 2015). This study addresses two research questions. First, how much service-level variation is there in child- and parent-reported SDM in a sample of cases
from child and youth mental health services in England? Second, are there specific patient demographics or case characteristics associated with SDM in a sample of cases from child and youth mental health services in England?

A pre-existing dataset was used for this study which is held and managed by CORC based at the AFNCCF. Case characteristics were examined using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997), whilst reported experience of SDM was measured using a subset of items from the Experience of Service Questionnaire (ESQ; Commission for Health Improvement, 2002) which is similar to previous research undertaken (Edbrooke-Childs et al., 2015). To address these questions, mixed effect logistic regressions were employed using STATA 14 (StataCorp, 2015). The findings from this chapter provide contextual information (e.g. potential target demographics) that can be used to inform the development of SDM interventions.

3.6.3 Studies 3 and 4 (Chapter 6 and 7)

Studies 3 and 4 explore the barriers and facilitators to SDM from the perspectives of clinicians (Study 3), as well as young people with mental health difficulties and their parents (Study 4). Barriers and facilitators around this topic have not been widely researched in the UK, apart from a few studies which focus on new services or inpatient settings (e.g. Offord et al., 2006; Pycroft et al., 2013). Reviews in similar areas, such as person-centred care, do exist (Gondek et al., 2016). However, findings from these indicate that many studies took place in countries with different healthcare systems to the UK or which did not intend to examine barriers and facilitators (e.g. Simmons et al., 2011).

In both of these studies, the TDF (Cane et al., 2012) was employed to provide a theory-led approach to examining the barriers and facilitators to SDM. As
mentioned previously, this was done in an attempt to address the theory-practice gap (Elwyn et al., 2011). Thus, the research question for these chapters was: Utilising the TDF (Cane et al., 2012), what do clinicians, young people and parents perceive to be the barriers and facilitators to SDM? Results were analysed using a deductive thematic analysis based on the 14 key domains of the TDF (Cane et al., 2012). A qualitative analysis was conducted using NVivo 11 (QSR International, 2015). Findings from these chapters provide an overview of the theory-led barriers and facilitators to SDM from the perspectives of the key stakeholders, and this information is used in later chapters to develop an SDM intervention.

3.6.4 Study 5 (Chapter 9)

Following the development of an intervention to facilitate SDM in child and youth mental health settings using the BCW (Michie et al., 2014), Study 5 details the process of testing the intervention in CAMHS. This is important as many developed interventions do not undergo user testing prior to their release (Durand et al., 2008). The aim of testing was to understand how stakeholders felt about a newly developed intervention and to determine whether further changes were needed to make this intervention more useful and acceptable. The research questions for this study were: First, what do young people, parents and clinicians think about the DAs in terms of their acceptability and usefulness? Second, what do clinicians think about the educational and training package in terms of its acceptability and usefulness? For DAs, acceptability and usefulness were first examined using PDSA cycles. This consisted of iterative cycles of feedback gathered from stakeholders, which were then incorporated into the DAs and retested. This was then followed up with interviews with clinicians after the finalised DAs had been used in the assessment clinic for two months. For the education and training package, acceptability and usefulness
were examined using a survey with open ended responses. Data were analysed using NVivo 11 (QSR International, 2015).

3.7 Research paradigms in this thesis

Epistemology refers to the ‘relationship between the knower or would-be knower and what can be known’ (Guba & Lincoln, 1994, p. 201). There are various epistemological stances which can be adopted when approaching research. These lie on a continuum that ranges from positivism to interpretivism. Positivism refers to the existence of an objective reality that is not mediated by our senses (Scotland, 2012). Here, the researcher and what is being studied are independent from one another. The researcher is impartial, which means that knowledge which is deduced is factual and value-free (e.g. not influenced by society or one’s own values) (Scotland, 2012).

On the other hand, interpretivism posits that there is not an objective reality. Reality is subjective and unique for each individual, and one individual can have many different realities (Scotland, 2012). In this epistemology, reality is mediated by one’s senses such as sight, smell, and touch. Meaning and knowledge are needed by individuals to understand reality. Without these, reality does not exist (Grix, 2004). Importantly, as knowledge and understanding are mediated by the world in which individuals live, time, society, and culture can influence each individuals’ reality (Scotland, 2012).

The overall thesis draws on a post-positivist, critical realist stance. This is a flexible middle ground between positivism and interpretivism, which acknowledges that an objective reality exists, but we are not able to express it fully through mediums such as language or numerical data (Teddlie & Tashakkori, 2009). It further holds that individuals influence, and are influenced by, the social structures around them (Teddlie & Tashakkori, 2009). Thus, in the
context of this thesis, stakeholders’ views and experiences are considered to be their reality, but they are also conceptualised as having been shaped by various factors (e.g. political, organisational or social factors).

A critical realist methodology fits well with the format and aims of this thesis. Firstly, a critical realist perspective discerns that the behaviour phenomena being studied have mechanisms which can result in particular outcomes (Bhaskar, 2008). However, it acknowledges that these outcomes are dependent on the context of the intervention (Byrne, 2013; Fletcher et al., 2017). Through the analysis of the views of the stakeholders, a unique set of domains presents itself which is specific to the services that are taking part in the research.

Secondly, critical realism acknowledges that the use of theory can be helpful in generating knowledge. However, knowledge is ultimately shaped by the theory that is chosen, and multiple theories can be used to explain the same behaviour (Teddlie & Tashakkori, 2009, p. 68). The use of different singular theories in the facilitation of SDM, as well as the emergence of frameworks which incorporate multiple theories, is thus compatible with a critical realist perspective.

Lastly, whilst critical realism has traditionally been suited to quantitative methodologies (Teddle & Tashakkori, 2009), this stance is gaining increasing recognition in qualitative research (Fletcher, 2017; Roberts, 2014). In such instances, a critical realist approach to qualitative research may allow the PhD candidate to understand the potential mechanisms of change (Bhaskar, 2009). In this thesis, this is achieved through the use of the TDF (Cane et al., 2012), which is employed to conduct a deductive thematic analysis.
Chapter 4 A systematic review of SDM interventions in child and youth mental health: Theories, IFs and BCTs
4.1 Introduction

The application of theory to interventions has been highlighted as important in intervention development (Craig et al., 2008, 2013). Reviews in Chapter 3 highlighted that explicit theory is often missing in adult SDM interventions (Bowen et al., 2006; Durand et al., 2008; Sheehan & Sherman, 2012). When theory is included in SDM interventions, Expected Utility Theory (Bernoulli, 1954) or the ODSF (O’Connor, 2006) are the most commonly used. Yet, the degree to which both of these theories have been explicitly applied to interventions is unclear (Bowen et al., 2006; Durand et al., 2008; Sheehan & Sherman, 2012).

Theories may also have limitations when applied to interventions. For example, Expected Utility Theory (Bernoulli, 1954) is a normative theory of decision making that outlines how people make decisions under ideal circumstances, and, therefore, it does not address how people make decisions in the real-world. In addition, this theory does not take into account patient values and preferences (Bekker, 2009; Fagerlin et al., 2013). On the other hand, developers of the ODSF (O’Connor, 2006) outline a need to examine its use in areas related to child and youth mental health, including interventions with young people, long-term conditions and routine care (Stacey et al., 2010). Theory has yet to be examined in SDM interventions in child and youth mental health, as a recent scoping review only identified the interventions that exist without examining whether theory was used (Cheng et al., 2017).

If, as models and experts suggest, SDM is a set of behaviours or skills that can be taught to stakeholders (Charles et al., 1997, 1999; Elwyn et al., 1999; Legare & Thompson-Leduc, 2014; Makoul & Clayman, 2006; Towle & Godolphin, 1999), then it is important to understand the specific ways in which interventions attempt to change behaviours in order to facilitate SDM. The
review by Cheng et al. (2017) grouped interventions under the approaches specified by the Health Foundation (Da Silva, 2012), according to the approach the tool takes to SDM. Whilst practical, this standpoint neglects the unique features within each intervention which may cause individuals to behave in different ways. Examining these elements through the lens of IFs and BCTs will allow researchers to understand the drivers of change that are present and those that could be contributing to increased SDM and better outcomes. There is currently a need to examine theory, IFs, and BCTs when designing SDM interventions, as this has not previously taken place in the field of child and youth mental health.

4.1.1 Aims of the present research

This study has two aims: First, to conduct an updated review of the interventions intended to facilitate SDM in child and youth mental health, and explore the theories, IFs and BCTs that are present in each intervention. Second, to examine whether any of these aspects may result in increased SDM and better outcomes.

4.1.2 Research questions

Consistent with the above aims, this review answers four research questions:

1) Which theories and/or frameworks are being used in SDM interventions in child and youth mental health?

2) Which IFs are being used to facilitate SDM in child and youth mental health?

3) Which BCTs are being used to facilitate SDM in child and youth mental health?
4) Is it possible to draw any links between theories, IFs, BCTs, SDM and outcomes?

4.2 Method

4.2.1 Protocol and registration

An unregistered protocol was produced prior to the start of the work on this review. The review was carried out in accordance with PRISMA guidelines (see Appendix 4a for the checklist).

4.2.2 Eligibility criteria and rationale

Ten criteria were used to determine eligibility for this review; these are outlined in Table 4-1 along with the rationale for inclusion.

Table 4-1 An outline of eligibility criteria for this review and the rationale for each point

<table>
<thead>
<tr>
<th>Eligibility criteria</th>
<th>Rationale and further information</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Described an SDM intervention (tool, technique, technology or model)</td>
<td>• Criteria 1 through 7 are the same criteria used in the review by Cheng et al. (2017). This was assembled by experts in SDM in child and youth mental health and was also based on previous reviews. This review intends to examine the same participants and interventions in an updated search and to focus on additional aspects such as theory, IFs, and BCTs.</td>
</tr>
<tr>
<td>2. Did not use only a questionnaire to provide feedback on SDM (e.g. Butler, 2014) without the presence of an SDM tool, technique or approach</td>
<td></td>
</tr>
<tr>
<td>3. Included sufficient detail on the SDM intervention for quality assessment to be undertaken</td>
<td></td>
</tr>
<tr>
<td>4. Took place in a mental health setting or was aimed at participants with mental health difficulties</td>
<td></td>
</tr>
<tr>
<td>5. Included a child or adolescent population (or)</td>
<td></td>
</tr>
<tr>
<td>6. Included carers of children or adolescents</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>7.</td>
<td>Record in English language</td>
</tr>
<tr>
<td>8.</td>
<td>Included a comparison group</td>
</tr>
<tr>
<td>9.</td>
<td>Included a measure related to decision making, patient participation or involvement</td>
</tr>
<tr>
<td>10.</td>
<td>Included sufficient detail on the SDM resource for extraction of IFs and BCTs</td>
</tr>
</tbody>
</table>

### 4.2.3 Information sources and search

Six research databases – PsycINFO, EMBASE, Medline, PubMed, Web of Science and Cochrane Libraries – were searched from 1st September, 2016,\(^7\) to December 22nd, 2016. The search strategy included the three concepts and search strategy outlined in section 2.1.1.

---

\(^7\) Dates at which the Cheng et al. review (2017) terminated its searching
Reference checking of articles was conducted, and relevant journals were hand searched. These journals included:

- Patient Education and Counselling (PEC)
- Health Expectations
- European Child and Adolescent Psychiatry (ECAP)

In addition, one DA database and one SDM Facebook group were consulted. These were:

- The Ottawa DAs Database
- An SDM Facebook group
  (https://www.facebook.com/groups/SharedDecisionMaking)

### 4.2.4 Study selection

The study selection was completed by one researcher (DH) using a two-stage process. The first stage involved screening article titles and abstracts, during which all records were screened and any results which were not relevant (e.g. adult mental health or physical health) were excluded. The second stage consisted of full-text screening. The exclusion of papers at each stage is highlighted in Figure 4-1.

### 4.2.5 Data collection process

For each article included, data were extracted independently by two researchers (DH and RT). This included author, year and publication date,
participant details, study design, intervention, theoretical background, IFs\textsuperscript{8}, BCTs\textsuperscript{9}, process measures and outcome measures. Online training in BCTs was provided to the researchers extracting the data (http://www.bct-taxonomy.com/), and BCTs were checked against their corresponding definitions (Michie et al., 2014). The authors and intervention developers of resources deemed acceptable for inclusion were contacted to establish whether any further information on the intervention component was available (e.g. a manual or protocol). All of the authors (4/4; 100\%) replied to the request for further information. Three authors (75\%) sent further information, and one author (25\%) asked for clarification but did not reply to follow-up by the PhD candidate. For extracted IFs and BCTs, a good level of agreement was obtained between the researchers DH and RT (Kappa = 0.98 and 0.86 respectively). Any discrepancies were resolved by discussion and agreed upon by the researchers. The finalised IFs and BCTs were submitted to two research psychologists (EV and AS) working in behaviour change. From this, one additional BCT ‘credible source’ was included, as the information provided to parents and young people came from trained healthcare professionals who are experts in diagnosis and treatment.

\textsuperscript{8} Intervention functions describe the underlying causal mechanisms an intervention utilises to change behaviour (Colquhoun et al., 2014).

\textsuperscript{9} Behaviour change techniques are defined as the smallest components of behaviour change interventions, which on their own and in favourable circumstances, can bring about change (Michie et al., 2013).
4.2.6 Risk of bias within studies

There is a paucity of quality assessment tools which examine both randomised and non-randomised studies. Those that do examine both omit key domains necessary for assessing internal validity (Deeks et al., 2003). One tool that has been recommended for use when examining randomised and non-randomised studies is the EPHPP Quality Assessment Method (Thomas, Ciliska, Dobbins, & Micucci, 2004). This tool allows for the examination of studies in relation to selection bias, study design, confounders, blinding, data collection method, withdrawals and drop out. The EPHPP Quality Assessment Method may have some advantages over other quality assessment tools that examine both randomised and non-randomised studies, as it is easy to use and has been evaluated as suitable for systematic reviews with no modifications (Deeks et al., 2003). The criteria used to evaluate each paper is outlined in Appendix 4b.

Each study that met inclusion criteria was also independently quality assessed by two researchers (DH and RT). With regard to the quality assessment, an excellent level of agreement was obtained between the researchers (Kappa = .92). Any discrepancies were resolved by discussion and changes were agreed upon by both researchers.

4.2.7 Ethical approval

Ethical approval was not needed for this systematic review, as it involved synthesising the findings from previous studies in which informed consent had been obtained from the participants.
Figure 4-1 Search flowchart
4.3 Results

The 22 records included in the original scoping review (Cheng et al., 2017) were combined with the further 201 records identified through database searching. Three additional records were also identified through referencing and library searching. Overall, 226 records were screened at the first stage. Screening resulted in the exclusion of 159 records. The most common reason for exclusion was that the study was set in the area of physical health \((n = 69)\). Second stage screening resulted in the exclusion of 63 results, with the most common reason for exclusion being that the study did not involve an SDM resource \((n = 29)\). A total of four papers met the inclusion criteria for this review. Study characteristics, including BCTs, IFs, process and outcome measures, are indicated in Table 4-2.

Table 4-3 presents study results following the use of the EPHPP Quality Assessment Method (Thomas et al., 2004) used to assess risk of bias within and across studies.

Of the four studies that met inclusion criteria, two were aimed at parents as the decision makers (Brinkman et al., 2013; He et al., 2016), one was aimed at both young people and parents (Hogue, Lichvar, & Bobek, 2016), and one was aimed at young people (Adelman et al., 1990). All four studies were from the US. The most common presenting difficulty was ADHD \((n = 2)\) (Brinkman et al., 2013; Hogue et al., 2016), followed by learning disabilities (Adelman et al., 1990) and behavioural problems (He et al., 2016).

4.3.1 Modality of SDM interventions

Of the four interventions that were identified, one involved a therapeutic approach to exploring ADHD medication known as the Medication integration
Another involved participants explicitly choosing their own treatment (He et al., 2016). Another was a DA, which consisted of choice cards related to ADHD medication (Brinkman et al., 2013). The final intervention was a pre-conference workshop aimed at mobilising patients to engage in decision making (Adelman et al., 1990).

4.3.2 Behaviour Change Techniques used in SDM interventions

Overall, fifteen BCTs were identified across the four interventions. The number of BCTs per intervention ranged from one to 11, with a mean of 4.80 per intervention (SD = 4.15). The most frequently used BCT was ‘credible source’, which appeared in three interventions. This was followed by ‘behavioural practice and rehearsal’, ‘habit formation’, and finally, ‘pros/cons’. Each of these BCTs appeared in two interventions, while all the remaining BCTs appeared in only one intervention.

There were no BCTs that were more frequently aimed at young people, as BCTs aimed at this group appeared only once across each of the interventions. This was also the case for clinicians. However, for parents, the most frequently used BCT was ‘credible source’, which appeared in three interventions. This was followed by ‘goal setting (outcome)’, ‘information about health consequences’ and ‘pros/cons’ – each of which appeared in two interventions.
### Table 4-2 Characteristics of interventions included in the final review

<table>
<thead>
<tr>
<th>Author, year of publication, and country</th>
<th>N</th>
<th>Comparison and design</th>
<th>Intervention and theoretical background</th>
<th>Intervention function(s)</th>
<th>Behaviour change techniques</th>
<th>Process measure: decision making/involvement/participation</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adelman, et al. (1990), US</td>
<td>85 young people referred to a clinic for possible learning disabilities</td>
<td>Intervention vs placebo or no intervention</td>
<td>Pre-conference workshop for young people to assist with psychoeducational decision making</td>
<td>With young people 'Education' 'Training'</td>
<td>With young people 8.1 'Behavioural practice/rehearsal' 8.3 'Habit formation'</td>
<td>Ø Young person's participation (observer, young person, parent)</td>
<td>Ø Conference satisfaction (young person, parent, psychologist) Ø Motivation for future participation (young person, parent) ^ Motivation for future participation (psychologist, for both</td>
</tr>
<tr>
<td>Study (Year, Country)</td>
<td>Sample</td>
<td>Intervention</td>
<td>Outcomes</td>
<td>Qualitative Measures</td>
<td>Parent Knowledge</td>
<td>Decisional Conflict</td>
<td>Follow-up</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------</td>
<td>--------------</td>
<td>----------</td>
<td>----------------------</td>
<td>----------------</td>
<td>---------------------</td>
<td>----------</td>
</tr>
<tr>
<td>Brinkman (2013), US</td>
<td>44 parents of young people with ADHD, 7 paediatricians</td>
<td>SDM vs usual care Controlled clinical trial</td>
<td>Pre-encounter cards, booklet, DA, and clinician training</td>
<td>With clinicians ‘Education’ ‘Training’ ‘Modelling’ With parents ‘Education’ Both parents and clinicians ‘Environmenta l restructuring’ ‘Enablement’</td>
<td>With clinicians 6.1 ‘Demonstration of behaviour’ 7.1 ‘Prompts/cues’ With parents 1.3 ‘Goal setting (outcome)’ 4.1 ‘Instruction on how to perform behaviour’ 5.1 ‘Information about health consequences’ 9.1 ‘Credible source’ 9.2 ‘Pros/cons’ Both parents and clinicians</td>
<td>^ Option Scale (Elwyn et al., 2005)</td>
<td>^ Parent knowledge Ø Decisional conflict* Ø Follow up calls and visits Ø Prescriptions written Ø Teacher and parent behavioural ratings Ø Titration of medication Ø Number of days covered with medication Ø Physician satisfaction with choice</td>
</tr>
</tbody>
</table>

* IPDAS - Individualized Patient Decision Aids Scale
<p>| He et al. (2016), US | 129 families referred to clinic for Parent Management-Training Oregon (PMTO) model for child behaviour difficulties | Treatment choice vs no choice Randomised control trial | Choosing treatment No theoretical background specified | With parents ‘Education’ Parents 9.1 ‘Credible source’ | 12.5 ‘Adding objects to environment’ | Chose treatment | v Drop out of treatment |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Additional Details</th>
</tr>
</thead>
</table>
| Hogue et al. (2016), US | 3 MIP therapists and 35 young people with ADHD | Medication integration protocol vs historical control | A therapeutic approach (MIP) promoting family decisions about medication | With young people and parents 'Education' 'Enablement' With clinicians 'Education' 'Training'
<p>| | | | No theoretical background specified | With young people and parents 1.2 ‘Problem solving’ 1.3 ‘Goal setting (outcome)’ 1.5 ‘Review behavioural goals’ 1.7 ‘Review outcome goals’ 5.1 ‘Information about health consequences’ 5.3 ‘Information about social/environmental consequences’ 9.1 ‘Credible source’ 9.2 ‘Pros/cons’ 13.2 ‘Framing/ reframing’ With clinicians | ^ Family decision making | ^ Psychiatric evaluation completion ^ Prescribed any medication ^ Prescribed ADHD medication Ø Days on ADHD medication |</p>
<table>
<thead>
<tr>
<th>Measure increased</th>
<th>Measure decreased</th>
<th>No change on measure</th>
<th>International Patient Decision Aid Standards (IPDAS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>159</td>
<td>1</td>
<td></td>
<td>* Authors report this finding as significant at $p &lt; 0.06$.</td>
</tr>
</tbody>
</table>

8.1 ‘Behavioural practice/rehearsal’
8.3 ‘Habit formation’

*Measure increased, \(^{\ast}\) Measure decreased, \(^{\phi}\) No change on measure, \(^{1}\) International Patient Decision Aid Standards (IPDAS) \(^{2}\) Ottawa Decision Support Framework, *Authors report this finding as significant at $p < 0.06$, \(^{5}\) Parents were allocated to choose a treatment of their choice, or be randomly allocated a treatment (no choice).
Table 4-3 EPHPP Quality Assessment Method (Thomas et al., 2004) for risk of bias

<table>
<thead>
<tr>
<th>Paper</th>
<th>Selection Bias</th>
<th>Study design</th>
<th>Confounders</th>
<th>Blinding</th>
<th>Data Collection</th>
<th>Withdrawal and Dropout</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adelman et al. (1990)</td>
<td>Moderate</td>
<td>Strong</td>
<td>Weak</td>
<td>Moderate</td>
<td>Weak</td>
<td>N/A</td>
<td>Weak</td>
</tr>
<tr>
<td>Brinkman et al. (2013)</td>
<td>Moderate</td>
<td>Strong</td>
<td>Weak</td>
<td>Weak</td>
<td>Strong</td>
<td>Strong</td>
<td>Weak</td>
</tr>
<tr>
<td>He et al. (2016)</td>
<td>Moderate</td>
<td>Strong</td>
<td>Weak</td>
<td>Moderate</td>
<td>Strong</td>
<td>Weak</td>
<td>Weak</td>
</tr>
<tr>
<td>Hogue et al. (2016)</td>
<td>Moderate</td>
<td>Moderate</td>
<td>Weak</td>
<td>Weak</td>
<td>Moderate</td>
<td>N/A</td>
<td>Weak</td>
</tr>
</tbody>
</table>
4.3.3 Intervention functions used in SDM interventions

Across the four studies, five different IFs were identified. Per study, the number of IFs ranged from one to five, with a mean of 2.75 ($SD = 1.71$). The most frequently appearing IF was ‘education’, which was identified in all four interventions. This was followed by ‘training’, which was present in three interventions. 'Enablement' was present in two interventions, whilst ‘modelling’ and ‘environmental restructuring’ were each present in one intervention.

For parents, the most frequently used IF was ‘education’, which was found in three interventions. This was followed by ‘enablement’, which was found in two interventions, and ‘environmental restructuring’, which appeared in one intervention. For young people, ‘education’ was also the most frequent IF, as it appeared in two interventions. This was followed by ‘training’ and ‘enablement’, each of which appeared in one intervention. For clinicians, ‘training’ and ‘education’ were present in two interventions. This was followed by ‘modelling’, ‘environmental restructuring’ and ‘enablement’, which were each present in one intervention.

4.3.4 The theory used in interventions to facilitate SDM in child and youth health

None of the four identified interventions explicitly mentioned theoretical underpinnings. However, the ADHD choice cards (Brinkman et al., 2013) were developed in accordance with the International Patient Decision Aid Standards (IPDAS). These standards draw on some theory to ensure that the relevant content is included when developing DAs (O’Connor, Llewellyn-Thomas, & Stacey, 2005).
4.3.5 Relationships between IFs, BCTs and Process and Outcome Measures

The next section explores each intervention in relation to IFs, BCTs and whether or not the study found a difference in process and outcome measures when the experimental group was compared to the control group.

Table 4-4 details the IFs present in each study and indicates whether an increase in decision making was found. Similarly, Table 4-5 illustrates the BCTs present in each study and indicates whether an increase in decision making was observed.

4.3.5.1 Pre-conference workshop for increasing motivational readiness
(Adelman et al., 1990)

In this study, two IFs were aimed at young people, including ‘education’ and ‘training’. Two BCTs were also aimed at young people, including ‘behavioural practice and rehearsal’ and ‘habit formation’. Young people who were randomised to the pre-conference workshop did not score any differently on participation, satisfaction, motivation on future participation or perceived control when compared to those who were in the control arm.
Table 4-4. Intervention functions present and whether the study findings indicated an increase in SDM

<table>
<thead>
<tr>
<th>Study, intervention and target group</th>
<th>Education</th>
<th>Training</th>
<th>Modelling</th>
<th>Environmental Restructuring</th>
<th>Enablement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adelman et al. (1990)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-conference workshop</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Young people</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Brinkman et al. (2013)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADHD choice cards</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Clinicians</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>He et al. (2016) Parents choosing treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Hogue et al. (2016) MIP</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Young people</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Parents</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Clinicians</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

✓ Study reported an increase in decision making participation, X Study reported no increase in decision making participation
Table 4-5. Behaviour change techniques present in studies and whether the study found increased SDM

<table>
<thead>
<tr>
<th>Study and target group</th>
<th>1.2</th>
<th>1.3</th>
<th>1.5</th>
<th>1.7</th>
<th>4.1</th>
<th>5.1</th>
<th>5.3</th>
<th>6.1</th>
<th>7.1</th>
<th>8.1</th>
<th>8.3</th>
<th>9.1</th>
<th>9.2</th>
<th>12.5</th>
<th>13.2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adelman et al. (1990)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-conference workshop</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Young people</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Brinkman et al. (2013)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADHD choice cards</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinicians</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>He et al. (2016)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents choosing treat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Hogue et al. (2016)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MIP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Young people</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinicians</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1.2 Problem solving, 1.3 Goal setting (outcome), 1.5 Review (behavioural) goals, 1.7 Review (outcome) goals, 4.1 Instructions on how to perform the behaviour, 5.1 Information about health consequences, 5.3 Information about social and environmental consequences, 6.1 Demonstration of the behaviour, 7.1 Prompts/cues, 8.1 Behavioural practice/rehearsal, 8.3 Habit formation, 9.1 Credible source, 9.2 Pros and cons, 12.5 Adding objects to the environment, 13.2 Framing/reframing, ✓ Study reported an increase in decision making participation, X Study reported no increase in decision making participation
4.3.5.2 ADHD choice cards (Brinkman et al., 2013)

For the ADHD choice cards, five IFs and three BCTs were aimed at clinicians. These IFs were ‘education’, ‘training’, ‘modelling’, ‘environmental restructuring’ and ‘enablement’. The BCTs in this study included ‘demonstration of behaviour’, ‘prompts/cues’ and ‘environmental restructuring’. For parents, there were three IFs and six BCTs present. The IFs were ‘education’, ‘environmental restructuring’ and ‘enablement’. The BCTs were ‘goal setting (outcome)’, ‘instruction on how to perform behaviour’, ‘information about health consequences’, ‘credible source’, ‘pros/cons’ and ‘adding objects to the environment’.

Parents involved in the intervention who used the ADHD choice cards were found to have higher levels of involvement in decision making, which was recorded by an independent observer (Brinkman et al., 2013). In relation to outcome measures, parents who used the ADHD choice cards had increased levels of knowledge around medication. However, there were no differences in decisional conflict, follow-up calls and visits, prescriptions written, teacher and parent behavioural ratings, titration of medication, number of days covered with medication or physician satisfaction with the choices that were made.

4.3.5.3 Parents choosing treatment (He et al., 2016),

Only one IF aimed at parents was present in this study: ‘education’. Similarly, one BCT (‘credible source’) was also aimed at parents. Those who were randomised to make a decision about treatment had lower rates of dropout when compared to parents who did not have a choice (He et al., 2016). No other outcomes were examined in this study.
4.3.5.4 Medication Integration Protocol (Hogue et al., 2016).

In this study, two IFs ‘training’ and ‘education’ were aimed at clinicians, whilst two IFs ‘education’ and ‘enablement’ were aimed at both parents and young people. Two BCTs were aimed at clinicians. These included ‘behavioural practice and rehearsal’ and ‘habit formation’. Nine BCTs were aimed at both parents and young people: ‘problem solving’, ‘goal setting (outcome)’, ‘review of behavioural goals’, ‘review of outcome goals’, ‘information about health consequences’, ‘information about social and environmental consequences’, ‘credible source’, ‘pros/cons’ and ‘framing/reframing’.

Compared to a historical control, families who used the MIP (Hogue et al., 2016) had higher levels of family decision making with the clinician, as recorded by an independent observer. With regard to outcomes, families receiving the MIP were significantly more likely to have a completed psychiatric evaluation, to be prescribed any medication or to be prescribed a medication for ADHD compared to the control. However, no differences were found regarding the number of days on ADHD medication (Hogue et al., 2016).

4.3.6 Exploring relationships between BCTs, IFs and process and outcome measures across interventions

The heterogeneity of the interventions and process and outcome measures precluded the pooling of results for meta-analysis. Two interventions reported increased participation in decision making (Brinkman et al., 2013; Hogue et al., 2016), whilst a third intervention manipulated participation in decision making by randomising parents to choose treatment or not (He et al., 2016). The intervention that was aimed only at young people did not find any differences in participation in a psychoeducational decision making conference (Adelman et al., 1990). The next section explores the IFs and BCTs that were used across interventions and examines their potential relationship with the process and outcome measures.
Across studies, in which there was increased participation or involvement in decision making, the IF ‘education’ was present. In fact, ‘education’ was used six times (three times with parents, twice with clinicians, and once with young people), while ‘enablement’ was used four times (once with clinicians, once with young people and twice with parents), ‘training’ was used twice (both with clinicians), ‘environmental restructuring’ was used twice (once with parents and once with clinicians) and ‘modelling’ was used once (with clinicians). In interventions where no difference was found, the IFs ‘training’ and ‘education’ were used solely with young people.

Across the interventions that found increased participation or involvement in decision making, the BCT ‘credible source’ was used four times (three times with parents and once with young people). ‘Goal setting (outcome)’, ‘information about health consequences’, and ‘pros/cons’ were each used three times (twice with parents and once with young people). The BCTs ‘problem solving’, ‘review (behaviour) goals’, ‘review (outcome) goals’, ‘information about social and environmental consequences’ and ‘framing/reframing’ each appeared twice across studies (once with parents and once with young people). ‘Adding objects to the environment’ also appeared twice (once with parents and once with clinicians). The remaining BCTs all appeared once, and were all aimed at clinicians. These included ‘demonstration of the behaviour’, ‘prompts/cues’, ‘behavioural practice and rehearsal’ and ‘habit formation’. In the interventions where no differences were found, two BCTs appeared. These were ‘habit formation’ and ‘behavioural practice and rehearsal’, and both were aimed at young people.

Interventions that were found to increase participation in decision making were examined in relation to outcomes. However, only one outcome, prescriptions written for ADHD, was present in more than one study (Brinkman et al., 2013; Hogue et al., 2016). No difference was found in the number of prescriptions written for ADHD in one intervention (Brinkman et al., 2013), whilst the other
intervention found an increase in ADHD prescriptions written (Hogue et al., 2016).

There are some similarities between the IFs that appeared in the two studies that measured prescriptions written for ADHD. ‘Education’ and ‘enablement’ were both used with parents in these interventions, and ‘training’ and ‘education’ were used in both studies with clinicians. In terms of differences, the ADHD choice cards (Brinkman et al., 2013) used ‘enablement’ and ‘modelling’ with clinicians, as well as ‘environmental restructuring’ with both parents and clinicians. Conversely, the MIP (Hogue et al., 2016) used both ‘education’ and ‘enablement’ with young people.

Both of these interventions used several similar BCTs. These included ‘goal setting (outcome)’, ‘information about health consequences’, ‘credible source’ and ‘pros/cons’, all of which were aimed at parents. In terms of differences between the interventions, the ADHD choice cards (Brinkman et al., 2013) used the following BCTs with parents: ‘instructions on how to perform the behaviour’ and ‘adding objects to the environment’. On the other hand, ‘problem solving’, ‘review (behaviour) goals’, ‘review (outcome) goals’, ‘information about social and environmental consequences’ and ‘framing/reframing’ were used in the MIP (Hogue et al., 2016). For clinicians, the ADHD choice cards included ‘demonstration of the behaviour’, ‘prompts/cues’ and ‘adding objects to the environment’, compared with ‘behavioural practice and rehearsal’ and ‘habit formation’ in the MIP (Hogue et al., 2016).

Additionally, the MIP (Hogue et al., 2016) included young people in the intervention. The following BCTs were included for young people: ‘problem solving’, ‘goal setting (outcome)’, ‘review behavioural (goals)’, ‘review outcome goals’, ‘information about health consequences’, ‘information about social and environmental consequences’, ‘credible source’, ‘pros/cons’ and ‘framing/reframing’.
4.3.7 Quality assessment for risk of bias

The results from the quality assessment are depicted in Table 4-3. Overall, all four studies received ratings of ‘weak’, as they contained two or more weak sections. A discussion of each section follows below.

Selection bias is made up of two elements, which are the representativeness of the study population and the percentage of individuals agreeing to participate. All the studies involved individuals who were partially representative of the population. For example, they included participants who were recruited from a clinic in a systematic way, but who were not randomly selected from a comprehensive list. Similarly, all the studies had reasonably high levels (60-70%) of individuals who agreed to participate when they were approached. This gave all of the studies a score of ‘moderate’ in terms of selection bias.

For study design, three studies were RCTs or clinical control trials, which received a ‘strong’ rating (Adelman et al., 1990; Brinkman et al., 2013; He et al., 2016), whilst the fourth study compared the intervention group to a historical control (Hogue et al., 2016), which resulted in a moderate rating.

Confounding variables were highlighted in two studies. In one study, this was the marital status of the parents (Brinkman et al., 2013), whilst in the other it was the academic and treatment referral source (Hogue et al., 2016). In both instances, it was not possible to tell whether this was controlled for in the analysis. In the other two studies, it was not possible to determine whether there were any confounding variables (Adelman et al., 1990; He et al., 2016). This resulted in all of the studies receiving a rating of ‘weak’ for confounders.

Blinding is made up of two sections, including whether the outcome assessors were aware of the intervention exposure status of the participants and whether participants knew the research question. In two studies, outcome assessors were aware of the exposure status of participants (Brinkman et al., 2013; Hogue et al., 2016), whilst in the other two they were not (Adelman et al., 1990; He et
al., 2016). In all four studies, it was not possible to tell whether participants knew the research question. This resulted in two studies receiving a rating of ‘weak’ (Brinkman et al., 2013; Hogue et al., 2016) and the other two studies being rated as ‘moderate’ (Adelman et al., 1990; He et al., 2016).

For data collection methods, two studies used validated questionnaires or metrics for outcome and process measures (Brinkman et al., 2013; He et al., 2016). One study used some outcome measures which would be considered valid, and also included other questions which were created for the purposes of the study (Hogue et al., 2016). Lastly, one study did not use validated questionnaires (Adelman et al., 1990). This resulted in two studies receiving a rating of ‘strong’ for data collection methods (Brinkman et al., 2013; He et al., 2016), one receiving a rating of ‘moderate’ (Hogue et al., 2016) and one receiving a rating of ‘weak’ (Adelman et al., 1990). Two studies reported on both withdrawals and dropouts. One study had less than a 20% dropout rate (Brinkman et al., 2013), whilst the other study had more than 40% dropout (He et al., 2016). The other two studies contained only one time point for data collection, and, therefore, dropout and withdrawal were not studied (Adelman et al., 1990; Hogue et al., 2016). This resulted in one study receiving a rating of ‘strong’ (Brinkman et al., 2013), one receiving a rating of ‘weak’ (He et al., 2016) and the other two receiving no rating. (Adelman et al., 1990; Hogue et al., 2016).

4.4 Discussion

The aim of this study was to explore the theory, IFs, and BCTs that have been used in SDM interventions and to observe whether the use of any of these resulted in increased SDM and better outcomes. The small number of heterogeneous studies (in terms of population, design and measures) precluded a meta-analysis from being undertaken. Instead, a narrative synthesis was conducted. Each research question is addressed below.
4.4.1 Use of theory in interventions

Overall, three of the four identified interventions were not underpinned by theory, whilst one outlined the use of the IPDAS guidelines. The IPDAS guidelines do appear to contain some theory (O'Connor et al., 2005). According to the IPDAS guidelines, the ADHD choice cards meet all seven criteria for the definition of a patient DA, as well as seven out of nine criteria for lowering the risk of a patient making a biased decision. However, recent criticism has questioned the use of theory in the IPDAS guidelines (Bekker, 2010; McDonald, Charles, & Gafni, 2014). Critics have stated that the documentation related to the IPDAS section, ‘presenting probabilities in an unbiased and understandable way’ is ill-defined, not conceptually clear and lacking in both theoretical and empirical support (McDonald et al., 2014). These concerns have been echoed by others, with critics suggesting that the IPDAS guidelines need to be critically considered from both theoretical and empirical perspectives. This will allow for the development of tools which are able to maintain their scientific integrity while functioning in real-world healthcare settings (Bekker, 2010).

The proportion of interventions using theory is lower in this review when compared to previous research (Bowen et al., 2006; Durand et al., 2008; Sheehan & Sherman, 2012). As previous reviews mainly focused on adult physical health interventions involving the clinician and patient, the lower proportion of interventions using theory in this review could reflect the complexities of applying theory when multiple stakeholders are involved or to mental health settings. Unlike previous reviews, none of the prominent theories or theory-laden frameworks were used in the interventions included in this review. This may highlight the growing recognition of the difficulties which pertain to the theory-practice gap, as well as the recognition of the need for a more pragmatic approach that considers not only cognitive theory, but also how the environment and tools influence decision making (Elwyn et al., 2011). The TDF (Cane et al., 2012) has been proposed by the PhD candidate as a potential solution to these difficulties.
4.4.2 Intervention functions

Five out of nine possible IFs were identified in this review as having the potential to affect SDM. The most frequently used IF for both parents and young people was ‘education’. For parents, this was followed by ‘enablement’ and ‘environmental restructuring’, whilst for young people this was followed by ‘enablement’ and ‘training’. This suggests that developers believe that parents and young people lack the knowledge required in order to participate in SDM and, therefore, require support in overcoming barriers.

The IFs ‘education’ and ‘enablement’ showed promise in increasing SDM with parents. For young people, ‘enablement’ whilst used once, could potentially be useful for increasing SDM, whilst ‘education’ produced contradictory results. Other IFs (e.g. environmental restructuring) may also be considered potentially relevant though a lack of studies makes this difficult to distinguish.

The discovery that ‘education’ was an IF linked to increased participation with parents is supported by previous reviews of patient behaviour change interventions (Meader et al., 2017). Moreover, there is support in the wider literature for educating and enabling individuals as a method of increasing participation in SDM. A Cochrane review of the use of DAs across healthcare settings found that these tools educated and enabled individuals in the following ways: improved the patients’ knowledge of treatment options, helped patients understand what mattered most to them, provided patients with more accurate expectations of the risks and benefits between options, and helped patients to participate more in decision making (Stacey et al., 2017).

However, Meader et al. (2017) also identified ‘training’ and ‘persuasion’ as additional useful IFs for patient interventions aimed at changing behaviour. The lack of emphasis on training and the absence of persuasion in this review may be due to the differences between the aims and philosophies of the interventions, as well as practical issues with implementation. For example, in SDM, emphasis is placed on exploring, discussing and deliberating upon
different options or decisions, while stressing that there is no one ‘right’ course of care or treatment (e.g. Makoul and Clayman, 2006). This differs from health promotion or risk reduction behaviours, whereby there is a preferred option toward which the healthcare professional guides patients (e.g. stopping smoking). Thus, in the latter example, persuasion may be regarded as appropriate, while it would be inappropriate in SDM as it places pressure on the patient to choose a particular treatment. The increased use of enablement found in this review is not surprising, as helping the patient express their values, views and preferences fits with the philosophies and aims of SDM.

Other possible IFs such as ‘incentivisation’ found in the Meader et al. (2017) review on patient behaviour change may also not be appropriate for SDM. ‘Incentivisation’ involves creating the expectation of a reward (Michie et al., 2014, p. 111). In the context of SDM, unduly influencing patients in the direction of a particular option, which directly opposes the notion of a shared partnership that takes into account the values and preferences of all the stakeholders. Moreover, both this review and the previous review (Meader et al., 2017) found no studies that included the IFs ‘coercion’ or ‘restriction’. This suggests that developers designing patient interventions for a wide range of behaviours may not view punishment or the imposing of rules as appropriate mechanisms for change.

For clinicians the most frequently used IFs were ‘education’ and ‘training, both of which were linked with increased participation in decision making. Other IFs (e.g. environmental restructuring, modelling, and enablement) may also be considered potentially relevant though a lack of studies makes this difficult to distinguish. These findings are supported by an earlier review on IFs and clinician behaviour, which found that both ‘education’ and ‘training’ were the most useful IFs, followed by ‘modelling’ and ‘environmental restructuring’ (Chauhan et al., 2017). This suggests that intervention developers believe that clinicians lack both the knowledge and the skills necessary to perform SDM as
well as other target behaviours, and may need help such as through seeing the
demonstrated and changing the environment to make behaviour change occur.

4.4.3 Behaviour change techniques

Fifteen out of 93 possible BCTs were identified in SDM interventions. There was
no one BCT which was most frequently used with young people, although 11
BCTs were used overall with this population. Similarly, 11 different BCTs were
used with parents. However, the most frequently used BCT with parents was
‘credible source’. This was followed by ‘goal setting (outcome)’, ‘information
about health consequences’ and ‘pros/cons’.

The BCTs that have been identified as increasing participation and decision
making in other patient behaviour change interventions do not generally
correspond to those in the present review (Bartlett et al., 2014; Golley et al.,
2011; van der Kruk et al., 2013). As stated above, intervention aims and
philosophies in SDM versus those that promote healthy patient behaviours are
dissimilar, which may account for the use of different BCTs.

Five BCTs were used with clinicians. However, like the BCTs used for young
people, each of these appeared only once. There is some overlap between the
BCTs found in this review and those posited as being useful for changes in
clinician behaviour in other reviews (Cadogan et al., 2016; Craig et al., 2017;
Mc Sharry et al., 2016; Sinnott et al., 2015). In particular, ‘demonstration of
behaviour’ and ‘behavioural practice and rehearsal’ appear across all the
studies that target clinicians (Cadogan et al., 2016; Craig et al., 2017; Mc
Sharry et al., 2016; Sinnott et al., 2015). This highlights the importance of a
clinician’s ability to observe and practice the target behaviour in order to apply it
clinically. However, these studies have not tested the effectiveness of these
BCTs, so this supposition remains theoretical.
Mapping IFs and BCTs allows for speculation regarding why some interventions are successful and others are not. The ADHD choice cards (Brinkman, 2011) and the MIP (Hogue et al., 2016) found increased participation in the intervention group. Within each, a number of different IFs and BCTs were identified. From the perspective of the BCW, which guides intervention development (Michie et al., 2014), the chosen BCTs are appropriate for the IFs selected and would be considered appropriate for targeting behaviour change. Conversely, the psychoeducational workshop (Adelman et al., 1990) did not find increased participation, which was an intended outcome of this intervention. When the BCTs included in this intervention were mapped onto the IFs, no BCTs were identified for ‘education’. If the aim of the workshop was to both educate and train young people prior to making decisions, the lack of BCTs linked to the IF ‘education’ could explain why increased participation was not observed.

4.4.4 Wider findings

An interesting observation across the studies in this review is that all the interventions focused on externalising behaviours, including ADHD, behavioural difficulties or learning difficulties. This is consistent with the findings from the original scoping review in which the majority of the studies focused on externalising difficulties (Cheng et al., 2017). There is some research to suggest that increased externalising difficulties are associated with lower levels of SDM (Butler, 2014; Butler et al., 2015; Fiks et al., 2010). However, other research which includes internalising disorders suggests that this may be related to the severity rather than the type of difficulty (Butler et al., 2015). The reasons why externalising difficulties are more likely to be addressed in SDM interventions remain unclear. However, with research demonstrating that children with externalising difficulties are more likely to be diagnosed at a younger age (Park, Bang, & Kim, 2014), it is likely that parents would take the active or sole role in the decision making process. Thus, SDM in externalising difficulties may fit with
the traditional models which take place between an adult ‘patient’ and the clinician and are, therefore, easier to design and address.

It is important to note that all of these studies originated in the US. One reason for this may be that the US has led the way in SDM since the President’s Commission in 1982 (President’s Commission for the Study of Ethical Problems in Medicine, Biomedical, 1982). However, it is also one of only two countries that has not signed or ratified the CRC (1989), a key milestone in involving children and young people in SDM (UN News, 2015). These conflicting positions may also account for the prominence of parents being involved in SDM interventions developed in the US – as there is a need to recognise involvement of individuals within their care and treatment, yet there is uncertainty to whether young people can, and are able to be involved due to issues such as capacity (see Chapter 2).

Accordingly, caution should be taken when translating interventions into UK settings. For example, in relation to the treatment and diagnosis of ADHD, it has been suggested that cultural differences have led to a more medicalised approach in the US (Smith, 2017). Moreover, there are substantial differences between the UK and the US healthcare systems. One primary difference is the cost of care, which can be an important determining factor when choosing treatment. This is evident in resources such as the decision choice cards, in which cost has its own card and which are explicitly outlined for each treatment (Brinkman et al., 2013).

4.4.5 Strengths and limitations

This is the first study to examine theory, IFs, and BCTs for SDM in child and youth mental health. A strength of this study is that it examines which IFs and BCTs are used with each stakeholder in the decision-making process, as well as the effect that this may have on increasing participation in SDM. However, given the small number of studies which score poorly on quality assessment,
findings from this review must be treated with caution. This is further compounded by the different process and outcome measures used in these studies, as well as a focus on different presenting problems which does not allow for meta-analysis. Despite this, there appear to be a number of possible IFs and BCTs, particularly for parents, which could help to facilitate SDM.

A further strength of this study is the use of two researchers (DH and RT) to extract the data from the papers and conduct the quality assessment of these studies. This mitigates the risk of systematic bias within the study, while also decreasing the total number of errors in data extraction and quality assessment (Buscemi, Hartling, Vandermeer, Tjosvold, & Klassen, 2006). With regard to the data extraction, online training was completed by both researchers to ensure consistency in identifying and recording BCTs. The researchers were required to score at least 90% correctly on the assessment for this training before coding for the present review. High levels of agreement were obtained for both data extraction and quality assessment, which suggests that the reliability is high. Intervention functions and BCTs were then checked by two psychologists specialising in behaviour change to ensure that the coding was correct. This additional layer, which resulted in one change, also increased the reliability of these findings.

Limitations to this study also exist. First, despite an updated review of the literature and discussions with SDM experts, it is possible that some studies were missed. In particular, as this research built on the Cheng et al., (2017) study, which the PhD candidate is joint first author, a rescreening of the original results was not undertaken. This means that any studies which were missed in the original review would also have been omitted from the present review.

Second, in line with BCT training, the researchers adopted a conservative view when it came to extraction, as they only included the BCTs that were explicitly mentioned in the papers. Those that required interpretation were excluded if
further information or clarification could not be obtained. This resulted in some BCTs being excluded despite their potential relevance.

Third, fidelity to the protocols and interventions discussed in the papers was not examined. Thus, the mention of a BCT in a study did not guarantee it was actually used in the intervention. Additionally, most studies gave little or no information about the control group, which meant that the BCTs used within these groups were often not able to be examined. As a result, it is likely that some BCTs, such as ‘information about health consequences’, could have been discussed in the control, but researchers were unable to assess their impact as part of the intervention as they were not explicitly mentioned.

To overcome the latter two limitations, better reporting of interventions is needed. The MRC guidelines emphasise the importance of this (Craig et al., 2008). Uptake and interest in the BCW (Michie et al., 2014) may help to improve the clarification of explicit BCTs in interventions. Researchers and clinicians in the field of SDM may also wish to consider incorporating the language and reporting of BCTs into guidelines and frameworks for intervention design. They might also adapt the existing models to highlight the BCTs that may be helpful in adapting clinician and patient behaviour to facilitate equal participation in treatment.

4.4.6 Conclusions

This review provides the first evidence of the theories, IFs and BCTs that are being used in interventions to facilitate SDM in child and youth mental health. In line with wider findings, a lack of theory is present in such interventions. However, the degree, up to the present time, to which traditional theories have been useful for intervention development has been questioned, as they tend to focus on one or a few key areas of decision making, neglecting other factors (Elwyn et al., 2011).
The IFs ‘education’ and ‘enablement’ may be useful for intervention developers to consider when increasing SDM for parents, whilst ‘enablement’ for young people could potentially be useful at increasing SDM. On the other hand, for clinicians the IFs ‘education’ and ‘training’ should be considered. These fit within the wider literature of behaviour change as well as the philosophies of SDM. In order to be better involved in the decision-making process, individuals need knowledge as well as to be enabled to be involved, whilst clinicians need to be educated and trained to move away from the traditional paternalistic style of care.

Whilst no concrete conclusions can be drawn about the BCTs that are associated with increased SDM and better outcomes, there are a number of evidence-based suggestions which may be useful for developers of SDM interventions in child and youth mental health. Slightly more evidence of increased SDM and better outcomes have been found for the BCTs ‘credible source’, ‘pros/cons’, ‘information about health consequences’ and ‘goal setting (outcome)’ for parents. Intervention developers may wish to use these BCTs when designing SDM interventions that target parents and clinicians. Further information should be sought regarding the IFs and BCTs that could be effectively used with young people, parents and clinicians. To accomplish this, the BCW (Michie et al., 2014) advises working with stakeholders to identify the barriers and facilitators to the target behaviour, which are undertaken in Chapters 6 and 7. However, prior to this, the next chapter examines the current practice of SDM in child and youth mental health settings in England to determine whether there are certain demographic or clinical characteristics that should be targeted to improve SDM within this context.
Chapter 5 Current practice of SDM in child and youth mental health settings in England
5.1 Introduction

Service variation in treatment provision has been demonstrated across the UK in child and youth health care settings (Rightcare, 2012, 2016). In this field, a government report highlighted the existence of unacceptable variation and a lack of consistency across services (Department of Health, 2015, p. 22). Research in related areas to SDM also report variation in the practice of including young people (Jacob et al., 2017). In this study which examined goal-based outcomes, which are considered to be an active form of SDM (Da Silva, 2012), findings indicated high levels (39%) of variation between services when it comes to the setting and tracking of goals. However, the relationship between such variation and SDM more generally remains unknown.

Previous research outlined in Chapter 2 demonstrated that SDM is associated with several predictors in child and youth mental health settings. In terms of case characteristics, lower levels of symptomology and impairment in children and young people have been found to be associated with higher levels of SDM experience as reported by parents (Butler, 2014; Butler et al., 2015; Fiks et al., 2010). Two of these studies focused on externalising difficulties (Fiks et al., 2010) whilst the other study examined both internalising and externalising difficulties (Butler et al., 2015).

With reference to demographic characteristics, neither the ages nor genders of young people have been found to predict parent-reported experiences of SDM (Butler et al., 2014, 2015). The role of ethnicity in SDM has produced mixed results. One study found that being Latino was associated with lower reported experiences of SDM (Butler et al., 2014), whilst other studies have not found any association between ethnicity and SDM (Butler et al., 2015; Fiks et al., 2010). However, these studies are all limited by their reliance on parent-reported SDM, which may not be representative of what young people would report. Moreover, all studies were conducted within the US healthcare system which differs substantially from the UK in terms of insurance practices.
Only one study examined SDM using young person-reported experiences (Edbrooke-Childs et al., 2015). Conducted in the UK, findings from this study suggest that high levels of SDM, as reported by both parents and young people, are associated with an improvement in psychosocial difficulties. Importantly, further analysis showed that child-reported experiences of SDM were only associated with higher levels of child-reported improvements when their parents also reported higher levels of SDM. This led the authors to conclude that SDM should involve young people and their caregivers in order for treatment outcomes to be effective (Edbrooke-Childs et al., 2015). However, the individual predictors associated with SDM were not examined in this study.

The above literature highlights the lack of studies on SDM. Particularly absent are studies related to service-level variation and factors that predict SDM for young people. Therefore, there is a need for research into young people’s reported experiences of SDM, as well as an investigation of the current levels of variation in SDM with both parents and young people in services.

### 5.1.1 Aims of the present research

This study has two aims. First, it aims to examine service-level variation in experiences of SDM as reported by young people and parents. Second, it aims to explore the association between patient demographics, case characteristics and experiences of SDM as reported by young people and parents.

### 5.1.2 Research questions

This study addresses two research questions. First, how much service-level variation is there in child- and parent-reported SDM in a sample of cases from child and youth mental health services in England? Second, are there specific patient demographics or case characteristics associated with SDM in a sample of cases from child and youth mental health services in England?
5.1.3 Hypotheses

It is hypothesised that:

H$_1$: There will be a high amount of service-level variation in SDM reported by young people and parents.

H$_2$: Demographic variables will not predict the levels of SDM for young people and parents.

H$_3$: Lower levels of SDM reported by young people and parents will be associated with increased severity in case characteristics for young people and their parents.

H$_4$: Lower levels of SDM reported by young people and parents will be associated with impairments in functioning for children and young people.

5.2 Methods

5.2.1 Participants

The Child Outcomes Research Consortium (CORC) is a practice research network of clinicians, managers, commissioners and funders who provide services related to the mental health and wellbeing of children and young people (CORC, 2002). Services pay a fee to subscribe to CORC and submit routinely collected data to help inform clinical practice, evaluation, auditing and service-improvement initiatives.

For the analysis involving young person-reported experiences of SDM, children and young people were only included if their data were reported in the CORC dataset up to 2015, if they had completed the SDQ (Goodman, 1997) prior to assessment and if they had completed the Experience of Care Survey (Commission for Health Improvement, 2002) at the end of assessment. This resulted in a final sample of 1,705 young people across 28 services. The mean
number of participants in each service was 63.00 (range 15-138) Table 5-1 provides an overview of demographic and case characteristic information for the final sample of young people.

Table 5-1 Characteristics of young people in the sample who reported on experiences of SDM

<table>
<thead>
<tr>
<th>Demographic and case characteristics</th>
<th>N = 1,705</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female (% sample)</td>
<td>1,187 (69.61%)</td>
</tr>
<tr>
<td>Age mean (sd)</td>
<td>14.43 (1.74)</td>
</tr>
<tr>
<td>Ethnicity White (% sample)</td>
<td>1,275 (74.78%)</td>
</tr>
<tr>
<td>Any other background (% sample)</td>
<td>430 (25.21%)</td>
</tr>
<tr>
<td>Internalising score mean (sd)</td>
<td>9.76 (3.81)</td>
</tr>
<tr>
<td>Externalising score mean (sd)</td>
<td>8.27 (3.75)</td>
</tr>
<tr>
<td>Impact mean (sd)</td>
<td>3.50 (2.66)</td>
</tr>
</tbody>
</table>

Data were descriptively compared to the CYP IAPT national dataset (Wolpert, Jacob, et al., 2016). This comparison revealed that there were a higher number of females (69% vs 52%) and a lower number of individuals who identified as ‘White’ (75% vs 82%) within the current sample. This national sample only used three subscales of the SDQ, so comparing the internalising and externalising difficulties were not possible.

A similar protocol was followed for parent-reported SDM. Parents were included if their data were reported in the CORC dataset up to 2015, if they had completed the SDQ for their child or young person (Goodman, 1997) prior to assessment, and if they had completed the ESQ (Commission for Health

10 Obtained from the SDQ (Goodman, 1997)

11 Scored out of 20
Improvement, 2002) at the end of assessment. This resulted in a final sample of 2,005 cases across 28 services. The mean number of participants in each service was 71.07 (range 19-223) Case characteristics are presented in Table 5-2.

Table 5-2 Characteristics of children in the sample whose parents reported on experiences of SDM

<table>
<thead>
<tr>
<th>Demographic and case characteristics of young person</th>
<th>N = 2,005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female (% sample)</td>
<td>1,036 (51.67%)</td>
</tr>
<tr>
<td>Age mean (sd)</td>
<td>10.76 (3.66)</td>
</tr>
<tr>
<td>Ethnicity White (% sample)</td>
<td>1,500 (74.81%)</td>
</tr>
<tr>
<td>Any other background (% sample)</td>
<td>505 (25.19%)</td>
</tr>
<tr>
<td>Internalising score mean(^{12}) (sd)</td>
<td>9.15(^{13}) (4.15)</td>
</tr>
<tr>
<td>Externalising score mean(^{12}) (sd)</td>
<td>9.00(^{13}) (4.77)</td>
</tr>
<tr>
<td>Impact mean (sd)</td>
<td>4.19 (2.94)</td>
</tr>
</tbody>
</table>

Compared to the national figures obtained from CYP IAPT (Wolpert, Jacob, et al., 2016), there were the same number of females (52%) and a lower number of individuals who identified as ‘White’ (75% vs 82%) within the current sample. As above, this national sample only used three subscales of the SDQ, so comparing the internalising and externalising difficulties was not possible.

\(^{12}\) Obtained from the SDQ (Goodman, 1997)

\(^{13}\) Scored out of 20
5.2.2 Measures

5.2.2.1 Demographic characteristics

Demographic characteristics (age, gender, and ethnicity) were collected and recorded by services as part of routine data collection. Ethnicity was recorded using the 2001 Census (Office for National Statistics, 2001) and based on self-report by the young person or their parent/guardian. For the purposes of analysis, ethnicities were first grouped into the following categories: White (including White British, Irish and Other White background), Asian (including Indian, Pakistani, Bangladeshi and Other), Mixed (including Mixed White and Black Carribean, Mixed White and Black African, Mixed White and Asian, and any other mixed background), Black or Black British (including Caribbean, African and Other), and other ethnic groups (including Chinese and Other). In the final sample, the Asian, Black, Mixed and other categories all had frequencies of 5% or less and were grouped under the heading of ‘Any other ethnic background’.

5.2.2.2 Case characteristics

Case characteristics were measured by parent- or child-reported scores on the SDQ at the start of the assessment appointment (Goodman, 1997). This 25-item questionnaire captures emotional and behavioural difficulties (Goodman, 1997, 2001). Each item is scored on a three-point scale, which ranges from ‘Not True’ (0) to ‘Certainly True’ (2). The SDQ can be scored across its five subscales (emotional symptoms, conduct problems, hyperactive-inattention, peer relationship problems, and prosocial behaviour). It can also be scored on two overarching subscales, which include the ‘internalising’ scale (made up of the emotional and peer relationship subscales) and the ‘externalising’ scale (made up of the conduct problem and hyperactive-inattention subscales). The SDQ also has an ‘impact score’ which measures the effect of mental health difficulties on everyday aspects of the young person’s life. This includes home
life, friendships, classroom activities and leisure activities (Goodman, 1997). Each area is scored on a four-point Likert scale ranging from 'Not at All' and 'Only a Little' (both scoring 0) to 'A Great Deal' (2).

The SDQ is suitable for child and young person self-report from the age of 11 and for proxy reporting from the age of two (Goodman, 1997). It is one of the most commonly used measures for wellbeing and mental health and was recently added as a new indicator of children’s mental health by the Office for National Statistics (Office for National Statistics, 2015). It is considered acceptable for both clinical and research purposes (Goodman, 1997; Goodman, Ford, Simmons, Gatward, & Meltzer, 2000), and it has been proven to have good internal consistency (Goodman, 2001; Yao et al., 2009), concurrent validity (Muris, Meesters, & van den Berg, 2003) and discriminant validity (Lundh, Wangby-Lundh, & Bjarehed, 2008). Test re-test reliability has been found to be moderate for the SDQ (Yao et al., 2009). Within this dataset the internal consistency for the externalising scale was .64 and .73 for young person and parent reports respectively. For internalising difficulties, internal consistency was .50 and .48 for young person and parent reports respectively.

5.2.2.3 Shared decision making

Consistent with previous research (Edbrooke-Childs et al., 2015), reported experiences of SDM in the present study have been extracted from four questions on the ESQ (Commission for Health Improvement, 2002), which is completed by either the young person or their parent. These were collected at the end of the assessment appointment. The four questions measure the provision of information about the presenting problem or possible treatment options (‘I have been given enough explanation about the help available here’), and the extent to which there has been discussion and consideration of the patient’s preferences regarding the presenting difficulty or treatment options (‘I felt that the people who saw me/my child listened to me’, ‘It was easy to talk to
the people who saw me/my child’, ‘My views and worries were taken seriously’). These items were chosen as they correspond to the aspects of SDM behaviour defined by Makoul and Clayman (2006) (Edbrooke-Childs et al., 2015). Each question is scored on a three-point Likert scale which ranges from ‘Certainly True’ (1) to ‘Certainly Not True’ (3). A fourth option, ‘don’t know’, was excluded from analysis as missing data, as it was not possible to ascertain from this the degree to which participants thought SDM was occurring. Within this dataset the internal consistency of the scales was found to be .91 for young person reported experience of shared decision making and .94 for parent reports of shared decision making.

5.2.3 Analytic strategy

For the purposes of this research, SDM was dichotomised as either ‘1’, ‘gold-standard SDM’ (representing a score of ‘3’ across all four items of the ESQ), or ‘0’, ‘non-gold standard SDM’ (representing a score of less than ‘3’ across items) and analysed using mixed effect logistic regressions. The rationale for this was the following: Firstly, patient-reported experience measures such as the ESQ (Commission for Health Improvement, 2002) tend to be skewed toward the top of the scale (Brown, Ford, Deighton, & Wolpert, 2014). This also appeared to be the case in this sample, where the majority of the parents (75%) and young people (60%) reported a top score of ‘3’ across all the questions. Deviation from this warrants further investigation. A precedent has been set for such an approach, as SDM measures such as CollaboRATE (Elwyn, Barr, et al., 2013) advocate this split between gold standard and non-gold standard SDM and other research utilises this approach (e.g. Forcino et al., 2017).

For case characteristics, the two overarching subscales, internalising and externalising, were used for analysis. Higher scores on these subscales indicate greater difficulties. These scales were employed for the following reason: Previous studies examining SDM have focused on the severity of the internalising vs externalising difficulties, rather than the individual diagnoses
(Butler, 2014; Butler et al., 2014, 2015). The use of the SDQ to examine the constructs of the internalising and externalising difficulties has been found to be justified, as the authors of the measure conclude that there is no single best use of subscales and its proper use ultimately depends on the study aims (Goodman, Lamping, & Ploubidis, 2010). In this instance, utilising these internalising and externalising subscales will allow for a better comparison with previous research. These scales have also been used in other clinical studies (Chalfant, Rapee, & Carroll, 2007). In addition, it has also been noted by the authors of the questionnaire that the five hypothesised subscales may not address discrete constructs (Goodman et al., 2010).

Data were analysed using STATA 14 (StataCorp, 2015). Logistic regression is appropriate for analysing a binary outcome, which in this instance was gold-standard SDM or not gold-standard SDM. Thus, logistic regression was employed to examine demographic and case characteristics in relation to whether gold standard SDM was experienced or not. Prior to hypothesis testing, the assumptions for logistic regression were tested and no assumptions were found to be violated. Following this, hypotheses were tested using mixed-effect logistic regressions. The use of a mixed effect model allows researchers to account for the fact that children who are seen in one service are more likely to have similar services offered to them, due to a similar culture and geographical region, than children seen in different services. Mixed effect models take into account the fact that data may be nested in this way, which allows for residual components at both the child and service level. This service residual, or ‘service effect’, represents the variation accounted for by the nesting of children in services and is likely to reflect service characteristics that can affect child outcomes as outlined above.

Three models were tested to examine variance at the service level. In Model 0 (the null model), the intraclass correlation coefficient was computed to examine the variance explained at the service level. In Model 1 (the first step),
demographic information was entered, including gender (coded ‘1’ for female, with male as the reference category ‘0’), ethnicity, (coded 1 for ‘any other ethnic background’, with ‘White’ as the reference category ‘0’) and mean-centred age. In Model 2 (the second step), the severity of case characteristics and impact were examined. To determine the model fit, Akaike’s Information Criterion (AIC; Akaike, 1973) was employed to find an appropriate balance between the model fit and the parameters (Burnham & Anderson, 1998). A lower value on the AIC represents a better model fit.

5.2.4 Ethical approval

Access to this pre-existing dataset was applied for by the PhD candidate and approved by the CORC board (see Appendix 5b for approval). Data were presented to the PhD candidate in an anonymised format with the participants’ names as well as the names and locations of services omitted. As data used for this project involved the secondary analysis of routinely collected and anonymised data, ethical approval was not needed in line with the Governance Arrangements for Research Ethics Committees.

5.3 Results

An examination of correlations (see Tables 5.3 and 5.4) revealed that no independent variables were highly correlated. The variance inflation factor (VIF) for predictor variables in both young person and parent-reported experiences of SDM was found to be acceptable (range 1.01 to 1.26 respectively), which indicated that multicollinearity was not present (Miles & Shevlin, 2001).
Table 5-3 Correlation matrix for predictor variables included in young person-reported experiences of SDM

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Age</td>
<td>0.17***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Ethnicity</td>
<td>0.03</td>
<td>0.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Internalising</td>
<td>0.23***</td>
<td>0.21***</td>
<td>-0.04</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Externalising</td>
<td>-0.06*</td>
<td>-0.05</td>
<td>-0.09**</td>
<td>0.31***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Impact</td>
<td>0.12***</td>
<td>0.17***</td>
<td>-0.05*</td>
<td>0.39***</td>
<td>0.38***</td>
<td></td>
</tr>
</tbody>
</table>

N = 1,705, *p < .05, **p < .01, ***p < .001

Table 5-4 Correlation matrix for predictor variables included in parent-reported experiences of SDM

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Gender of young person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Age of young person</td>
<td>0.25***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Ethnicity of young person</td>
<td>-0.06**</td>
<td>-0.07**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Internalising</td>
<td>0.03</td>
<td>0.15***</td>
<td>-0.05*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Externalising</td>
<td>-0.25***</td>
<td>-0.26***</td>
<td>-0.01</td>
<td>.27***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Impact</td>
<td>0.17***</td>
<td>0.13***</td>
<td>0.02</td>
<td>-0.23***</td>
<td>-0.39***</td>
<td></td>
</tr>
</tbody>
</table>

N = 2,005, *p < .05, **p < .01, ***p < .001

5.3.1 Mixed effect logistic regressions

5.3.1.1 Young people

Mixed effect logistic regressions are shown in Table 5-5. The null model (Model 0) revealed that 46% of the variance in young people’s experiences of SDM was explained at the service level, which indicates that mixed effect regressions
are appropriate. In Model 1, demographic information was added that significantly improved the model fit ($\chi^2(3) = 11.37, p < .05$) when compared with the null model. Age was found to be a significant predictor of SDM, as the increased age of the young person resulted in a greater likelihood that the young person would report experiencing gold standard SDM. In Model 2, case characteristics were included which significantly improved the model fit ($\chi^2(3) = 9.83, p < .05$) when compared to Model 1. Age and internalising difficulties were found to be significant predictors of SDM, with higher age and lower internalising difficulties predicting better SDM. For internalising difficulties, increased severity as reported by young people meant that they were less likely to report experiencing gold standard SDM. The three models were assessed using the AIC (Akaike, 1973) to examine which model was the best fit. Model 3 was found to have the lowest AIC and thus was selected as the model that best fit the data.
Table 5-5 Mixed effect logistic regressions with demographic and case characteristics predicting young-person-reported experiences of SDM

<table>
<thead>
<tr>
<th>Parameter estimates</th>
<th>Null model: β (SE), OR, 95% CI for OR</th>
<th>+ Demographics: β (SE), OR, 95% CI for OR</th>
<th>+ Case Characteristics: β (SE), OR, 95% CI for OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>.33 (.21) 1.39 .92 -- 2.10</td>
<td>.40 (.23) 1.50 .96 -- 2.35</td>
<td>.86 (.28) 2.36 1.35 -- 4.10</td>
</tr>
<tr>
<td>Gender (Ref: ‘Male’)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘Female’</td>
<td>-.06 (.12) .94 .74 -- 1.19</td>
<td>.00 (.12) 1.00 .78 -- 1.27</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.16 (.03)** 1.11 1.04 -- 1.18</td>
<td>.12 (.03)** 1.12 1.05 -- 1.21</td>
<td></td>
</tr>
<tr>
<td>Ethnicity (Ref: ‘White’)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘Any other ethnic background’</td>
<td>-.15 (.13) .86 .66 -- 1.12</td>
<td>-.16 (.13) .85 .65 -- 1.10</td>
<td></td>
</tr>
<tr>
<td>Internalising difficulties</td>
<td></td>
<td>-.05 (.02)** .96 .92 -- .99</td>
<td></td>
</tr>
<tr>
<td>Externalising difficulties</td>
<td></td>
<td>-.01 (.02) .99 .96 -- 1.03</td>
<td></td>
</tr>
<tr>
<td>Total impact</td>
<td></td>
<td>.00 (.03) 1.00 .95 -- 1.05</td>
<td></td>
</tr>
<tr>
<td>Service-level variance</td>
<td>1.09 (.36) 1.09 .57 -- 2.08</td>
<td>1.09 (.36) 1.09 .57 -- 2.07</td>
<td>1.10 (.36) 1.10 .58 -- 2.10</td>
</tr>
</tbody>
</table>

N = 1,705, *p < .05, **p < .01, ***p < .001
### Table 5-6 Mixed effect logistic regressions with demographic and case characteristics predicting parent-reported experiences of SDM

<table>
<thead>
<tr>
<th>Parameter estimates</th>
<th>SDM</th>
<th></th>
<th>+ Demographics</th>
<th>+ Case characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Null model</td>
<td>Model 0: β (SE), OR, 95% CI for OR</td>
<td>Model 1: β (SE), OR, 95% CI for OR</td>
<td>Model 2: β (SE), OR, 95% CI for OR</td>
</tr>
<tr>
<td>Constant</td>
<td>1.15 (.31)</td>
<td>1.73 – 5.79</td>
<td>1.20 (.32)</td>
<td>1.78 – 6.22</td>
</tr>
<tr>
<td>Gender (Ref: ‘Male’)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘Female’</td>
<td>.15 (.12)</td>
<td>1.16</td>
<td>.92 – 1.46</td>
<td>.10 (.12)</td>
</tr>
<tr>
<td>Age</td>
<td>.01 (.02)</td>
<td>1.01</td>
<td>.97 – 1.05</td>
<td>.01 (.02)</td>
</tr>
<tr>
<td>Ethnicity (Ref: ‘White’)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘Any other ethnic background’</td>
<td>-.38 (.14)***</td>
<td>.69</td>
<td>.52 - .90</td>
<td>-.39 (.14)***</td>
</tr>
<tr>
<td>Internalising difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Externalising difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Impact</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service-level variance</td>
<td>2.40 (.87)</td>
<td>2.40</td>
<td>1.20 – 4.79</td>
<td>2.42 (.85)</td>
</tr>
</tbody>
</table>

N = 2,005, *p < .05, **p < .01, ***p < .001
5.3.1.2 Parents

Mixed effect logistic regressions are shown in Table 5-6. The null model (Model 0) revealed that 42% of the variance in parent-reported experiences of SDM was explained at the service level, which indicates that mixed effect regressions are appropriate. In step one (Model 1), demographic information was added which significantly improved the model fit ($\chi^2(3) = 10.32, p < .05$). The ethnicity of the young person was found to be a significant predictor of parent-reported experience of SDM. Parents whose young person was identified as ‘Any other ethnic background’ were less likely to report experiencing gold standard SDM when compared with parents whose young person was identified as ‘White’. In step two (Model 2), case characteristics were added which significantly improved the model fit ($\chi^2(3) = 16.53, p < .001$). Ethnicity was still found to be significant in predicting parent-reported SDM, as well as internalising difficulties and externalising difficulties. Parents who increased the severity of internalising or externalising difficulties were less likely to report experiencing gold standard SDM. The three models were assessed using the AIC (Akaike, 1973) to examine which model was the best fit. Model 3 was found to have the lowest AIC and was selected as the model that best fit the data.

5.4 Discussion

The aim of the present research was to explore whether case characteristics are associated with young people and parents’ experiences of SDM as well as the amount of variation in SDM at the service level. To the best of the PhD candidate’s knowledge, these results are the first to report on the associations related to children and young people’s reported experiences of SDM. Previous research has focused only on associations between the case characteristics
and parent-reported experiences of SDM (Butler, 2014; Butler et al., 2015; Fiks et al., 2010; Golnik et al., 2012).

The first hypothesis for the current research was that there would be high levels of variation across services with regard to young people and parents’ reported experiences of SDM. This hypothesis appears to be supported for both young people and parents, as results from this analysis indicate that 46% of the variation for young people and 42% of the variation for parents can be explained at the service level. The amount of service-level variation in this study is slightly higher than previous reports of SDM related to goal setting and tracking (Jacob et al., 2017). Given that service-level factors were not available for this study, these could not be further investigated. However, qualitative research suggests that service and clinician-level factors influencing SDM include clinician attitude, service culture, setting (inpatient or outpatient) and the resources that are available (Gondek et al., 2016; LeFrançois, 2008; LeFrançois, 2007; Simmons, 2011; Simmons et al., 2013). Such factors merit further investigation in future research.

The existing variation between services indicates that developing a SDM intervention could be useful, as it would have the potential to improve the consistency and systemisation of SDM across services. Training clinicians may be one way to achieve this, although most programmes involving clinicians in training vary widely in their subject matter and many have not been evaluated (Diouf, Menear, Robitaille, Guérard, & Légaré, 2016). Alternatively, tools to facilitate SDM could also be used. For example, research demonstrates that DAs can increase the involvement of patients in their care and increase the likelihood of patients making value-congruent decisions (Stacey et al., 2014).

The second hypothesis for this research was that the demographic characteristics of young people and parents would not be associated with SDM. For young people, this hypothesis is partially supported, as gender and ethnicity
were not found to be associated with SDM. However, age was found to be a predictor of SDM for young people. With each year of increased age, there was an 12% increase in the odds that the young person would experience gold standard SDM. Similarly, the second hypothesis was partially supported for parents. However, the demographics for parents differed from those for young people. The age and gender of the young person were not found to be associated with SDM for parents, whilst ethnicity was found to predict SDM for parents. Specifically, the parents of young people who were classified as ‘any other ethnic background’ were 32% less likely to report experiencing gold standard SDM when compared to parents whose young person was classified as ‘White’.

The finding that gender is not associated with SDM is consistent with previous research (Butler, 2014; Butler et al., 2015; Fiks et al., 2010). However, an unexpected finding was that the young person’s age predicted young person-reported SDM, whilst the young person’s ethnicity predicted parent-reported SDM. With regard to age, this may support the view held by many clinicians and parents that young people are ‘doubly incapacitated’ due to having both developmental and mental capacity difficulties (Coppock, 2005, p. 150; LeFrançois, 2008). As age increases, young people may only contend with one ‘deficit’ (mental-capacity difficulties) which does not preclude SDM. Despite this, research and policy suggests that age should not be a barrier to involvement (Schachter et al., 2011; United Nations, 1989), and that other factors, such as the experience of the young person, should instead be taken into account (Alderson, 2017; Alderson & Montgomery, 1996). Importantly, these findings highlight the discrepancies between stakeholders (Hawley & Weisz, 2003) and may provide evidence that all views should be taken into account.

Ethnicity was not associated with young person-reported experiences of SDM in this sample. However, for parents, the ethnicity of their young person was a predictor of for parent-reported experience of SDM. Previous research indicated
that only parents of young people that were classified as Latin American reported lower experiences of SDM (Butler, 2014), which are a group that were not categorised in this sample. However, findings from this present study should be treated cautiously, as it was not possible to break ethnic groups down any further due to the small sample sizes within each subgroup. This means it is not possible to tell if all, or only certain ethnic groups, experience SDM differently.

Possible reasons for this finding could relate to cultural differences in talking or thinking about mental health. For instance, in some non-white cultures, mental illness is believed to be caused by external forces or other phenomena, and it is considered that it should be treated by religious leaders or other members of the community (Fernando, 2010). This could mean that parents of non-white young people report lower gold standard SDM as they feel that services are not culturally appropriate or accommodating their specific needs. Importantly, parents, rather than young people, may be more likely to hold these beliefs, as young people are able to assimilate better into other cultures (Birman & Poff, 2011; Hwang, 2006). This could explain why young people do not report lower SDM. An additional explanation for this finding may relate to socioeconomic power imbalances between members of white cultures and those of other cultures. The majority of NHS workers are white (NHS Employers, 2017), which may mean that service users from non-white backgrounds, in this case parents, feel a greater power imbalance due to their cultural, social and socioeconomic status. This could reflect negatively upon the responses given with regard to SDM.

The third hypothesis was that lower parent- and child-reported experiences of SDM would be associated with increased severity in case characteristics. This hypothesis was supported only for internalising difficulties in young person-reported SDM, whilst supported for both internalising and externalising difficulties and parent-reported SDM. For young people, each one-point increase in the severity of internalising difficulties on the SDQ was estimated to
decrease the odds the young person would report experiencing gold standard SDM by 4%. Similarly, for parent-reported SDM, the same estimated decreased odds ratio of 4% was found for each one-point increase in the severity of internalising difficulties. For externalising difficulties, each one-point increase in severity on this scale of the SDQ was estimated to decrease the odds that parents would report gold standard SDM by 3%.

The findings in this study that are related to parent-reported SDM are consistent with previous research which indicates that increased severity in both internalising and externalising difficulties predict lower reported experiences of SDM (Butler, 2014; Butler et al., 2015; Fiks et al., 2010). However, the difference in young people's reported experiences of SDM in relation to the internalising and externalising scores is a novel finding. Possible reasons for this difference could relate to the ways in which the profiles of externalising and internalising difficulties are distinct. For example, studies have demonstrated that shyness is linked to internalising difficulties, whilst low effortful control is linked to externalising difficulties (Oldehinkel, Hartman, De Winter, Veenstra, & Ormel, 2004; Ormel et al., 2005). It is therefore possible that young people who display traits such as shyness are less likely to express their values and preferences to a clinician and may be more challenging for clinicians to engage. This could result in these young people reporting lower scores of SDM.

An additional challenge is that clinicians frequently report that there is limited time to engage in SDM during appointments (Simmons et al., 2013), hence clinicians may not have the time they need to engage young people with internalising difficulties in SDM. Young people with internalising difficulties may also report lower SDM due to the manner in which they generally view the world. The cognitive triad for depression (Beck, Rush, Shaw, & Emery, 1979) suggests that individuals with depression, a common internalising difficulty, not only have negative views of themselves, but also of their future and of the
world. Thus, individuals with internalising difficulties may perceive SDM more negatively than their peers.

The final hypothesis was that the increased impact of case characteristics would result in lower reported experiences of SDM. For both parents and young people, impact was not associated with SDM. Therefore, this hypothesis was not supported by the findings of this study. This contrasts with previous literature which suggests that the impact of difficulties on daily functioning or impairments in school and extracurricular activities can affect parent-reported experiences of SDM (Butler, 2014; Butler et al., 2015). Reasons for this difference could be a greater emphasis on SDM in child and youth mental health with those who have impairments in the UK (Department of Health, 1991). Alternatively, it could also be the growing recognition that factors such as incapacity and impairment are not automatic reasons to exclude individuals from care and treatment decisions, and that there are many ways in which individuals can be meaningfully involved (Alderson & Montgomery, 1996; Paul, 2004).

5.4.1 Strengths and limitations

The following limitations should be considered when interpreting these findings. This study obtained data from the existing CORC dataset, which is composed of naturalistic, routinely collected data. Therefore, confounding variables and selection bias may apply, as data were not collected under controlled experimental conditions (Gilbody, House, & Sheldon, 2002). For example, as CORC does not require its members to collect particular measures, members are free to collect only those metrics which are important to their service. It is also important to consider that there may be variation in how data was collected and coded by services, which again could affect any inferences that are drawn. As such, further experimental research with data collected under controlled conditions is needed to replicate these findings. Reliance on the CORC dataset
also meant that there were limitations related to the variables that were available. Given that predictors such as diagnosis, perceived stigma, parental education and level of deprivation have been found to be associated with SDM (Butler, 2014; Butler et al., 2015; Fiks et al., 2010), these variable should also be investigated in future research.

A further limitation is the use of four items from the Experience of Care Survey (Commission for Health Improvement, 2002) for experiences of SDM. Whilst these items have been used to assess SDM in previous research (Edbrooke-Childs et al., 2015), the extent to which they measure key aspects of SDM is questionable. For example, there are no overt statements on the ESQ that outline that options were presented and discussed, which is a key aspect of SDM across all the models and the working definition used in this thesis (see Chapters 2 and 3). However, given that there are no validated measures for SDM with young people and current measures tend to focus on different elements of SDM (Bouniols, Leclère, & Moret, 2016), these questions on the ESQ may be used as a proxy until existing measures are validated with, or specific measures are developed for, a child and youth mental health population. Once these measures are developed, research should explore the convergent validity between the measure of SDM used in this study and any validated measures.

Another limitation of the Experience of Care Survey (Commission for Health Improvement, 2002) is the method of listwise deletion which is used to calculate SDM. Respondents who selected ‘don’t know’ for any of the 4 questions on the ESQ were excluded as it was not possible to ascertain the degree to which they had experienced SDM. Whilst listwise deletion is commonly used in similar types of analyses, it is possible that deleting these cases may have introduced bias and increased the probability of type II errors in the sample (Allison, 2014). However, given the large sample size and small amount of individuals responding to this question with ‘don’t know’ (<5%), it could be argued that only
a limited loss of power could have occurred in this sample as a result of listwise deletion (Allison, 2014).

Lastly, the lack of service-level characteristics is a limitation. Whilst this study benefitted from a large dataset provided by CORC, these data could only be accessed if the services involved were anonymous. As a result, little is known about the services that were involved in this analysis. This is particularly important given the high levels of variation in SDM due to service-level factors. For example, it is not known whether included services were inpatient settings or community-based. Setting can affect experience of SDM, as research suggests that young people in inpatient settings report having little say over care and treatment decisions (LeFrancios, 2008). Consequently, further research should be undertaken to determine the effect of service-level factors on SDM.

Notwithstanding these limitations, this study has several strengths. This is the first study to examine associations between demographic and case characteristics with experiences of SDM as reported by children and young people, rather than only as reported by their parents. Findings here suggest that there are some key similarities and differences related to the factors associated with SDM as reported by parents and young people. These factors, such as type of difficulty, age and ethnicity, should be taken into account by clinicians when they are practicing SDM. Additionally, this is the first study to acknowledge the nesting of patients within services when examining factors that predict SDM. Given that high levels of variation were observed which were consistent with similar areas such as goal setting (Jacob et al., 2017), researchers working with large datasets should examine the amount of variation caused by nesting. If high, this method of analysis can be used so as to not treat units as independent observations and to draw correct inferences.
5.4.2 Conclusions and clinical implications

The findings from this study indicate that the increased severity of internalising and externalising difficulties, the decreased age of the young person and being an ethnicity other than ‘White’ all predict lower odds of experiencing gold standard SDM. As such, these factors may be considered to be a good foundation upon which to build an intervention.

The finding that ethnicity predicted parent-reported experience of SDM could have important implications. Whilst factors explaining this finding are currently unclear, services and clinicians could attempt to address this in several ways. Tools used to facilitate SDM, such as psychoeducational information and decisions aids, could be translated into a wider range of languages so that parents are able to understand information in a language with which they feel comfortable. However, it may also be that clinicians are implicitly biased against or in favour of particular ethnic groups (Blair et al., 2013). In such instances, services may benefit from providing training around cultural competence as well as from recruiting more diverse workforces that are representative of local populations.

In relation to SDM being affected by the severity of young people’s difficulties, clinicians and services may wish to adopt different approaches to engaging in SDM with young people with more severe presentations. For example, it may be beneficial to have a longer, one-off assessment appointment or an extended assessment appointment spread over a few sessions to better ascertain the needs and preferences of these individuals, as they may be harder to engage. Moreover, as young people highlight that being listened to, respected, and validated are important aspects of being involved in care and treatment (Gondek et al., 2016), clinicians should be particularly mindful of these skills when working with young people whose difficulties are reported as more severe. In such circumstances, resources such as ‘Next Step Cards’ (Chesire
and Wirral Partnership NHS Foundation Trust, 2012) may be useful, as they provide a flexible and young person friendly way understanding values and preferences, which doesn’t rely on verbal communication.

Given that both young people and parents are usually present during appointments (Lipstein et al., 2016) and the variable ‘internalising disorders’ predicted lower gold standard SDM for both stakeholders, this factor could also be considered as the focus of an intervention. Whilst a number of approaches and tools have been developed to facilitate SDM, those that are targeted, rather than generic, are mostly aimed at externalising disorders and are specifically for parents (Cheng et al., 2017). The few tools that target internalising difficulties tend to focus on parents or much older adolescents (e.g. Simmons et al., 2016). Consequently, an intervention targeting both young people and parents has not yet been developed.

As just under half of the variation in parent- and child-reported experiences of SDM is due to service-level factors, more should be done by and within services to reduce this variation. Barriers and facilitators identified in other healthcare settings, such as team structure, differing available resources and service culture, may be applicable here (Gondek et al., 2016; Gravel et al., 2006; Joseph-Williams et al., 2013). However, the unique differences in child and youth mental health (see Chapter 3) compared to other settings mean further exploration is justified. For this reason, the next chapters qualitatively explore the barriers and facilitators to SDM in child and youth mental health, examining both individual and service-level factors from the perspectives of young people, parents and clinicians.
Chapter 6 Barriers and facilitators to SDM in child and youth mental health: A qualitative study with clinicians
6.1 Introduction

The findings from Chapter 5 suggested that almost half of the variation in SDM for both young people and parents can be attributed to service level factors. Moreover, when taking into account service level variation, both young people with internalising difficulties and their parents were less likely to report receiving gold standard SDM as the difficulties increased in severity.

Given these findings, it is important to examine what clinicians believe the barriers to SDM to be in order to develop a tool to facilitate SDM. Within the person-centred care review, six studies identified the barriers and facilitators to SDM from the perspectives of clinicians (Abrines-Jaume et al., 2016; Kovshoff et al., 2012; LeFrançois, 2008; Pelto-Piri et al., 2013; Simmons et al., 2013; Tam-Seto & Versnel, 2015). Prominent barriers and facilitators to involvement in decision making were the capacity of the young person (Abrines-Jaume et al., 2016; LeFrançois, 2008; Simmons et al., 2013; Tam-Seto & Versnel, 2015); parental involvement (Kovshoff et al., 2012; Tam-Seto & Versnel, 2015); flexibility around treatment (Abrines-Jaume et al., 2016; Kovshoff et al., 2012; Pelto-Piri et al., 2013; Tam-Seto & Versnel, 2015) and listening to, respecting and validating the young person (Kovshoff et al., 2012; Pelto-Piri et al., 2013).

One study, which explored clinician decision making around treatment for young people with depression, identified a number of additional barriers and facilitators (Simmons et al., 2013). These included what treatment options were available, what information resources were available and whether these were age appropriate, whether there was an evidence base for the treatment, whether the professionals involved agreed with the treatment plan amongst themselves, whether the clinicians were willing to talk about side effects, the team culture around decision making and factors relating to information sharing and confidentiality.
Whilst these studies provide some insight into the barriers and facilitators to SDM, they also have limitations. One limitation is that whilst these studies do explore SDM, many did not intend to examine the barriers and facilitators; which may mean some were missed. A second limitation is that only one study focused on an internalising difficulty (Simmons et al., 2013), providing limited information as to why young people and parents in this group were less likely to report gold standard SDM. Lastly, half of the studies took place outside the UK (Pelto-Piri et al., 2013; Simmons et al., 2013; Tam-Seto & Versnel, 2015) and were conducted within different cultures and healthcare systems, which could affect clinicians’ views regarding SDM.

With much of the research to date having had no explicit aim of exploring SDM or being focused on aspects other than internalising disorders, as well as being conducted outside of the UK; there was scope for a study that explored the views of UK clinicians with regard to the barriers and facilitators to SDM with young people with internalising difficulties.

6.1.1 Aims of the present study

Based on the above, this study aimed to explore clinicians’ views of the barriers and facilitators around SDM with young people who have internalising disorders along with their parents, within two services in England.

6.1.2 Research question

Utilising the TDF (Cane et al., 2012), what do clinicians perceive to be the barriers and facilitators to SDM with young people who have internalising difficulties along with their parents?
6.2 Methods

6.2.1 Setting of the study
Two NHS Trusts took part in the study. One NHS Trust (Site A) consisted of a single mental health clinic based in the east of England. This clinic was based in the community and consisted of both targeted and specialist services for young people (Tiers 2 and 3). The second NHS Trust consisted of four mental health clinics based in the Midlands. This also consisted of both targeted and specialist services for young people (Tiers 2 and 3).

6.2.2 Recruitment
To raise awareness regarding the research, the PhD candidate presented details of this study at clinician team meetings. This included outlining the aims of the study, what taking part would involve, and answering any questions clinicians had. Expression of interest forms were left for clinicians to complete and place in a box (see Appendix 6a), and these also contained the PhD candidate’s email address for direct contact. To meet the inclusion criteria for this study, the clinician had to be seeing patients, have a good understanding of English and be willing to discuss SDM with the PhD candidate.

6.2.3 Participants
Fifteen clinicians from the two sites participated in this study. Seven clinicians were recruited from Site A and eight from Site B. The majority of the clinicians were recruited through convenience sampling (n = 11), whilst additional clinicians were recruited through snowball sampling (n = 4). The clinicians were aged between 27 and 55 years old (\( M = 43.11, SD = 9.65 \)). Two identified as male (13%) and the remainder identified as female (87%). With regard to ethnic background, nine clinicians identified as White British (60%), four as Asian British (27%), one as Asian Indian (7%) and one as Black British (7%). In terms of professional groupings, there were five clinical psychologists (33%), three
trainee psychologists (20%), two psychiatrists (13%), four mental health nurses (27%) and one CBT therapist (7%). The clinicians had been working in their professions between three months to 11 years. At the time of their interviews, all the clinicians worked in mental health services intended for young people aged 16 years or below. The clinician interviews lasted between 24 and 62 minutes ($M = 38.24, SD = 8.89$).

6.2.4 Procedure

The creation of the interview schedule was developed in accordance with the TDF (Cane et al., 2012). The TDF was chosen as it explores the barriers and facilitators to behavioural phenomena, whilst being underpinned by theoretical constructs. This may be one solution to the theory-practice gap outlined by Elwyn et al., (2011) which observes that theories fail to take into account the multiple aspects of SDM.

Once created, the interview schedule was shown to a researcher (SS) in the Centre of Behaviour Change at University College London. This resulted in a modification to the section on social influences, which aimed to elicit any information on conflict or communication. Interview schedules were then mock tested with one clinician, one trainee clinician and a doctoral researcher to ensure comprehension and clarity. No changes were made as a result of this testing. Two subsequent changes were made as the interviews progressed and the PhD candidate reflected on interviews after they had occurred in order to continue developing the schedule (see Reflexivity 6.4.4 for a full account). One change made to the introduction was that the PhD candidate needed to be more explicit about the organisation they represented in order to develop a rapport with the clinicians and elicit more nuanced and honest perspectives. The PhD candidate stated that they were from an organisation that promoted SDM, was not an expert in it, and wanted to hear its positive and negative aspects from those who worked with patients. Secondly, it became apparent
that some clinicians were not familiar with the term SDM. Thus, the PhD candidate first asked the clinicians if they had heard of, or used the term, and what they thought it meant prior to questioning them further on its barriers and facilitators (see Appendix 6b for the clinician interview schedule).

The clinicians who expressed an interest in the project were provided with further information in an information sheet via email (see Appendix 6c), and a time was arranged to follow up on any questions they had. Participants who still wanted to take part after their questions were answered were asked to sign a consent form (see Appendix 6d). Interviews were arranged at times convenient for the clinicians, which meant they could take place either over the phone or in person. This resulted in five clinicians participating in a focus group, five participating in face-to-face interviews, and the remaining five participating in telephone interviews. All the clinicians who participated in the focus group were from the same service (Site B). Prior to the commencement of the interviews, the clinicians were re-briefed on the study aims and reminded of the voluntary nature of the study, that they could stop at any time and that the discussion would be recorded. The clinicians were then asked questions corresponding to the TDF about what they believed to be the barriers and facilitators to SDM with young people with internalising difficulties and their parents. The discussions were transcribed verbatim.

6.2.5 Data analysis

The transcribed interviews were analysed using a thematic analysis (Braun & Clarke, 2006). This flexible method is used to identify patterns of meaning within data among participants and is not allied to any particular framework. As such, it may be used within any theoretical framework, as well as in the absence of one (Braun & Clarke, 2006). For the purposes of this study, the thematic analysis was applied in the context of the TDF (Cane et al., 2012) in order to examine the barriers and facilitators to SDM. As the data was analysed within the context
of the TDF, this constitutes a deductive ‘theory-led’ approach, rather than an inductive ‘bottom-up’ approach to the analysis. The epistemological stance taken to data analysis was that of a critical realist, acknowledging that reality exists but that we are not able to express it fully though mediums such as language or numerical data (Teddle & Tashakkori, 2009). This was further outlined in Chapter 3 (see section 3.7)

Another consideration was the PhD candidate’s subjectivity when conducting the analysis. Despite using the TDF to examine the barriers and facilitators to SDM in child and youth mental health, it was acknowledged that the PhD candidate’s own experiences, beliefs and biases could influence the themes and subthemes. Thus, whilst undertaking data analysis, it was important for the PhD candidate to be aware of how pre-existing knowledge, beliefs and experiences could influence interpretation. To do this, a diary was kept in which biases were recorded. These were shown to supervisors and discussed during the supervision of the data analysis.

Braun and Clark (2006) outline six steps that are undertaken as part of a thematic analysis. These consist of familiarising oneself with the data, the generation of codes, searching for themes, the reviewing of themes, defining and naming themes and producing a report. Importantly, these stages are not linear but are ‘recursive’ demanding the PhD candidate move backwards and forwards between steps. Each step is outlined in more detail below.

6.2.5.1 Familiarisation with the data

This stage involves the PhD candidate immersing themselves in the data so that they are aware of the content (Braun & Clarke, 2006). This occurs through the transcription of the data as well as through reading and rereading the data once it is transcribed. As part of this ‘active’ process, after the first reading of all the transcripts, subsequent readings involved the PhD candidate noting down
potential codes in the margins of the transcripts whether on paper, or in a notebook if reading from the computer. The PhD candidate also consulted a notebook that was used as part of the interview process, in which notes were written after the interviews or focus groups had taken place.

6.2.5.2 Generation of codes

After familiarisation with the transcripts, the PhD candidate generated initial codes from the dataset (Braun & Clarke, 2006). These are basic units of analysis which on their own do not form themes, but may form the foundations of themes. A ‘theory-driven’ approach to the data was employed in which initial codes corresponded to the research question with a focus on the barriers and facilitators to SDM. The transcripts were uploaded into NVivo 11 (QSR International, 2015) and each transcript was systematically coded. The length of the initial individual codes and the amount of coding in each transcript varied. At this stage, some codes overlapped, particularly within intertwined sections such as ‘skills’ and ‘knowledge’. This stage resulted in the generation of 107 initial codes across the transcripts.

6.2.5.3 Searching for themes

The next step of thematic analysis involves moving from initial codes to broader themes (Braun & Clarke, 2006). Due to the deductive, theory-driven nature of this research, codes were initially sorted into the 14 key areas which constitute the TDF (Cane et al., 2012). This approach has been suggested as a way of using the TDF to code data (Francis, O’Connor, & Curran, 2012). Codes which did not fit into any of the domains were placed in an ‘unsorted’ category, and codes that fitted under more than one area were placed under the respective areas. After the codes were initially sorted, they were then grouped into potential themes based on the similarities of the barriers or facilitators being discussed.
6.2.5.4 Reviewing of themes

The next stage of the process involved reviewing and refining the themes. Each theme should be ‘coherent and meaningful’, ‘distinct’, and ‘have enough data to support them’ (Braun & Clarke, 2006, p. 20). This stage involved two phases. Firstly, the PhD candidate reviewed the themes at the coded data extract level, and secondly, the themes were reviewed at the dataset level (Braun & Clarke, 2006). For the first phase, the PhD candidate revisited the codes in NVivo 11 (QSR International, 2015), and examined how they fitted together, as well as whether they were representative of the passage from which they were extracted. As part of this process, a thematic map or table may be useful (Braun & Clarke, 2006). The second phase consisted of rereading all the transcripts in the dataset. This was to ensure that the themes fitted within the context of the wider dataset, as well as to code any themes which may have been previously missed (Braun & Clarke, 2006). This phase was also performed in NVivo 11 (QSR International, 2015) due to the ease with which corresponding themes and codes could be edited and moved. However, no new themes were identified.

6.2.5.5 Defining and naming of themes

This penultimate step of thematic analysis involves capturing the ‘essence of what each theme is about’ (p. 22). This consists of ensuring that the theme is not too broad or heterogeneous and that each theme is provided with an appropriate title. Due to the deductive nature of this analysis, overarching themes (e.g. Capability) and themes (e.g. Skills) were already predefined, although there was also scope to define subthemes.

6.2.5.6 Producing a report

This last step of thematic analysis, producing a report, is outlined below in the results section. In line with the BCW (Michie et al., 2014), this is produced as a
‘behavioural diagnosis’ report; where barriers and facilitators across the different theoretical domains are summarised in terms of their capability, opportunity, and motivation to change clinician practice. The findings from the ‘behavioural diagnosis’ are then compared to the previous literature.

6.2.6 Ethical considerations

Ethical consideration was sought and obtained from the London Hampstead NRES Committee (REC ref: 15/LO/0997 (see Appendix 6e for approval)). As part of this process, the clinicians were required to read the information sheet and provide their fully informed consent in order to take part in the study. The information sheet explained the aims and purpose of the study, that it was up to the clinician to decide whether they wanted to participate, and that whatever they chose would not affect their legal or employment rights. Clinicians were also reminded that they could withdraw after taking part, that their transcribed interviews would be anonymised and that the results would not identify them. Additionally, it was noted that data would be processed in accordance with the Data Protection Act (1998) and information governance policies at the AFNCCF.

6.2.7 Trustworthiness of the research findings

Whilst quantitative methodologies can be evaluated in terms of reliability and validity, the same criteria cannot be used for qualitative disciplines (Yardley, 2000). However, to try to establish trustworthiness, some quality standards are required (Lincoln & Guba, 1985; Shenton, 2004; Yardley, 2000). Shenton (2004) has developed guiding criteria that help to establish the trustworthiness of research findings.

Nine of Shenton’s (2004) recommendations were addressed in the current research study to ensure credibility. First, data in this study was triangulated through the use of different qualitative methods, including face-to-face
interviews, telephone interviews and focus groups. This allowed individuals to express thoughts, beliefs and feelings which they may not have expressed in other qualitative contexts, and it allowed the PhD candidate to overcome the limitations of each individual method. Second, to ensure honest responses, the PhD candidate built rapport with participants. This was achieved through regular attendance on a monthly basis at services for team meetings and informal engagement with the clinicians outside of the meetings. Prior to data collection, participants were reminded that they were allowed to speak freely, and that their responses would be anonymised in the results. Third, frequent supervision sessions were held between the PhD candidate and supervisors. With the first supervisor, this was on a quarter-yearly basis, and with the second supervisor, this was fortnightly. This allowed the PhD candidate to develop ideas, check his developed coding key and possible interpretations of the data, as well as to avoid bias. Fourth, peer scrutiny was employed, as the PhD candidate presented the findings to his peers and supervisors at two departmental meetings and three conferences (see papers and conferences associated with this thesis, p. 7-8). Fifth, a diary was kept which allowed the PhD candidate to note ideas, behaviours and developments as they occurred. This is further explored in the reflexive commentary section following the analysis. Sixth, the background, qualifications and experience of the PhD candidate were provided to the participants. The first two appeared on the information sheet, whereas the latter formed part of the opening statement about the PhD candidate. Seventh, ‘member checks’ were employed in which the participants were presented with the findings to ensure the PhD candidate’s interpretation was consistent with what the participants had said. This was in the form of group presentations to teams that had participated in the study. While it is more conventional to have individuals check findings, the group presentations were deemed more appropriate and less burdensome due to the constraints on the clinicians’ time. No changes were made as a result of these findings. Eighth, the PhD candidate developed a comprehensive description and understanding of
the behavioural aspects of SDM in the form of literature reviews prior to the commencement of the data collection (see Chapters 1 and 2). This allowed for a comparison of the findings with previous work, which is at the heart of qualitative enquiry (Silverman, 2000). Ninth, as the research planned to examine both the barriers and facilitators to SDM, a negative case analysis, where the data opposed the main theme findings, was also assessed within the results.

Whilst a number of strategies were employed to boost the credibility of the findings, some suggestions by Shenton (2004) were not possible. This included the use of random sampling, which could have resulted in a wider, more diverse range of responses in relation to SDM, but was not seen as appropriate by the participating sites. Additionally, iterative questioning was not undertaken, as the interview schedule already had 14 areas to cover and any additional questions would have resulted in a greater time burden on clinicians.

6.3 Results

Overall, 21 subthemes across ten domains of the TDF (Cane et al., 2012) were identified as factors that were barriers or facilitators to SDM. These spanned all three areas of the COM-B model described below (Michie et al., 2014). The results are highlighted in Table 6-1 below.
Table 6-1: Clinician barriers and facilitators to SDM using the TDF (Cane et al., 2012).

<table>
<thead>
<tr>
<th>COM-B</th>
<th>TDF</th>
<th>Barriers and facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capability</td>
<td>Knowledge</td>
<td>An awareness of the philosophy of SDM but not always the term</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A lack of knowledge regarding care and treatment options</td>
</tr>
<tr>
<td></td>
<td>Cognitive and interpersonal skills</td>
<td>The overlap between core therapeutic skills and skills needed for SDM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negotiation and containment as ‘new' skills needed for SDM</td>
</tr>
<tr>
<td></td>
<td>Memory, attention, and decision making processes</td>
<td>The availability of options may affect what is presented to the young person and family</td>
</tr>
<tr>
<td></td>
<td>Behavioural regulation</td>
<td>A lack of clarity around whether there are guidelines and protocols for SDM</td>
</tr>
<tr>
<td>Opportunity</td>
<td>Environmental context and resources</td>
<td>Reviews of treatment and goals, whilst considered important, are conducted sporadically</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facilities not conducive to SDM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Limited or a lack of psychological interventions for SDM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Administration and time constraints that inhibit SDM</td>
</tr>
<tr>
<td></td>
<td>Social influences</td>
<td>Procedural influences stop SDM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Team members positively and negatively influencing decisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dominating parents</td>
</tr>
<tr>
<td>Motivation</td>
<td>Professional role and identity</td>
<td>Shared decision making is something CAMHS clinicians ‘do’</td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------------------------------------------------</td>
<td>---------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Overruling a young person’s wishes due to professional standards</td>
</tr>
<tr>
<td>Beliefs about consequences</td>
<td></td>
<td>Shared decision making empowers young people and families</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shared decision making takes too much time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shared decision making can make psychological problems worse</td>
</tr>
<tr>
<td>Beliefs about capabilities</td>
<td>Feeling confident engaging in SDM</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Feeling less confident due to a lack of knowledge around options</td>
</tr>
<tr>
<td>Emotion</td>
<td>Feeling overwhelmed which inhibits SDM</td>
<td></td>
</tr>
</tbody>
</table>
6.3.1 Capability

Capability consists of four domains: Knowledge, Skills, Memory/Attention, Decision Making Processes and Behavioural Regulation.

6.3.1.1 Knowledge

Knowledge refers to ‘an awareness of the existence of something’ and covers constructs including ‘procedural knowledge’ and ‘knowledge of task environment’ (Cane et al., 2012, p. 13). The interviews and focus groups with the clinicians led to the identification of the following two subthemes: an awareness of the philosophy of SDM but not always the term, and a lack of knowledge regarding care and treatment options.

An awareness of the philosophy of SDM but not always the term

The majority of clinicians in this sample were aware of SDM as a concept, and as such what SDM entailed. When asked to provide a definition, they outlined examples such as partnership, eliciting patient values and preferences, as well as identifying treatment options.

*It’s about us not being the expert all the time, it’s about being very explicit about what we can offer, what we’ve got… asking them what helps, what’s been helpful, as well as what we automatically think we may be able to offer them…and not us always sitting in that medical expert model…to keep the parents and families as the experts in their own lives really* (Mental Health Nurse 4).

Whilst this suggests an understanding of some of the elements and qualities associated with SDM in child and youth mental health, not all of the clinicians stated they would use the term ‘SDM’. Interestingly, the clinicians who had not
received any CYP IAPT\textsuperscript{14} training seemed less inclined to use the term ‘SDM’. Despite not knowing or using the specific term, all the clinicians believed that the concept of SDM was something that they clinically practiced.

\textit{It’s been only recently that I have been told about this shared decision-making, the term specifically…. I know what the meaning is. I think we have used the shared decision issues [for] a very long time… I mean, when we see patients in our clinic, when we think about treatments, when we offer treatments … asking their opinions and taking that into consideration} (Psychiatrist 2).

When asked what terms they use instead, some clinicians mentioned ‘informed consent’, (Psychiatrist 2). This concept, which is related to SDM, has some underlying similarities though doesn’t aim to actively involve the patient, nor elicit values or preferences. The clinicians also outlined the broad nature of decisions that could take place during the clinical encounter, including aspects such as ‘goal setting and choosing what treatment to focus on’ (Trainee Psychologist 1), ‘choosing a treatment option’ (Mental Health Nurse 4), or ‘when to be seen’ (Clinical Psychologist 2).

\textbf{A lack of knowledge regarding care and treatment options}

Whilst the clinicians highlighted multiple ways young people and families could be involved during appointments in CAMHS, a particular barrier for the clinicians was a lack of knowledge regarding the available care and treatment options for patients. This was particularly prominent when it came to the resources available outside of CAMHS.

\textsuperscript{14} CYP IAPT is a service transformation programme that aims to improve the existing Child and Adolescent Mental Health Services (NHS England, 2016).
Five years ago, there were a lot more resources out there, you felt comfortable signposting outside, you had better links, and I think over the years, as things have dwindled, I find myself struggling to see what’s out there as well (Clinical Psychologist 5).

The clinicians reported that funding cuts to community resources and voluntary organisations meant they did not know where to signpost with regard to other services. Even when resources were available, the clinicians tended to be cautious in making referrals due to long waiting lists or not knowing the quality of the service.

The interviews with the clinicians also demonstrated that some were not aware of certain options within their own service.

I am just thinking of us trainees for example, moving from placement to placement, how are you aware of all the options available? Or if you are aware of the three options rather than the five, you’re only going to present the three that you know about (Trainee Psychologist 2).

This was true for trainees who were on rotation as part of their training, but it was also the case for new members of staff who had just joined the service. In both situations, the clinicians acknowledged the possibility of not knowing all of the options within their service. They posited that this limited the scope of SDM with the patient, as they were only offering them a subsection of possible options.

6.3.1.2 Skills

Skills refer to ‘an ability or proficiency acquired through practice and covers constructs including the development of skills, competence, practice and interpersonal skills’ (Cane et al., 2012, p. 13). The clinician interviews and focus groups identified the following two subthemes: the overlap between core therapeutic skills and SDM, and negotiation and containment as ‘new’ skills required for SDM.
The overlap between core therapeutic skills and the skills needed for SDM

When asked to outline the skills that were needed for SDM, clinicians suggested being ‘open’, (CBT Therapist 1) ‘honest’, (Clinical Psychologist 3) ‘transparent’ (Clinical Psychologist 2), and ‘listening to young people and parents’ (Psychiatrist 1) as being important.

I think the basics, just to be listening well, to be a little bit more involved — to be actually listening properly and using what is being said rather than make your own points around it. I think it’s just the ability to connect with the people they work with really; I think that’s the main thing. It’s just about rapport-building and being quite transparent in what you’re doing (Therapist 1).

The clinicians commented on how this overlapped with skills acquired as part of their professional training, as well as through enhanced courses such as CYP IAPT in which skills around SDM were explicitly practiced. Clinical Psychologist 2 outlined that CYP IAPT training had helped to improve their SDM skills through ‘thinking about how it looks and how it works’ and adapting their skillset to work with different groups. Whilst these skills were acquired during training, the clinicians noted that supervision was important to keep them sharp as well as to refine them.

I think you need good supervision and I think you need practice doing it, people observing you and critiquing you, to improve your skills to get better at it (Clinical Psychologist 3).

However, time for supervision to improve SDM skills was often described as limited. This was due to increased patient demand, lengthy waiting lists and decreased resources.

Negotiation and containment as ‘new’ skills needed for SDM

The clinicians discussed how SDM in child and youth mental health incorporates multiple stakeholders’ preferences, values and views, which could
lead to disagreements between parties on how to proceed with care and treatment.

The young person and the family can have very conflicting views about what needs to happen, and the clinician may have differing views as well, and I suppose that can be quite a tricky thing, in terms of if you’re trying to have a shared approach (Mental Health Nurse 2).

Some clinicians identified the key skills for navigating this scenario as negotiation and containment. Other more senior clinicians outlined that negotiation was a skill that was not previously needed when training as a practitioner, but in light of an increased emphasis on involving the young person and family in therapy, it was becoming ‘one of the hot skills now …cause if you can’t negotiate your way out of a paper bag then you are absolutely stuffed’ (Clinical Psychologist 3). For another clinician, negotiation and containment were described as a necessary part of the SDM process and important to ensuring that all the individuals felt included and engaged.

Containment and negotiation…the dance of reciprocity, two steps forward and four steps back, and onto the side, a little jiggy then move forward again…you need to be careful not to alienate one individual (Mental Health Nurse 4).

The clinicians worried that the loss of engagement with an individual due to a lack of inclusion was potentially very detrimental. They explained that a disengaged young person who had not been included in choosing their treatment may be less likely to participate in therapy. Conversely, by not including a parent, the clinicians worried that the parent may choose not to bring the young person back to a subsequent session.

6.3.1.3 Memory, attention and decision making processes

Memory, attention and decision making processes refer to ‘the ability to retain information, focus selectively on aspects of the environment and choose
between two or more alternatives’, and involves constructs including ‘memory’, ‘attention’, ‘decision making’ and ‘cognitive overload/tiredness’ (Cane et al., 2012, p. 14). The clinician interviews and focus groups identified the following subtheme: the availability of options may affect what is presented to the young person and family.

The availability of options may affect what is presented to the young person and family

The clinicians acknowledged that as part of their role, they were responsible for outlining the different treatment options to young people and their families. However, the clinicians were divided about which options to make patients aware of. Some clinicians highlighted that they would only suggest options that were available within their service.

*Something [treatment option] that we didn’t offer? I don’t think I would necessarily point that out* (Clinical Psychologist 4).

The clinicians justified limiting the options to what was available by explaining that they did not want to rupture the therapeutic relationship, or make therapy more challenging, as then individuals may not be able to have their first choice of treatment.

*To say [to a parent or young person], ‘if there was a group running we would put you in for that, but as there isn’t, we are going to go for second best because the group’s not running’, really that wouldn’t sit well with me. That would inflame some parents, and that’s not acceptable really. We need to be mindful* (Mental Health Nurse 1).

Conversely, other clinicians spoke of making a conscious choice to inform individuals about all their options, regardless of whether they were available in the service or not.

*I think information’s key, I think the whole thing that…families need to be given the information and they can make the decisions for*
themselves about where they go and what supports they might get, so I think they should [have all options] (Mental Health Nurse 2).

This, clinicians stated, was the ‘spirit’ of SDM, as young people and families had a right to choose to seek treatment elsewhere if they desired, be that within CAMHS, through third sector organisations or privately.

6.3.1.4 Behavioural regulation

Behavioural regulation refers to ‘anything aimed at managing or changing objectively observed behaviour’ and covers constructs including ‘self-monitoring’, ‘action planning’ and ‘habit breaking’ (Cane et al., 2012, p. 13). The clinician interviews and focus groups identified the following subthemes: First, a lack of clarity around whether there are guidelines and protocols for SDM; and second, the reviewing of treatment and goals, whilst considered important, is conducted sporadically.

A lack of clarity around whether there are guidelines and protocols for SDM

There was confusion amongst the clinicians as to whether there were guidelines and protocols for SDM in child and youth mental health. No clinicians described reading explicit guidelines pertaining to SDM. However, some clinicians speculated that such documents could exist.

Well I don’t know [if there are protocols/guidelines], I would assume there might be (Mental Health Nurse 1).

Other clinicians did not believe there were any protocols or guidelines, but they cited similar documentation which may be useful to help embed or facilitate SDM, such as: ‘protocols around consent and all that sort of stuff’ (Clinical Psychologist 1).
One clinician questioned whether a lack of protocols around the topic could account for the variations in SDM practice that they believed existed in their service: ‘Well its difficult, if everybody has a different idea of what it is’ (Psychiatrist 1). They posited that having protocols or guidelines would be helpful particularly for more junior members of staff and others not familiar with SDM: ‘it would be good to have something standard so that everybody can do it’ (Psychiatrist 1). However, others, such as Clinical Psychologist 2, worried that clinicians would view a protocol with contempt, as ‘clinicians might then see it as something else they’ve got to do’.

**Reviews of treatment and goals, whilst considered important, are conducted sporadically**

Consistent with models of SDM, the clinicians stated the importance of reviewing treatment progress and goals with young people and families to understand how the young person is progressing.

> Reviewing progress is really important, that you review what is happening with that young person, because if you don’t review, you don’t know what has helped, how much progress has been made, and where you next need to go, your next step, so reviewing progress is very important, and making changes if needed (Mental Health Nurse 1).

Whilst most of the clinicians highlighted that this was helpful in helping plan subsequent sessions, reviewing was also seen by some clinicians as useful when there had been discordant views between parties and one option for treatment was chosen over the other. In this instance, reviewing allowed clinicians ‘to go back and review that and say has that worked or not, and has that changed opinions about where we need to be going or what needs to happen’ (Mental Health Nurse 2).

Despite the perceived importance of reviews by clinicians, it was acknowledged that often these were not completed on time or only on an ad hoc basis.
I will ask about the next one, and the review as such, is usually every 6 sessions, sometimes that happens, sometimes that doesn’t, and sometimes it’s partial follow up, so it’s not very concrete at the moment (Psychiatrist 1).

The reasons highlighted for reviews being missed were often being busy or not having enough time (see 6.3.2.1, Environmental context and resources). To attempt to compensate for this, some clinicians wrote notes in diaries. Another clinician explained that in a previous service, electronic reminders would pop up on their computer when every review was due, which would help them to remain on course.

Where I worked previously, every thirteen weeks it was on the computer system and it popped up that this review needed to happen, which doesn’t seem to happen as much here. It is a bit more left to clinicians to decide when that may, or may not happen so that could be something that might be helpful I think (Mental Health Nurse 2).

6.3.2 Opportunity

Opportunity consists of two domains: Environmental context and resources and social influences.

6.3.2.1 Environmental context and resources

Environmental context and resources refers to ‘any circumstance of a person’s situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour’, and it covers constructs including ‘resources, a person’s interaction with the environment, and environmental stressors’ (Cane et al., 2012, p. 13). The clinician interviews and focus groups identified the following subthemes: the facilities not being conducive to SDM, limited or lacking psychological interventions, administration/time constraints that inhibit SDM and procedural influences that affected SDM.
Facilities not conducive to SDM

Many of the clinicians spoke of the facilities in CAMHS as not being conducive to SDM with young people and families. For some, this extended to the building in which their CAMHS was located. They explained that the appearance and ambiance of the building, which felt like entering an adult medical environment, contradicted the philosophy of young people being treated as equals when it came to having an appointment.

Better facilities; our offices are grim. Especially for young people, it’s just horrible. I think because it looks office-y and it looks clinical and it looks really official, that wouldn’t exactly give you — it’s like going into your doctor’s office and being told that you’re an equal partner really; it doesn’t feel particularly believable (Therapist 1).

In addition to the building itself, the clinicians stated that the rooms in which appointments took place needed to be ‘right’ in order for SDM to take place.

The environment you see people in is so important, to have a room that’s big enough, seats that are comfy enough, the small things, the heating, the temperature of the room (Clinical Psychologist 3).

Several clinicians believed that their therapy rooms were not conducive to SDM with young people. Aspects related to layout, a lack of space or the temperature limited the amount of time clinicians wanted to spend there, resulting in shorter appointments in which different options may not be fully explored.

We have a room over there…and it’s hot, suffocating (Mental Health Nurse 4)

…You instinctively want to cut down on conversation to get out of there, out of the room, so its basic things like that (Clinical Psychologist 3).

Limited or a lack of psychological interventions for SDM
The clinicians frequently outlined that only certain types of psychological support were available within their services. Not offering particular treatments resulted in the clinicians feeling that families were ‘getting a raw deal with what we can provide’ (Therapist 1). In the most extreme cases, the clinicians felt that there was no decision to be made or shared, as the only choice was between the treatment being offered or no treatment at all.

For example, the family therapist within the community, there’s been a move to the eating disorder team…so for self-harm it is CBT or nothing (Clinical Psychologist 4).

On the other hand, even when different types of psychological support were available, access to them could be precluded by being placed on a long waiting list. This was often more pronounced when therapies were longer, specialist or more intensive.

We’re quite often having to have the conversation even if we do have something. Sometimes there’s a wait, which can be difficult for families if they’re wanting something, for example like play therapy, because it’s quite an intensive therapy, there’s always a waiting list (Clinical Psychologist 1).

This was seen by the clinicians as having an effect on SDM, as it resulted in families (who were often desperate and had already been on a waiting list) choosing the option with the shortest waiting time rather than the option that would fit best with their specific values or preferences.

Sometimes you don’t come to the decision about the preferred option ‘cause it’s going to take an extra three months to get to that bit over the other treatment (Mental Health Nurse 2).

Administration and time constraints that inhibit SDM

A lack of staff members and increased patient demand were perceived factors affecting SDM according to a majority of the clinicians interviewed. The clinicians spoke of completing assessments with one patient knowing there
were other people waiting to be seen outside. During the assessment process, some clinicians highlighted that they felt they only had the capacity to focus on getting everything they needed completed within the allocated time, rather than being able to focus on the longer term wishes of the young person and family.

If you have a time constraint around assessment and you’ve got five bits of paper to fill out, you’re going to try your best to get the information from the client; you’re not necessarily going to be thinking about the client in the longer term, if that makes sense…so it might be that rash decisions get made or it’s a short-term decision rather than thinking about the child’s needs as a whole and how they would engage in that longer term (Clinical Psychologist 1).

In such instances, the clinicians hoped that a more participatory, equal approach would be employed by the next person seeing the patient. Time constraints were not just limited to assessment appointments. A few clinicians also highlighted the shift from shared to more directive decision making when clinics were busy in order to try to keep to time.

I try to do [SDM] without overrunning, but it becomes difficult to manage the rest of the cases, because one has taken over more than an hour, then you begin to feel your own anxiety gets in the way…you become more dominant in a way, to say this is what you should do, this is what will help you, and you become more directive I suppose (Psychiatrist 1).

Procedural influences stopping decision making

Some clinicians spoke of how the arrangement of services and systems affected their ability to engage in SDM with young people and families. For example, it was highlighted that in one service young people needed to reach a certain threshold in order to obtain help in CAMHS.

Sometimes a family will come and say we really, really need CAMHS. That’s what we want. Whereas, following the assessment it may be that they might not meet our threshold, so we’ll be saying
that our service wouldn't be the best way forward (Clinical Psychologist 4).

When this threshold was not met and a young person could not be accepted into the service, the clinicians felt that they could not make a shared decision with the young person and family that was consistent with their wishes and preferences. Instead, the clinicians tried to find or recommend voluntary organisations which the young person and family could access.

Even when the clinicians did accept a young person and their family into the service, their presenting problem could lead them down a specific treatment path, leaving few options to be explored when it came to SDM. For one clinician, this was particularly relevant in the CYP IAPT pathway for anxiety and depression where CBT was the emphasised treatment modality in their service.

So for anxiety and depression… we’ve had quite a few people going for IAPT training – so, the anxiety and depression pathway. So within that is CBT, because we know that’s what evidence – because that’s what we’ve been trained in – … the evidence shows CBT is effective… now we’d say CBT [to young people and families for treatment] (Clinical Psychologist 2).

6.3.2.2 Social influences

Social influences refer to ‘interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours’ and covers constructs including ‘social norms, social comparisons, modelling, social support and social pressure’ (Cane O’Connor & Michie, 2012., p 14). The clinician interviews and focus groups identified that team members can influence decisions, along with dominating parents.

Team members positively and negatively influencing decisions

All the clinicians in this sample felt that SDM was part of the service culture as well as part of their professional role. In keeping with this culture, many
clinicians often spoke of discussing cases and options with colleagues. This could be at wider assessment meetings or at weekly or monthly team meetings.

As a team, we often feedback cases to the team, or talk about a client that you know is struggling, or we’d like to get more ideas, can we talk about it as a whole team, then we’ll come back as a team and present that and talk about that and get a lot more ideas coming through about what we can do, as we have so many different professional backgrounds here and specialists in different types of therapy, and it really helps to get that perspective and feedback (Mental Health Nurse 2).

The majority of clinicians found this helpful, particularly with complicated or difficult cases, as it allowed them to exchange ideas about the different types of care and treatment that might be useful. However, some of the clinicians questioned whether too much input from other professionals might be unhelpful, as a larger number of voices increased the probability that a young person could then be forgotten about.

So yes, certainly dynamics, relationship….I suppose, between other professionals and that can be within the team or outside the team as well. It’s sometimes hard to hold the young person in mind if you’ve got too many voices kind of going over them, really (Clinical Psychologist 2).

**Dominating parents**

Whilst the clinicians described how SDM involved listening to young people and parents as experts, several clinicians reported that sometimes parents demanded their children be seen in CAMHS even if the assessment suggested they did not meet the threshold.

She’s pretty much dragged him to an appointment. So the care plan with my patient, I’m saying “What do you want to do?” and [the young person’s] like, “This is actually quite manageable really. I don’t really want to do anything about it,” whereas Mum’s really clear that it’s causing tension in the home and it can’t carry on; that she wants zero habits all the time (Therapist 1).
In such circumstances, the clinicians reported feeling obligated to keep these cases open, even though they felt that there was little they could do for the young person and family. This meant overriding the young person’s feelings or wishes in order to placate the parent. The clinicians explained that in the most extreme cases, the young person’s case would be kept open for a long period of time until the parents accepted that there was nothing wrong.

6.3.3 Motivation

Motivation consists of eight domains: Professional role and identity, beliefs about consequences, beliefs about capabilities, optimism, intentions, goals, reinforcement and emotions. Four of these domains were highlighted by clinicians as being important for SDM: professional role and identity, beliefs about consequences, beliefs about capabilities and emotions.

6.3.3.1 Professional role and identity

Professional role and identity refer to ‘a coherent set of behaviours and displayed personal qualities of an individual in a work setting’ and covers constructs including ‘professional identity, professional role, leadership and organisational commitment’ (Cane et al., 2012, p. 13). The clinician interviews and focus groups identified the following two subthemes: firstly, SDM being something CAMHS clinicians do; and secondly, overruling a young person’s wishes due to professional standards.

Shared decision making is something CAMHS clinicians ‘do’

All the clinicians interviewed mentioned they felt that SDM was a routine part of their practice that was intertwined with their role in child and youth mental health.

*That’s always been my approach. And, to be honest, I try to do that with everything else, so for example, if I’m using CBT, I try to do so in*
a collaborative way, asking for their views and opinions (Trainee Psychologist 3).

The clinicians outlined that in order to develop an effective treatment and care package for young people and families, it was important to take into account their preferences and cultural values, as these were ‘aspects in themselves, their culture and their lives’ (Nurse 2). Elaborating on this further, clinicians outlined they sometimes employed techniques such as ‘picture drawing’ (Clinical Psychologist 4) with the young person to help them understand their difficulty or to elicit their views. Checking back in was also seen as valuable, as it ensured that everyone was on the same page and had developed a complete picture together. The clinicians saw this as necessary to be able to plan and proceed with treatment.

What I am doing is when they’re saying the problem, I am trying to formulate and understand their problem or difficulty, and then the treatment options, which ones may not be available…Yes, so I share my formulation with them based on what they have told me and what information I have gathered…to check out whether it is accurate, what I have heard and understood, and whether they agree with what I am saying or whether I need to add anything that I have missed out (Psychiatrist 1).

Given the context of developing a picture together as experts prior to discussing treatment options, SDM with young people and parents was nearly always seen as ‘appropriate’ by the clinicians in this sample. However, this was sometimes confounded by comprehension issues due to learning difficulties or families having English as a second language.

**Overruling a young person’s wishes due to professional standards**

Whilst the clinicians acknowledged that SDM was part of their practice, many spoke of the professional boundaries and standards that needed to be upheld which were sometimes at odds with SDM. The clinicians frequently cited capacity issues around mental health difficulties which meant that a young
person could make risky decisions which would not be in their best interests if they compromised their safety.

Someone’s decision making may be impaired due to a psychotic episode, low BMI due to an eating disorder, or suicidal… and the decision of the child or young person may that they don’t want to go into hospital, or talk to the professional, but again it is about keeping the young person safe (Trainee Psychologist 2).

When situations such as these were encountered by the professionals, the role of the parents often became more prominent and shared decisions tended to occur between the clinician and the parents. In less extreme but still risky situations, for example around the disclosure of self-harm, the clinicians again felt the need to safeguard the young person by informing their parents or guardians of what had been discussed. As this was often against the wishes of the young person, the clinicians felt that it clashed with the practice of SDM as there was no ‘shared decision’ to be made. To try and counteract this, one clinician built in decision making with the young person around what and how to tell the parent:

In most cases, when I've had a really good working relationship with people and we've talked about what the choices are with those types of decisions [risk and self-harm], more often than not, the young person is like, ‘Well, okay,’ and we'll come to an agreement about how much we will tell a parent or a carer or teacher in order to keep them safe (Clinical Psychologist 1).

It was felt by Clinical Psychologist 1 that these small decisions helped to empower the young person during a time which could potentially be very destabilising.

6.3.3.2 Beliefs about consequences

Beliefs about consequences refer to the ‘acceptance of a truth, reality, or validity about outcomes of a behaviour in a given situation’ and covers
constructs including ‘beliefs, anticipated regret and outcome expectancies’ (Cane et al., 2012, p. 13). The clinician interviews and focus groups identified the following subthemes: SDM empowers young people and families, SDM takes more time and SDM results in worse psychological problems.

**Shared decision making empowers young people and families**

The majority of clinicians outlined a benefit of SDM with young people and families related to patient empowerment.

> They are empowered, it helps therapy so much and in so many ways, that it moves the process, that they are engaged in things that you are doing and the throughput happens, because there are a number of factors happening, they become more empowered, they engage with the therapy, the evidence-based intervention, or evidence-informed practice – whatever is happening, they take that up better and you see the outcome that you would expect (Clinical Psychologist 5).

Giving the patient a sense of autonomy and control to help meaningfully shape treatment was seen by the clinicians as crucial if care and treatment were ultimately going to be successful. The clinicians described empowerment through SDM as a vehicle for change; which could positively impact on other outcomes, or decrease the likelihood that a young person and family would stop attending appointments.

**Shared decision making takes too much time**

Time was an important factor for the clinicians when it came to SDM, with many feeling that it took longer to implement treatments involving SDM as opposed to a more paternalistic approach in which the clinicians made the decisions.

> [SDM] could slow down the pace or slow down the work because you've got to work at their pace, when they're ready to access and take in that information (Mental Health Nurse 3).
The clinicians felt that it could take longer to make decisions in certain circumstances or with particular individuals. This included situations with very young people, individuals with learning disabilities, when patients did not come prepared to make a decision or when there were multiple parties involved. Moreover, some clinicians felt that SDM was not always possible in one therapy session. In particular, some decisions had important implications for the patient and family and, thus, could require more thought, reflection or weighing up of the pros and cons prior to a decision being made.

*I don’t always think that in this service, that actually there is enough time spent on [SDM]… if we are talking about, I don’t know, different processes which would involve going to hospital, or going to a different type of service, or sitting down face-to-face weekly for sixteen weeks, that’s quite an impact on your life, I think we need to give people adequate time to make those decisions (Clinical Psychologist 3).

Not all the clinicians mentioned time as a factor that affects SDM, and one clinician felt that it actually did not take any extra time as it was *‘not something that was separate’* and should be *‘built into normal practice’* (Clinical Psychologist 1). Another clinician outlined that whilst SDM may initially take longer, it could result in more engaged and motivated patients over the long term which would then positively impact on the initial time invested.

*Initially it is more time consuming, I don’t think that would bear out over time as it helps with motivation, but initially I think yeah* (Clinical Psychologist 3).

**Shared decision making can make psychological problems worse**

One clinician outlined that SDM may not be in the ‘interests’ of the young person and family as they were likely to choose treatments which may minimise psychological distress or discomfort. The example here was specifically in relation to phobias, where the clinician described how not engaging in exposure therapy could exacerbate problems in the longer term.
When someone is behaving in a way which in the short-term might alleviate their anxiety, so, for example, ‘I don't want to go outside because it's scary’. Okay, in the short term that's going to make the anxiety go away but then the behaviour reinforces and they stay in the house for six months. So the disadvantage of being person-centred and going along with their decision there is actually that sometimes they can remain stuck if they're unwilling to engage in a therapeutic technique for which there is pretty good evidence works really well. And so, I guess, that's why I would sometimes disagree with some of these decisions (Trainee Psychologist 3).

In the longer term, the clinician felt this could affect the young person’s chances of making a good recovery. In order to rectify this situation, the clinician spoke about actively trying to persuade the young person to engage in treatment while admitting that they did not want to or were not able to ‘force’ treatment. Ultimately, if the young person could not be persuaded, the clinician conceded defeat.

6.3.3.3 Beliefs about capabilities

Beliefs about capabilities refers to an ‘acceptance of the truth, reality, or validity about an ability, talent or facility that a person can put to constructive use’ and covers constructs including ‘self-confidence, self-esteem and perceived behavioural control’ (Cane et al., 2012, p. 13). The clinician interviews and focus groups identified the following two subthemes: feeling confident in engaging in SDM, and not feeling confident due to a lack of skills/experience or lack of knowledge.

Feeling confident in engaging in SDM

In most instances, the clinicians stated that they were capable and confident in engaging in SDM with young people and families.

…I feel comfortable and confident [in engaging in SDM], yes… (Psychiatrist 1).
This was often attributed to the concept being part of their professional training, as well as a culture within CAMHS which aims to foster SDM with young people and families.

**Feeling less confident due to a lack of knowledge around options**

A few clinicians outlined that they did not feel confident discussing particular psychological therapies with young people and families.

> There’s something in our service called cognitive analytic therapy and when I explain it to families I don’t really feel that confident because I’ve never really worked within that model or understand it that much. But I guess, that’s just about my learning that I need to go and speak with somebody and get more information and get people to help me understand it a bit more (Clinical Psychologist 4).

The clinicians conceded that to address this they needed to obtain more information so that they felt more comfortable talking about different therapies. When it came to discussing medication, several clinicians felt they were unable to articulate this as well as another professional who had more knowledge on the topic.

> You might also want to bring in another professional who knows more when you need to talk about something…say, for example, you’ve got a situation whereby you feel that this person really needs to have medication. Obviously, the best person to talk about medication’s a doctor, so the way the doctor would try to explain the side effects of the medication (Mental Health Nurse 3).

To overcome this, the clinicians often tried to have a medic or nurse practitioner attend the session if they knew the issue of medication would arise. Alternatively, they would book a subsequent appointment with said individuals to discuss the possibility of medication and different options in that regard.
6.3.3.4 Emotions

Emotions refer to ‘a complex reaction pattern, involving experimental, behavioural and physiological elements, by which an individual attempts to deal with a personally significant matter or event’ and covers constructs including ‘fear, anxiety, stress, positive/negative affect and depression’ (Cane et al., 2012, p. 13). The clinician interviews and focus groups identified the following subtheme: feeling overwhelmed which inhibited SDM.

Feeling overwhelmed which inhibits SDM

Many of the clinicians reported needing to be ‘in the right state of mind’ to engage properly in SDM with young people and families. The majority of clinicians in this sample reported feeling stressed and overwhelmed with the amount of work that they had to do and the number of patients they had to see. In some instances, this impacted on SDM, as clinicians could forget to mention the availability of some options.

*Everyone’s really, really overstretched, overwhelmed. So maybe for some staff, what might happen is that they maybe think actually there could be this other treatment option that we could consider with the family, but then they might forget* (Clinical Psychologist 4).

Other clinicians outlined how stress impacted on their ability to participate in SDM, as it stopped them from asking questions and listening to the young person and family, and instead they ‘prescribed’ the normal treatment without taking into account the values and preferences of the young person and family.

*What we are dealing with is emotional difficulties and behavioural problems, and it can make a huge impact actually, if you’re not able to have that space in your head to think about what can be the options, or, the normal human tendency is to go back to what you would have normally done, or what you know best will work, and then give it to the patient, rather than ask them, so yes, stress levels are quite important* (Psychiatrist 1).
6.4 Discussion

The aim of this chapter was to investigate healthcare professionals’ perspectives on the factors that affect SDM with young people who have internalising disorders along with their parents. Ten of the fourteen domains in the TDF (Cane et al., 2012) were identified in the interviews. However, the following four domains were not found when analysing young people or parents responses to the barriers and facilitators to SDM: optimism, intentions, goals and reinforcement. The next section explores the COM-B ‘behavioural diagnosis’ in terms of previous literature, as well as the implications for intervention design and development.

6.4.1 ‘Behavioural diagnosis’

The findings in this study related to the clinicians’ perceptions around capability with regard to SDM suggested that the clinicians have knowledge of the principles behind it, though the specific term was one that appeared to be more limited to those who had received CYP IAPT training. The clinicians reported not always knowing about the treatment options that were available. This was particularly pertinent when talking about the care and treatment options that were available outside of the NHS or their service. However, some of the newer clinicians acknowledged that they had a limited knowledge of the available options within their own services.

In terms of skills, the clinicians outlined that many ‘core’ therapeutic skills overlapped with ones they thought necessary to engage in effective SDM. Once these were acquired, it was through supervision that they were further refined. Additional skills which were not seen as part of the clinicians’ ‘core’ skillset but were needed to engage in SDM during times of discord between stakeholders were ‘negotiation’ and ‘containment’. Regarding decision making, some of the clinicians reported that they made decisions about what to tell young people and parents based on the availability of certain options within services, while
omitting others (even those with an evidence base) when the service did not offer it. Lastly, the clinicians reported that they were not aware of any specific guidance or protocols on how to implement SDM. In addition to this, reviewing progress of care and treatment was seen as an important part of SDM, though this was not conducted frequently enough due to other competing priorities.

In terms of opportunities for SDM, the clinicians felt that multiple environmental factors often detracted from SDM with young people and families. In particular, the clinicians felt that the buildings they worked in were not very welcoming or ‘young person-friendly’, which was at odds with telling young people their views were welcome. Similarly, some clinic rooms were not arranged in a way that was conducive to SDM due to a poor layout or issues such as a lack of temperature regulation. Limited psychological interventions due to only certain staff being trained in particular therapies also affected SDM, as this often meant that either certain options were not available, or, if they were, young people and families could be subjected to long waiting lists. Moreover, corresponding to the funding cuts and increased demand for services, the clinicians felt that they were having to do more with less. This affected SDM as the clinicians could not spend any additional time with young people and families due to there being another patient and family waiting.

Procedural influences also impacted upon SDM, as services set a threshold for young people and families to be able to attend CAMHS. Not reaching this threshold meant services in the clinics were not available to some young people and families who desired access to them. Moreover, due to the implementation of a CYP IAPT pathway for depression and anxiety, options that were previously accessible were reduced or removed for ones that were supported by the evidence base. The clinicians also spoke of professional-to-professional influences affecting SDM. In some instances, this could be a facilitator to SDM when professionals discussed a complex case with others and used the meeting to explore next steps and ways forward. However, at other times too
much input from others meant it was harder to keep the young person and their views in mind. In other situations, parents’ views dominated the appointment which could lead to young people receiving treatment they did not feel they needed or wanted.

Lastly, the clinicians outlined several factors related to motivation and SDM. They felt their role as a child mental health professional was consistent with the practice of SDM, allowing them to construct a joint understanding of the difficulties and ways forward. On the other hand, another part of their role was a duty of care to that young person. This sometimes meant that decisions were made by the professional and enacted without the approval of the young person. Most often, this was in relation to risk or safeguarding issues, or perceived issues around capacity. The majority of clinicians viewed SDM as having a positive impact on outcomes, believing that it empowered young people and families, which, in turn, had positive therapeutic and clinical effects.

However, for some difficulties like anxiety, SDM was seen as something that could have a detrimental effect on outcomes, with one clinician outlining that patients would choose not to have exposure therapy to avoid distress in the short-term, which could result in larger problems later on. Clinicians also regarded SDM as taking more time than a paternalistic approach, particularly when working with multiple stakeholders or those with decreased capacity or learning difficulties. With regard to beliefs about capabilities, most of the clinicians felt confident participating in SDM with young people and families. However, some clinicians felt less confident discussing particular options with which they were less familiar or options in which medication was involved if they were not medically trained. Lastly, clinicians outlined feeling emotionally overwhelmed due to their workload, which resulted in the tendency to forget certain options or to not ask questions which would allow for preference-sensitive decisions to be made.
6.4.2 Situating the findings within the literature

The skill of ‘listening’ was identified by the clinicians as important in facilitating SDM, along with other skills such as ‘honesty’, ‘openness’, ‘transparency’ and ‘empathy’. These findings are similar to the skills mentioned in previous research, in which listening, along with the need to respect and validate the young person and parents (Kovshoff et al., 2012; Pelto-Piri et al., 2013), was identified. The majority of skills cited here appear to revolve around having more honest discussions with young people and families. This is aligned with the philosophy of SDM, within which both the clinician and the young person and family contribute skills, knowledge and experience to form partnerships (Coulter, 2009; Coulter & Collins, 2011; Da Silva, 2012). The clinicians described skills related to SDM that were acquired during their professional training and could be honed and refined through supervision. ‘New’ skills which clinicians believed to be important centred around resolution, specifically negotiation and containment. Whilst negotiation has been mentioned as important in some other models (e.g. Makoul & Clayman, 2006), containment appears to be a novel finding. This could highlight the unique situation that exists when working with children and young people of having multiple stakeholders involved in the process of SDM (Lipstein et al., 2016), each with their own values and preferences. This corresponds with findings indicating that discordant views are frequent between parents, young people and clinicians (Hawley & Weisz, 2003; Yeh & Weisz, 2001).

The importance of a young person’s capacity to be involved in decision making was also highlighted in this study, and it has been a prominent finding in previous research (Abrines-Jaume et al., 2016; LeFrançois, 2008; Simmons et al., 2013; Tam-Seto & Versnel, 2015). Within this context, clinicians explained that in order to protect a young person with limited capacity, they might overrule their wishes or preferences. However, findings in this study exclusively relate to capacity in relation to mental illness, with professionals citing cases of low BMI,
and suicidality. This contrasts with some of the literature that also includes professionals citing age as a factor when determining whether young people can be involved (LeFrançois, 2008; Simmons et al., 2013), and it corresponds with assertions by other academics, such as Alderson and colleagues, that age is not a barrier to involvement (Alderson, 2017; Alderson & Montgomery, 1996; Alderson et al., 2006; Sutcliffe et al., 2004).

A lack of information sharing has been highlighted as a barrier to SDM (Simmons et al., 2013). The findings from this study may shed some light on some of the potential reasons why information may or may not be shared. One possible reason identified is that professionals may not know what treatment options are available outside of the service. For professionals new to the service as well as trainees, they may also be unaware of the options available within their own services. An alternative explanation arising from the findings in this study may be that some professionals may not feel comfortable or confident outlining different treatment options. This was particularly the case around medication, but also existed for some types of psychological interventions where some professionals have little knowledge.

Both this study and previous research (Simmons et al., 2013) have highlighted resource issues as factors that affect SDM. Finite resources meant that treatment options were either not available or had lengthy waiting lists prior to access. A consistent finding across this study and previous studies suggests a lack of time as a barrier to SDM (Simmons et al., 2013). The clinicians stressed that increased patient demand resulted in patients and families often being seen back-to-back, which meant that clinicians had little or no time to explore their options in depth. In some circumstances, this also led to a more directive, rather than shared, approach to decisions concerning treatment. Whilst time barriers in SDM are a common concern for clinicians across clinical contexts with regards to SDM (Gravel et al., 2006; Joseph-Williams et al., 2013), the
likelihood of SDM significantly increasing session time has been refuted by researchers (Legare & Thompson-Leduc, 2014).

The confines of service regulations also appear to be a barrier to SDM. For example, the allocation of cases to particular CYP IAPT pathways could limit the treatment options recommended for particular presenting difficulties. Similarly, services imposing minimum entry criteria meant that even if a young person or parent wanted help or support, they would not be entitled to it from services for which they did not meet the threshold. The impact of service regulations corresponds with identified barriers to SDM, where adherence to rigid protocols and operating procedures result in young people not having their needs met and not receiving tailored treatment (Tam-Seto & Versnel, 2015).

The roles of other team members as a facilitator to SDM appears to be a novel finding. This may be through clinicians asking colleagues for advice regarding cases they are unsure about, or alternatively, colleagues being used as a source of support when the assessing clinician does not feel comfortable discussing particular treatment options. It has also been previously documented that other professionals can be a barrier to shared healthcare decisions. However, this was specifically in relation to disagreements between professionals over courses of treatment (Simmons et al., 2013). In this study, rather than disagreements between staff being a barrier to SDM, the clinicians highlighted that involving other professionals could lead to situations where the young person and parents’ views became lost due to the number of individuals involved.

An interesting finding was around the use of the term ‘SDM’ and the professionals’ knowledge with regard to this term. Notably, it appeared that individuals and services not associated with CYP IAPT were less familiar with the term, though all could give related definitions and believed that SDM was something that they practiced. This contrasts with the rise in the research
literature on SDM (Makoul & Clayman, 2006), as well as healthcare and governmental policy on the topic which emphasises putting young people and families at the heart of decision making (Chief Medical Officer’s Annual Report, 2012; Department of Health, 2015). Considering the NHS’ aim of rolling out CYP IAPT to all CAMHS services by 2018 (NHS England, 2016), an increasing number of clinicians are likely to become familiar with this term.

Previous research has also highlighted that the sexual side effects of medication were a barrier to SDM with young people, as clinicians felt uncomfortable discussing such topics (Simmons et al., 2013). Side effects were also highlighted by a few clinicians in the present study, however, this was in the context of clinicians feeling they did not have enough knowledge about side effects to adequately discuss them with the patient. That sexual side effects have not been mentioned here could be due to differences in the age ranges worked with, as services in this study worked with young people aged 0-18 years, as compared with 12-25 years in the aforementioned study (Simmons et al., 2013). Alternatively, this may also reflect differences in the samples related to those who could prescribe medication, with the present sample consisting of two medics (13%), compared with nine (41%) medics interviewed for the Simmons (2013) study.

6.4.3 Strengths and limitations

Previous research in the field of SDM around barriers and facilitators has been limited to services or clinicians working outside the UK (Pelto-Piri et al., 2013; Simmons et al., 2013; Tam-Seto & Versnel, 2015) or working with specific populations (Kovshoff et al., 2012; LeFrançois, 2008). A strength of this study is that it examines a wide range of clinicians’ views regarding SDM across two outpatient services in the UK that work with young people and families. This adds breadth to the current literature on the topic, as it outlines some of the
commonalities regarding the barriers and facilitators to SDM, as well as identifying nuanced individual views.

As outlined in the previous chapter, a further strength of this study is the use of the TDF (Cane et al., 2012). Rather than asking individuals what they believed to be the barriers and facilitators of SDM, a systematic approach examining fourteen domains and underpinned by theory was employed. This may help illustrate the full range of barriers and facilitators around SDM, rather than just the ones that were immediately apparent to participants during the interview. Moreover, a semi-structured approach to the interviews was undertaken, which involved asking patients to elaborate on answers and allowed for deviation from the set TDF questions. This allowed for a richer narrative to be formed and provided further context to the barriers and facilitators around SDM.

In addition to the strengths of the study, the limitations should also be considered. Whilst teams of clinicians attended the presentations, relatively few clinicians decided to take part in the interviews or focus groups. As a result of this, a convenience sample composed of clinicians who wanted to take part was used. This sample is therefore unlikely to represent the broad range of views held in relation to SDM and is subject to selection bias. For example, the clinicians who chose to take part in the study may have had a particular interest in SDM or believed that they were skilled at SDM and wanted to share their experiences.

A way to overcome this would be to employ different sampling techniques, such as purposeful or random sampling. However, services and clinicians taking part stated did not find this acceptable. To move away from a pure convenience sample, snowball sampling was employed whereby the PhD candidate asked the clinicians being interviewed whether they knew of anyone who held different views and might be willing to be interviewed. This was partially successful as it yielded a few additional interviews, which may have helped to provide a richer
and more varied account of the barriers and facilitators. Researchers may wish to employ such techniques in future research if other sampling techniques are unsuccessful or unpalatable to the research participants.

The use of the TDF (Cane et al., 2012) may also be considered a limitation. Whilst it covers fourteen domains of barriers and facilitators collapsed from the theory, working within this framework could be argued to limit researchers when undertaken data analysis. Imposing a framework on data this way could mean that data is missed in analysis as it falls outside the framework. This may be particularly important as the TDF is a framework still in its infancy, evidenced by the creation of two additional domains since its first conceptualisation (Cane et al., 2012). Further refinement of expansion of the framework would mean that certain aspects would not have been covered in this study.

6.4.4 Reflexivity

My role in the research process also needs to be considered. This PhD is funded by University College London and the EBPU, who are strong advocates of SDM. Both have previously published on the importance of SDM, developed tools to facilitate it and are involved with CYP IAPT which is underpinned by SDM principles. Entering the project already knowing some of the work in this area, I was aware I held the following assumptions and assertions and these were recorded in a reflective diary: Firstly, that most clinicians thought they were skilled at SDM despite young people and parents reporting contrary results. Secondly, that all clinicians should be practicing SDM, and lastly, being the title of my PhD scholarship, I had to develop an intervention to overcome this.

In the early interviews, I expected the majority of the clinicians to state that they already thought they and their colleagues were good at SDM. I was ready to delve deeper to uncover any barriers to engaging young people in decision making. I was instead surprised by the clinicians’ candid self-assessments,
particularly in describing how they chose not to offer certain options, as well as admitting to not knowing the term ‘SDM’. This may have been helped by the structure of the TDF and examining both the facilitators and barriers to SDM, which may have seemed less intimidating and more balanced to the clinicians and provided me with a more neutral structure to follow.

Having conducted what I perceived to be much more balanced and reflective interviews than anticipated, I was able to critically revisit some of my assumptions – did clinicians need to practice SDM? Whilst age and capacity were not necessarily exclusion criteria for decision making, I wondered how they actually affected the SDM process in appointment sessions with increasing demands and decreasing resources. I also reflected that whilst I did believe SDM should be happening in child and youth mental health, I personally would not be impacted by the process in any way. I did not have any responsibility over or for the young people at these services and I reflected on how it would feel as a clinician, who does have that duty of care, to engage in a potential risky shared decision with a young person. Discussions with my supervisors (JEC and NM) made me much more aware of the assumptions outlined above and how I could be aware of and manage them. As a result, I outlined my organisation’s stance on SDM at the beginning of the interviews, as well as stating I was not an expert in the topic; but wanted to ascertain more about the positive and negative aspects of SDM.

Lastly, a further assumption I made as a researcher was that all the clinicians would know the term ‘SDM’. My familiarity with the term most likely stemmed from my department and its links with CYP IAPT. However, not all clinicians have received CYP IAPT training and, thus, may not be familiar with it as a term. After discovering that some clinicians did not know what SDM was, I reflected on the interviews and felt that as I had expected the clinicians to know the term, this may have created an uneven power dynamic between myself as a researcher and the clinician and led to a more stilted and closed interview. After
realising this, I modified the wording on the schedule to first enquire whether clinicians had heard of the term, and, regardless of this, to describe what they thought it meant. This appeared to address the power imbalance in subsequent interviews with the clinicians who had not received CYP IAPT training and led to a more open and free-flowing structure.

6.4.5 Conclusion

A number of barriers and facilitators have been identified through the clinician interviews as affecting SDM, both with the young people who have internalising difficulties and their parents. These fall across all three of the overarching areas of the COM-B model (Michie et al., 2014), suggesting that the targeting of capability, opportunity, and motivation could help facilitate SDM. Interestingly, many of these overlap with the findings from previous literature. These included: skills such as listening, the young person having limited capacity due to mental illness, not knowing what options are available and finite resources. Novel findings included: containment as a skill, clinician uncertainty over the term SDM, the use of team members to help offer suggestions when the clinician was stuck, and for one clinician a concern that SDM could make existing difficulties worse. This appears to be the first time these have been mentioned in relation to the wider literature on SDM in mental health.

Understanding what clinicians believed the barriers and facilitators to be, could help inform the intervention development. For example, leaflets could be made for all new clinicians on what options are available within their services. Alternatively, for options outside of CAMHS, clinicians could be made aware of the Youth Wellbeing Directory (Anna Freud National Centre for Children and Families, 2014) which provides information on services available in their area. However, other barriers, such as room and building layout, access to different treatments and more time to spend on SDM, would be difficult, if not impossible
to implement by the PhD candidate, and so need to be taken into account when considering the experience of SDM in the ‘real world’.

Whilst this study has provided insight into the barriers and facilitators from the perspective of clinicians, they are only one group of individuals involved in the process. Shared decision making with young people involves multiple stakeholders, including themselves and often their parents (Lipstein et al., 2016). This means that these perspectives should also be sought; this allows for the triangulation of findings and builds a comprehensive picture from which to develop the intervention. The next chapter explores young person and parent views on the barriers and facilitators to SDM.
Chapter 7 Barriers and facilitators to SDM in child and youth mental health: A qualitative study with young people and their parents
7.1 Introduction

There is a disparity between the perceived levels of involvement in decision making between the stakeholders in child and youth mental health. In a recent audit for CYP IAPT, most of the clinicians surveyed (83%) believed they always, or usually, practiced SDM; yet less than a third of young people (30%) and only half of parents felt they were given enough information to make a choice about treatment (Edbrooke-Childs, Calderon, et al., 2015). Moreover, findings from Chapter 5 identified that around half the variation in reported SDM is due to service-level factors, and even when accounting for services, both young people with internalising difficulties and their parents, were less likely to report receiving gold standard SDM as the young persons difficulties increased in severity. Understanding the barriers and facilitators to involvement at various levels (both individual and service) may help to uncover reasons for differences in service level variation, particularly as the dataset in Chapter 5 included only six predictors.

Five studies from the wider review of the barriers and facilitators to person-centred care (Gondek et al., 2016) focused on decision making in relation to care and treatment from the perspectives of young people (Iachini et al., 2015; Offord et al., 2006; Oruche et al., 2014; Pycroft et al., 2013; Simmons et al., 2011). Prominent barriers and facilitators for young people included: information sharing between clinicians and young people (Iachini et al., 2015; Simmons et al., 2011), whether clinicians listened to, respected and validated young people (Offord et al., 2006; Pycroft et al., 2013), communication between young people and clinicians (Pycroft et al., 2013; Simmons et al., 2011) and the role of parents in involvement (Iachini et al., 2015; Oruche et al., 2014). Others focused on the young person’s capacity (Simmons et al., 2011) and the available resources (Oruche et al., 2014).
Three of the studies in the review by Gondek et al. (2016) also examined the barriers and facilitators to SDM from the parents’ perspective (Iachini et al., 2015; Oruche et al., 2014; Simmons et al., 2011). Factors focused around: information sharing between clinicians, young people, and parents (Iachini et al., 2015; Simmons et al., 2011); confidentiality procedures and whether young people had the capacity for involvement (Simmons et al., 2011); providing culturally competent care and whether clinicians had knowledge of other services (Iachini et al., 2015); and what resources were available (Oruche et al., 2014).

Similarly to Chapter 6, the majority of these studies were conducted outside the UK, with two in the US (Iachini et al., 2015; Oruche et al., 2014) and one in Australia (Simmons et al., 2011). Of those from the UK, one focused on inpatients (Offord et al., 2006), and the other described a new service established to target hard-to-reach individuals (Pycroft et al., 2013). This calls into question whether such findings would be applicable in a UK outpatient setting and whether other factors may have been missed. Moreover, the majority of these studies did not intend to explore the barriers and facilitators to SDM; meaning key factors may not have been explored. Whilst two studies focused on internalising difficulties (Offord et al., 2006; Simmons et al., 2011), one was set on an inpatient eating disorder ward (Offord et al., 2006), which limits the translation of barriers and facilitators due to risk and safeguarding issues. The other (Simmons et al., 2011), whilst relevant, drew on much older young people with an average age of 20 years. This could mean it did not capture the unique barriers and facilitators for children, young people and adolescents, who due to their age, may have less of a say in decisions.

With a lack of studies focusing on young people’s and parental views on the barriers and facilitators to SDM, and those doing so being conducted abroad, or on specific populations likely to have additional barriers and facilitators, there is scope to explore this in UK outpatient child and youth mental health settings.
7.1.1 Aims of the present study

Based on the above, this study aims to examine the barriers and facilitators to SDM from the perspectives of young people with internalising difficulties along with parents in outpatient clinical settings in England.

7.1.2 Research question

Using the TDF (Cane et al., 2012), what do young people with internalising difficulties and parents perceive the barriers and facilitators to SDM to be in child and youth mental health?

7.2 Methods

7.2.1 Recruitment

Young people and parents were recruited through existing services involved in the project (Site A and Site B) (see 6.2.1 for more information about the services). Clinicians were asked to approach all the young people and parents within their caseloads who met the inclusion criteria to ascertain whether they would like to take part in the study. The details of the interested participants were given to the PhD candidate who then made contact and provided further information. Posters (see Appendix 7a) with the PhD candidate’s contact details were also placed in waiting rooms for individuals who were interested but were not approached by their clinician. To meet the inclusion criteria, young people and parents had to be current service users and have a good understanding of English. The exclusion criteria for young people were severe special educational needs and being aged under 12 years old. Only those aged 12 or over were included as previous research suggests that they can consent to treatment (Billick et al., 1998). Additionally, it has been stated taking into account numeracy and literacy are important (Schachter et al., 2011), and it was felt that going below aged 12 would mean that any intervention developed
would most likely require two versions to cater for both young people and parents.

7.2.2 Participants

Overall, ten parents and nine young people participated in this study. From Site A, four parents and three young people were recruited, whilst six parents and five young people were recruited from Site B. Of the parents and young people in the study, nine parents and young people were dyads, whilst one parent participated on their own. Clinicians were responsible for recruiting eight young people and their parents, and the remaining two parents and one young person were recruited via the posters in the waiting room.

The parents interviewed were aged between 37 and 53 years old ($M = 44.7, SD = 5.85$). All were female. Nine identified as ‘White British’ and one declined to answer regarding their ethnicity. The ages of the young people at the time of the interview ranged between 12 and 17 years ($M = 14.5, SD = 1.43$). The nine young people interviewed were all the biological offspring of the parents interviewed. Three were male and six were female. In terms of ethnicity, eight described themselves as ‘White British’ and one as ‘Mixed Race’. Time in child and youth mental health services ranged from 1.75 years through to nine years ($M = 3.19, SD = 0.98$). The diagnoses of the young people included depression ($n = 2$), anxiety ($n = 2$), self-harm ($n = 2$), autism with an internalising difficulty not specified ($n = 2$) and autism and anxiety ($n = 2$).

7.2.3 Procedure

The procedure was similar to the clinician interviews outlined in Chapter 6, including the design in accordance with the TDF (Cane et al., 2012), the inclusion of prompts, examination by a behaviour change expert (SS) and field testing. Field testing was undertaken with both a parent and a youth participation officer at the AFNCCF. No changes were made to the interview
schedule from the field testing or examination by the behaviour change expert. However, more general introductory questions were added part of the way through the study to help the participants feel more comfortable and at ease (See Appendix 7b for the interview schedule).

The young people and parents who expressed an interest in participating in an interview, either via clinician or by contacting the PhD candidate directly, were sent information sheets by email (see Appendices 7c, 7d and 7e) and a time was arranged to follow up on any questions they had. Following this, participants who still wanted to take part were asked to sign a consent form. For young people under the age of 16 years, an assent form was signed along with a parental consent form (see Appendices 7f, 7g and 7h).

All of the young people were biologically related to their parents, and joint parent-young people interviews were conducted for two reasons. Firstly, this limited the need for an additional researcher to be present when interviewing a young person for safeguarding reasons. Secondly, it was believed that young people would feel more comfortable with a parent present rather than a stranger. Eight parent-young person interviews were conducted at the participants’ homes, and one interview was at the mental health service attended by the participant. The additional sole parent took part in a phone interview.

Prior to the beginning of the interview, the participants were re-briefed on the study aims and reminded of the voluntary nature of the study, that they could stop at any time and that the discussion would be recorded. Questions in line with the TDF (Cane et a., 2012), with a focus on the barriers and facilitators to SDM were explored. Each question was first asked to the young person to avoid the young person basing his or her answers on their parent’s responses. Discussions were transcribed verbatim.
7.2.4 Data analysis

Interviews were transcribed and analysed using thematic analysis (Braun & Clarke, 2006) (see section 6.2.5 for a detailed outline).

7.2.5 Ethical considerations

Ethical considerations fell under existing approval from the London Hampstead NRES Committee (REC ref: 15/LO/0997). Accordingly, the participants were reminded that they could withdraw at any time during the interview process and that their care and treatment would not be affected. In addition, the participants were informed that the results would not identify individuals and that all data would be processed in accordance with the Data Protection Act (1998) as well as the Information Governance Policies at the AFNCCF.

7.2.6 Trustworthiness of the findings

Similar techniques to boost the credibility of the findings (Shenton, 2004) in the clinician interviews were also employed in these interviews with the young people and parents. This included: First, building a rapport with the participants by speaking to them over the phone, at which point the PhD candidate asked some general open questions not related to the research to help participants feel comfortable. Moreover, participants were assured that they could be honest in their answers, that the PhD candidate was not working for the service they attended and that their answers would not affect the care or treatment they received. Second, frequent supervision sessions were held between the PhD candidate and his supervisors. This allowed the PhD candidate to develop ideas, to check his developed coding key and possible interpretations of the data, as well as to recognise any biases through keeping a reflective diary (see point 4). Third, peer scrutiny was conducted using the same mechanisms (departmental meetings, conferences and supervisors) as the clinician interviews. Fourth, a reflective diary was maintained which allowed the PhD
candidate to note ideas, behaviours and developments as they occurred. This is further explored in the reflexive commentary section following the analysis.

Fifth, information about the background, qualifications and experience of the PhD candidate were also provided to the participants. Sixth, the participants were asked to provide feedback on themes, and those that did (n = 4) stated that the themes were appropriate and no changes needed to be made. Seventh, a comprehensive description and understanding of the behavioural aspects of SDM was undertaken by the PhD candidate in the form of literature reviews prior to data collection beginning (see Chapters 1, 2 and 5). Eighth, as the research planned to examine both the barriers and facilitators to SDM, a negative case analysis, in which data opposed the main theme findings, is also discussed in the results. Lastly, comparisons to previous literature are examined in the discussion.

As with the clinician interviews, the use of random sampling and iterative questioning were not employed because of low participant numbers and the length of the existing interview schedule. However, one technique that was employed in the clinician interviews but not in this case was the use of different qualitative methods to attain different responses and triangulate the findings. This was not done for pragmatic reasons, as it would have been necessary to arrange focus groups, and individual interviews with young people were not considered appropriate for safeguarding reasons.

7.3 Results

Overall, 16 subthemes across eight domains of the TDF (Cane et al., 2012) were identified as either helping or hindering SDM. These spanned all three areas of the COM-B model (Michie et al., 2014) and are highlighted in Table 7-1 below:
Table 7-1: Parental and young person barriers and facilitators to SDM using the TDF (Cane et al., 2012).

<table>
<thead>
<tr>
<th>COM-B</th>
<th>Theoretical Domain</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Capability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Knowledge</td>
<td>Different levels of awareness regarding involvement in decision making</td>
</tr>
<tr>
<td></td>
<td>Skills</td>
<td>Clinician listening skills inhibiting or facilitating SDM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clinician communication skills inhibiting or facilitating SDM</td>
</tr>
<tr>
<td></td>
<td>Memory, attention and decision making processes</td>
<td>Forgetting to ask questions or remember what was agreed</td>
</tr>
<tr>
<td></td>
<td>Opportunity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Environmental context and resources</td>
<td>A lack of options when it comes to treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Staff shortages inhibiting SDM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facilities not conducive to SDM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A lack of understandable resources</td>
</tr>
<tr>
<td></td>
<td>Social influences</td>
<td>School facilitating or inhibiting shared decisions around education</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Parents supporting young people's interests in SDM</td>
</tr>
<tr>
<td></td>
<td>Motivation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Beliefs about consequences</td>
<td>Shared decision making empowers young people</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shared decision making results in better treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shared decision making can result in the wrong decision</td>
</tr>
<tr>
<td></td>
<td>Beliefs about capabilities</td>
<td>Feeling capable of SDM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A lack of capacity can inhibit SDM</td>
</tr>
<tr>
<td></td>
<td>Emotions</td>
<td>Enhanced emotional states inhibiting SDM</td>
</tr>
</tbody>
</table>
7.3.1 Capability

The analysis of the young people’s and parental responses illuminated three domains related to capability in regard to SDM. These were: knowledge, skills, and memory/attention and decision making processes. Each domain is explored below.

7.3.1.1 Knowledge

Under knowledge, the following subtheme was identified from the young people and parents: different levels of awareness regarding involvement in decision making. This could be seen as a barrier or facilitator to SDM depending on the level of awareness.

**Different levels of awareness regarding involvement in decision making**

When asking young people and parents about their involvement in decision making, there appeared to be differences regarding whether they knew they could be involved. The majority of young people stated that they did not know they could be involved in decision making when they first came to child and youth mental health services.

*No, I didn’t…[know]…they just make decisions for me* (Young Person 7).

Young people suggested that this could be overcome during initial conversations with clinicians, which should focus upon the ways that the young person could be involved.

*I do think it needs to be outlined clearly because I can’t pinpoint the time when people have sat down with me and said this is about you, your parents and us. I’ve kind of just been asked the questions as do you feel safe and stuff* (Young Person 4)
Whilst not knowing they could be involved in SDM initially, the young people reported that their involvement in decisions did increase the longer they were in services.

*When I first started, when I first got medication I wasn’t given a choice. It was this is it. Now I’m definitely presented with more choices* (Young Person 6).

Conversely, unlike the young people, the majority of parents were aware they could be involved in care and treatment decisions from the beginning: ‘Yes, I knew I could be involved’ (Parent 1). One exception to this was Parent 8, who had attended services previously with another child and had not experienced any involvement in decision making.

*I wasn’t too sure really. I wasn’t sure because, as I said, my daughter had gone through it and she didn’t have a very good experience* (Parent 8).

Whilst most parents knew they could be involved in decisions, their role in this involvement was not overtly outlined by the clinician. Instead, it was implicitly linked with their role as the primary caregiver responsible for their young person. Moreover, translating this into actual involvement was sometimes difficult, particularly in the early stages which sometimes ‘felt like a fact-finding mission’ (Parent 6) to parents, or when parents felt that clinicians had a preferred treatment and they had to be ‘assertive’ (Parent 9) if they wanted something else for their child.

### 7.3.1.2 Skills

The analysis revealed that all the parents and young people mentioned the person-centred skills needed by clinicians for successful SDM. This resulted in two subthemes, clinicians listening skills inhibiting or facilitating SDM, as well as clinician communication skills inhibiting or facilitating SDM.
Clinician listening skills inhibiting or facilitating SDM

When it came to listening, the majority of the young people did not feel the clinicians listened to their point of view.

_The doctors would say, “It’s this…” And they wouldn’t actually listen to what I had to say, because I’d say, “No it’s not, I know that because…” And that was kind of detrimental because they’d say that, and then everyone would believe what they’d said_ (Young Person 2)

Other young people recounted similar experiences, outlining that they felt their clinician was not listening to them and instead acting ‘like a robot’ (Young Person 1) completing tasks. When it came to actual decision making, not having their views taken into account led the young people to feel ‘inferior’ (Young Person 9) and afraid to express their opinions as they felt they ultimately would not matter.

The parents reported a more mixed response when it came to SDM. Some reported feeling listened to, with clinicians taking into consideration things that mattered to them and checking to ensure that they were on the same page.

_They were great at listening, and they said what they thought that we could do, and to check that we were in agreement with it, and I certainly felt totally part of that_ (Parent 2).

Other parents reported feeling left out of the decision making process, either with their young person, or by the young person and clinician. In the latter scenario, this seemed to be more apparent as young people grew older and were seen by others as more capable.

_They don’t talk to the parents, they don’t…especially as the young person gets older, and it’s as if you’re non-existent_ (Parent 3).

Clinician communication skills inhibiting or facilitating SDM
A second important skill was effective communication by the clinician. The young people and parents highlighted that the way information was presented needed to be understandable if they were going to be involved in decision making. This was particularly important in the cases of parents and young people who were stressed about coping with a mental health difficulty.

Social and communication skills [are needed]... the way that you talk... I mean especially in this field I think especially, the way that you talk to children ... or parents who are usually absolutely stressed already (Parent 10).

Despite the need for clarity of communication, the interviewees described the excessive use of jargon or technical language by clinicians which they felt was a barrier to involvement.

It's almost shoving the theory and science of it down your throat, isn't it, .... they've been trained all their lives in clinical theory and different ways to deal with people, but nobody's ever told them or taught them how to deal with people on a social level and how to look after them in that sense (Young Person 9).

Such instances resulted in young people feeling confused, bewildered and not knowing how to proceed with treatment as they had not fully understood the information that was presented to them. To overcome this, young people suggested that presenting information in other formats such as visually, would be potentially useful.

If they could somehow show visually kind of like what they were going to do? Maybe as well as... And explaining it. Because I'm quite a visual learner, and I sometimes struggle to picture in my mind what they were describing. So if they could somehow visually show it to me, in some kind of way, that would be better (Young Person 2).

On the other hand, ‘good’ SDM was a process in which communication was seen as reciprocal and open-ended. If young people and parents had questions, these were answered by the clinician and vice versa.
They ask me how I feel and then it's, sort of like, a spider graph: it spreads off. So I ask, like, a question or something and then it either tries to resolve itself or yeah, but it's never really one person's opinion. It's always shared and everyone always asks if that's all right. It's never, that's what's going to happen (Young Person 1).

Engaging in this process allowed for decisions to be reached together, rather than having decisions imposed upon the young person. Importantly, for some young people and parents, it appeared that the correct deployment of such skills formed the foundation for the development of trust. When these skills were lacking, this meant that trust was not established.

It's like talking to a brick wall. They would make opinions for me, make decisions around me and about me that weren't true and I completely lost trust (Young Person 1).

This also meant that the young people and parents questioned whether the clinicians really had their ‘best interests’ in mind. Instead, it was often believed that the clinicians already had ‘their own agenda’ (Parent 6) and that the decision-making process was a form of lip service.

**7.3.1.3 Memory, attention and decision processes**

The analysis of young person and parental responses under the domain memory, attention and decision making indicated that the young people and parents sometimes forgot to ask questions or remember all the information concerning the decision. This is explored below.

**Forgetting to ask questions or remember what was agreed**

Whilst only mentioned by a few participants, it appeared that forgetting and remembering were sometimes associated with the individual’s emotions (see Emotions 7.3.3.3). For one parent, this was described in the context of the distress of looking after a child with a mental health difficulty, which made it difficult for the parent to make decisions in the first place.
When you've got a child that's sick, your thinking processes aren't very clear (Parent 4).

For other parents, the large quantity of information covered in a session made it difficult for them to remember things. Two parents spoke about taking notes during the appointment to remember what was discussed and agreed (Parents 6 and 10), whilst another parent spoke about everyone remembering ‘bits of the conversation’ (Parent 5) so they could recall it later on.

The young people also highlighted that they often forgot to ask questions which were important to them for decision making during the appointments. This was often related to aspects of their diagnosis, and it was particularly relevant to young people with anxiety.

I forget things because sometimes I get nervous and I forget to mention things, even thoughts I'm feeling or anything like that. So that doesn't help in decisions (Young Person 8).

As a result, not asking questions meant young people did not have the answers to help them to make preference-sensitive decisions.

7.3.2 Opportunity

The analysis of the young people’s and parental responses indicated that both domains related to opportunity were involved in SDM. These were: environmental context and resources, as well as social influences. Each is explored below.

7.3.2.1 Environmental context and resources

In the domain of environmental context and resources, the young people and parents spoke of the following barriers and facilitators: a lack of options regarding treatment, staff shortages affecting SDM, a lack of comprehensible resources and facilities not conducive to SDM.
A lack of options when it comes to treatment

A lack of available psychological resources was cited by both the young people and parents. In its bluntest form, rather than a choice between different options, the choice offered was that of treatment or no treatment at all.

*Options of treatments that I was presented with… it was just DBT* (Young Person 5).

Alternatively, while there may be multiple options available, there could be very long waiting lists to access them. Several parents described having to wait over a year to access talking therapies for their young person (Parents 8 and 9), whilst one young person was refused occupational therapy as resources were ‘spread so thinly’ (Parent 7). This resulted in parents and young people questioning the degree to which decisions were shared and whether there was even a decision to be made. Additionally, some parents also felt that the resources supplied were dictated by the clinicians’ agendas. One parent described being told that her case would be closed as she had refused medication for her child, until she pressed to be put on the year-long waiting list for CBT (Parent 9).

Staff shortages inhibiting SDM

Whilst low staff levels could be linked with the above theme, this was not explicitly identified by the young people and parents. Instead, staff shortages were seen as affecting SDM in the form of feeling rushed and little explanation on what options were available.

*I would say too big a workload for each individual member of staff, not enough time allocated for the parents, patients… I just feel like everything is rushed. It’s like you go in there, you sit down, they go, right, this, this, this, this, this. Okay, OCD, goodbye. See you later* (Parent 3).
The haste associated with appointments also resulted in decisions having to be made there and then, rather than allowing the young people and parents to think about their options in greater detail.

*I think you need time, not quick decision making. You need to think about it over a day or whatever time you have* (Young Person 8).

In instances of feeling rushed, this sometimes meant that the young people and parents questioned whether they had made the ‘right’ decision.

A more conspicuous way that staff shortages affected SDM was through the continuity of care. Some young people and parents highlighted that conversations and decisions made with one clinician were not known by others, which meant having to repeat previously shared information and decisions. Additionally, a lack of continuity meant that when it came to SDM, the young people had not built up a rapport within which they were comfortable expressing their views, values and preferences.

*We saw a lot of locums, so we didn’t actually get the consistency of actually having a psychiatrist long enough to develop a relationship with, who got to know us as a family, and who [young person] got to know to be comfortable to talk with, did you? You know, it… quite often it was a different psychiatrist every time, wasn’t it [young person]? You didn’t feel that you were really comfortable speaking with them* (Parent 7).

**Facilities not conducive to SDM**

Therapy rooms and the atmosphere of the clinic were also seen as important to young people and parents, as this was the environment in which decision making occurred. Both the young people and parents highlighted that therapy rooms were often not adequately designed to facilitate this process and made them feel uncomfortable. One young person likened the experience of being in a CAMHS appointment to being reprimanded in school, where they were placed into isolation if they had done something bad.
You kind of feel like you’re being told off in here. It’s like being in isolation (Young Person 3).

The parent of this young person described the room layout as ‘like you know you’re in front of a panel’ (Parent 3). Others spoke of the building as ‘oppressive’ (Parent 10), and described how the clinicians facing the computer rather than them created ‘an uncomfortable atmosphere as soon as you got in’ (Young Person 9). The parents and young people ultimately felt that these circumstances did not adequately allow for their views to be openly expressed.

A lack of understandable resources

Many young people and parents also highlighted that they needed simple, comprehensible informational resources to help them make sense of situations. Often, resources were presented on paper leaflets which the young people and parents found ‘too text book-y’ (Parent 9). This resulted in the parents and young people not knowing what option to choose and deciding in some cases to defer to the doctor.

Like we had about all the drug information for the medication. It needs to be really clear. The information needs to be presented in a format that people are able to understand, so they can make those informed decisions and feel comfortable about making it… You felt bombarded by it, or you feel like you just don't get what’s going on. That would be a very frightening and unnerving experience. And then you don't have your opinion; you let other people make it for you (Parent 1).

Whilst this mainly pertained to medication, there were also examples in which clear written information regarding therapies would also be beneficial. One young person stated that the CBT leaflets with which they were provided were not helpful. This young person then outlined a book they used was, as it was ‘in a way that I could understand... it was more aimed at teenagers; it didn’t have long confusing words, it put it very simply. It gave you pictures and diagrams…’ (Young Person 3).
However, some parents wondered whether all the information was appropriate to share with their offspring. One parent felt that sharing the side effects of medications would overwhelm young people, as prior knowledge of side effects ‘could be detrimental, because with medications there are side effects, that might scare [young] people into not taking it’ (Parent 2). Indeed, some parents chose to withhold some information about side effects from their young person for that reason.

_We didn’t disclose everything to her at that time in terms of the medication…_ (Parent 5).

When the desired information was unavailable during the clinical encounter, young people and parents sought it through other sources. This was mainly from the internet, which was considered potentially useful but also possibly unreliable.

_Because the internet’s a massive place. There’s so much misleading information_ (Young Person 4).

### 7.3.2.2 Social influences

Under the domain of social influence, analysis of the interviews with the young people and parents led to the identification of the following barriers and facilitators to SDM: school, which could be a barrier or facilitator; and parents, who were usually described as a facilitator.

**School facilitating or inhibiting shared decisions around education**

Both parents and young people viewed the young person’s school as impacting on decisions regarding returning to education. Most of the young people interviewed were not in school at the time of attending mental health services. Often, one of the decisions that was discussed was focused around whether the young person should return to school:
To decide which school or if you’re going to go back to school is quite a big decision, so in a way that, sort of like, gave me a boost of confidence (Young Person 1).

It was important for the school to be involved in this conversation in order for the decision to return to education to be enacted. This collaboration was viewed as being in the best interests of the young person, not only to support their learning and development, but also for their overall wellbeing.

The school was very involved actually; and it’s a very important part of a child’s life is their school and their teachers. And we had meetings actually with [young person’s] headmaster, and with the deputy head at the primary school, and I think they’re an important part actually as well in decision-making with the child. Because it’s not just about education, it’s about the wellbeing of the child, and their mental health’s important as well, at home and at school (Parent 2).

However, some schools were not supportive of the young person returning, as the school staff viewed their behaviour as risky or disruptive.

I do know this week of two young people that are currently excluded from education, who want to be back in school, but the school aren’t willing to take the risk associated with having them back. …So that young person has made a decision that they want to go back to education, but nobody [in school] is facilitating that (Parent 4).

Although young people, parents and clinicians may believe it to be a good decision for the young person to return to school, schools may prevent this from being an option in decision making due to their inability to support the young person.

Parents supporting young people’s interests in SDM

The majority of young people interviewed viewed their parents as important when it came to decision making. Some saw their parents as having ‘more
knowledge than they did’ (Young Person 7), which meant they were better placed to make the decision.

However, in other instances, young people viewed their parents as crucial in supporting them to make the right decision for themselves.

*I always like your support, Mum, [when making decisions] because it’s a nice feeling that someone’s behind you* (Young Person 8).

The parents viewed themselves as supporting the decisions made by the young person, provided that the young person was not severely incapacitated or planning to pick an option which could cause them harm (see Beliefs about capabilities 7.3.3.2).

Whilst parents were generally seen as supportive, a few young people also outlined how they appreciated some time alone with the clinicians.

*The other thing is, on the other hand, sometimes a child may not feel comfortable explaining things in front of the parent* (Young Person 2).

Time alone meant that the young people were able to discuss more personal things, preferences or reasons that may affect treatment and support, which they either did not want their parents to know about, or did not feel comfortable discussing in front of them.

### 7.3.3 Motivation

Three domains around motivation were identified within the young people and parental interviews in regards to SDM. These were: beliefs about consequences, beliefs about capabilities and emotions. Each of these is explored below:
7.3.3.1 Beliefs about consequences

Three subthemes were identified in relation to this domain. These included that SDM empowers young people, that SDM results in better treatment plans, and SDM can result in the wrong decision.

Shared decision making empowers young people

The young people stated that when they were involved in decision making, this made them feel empowered.

*It makes you feel more powerful and more trusting…when I couldn't make the decision, I felt horrible. And it was all going on without me* (Young Person 4).

This contrasted with the lack of involvement that occurred when the young people felt that decisions were made without them, which made one young person feel like ‘less of a person’ (Young Person 6). Such sentiments were also echoed by other young people who expressed emotions such as sadness and anger at being excluded from decisions.

*I don’t feel I was included enough and that made me feel definitely upset, left out, quite angry not to have a voice really. … She was always making the decisions and not really saying… You know, she was like, “Do this.” And not really, “Is this all right for you to do?”* (Young Person 8)

For the parents, feeling like they were not involved in decisions gave them a sense of disempowerment. One parent described feeling like a bystander in their young person’s care, which left them vulnerable and beholden to the clinician’s judgement.

*…as a parent, that can make you feel quite powerless and out of the loop and quite vulnerable. Like you’re making your child quite vulnerable because you’re trusting them with other people…* (Parent 4).
For another parent, a sense of disempowerment left them feeling like a failure and agreeing to whatever the clinicians suggested, even if they did not think it was correct: “‘Yeah, do whatever. Get everything…go on a parenting course’…I’ve already been on one….and agreeing with it’ (Parent 3).

**Shared decision making results in better treatment plans**

A common theme identified across the majority of the interviews for both the parents and young people was that being involved in decisions meant that they would obtain a treatment plan that was right for them. Importantly, they viewed their difficulties as unique to themselves, and in order to gain effective treatment, these factors needed to be taken into account.

*What you’re doing is you’re treating the child as an individual, and looking at their specific needs. And you know, we’re experts in ourselves* (Parent 8).

Consequently, the more involved parents and young people were, the more tailored and appropriate their treatment would be.

*The more you talk and reason with a patient, the more you might have an idea of the exact treatment that they should be getting* (Parent 6).

In addition, involving the young people in decisions also meant that ‘treatment could be changed if needed’ (Young Person 5). Other young people elaborated on this concept.

*If you allow people to have a say in their own care… then they can alter it because, ultimately, [young people] know what’s going to happen best for them, …if you have your own say in it, then you can kind of work it and fit it around you* (Young Person 9).

Positive ripple effects stemming from this included more ‘buy in’ from parents (Parent 9) and benefits to the young person’s ‘health and wellbeing’ (Young Person 8). Conversely, not being involved could result in a young person being
‘less likely to engage’ (Parent 4) and, as a result, not seeing ‘any real progress’ (Parent 5).

**Shared decision making can result in the wrong decision**

A few parents and young people discussed the negative impacts and consequences of making a ‘wrong’ decision. One young person described how they had difficulties weighing up different decisions and how they did not know which one to pick.

*If you make the wrong decision, that could be worse for you… I think it’s a great benefit to have a say, but it also can be bad sometimes if you make a bad decision, and you’ve got the option to do that, but you didn’t mean to. Because you’re only a child and sometimes you can struggle with what to do* (Young Person 8).

Here, support from parents and other responsible adults was important in helping young people to make the right decision. The possibilities of negative consequences were outlined by the parent of Young Person 8, who worried that making the wrong decision could cause their child to feel ‘more depressed or suicidal’.

The parents described feeling a greater sense of responsibility than young people when it came to decision making. Medication was often something parents felt strongly about and did not view as a first line treatment for their young person: ‘It’s not all about medication and I think that’s the biggest thing’ (Parent 9). Despite this, some parents questioned whether refusing treatment was necessarily the right thing, as their child might not be benefitting from something that may have actually helped.

*I think if a parent declines treatment then it could be detrimental to the child. And… I mean, you know, mental health is a roller coaster and it’s… As a parent it’s very hard, but you’d… It could be detrimental if you start refusing treatment for your child, and in the long run they’re not going to benefit* (Parent 2).
Other parents questioned how they would feel about the clinician letting them make such a decision.

*Or if a decision goes wrong and the parent has had 50% control and the psychiatrist has had 50% control, the parent’s obviously going to think, why didn’t they…? Because they are the experts, in the end* (Parent 4).

Thus, whilst the parents perceived different individuals as having particular expertise, they felt that clinicians should not allow them to make a decision which could be detrimental to their child’s wellbeing. They described how doing so could result in a loss of trust and a damaged relationship with both the clinician and service.

### 7.3.3.2 Beliefs about capabilities

With regard to beliefs about capabilities, two subthemes were identified: the parents’ beliefs that they were capable of being involved in SDM, and the young people’s capacity to be involved in SDM.

**Feeling capable of being involved in SDM**

During the interviews, the parents believed that they were capable when it came to being involved in care and treatment decisions.

*Yeah, I feel I have the capability to be involved* (Parent 2).

Reasons for this included the parents having an intimate knowledge of the young person, which was needed as part of the decision-making process, as well as knowing what may work and how the young person might respond. The parents believed that this contrasted with the clinicians’ vantage point, as they only received a ‘snapshot’ (Parent 2) of the young person when they came to the clinic.
Similarly, at the time the interviews took place, all the young people expressed that they were able to be involved in the decision making process. 

*I'm definitely capable* (Young Person 4).

However, when it came to previous involvement in decision making, the young people and parents had mixed opinions regarding the capabilities of the young people to make decisions. Whilst some felt that the young people were capable of being involved, others focused on whether the young people had the capacity.

**A lack of capacity inhibiting SDM**

The young people and parents both viewed a young person’s capacity as a significant factor that affected their ability to be involved in decision making. Capacity was described in an idiosyncratic manner and was not linked solely with age or having a specific mental health difficulty.

*I think it depends on understanding because you could have somebody that doesn't understand at my age. You can also have somebody who understands very well at my age. Equally a person who understands very well at 11 or somebody doesn't understand very well at 17. So, I think it depends on emotional understanding and maturity* (Young Person 9).

For several young people, this was explicitly outlined with respect to ‘Gillick competence’ (Young Person 6). Some young people described how this level of competence was necessary for young people to be completely involved in decision making. Other young people, whilst not able to articulate this in these exact terms, believed that young people with mental health difficulties were not capable of making good decisions on their own if they were ‘too ill’ (Young Person 5). One young person used their personal experience to justify their opinion.
I wasn't in a place to rationally be involved. And looking back now, I can understand that. I'm glad they didn't involve… Because it was for safety and risk, like high levels of risk (Young Person 4).

The parents also felt that a young person’s capacity could affect their ability to take part in SDM.

Obviously you couldn’t allow it to be entirely the patient’s decision if you didn’t think that their mental health was in the condition to make those sorts of decisions (Parent 7).

Despite acknowledging that capacity could affect SDM, the parents felt that young people ‘should still be able to be involved in decisions’ (Parent 2). Involvement was described through the process of listening to the young person so that ‘everything can be analysed afterwards as to how much of it you can actually accept and move forward with’ (Parent 6). Thus, whilst involvement was welcomed and encouraged by the parents and young people, a lack of capability or capacity was cited by interviewees as a justification for why a young person should not always have the final say.

7.3.3.3 Emotion

Enhanced emotional states can inhibit SDM

Barriers and facilitators to SDM around this theme involved enhanced emotional states. For the young people, these were sometimes linked to their mental health. In particular, it was highlighted that feeling anxious or stressed about certain types of treatment could make the young people feel less inclined to choose them:

If somebody feels like… If they get very stressed out over a certain treatment that they’re required to do, they can make themselves worse. So the doctor might say, “No, we’re not going to make you do it” (Young Person 2).
In addition to anxiety and stress, feeling sad or low were also suggested as emotional states that could negatively impact on SDM by causing young people to disengage from treatment.

*It’s so much to do with their state of mind. Some of them may already be so depressed that they think what’s the point? Nobody’s listening, or I’m never going to get any better* (Parent 6).

Others acknowledged that feeling strong emotions could make it harder to think and share decisions, as things could become ‘muddled…confused…not making sense’ (Young Person 3).

### 7.4 Discussion

The aim of this chapter was to investigate young people and parents’ perspectives of the factors that affect SDM in child and youth mental health. Eight of the fourteen domains in the TDF (Cane et al., 2012) were identified. The next section explores the COM-B ‘behavioural diagnosis’ in terms of previous literature and its implications for the intervention design and development.

#### 7.4.1 ‘Behavioural diagnosis’

In the context of capability and SDM, it is evident from the analysis of these interviews that the young people and parents have different levels of awareness related to involvement. During their interviews, the young people outlined that they knew they could be involved in decision making, although when they first attended services they were not made explicitly aware of this. Conversely, most of the parents were implicitly aware that they could be involved, though sometimes translating this into meaningful involvement could be difficult. The parents and young people detailed the skills needed by clinicians for SDM, including the ability to listen to the needs and values of young people and parents, as well as effectively communicating any important information. In
relation to memory, the young people and parents spoke about forgetting to ask questions or finding it difficult to remember information and decisions made during the appointment.

Regarding opportunity and SDM, the parents and young people identified a lack of options for treatment, with certain options not available and others with long waiting lists. Staff shortages were also highlighted as a barrier to SDM, as appointments and conversations around decisions could feel rushed as a result. Additionally, staff shortages affected continuity of care, with some parents and young people not being seen by the same clinician in subsequent appointments. This resulted in the young people not feeling comfortable sharing their opinions and preferences, as well as families having to repeat information they had already shared. A lack of understandable resources was also seen as a barrier, as the young people and parents felt they did not have the necessary information to be able to make a decision. In terms of the physical environment and SDM, the building and rooms where decisions were made were felt to be at odds with services that valued input from patients and families. Rooms were described as formal, and the building was oppressive. Regarding the social influences on SDM, school was seen as an important factor that impacted on decisions made in appointments around returning to education, as schools could facilitate or block these decisions. On a different vein, the young people believed that parents could facilitate decision making by supporting them. Despite this, the young people also stated that they also appreciated unaccompanied time with the clinician to express views, values and preferences, which they would not feel comfortable expressing in front of their parent(s).

Lastly, with regard to motivation, the young people and parents believed that being involved in decisions could result in tailored treatment plans, as well as the empowerment of young people. However, a negative consequence of this could be that the young person chose the wrong treatment, which could result
in the young person not getting better or getting worse. Both the parents and young people believed they were capable of being involved in decision making, though they acknowledged that in some circumstances this could be affected by the young person’s limited capacity. Despite these circumstances, the parents felt that the young people should be involved even if they could not be the ultimate decision makers. Finally, enhanced emotional states were identified as a barrier to involvement in decision making. For the young people, this was sometimes related to emotional difficulties they were experiencing, such as feeling sad or anxious.

7.4.2 Situating findings within the literature

Previous studies have highlighted the important role information plays in SDM. When information is given in a clear and understandable way, this can be a facilitator (Iachini et al., 2015; Simmons et al., 2011). Conversely, the same studies highlight that having no available information or receiving complex information can be a barrier. Similarly to previous literature, this study highlights that young people and parents want resources which are simple and understandable. Without such information, the young people and parents described struggling to be involved in decision making as they could not differentiate between options. When information was poor or lacking, the young people and parents described consulting other sources of information, such as books or the internet. This finding is also present in other studies (Simmons et al., 2011), in which young people mentioned consulting the internet, as well as family and friends. However, some individuals in this study cited the unreliable nature of information on the internet, which could be wrong or misleading.

Interestingly, one parent questioned whether all the information shared with young people needs to be age-appropriate, as giving young people information about side effects could encourage them not to choose a particular treatment. This, too, has been replicated elsewhere, for example, in the context of a young
person questioning whether they would engage in treatment if they had all the information beforehand (Simmons et al., 2011). Similar sentiments were also expressed by a clinician in Chapter 6 who described how they believed SDM could make long-term outcomes worse. As some academics propose that young people should have their views and preferences acknowledged regardless of age or capacity (Batten, 1996; Paul, 2004), withholding information that would inform a preference-sensitive decision runs contrary to involvement. This stance could be argued as being situated within a paternalistic model of care rather than one based upon SDM.

The role of communication between stakeholders has also been described in previous studies as a barrier to decision making (Simmons et al., 2011). Both the parents and young people in the present study viewed communication as an essential skill required by clinicians in order to engage in SDM. Specifically, clinician communication needed to be comprehensible to stakeholders in order for them to be meaningfully involved. Ways in which effective communication could be demonstrated by the clinician included the use of iterative questions, the removal of jargon from speech and the omission of complicated medical information. The importance of appropriate language has been highlighted in other studies, in which a young person’s numeracy and literacy level has been shown to be an important factor when sharing information during treatment discussions (Schachter et al., 2011).

Listening skills, which are closely associated with communication skills, were described as affecting SDM. Some young people and parents described how they felt clinicians did not listen to them and went through questions without paying attention to their responses, which caused them to feel inferior. Listening skills have also been highlighted in previous studies as a facilitator to decision making when they are present, and a barrier when they are absent (Offord et al., 2006; Pycroft et al., 2013). Potential reasons for this lack of listening skills have been discussed in the previous chapter, whereby, the clinicians described
feeling overextended as they needed to complete a number of tasks prior to the appointment ending.

Staff shortages were described as having an impact on the continuity of care, which affected decision making as the stakeholders had to repeat the same information to new clinicians. For young people, this prevented the opportunity of developing a relationship or rapport with a clinician which hindered their willingness to communicate. The findings that young people do not want to speak to multiple clinicians and that the development of trusting relationships with clinicians allows young people to ‘open up’ have also been described in other studies (Oruche et al., 2014; Pycroft et al., 2013; Simmons et al., 2011). This is particularly relevant in child and youth mental health in the UK, as individuals can be seen by one person for assessment and then be referred on to someone else for a specific treatment modality.

The role of parents in young people’s decision making was described as important by the parents and young people, as parents may possess greater knowledge than their child or could support them in making decisions. Previous studies have highlighted the role of parents as facilitators in decision making for similar reasons (Iachini et al., 2015; Oruche et al., 2014). However, one study produced mixed findings which outlined both the positive and negative consequences of parental involvement in their young person’s decision making (Simmons et al., 2011). On the one hand, parental involvement could mean that the young person felt supported. However, their involvement could be also detrimental, as the parent might unduly influence decisions. Within the present study, the young people stated that their parents were supportive of them being involved in decision making. Whilst no negative aspects of caregiver involvement were reported, the young people stated that they appreciated time on their own with the clinician to discuss things that they did not want their parents to hear. This hints at the potentially negative effects of parental involvement, as the amount of privacy afforded to the young person could
influence the conversation and the decision that is ultimately made. Alternatively, it is possible that young people did not overtly discuss the negative aspects of parental involvement as their parents were present during the interviews. This could have impinged on what they felt comfortable saying.

Both the young people and parents described the positives of being involved in decision making, which included the young person feeling empowered and receiving a tailored treatment plan that was right for them. Simmons et al. (2011) identified similar themes, finding that decision making was associated with adherence, the engagement process and empowerment. Another study described how involvement in decisions could motivate young people to participate in treatment (Oruche et al., 2014). One possible explanation for this could be that SDM helps create ‘buy in’ through the process of co-creation around treatment and values. This echoes the findings from Chapter 6, in which the clinicians regarded SDM as empowering and important if treatment was going to be successful.

Whether young people have the capacity to be involved in decision making has been discussed widely in the literature (e.g. Coppock, 2005; Ruhe et al., 2015). Results from this study indicated that both the young people and parents identified situations in which capacity might hinder a young person’s ability to participate fully in decision making. This was discussed both in terms of age and mental health diagnoses, and particularly with regard to Gillick competence for older adolescents. Previous literature suggests that capacity can be a barrier to decision making, however, this theme was identified in only a small number of patient cases in that study (Simmons et al., 2011). The parents interviewed in the present study believed that young people should still be involved in the decision-making process through having their views acknowledged and validated, despite the fact that they may not be the main decider. This aligns with previous research that states that there are differences between involvement in decision making and being the ultimate decision maker.
(Alderson & Montgomery, 1996; Simmons et al., 2011). The importance of being explicit about how young people can be involved and the reasons for this have been outlined in some models (Common Room Consulting, 2017), as well as in research (Paul, 2004). It should also be noted that more general models of SDM highlight that the decision-making preference can change over time (Charles et al., 1999), and this may also apply in the context of child and youth mental health.

Emotions were also identified in this study as a barrier to SDM in certain circumstances. For some young people, it appeared that these emotions were linked to their mental health difficulties, for instance, feeling anxious, scared or too depressed to make a decision. This finding appears to be novel when compared to the previous literature, as it explicitly outlines how emotions can affect the decision-making process. However, this could also be linked to a young person’s mental health diagnosis hindering their capacity to be involved, which has also been documented in the literature (Kaltiala-Heino, 2010).

The parents and young people described how emotions could impact on memory, as feeling scared, nervous or overwhelmed could prevent them from asking questions or remembering what was said. This is consistent with findings from other areas, in which the parents of young people with chronic physical health conditions reported that emotional distress affected their memory and decision-making processes (Kupst, Patenaude, Walco, & Sterling, 2003). There is potential to overcome this difficulty by using QPLs to help young people and parents remember to ask for information. Indeed, there is some research support for QPLs, with parents reporting high levels of satisfaction and lower levels of anxiety after their use, and clinicians believing that QPLs help parents navigate the conversation and reporting them as acceptable in practice (Ahmed et al., 2017).
The lack of options around care and treatment specifically with regard to SDM has not previously been documented by young people and parents. However, this matter has been stated by the clinicians in the previous chapter as well as by clinicians in another study (Simmons et al., 2013). This novel finding may be explained by whether young people and parents have previously accessed services, or alternatively, their length of time in services. Families new to services may not know the nature of the young person’s difficulty nor what the available options are. On the other hand, returning families, or those whom have been in contact with services for a longer period of time, may have a better idea of what resources are available or may help. Within the present study, all the young people and parents had lengthy and sustained contact with services which could explain the emergence of this theme.

Service facilities having the potential to hinder SDM also appears to be a novel finding that has not yet been documented in the literature outside this doctoral research. Both the young people and parents described the buildings as oppressive, which established a tone that contrasted significantly with the ethos of their views and preferences being welcomed. This links with the perception of the clinicians in Chapter 6 who felt that the buildings looked too clinical and created a power imbalance. In a similar vein, the young people described the room layout as formal, not conducive to having open and frank discussions and uncomfortable. This view was also supported by the clinicians, though in addition to the layout, the clinicians described how the lack of comfort within the rooms could be a barrier. Rooms could be too hot or cold, which resulted in clinicians limiting their conversations with young people and families so that they could leave quickly.

Potentially choosing the ‘wrong’ option was highlighted as a negative consequence of SDM, as it had the potential to impede recovery or make symptoms worse. Similarly to the other novel findings, this does not appear to have been previously documented in the published research, though it was
described by one clinician in Chapter 6. This clinician spoke of choosing the wrong option in relation to anxiety disorders and exposure experiments, which they felt patients would not do for short-term relief. Conversely, in this chapter, the young people and parents spoke more generally about making a wrong decision. To counteract such concerns, the clinician could present evidence regarding the possibility of becoming better with each option in comprehensible formats taking into account numeracy and literacy skills.

The literature on Goal Based Outcomes may provide further insight into how clinicians could help young people and parents make ‘right decisions’. Goal setting allows for the young person, parent and clinician to work together to create a shared language and understanding around why they have come to services, and what they want to achieve (Law & Jacob, 2015). Within this, there is room for negotiations around potential disparities between those involved, though the previous authors note, that ultimately the young person should agree to this and set their own goal. As part of goal setting, clinicians should help individuals understand how their goal may be achieved within the context of different treatments (Feltham, Martin, Walker, & Harris, 2018) and find values that underpin the goals that are set (Dryden, 2018). With this in mind, it is therefore plausible that goals set and underpinned by values, along with knowing how different treatments could help achieve this, result in young people and parents choosing the ‘right decision’ for them.

The impact school can have on decision making also appears to be a new finding. In the present study, school was often seen as essential to a young person’s recovery, with many young people not being in school whilst attending services. Consequently, returning to education was a decision to be considered during initial and follow-up appointments. Whilst this was a discussion point with the clinician, it was ultimately influenced by whether the school would facilitate or inhibit what was decided depending on their attitude towards mental illness and risk. This supports research findings that decision making in mental health
is not limited to treatment decisions, but includes other types of decisions (Freidl et al., 2016; Hamann et al., 2008; Slade, 2017). However, a consequence of this broader range of decisions is that more stakeholders are involved, thereby, adding complexity as there are more values and preferences to consider.

A lack of culturally competent care has also been highlighted in previous literature as a barrier (Iachini et al., 2015) but was not found in this study. This could be due to the homogeneous makeup of the young people and parents who took part, whereby, most identified as White British. Different findings may have been identified with a more diverse group of young people and parents from different cultures. Further research should investigate this by drawing on underrepresented populations in child and youth mental health, or by investigating SDM between young people and clinicians from different cultures.

7.4.3 Strengths and limitations

Previous studies examining barriers and facilitators have either focused on concepts related to SDM (Gondek et al., 2016), have been outside the UK (e.g. Simmons et al., 2011) or have examined specialist services set up for hard to reach populations (Pycroft et al., 2013). A strength of the present study is that it is the first to examine the barriers and facilitators to SDM for young people with internalising disorders and their parents in child and youth mental health services in England. This may provide some insight into how parents and young people see the barriers and facilitators to involvement in decisions and offer ways for services to improve SDM with this group.

As outlined in the previous chapter, a further strength of this study is the use of the TDF (Cane et al., 2012) to examine the barriers and facilitators to SDM. Rather than asking individuals what they thought the barriers and facilitators of SDM were, a more systematic approach was employed that examined fourteen domains and was underpinned by theory. Building on this work, whilst young people and parents were interviewed together, it may be useful in future
research for the clinician to have been interviewed at the same time about the same decision-making experience. This would allow for a comparison of the barriers and facilitators from all the perspectives related to the same treatment session, rather than the broader, more diverse experience identified here.

Limitations around use of the TDF and convenience sampling are the same as in Chapter 6 (see 6.4.3 for further commentary on these). Limitations specific to this chapter, include the presenting problems examined means that we cannot extrapolate to other difficulties such as eating disorders or psychosis. Indeed, such disorders may have their own unique specifications around SDM due to the level of cognitive impairment and associated aspects involving capacity. Similarly, no young people aged under 12 years, and very few individuals who classified themselves as ‘non-white’ were included in this study which again limits what can be deduced about the barriers and facilitators for young people and SDM in these populations. In relation to age, it is possible that children or younger adolescents are more likely to have greater parental involvement when it comes to decision making (Lipstein et al., 2016), which may uncover separate barriers and facilitators which have not been identified in this study.

A further limitation was the role of the clinicians in recruiting young people and parents to participate in this research. Whilst all the clinicians were asked to outline the research to all eligible participants within their caseloads, most young people and parents came from a few clinicians who were actively involved in the study. In an attempt to overcome this, posters about participation in the study were also put up in the waiting rooms. Whilst the posters recruited two parents and one young person to the study, the majority of the participants were referred by clinicians. The clinicians acting as gatekeepers could mean that the participants recruited in this study may not actually represent an accurate sample of the target population. For example, it may be that the clinicians involved in recruitment were advocates of SDM, and, thus, the young
people they recruited may have had a different experience of SDM compared with those who were not recruited by non-actively involved clinicians.

The majority of the young people and parents had been in contact with services for at least a few years at the time of the interview which could be considered a strength or a limitation. As a strength, these participants could be considered ‘experts by experience’, giving them a rich variety of encounters to draw upon concerning the barriers and facilitators to SDM. It also highlights how decision making with young people can change over time the longer, or more involved, they are with the services. Alternatively, it could also be considered a limitation as these are not representative of the individuals who access and are seen in services, as research suggests the modal number of appointments to services is one (Wolpert, Vostanis, et al., 2015). This could distort the barriers and facilitators they perceive to be important, or mean they have difficulty accurately remembering what the initial barriers and facilitators were when first accessing services.

The fact that the young people and parents were interviewed together could also be considered both a strength and a limitation. In terms of a limitation, it could be that individuals withheld information from the interview due to the presence of the other, which resulted in less rich and candid answers than if they had been alone. On the other hand, many young people appeared to be quite nervous in the interview, and the presence of someone familiar, who they trusted, may have allowed them to be more open.

7.4.4 Reflexivity

As in the previous chapter, I have considered my role and its impact on the research process. I held the following assumptions when I approached the project: firstly, as I was interviewing young people aged 12 years and over, I expected them to have a more active role in involvement than younger children. I was also aware that I expected the majority of the young people and parents
to actively want to be involved in their care and treatment decisions and to associate this with positive consequences.

While interviewing young people, I was struck by how shy and reserved some were when answering questions. This may have been due to my presence as an unknown individual who was asking them questions about themselves and their experiences with services. Interestingly, this did not appear to be age-specific or specific to a particular presenting problem. However, it did highlight the potential difficulties for clinicians working with such young people and trying to elicit their preferences and values, particularly on a tight assessment schedule. Whilst it was outlined in the method that young people would always be asked questions prior to their parents, situations where the young person was shy or reserved resulted in parents taking more of a lead, followed by the young people agreeing or disagreeing. In speaking with my supervisors about this, I became aware of two things: the importance of time for eliciting values and preferences which may not be afforded to young people, and the potential role of the carer in decision making even when the young person may have the capacity to make the decision themselves. As I was aware that I was a stranger to the participants, particularly to the young people who took time to open up, I made much more of an effort to engage them. This was both at the beginning of the project when I spoke to them on the phone prior to arranging the interview, and at the beginning of the interview in order to develop a rapport prior to commencing with the interview schedule. However, I am not sure whether this had much effect on the actual content of the interviews.

Whilst the young people and parents did want to be involved in decision making, the reflective accounts of some young people were that they would not have been ready to be involved in decision making when they first entered services due to being too unwell. This surprised me given the emphasis of placing young people and families at the heart of decision making (Department of Health, 2015), although the emphasis on families may take precedence in
such circumstances. It also struck me as interesting how young people outlined more of a change in involvement the longer they had been in services, though this needs to be further examined and explored. I wondered if these young people had more capacity for involvement because they had been in treatment, or if this was due to age or other factors.

Similarly, the anxiety around potentially making a ‘wrong’ decision was also something that surprised me, given the fact that SDM is not usually associated with negative outcomes. This allowed me to reflect that though there are many benefits associated with decision making, some young people and parents may not want to be involved in decision making due to the potential negative consequences. Indeed, choosing not to be involved in decision making is in fact a decision itself. Consequently, I tried to adopt a more neutral stance when it came to asking about both the positive and negative consequences around SDM when interviewing the young people and parents.

7.4.5 Conclusion
This study has identified a number of barriers and facilitators to SDM from interviews with young people and parents. Similarly to the clinicians, the barriers and facilitators fell across all three areas of the COM-B model (Michie et al., 2014), suggesting the targeting of capability, opportunity, and motivation could help facilitate the inclusion of young people and parents in care and treatment decisions. Some of the barriers and facilitators identified correspond with the previous literature, such as the importance of listening and communication skills, and how SDM can empower young people. On the other hand, some new findings have been uncovered, including how decisions around education are discussed in appointments and how school can affect these, as well as worries about the consequences of making the wrong decision.

Uncovering the barriers and facilitators from the young people and parental interviews on SDM can help inform the intervention development. For example,
providing young people with information prior to, or at the start of the appointment could increase their awareness that they can be involved in SDM. Alternatively, providing young people and parents with understandable resources about different options for care and treatment could also help facilitate their involvement.

Compared with the clinician interviews, less theoretical domains were found to act as barriers and facilitators to SDM. This could fit with assertions that the power balance is tilted towards clinicians and targeting clinician behaviour is essential for SDM to occur (Charles et al., 1999; Elwyn et al., 1999; Sandman & Munthe, 2010; Towle & Godolphin, 1999). However, to optimise and enhance SDM further, the barriers and facilitators identified by the young people and parents should be included. The similarities of the barriers and facilitators across both studies included facilities not being conducive to SDM, a lack of options when it comes to treatment and the need for core therapeutic skills to be able to involve young people and parents in treatment.

In order to develop an intervention to facilitate SDM, it was important to narrow down the list of barriers and facilitators identified in the last two chapters to consider which factors may be effective, as well as practical to target. The next chapter details which barriers and facilitators were selected, before outlining the intervention development process, and which BCTs and IFs were included.
Chapter 8 Developing an intervention to facilitate SDM in child and youth mental health
8.1 Introduction

As discussed in Chapter 3, whilst there are various existing frameworks for intervention development, most lack comprehensive guidance on how to develop the intervention (Correy et al., 2013). The BCW (Michie et al., 2014) can aid this process, as it provides step-by-step guidance on the intervention development process. Moreover, while most interventions are only based on one of a few key theories (Davis et al., 2015), the TDF (Cane et al., 2012), which is part of the BCW (Michie et al., 2014), allows for the most appropriate theories to be selected for an intervention in order to elicit behaviour change. Moreover, use of the TDF (Cane et al., 2012) addresses the theory-practice gap raised by Elwyn et al. (2011), as it combines multiple theories and targets the different behaviours which may affect SDM.

Aspects of the BCW (Michie et al., 2014) have guided earlier chapters of this thesis. Chapter 4 examined the theory, IFs, and BCTs used in interventions to facilitate SDM in child and youth mental health. The findings from this chapter suggested that theory was not being explicitly used to develop SDM interventions. The IFs ‘education’ and ‘enablement’ showed promise in increasing SDM with parents. For young people, ‘enablement’ whilst used once, could potentially be useful for increasing SDM for young people, whilst ‘education’ produced contradictory results. For clinicians when the IFs ‘education’ and ‘training’ were used, this resulted in increased SDM. Other IFs may also be considered potentially relevant though a lack of studies makes this difficult to distinguish. An examination of the BCTs indicated that ‘credible source’, ‘goal setting (outcome)’, ‘information about health consequences’, and ‘pros/cons’ could increase parental participation in decision making. For young people and clinicians, each BCT was only found once across all the interventions. These could potentially be used to create an SDM intervention, although these findings should be treated cautiously due to the limited evidence regarding the use of these.
Chapter 6 examined clinicians’ perspectives on the barriers and facilitators to SDM using the TDF (Cane et al., 2012). Overall, 21 themes across ten theoretical domains were identified as factors which may help or hinder SDM. These spanned all three areas of the COM-B model, which consists of capability, opportunity, and motivation (Michie et al., 2014). For capability, the barriers and facilitators were related to the domains of knowledge, cognitive and interpersonal skills, memory, attention and decision making processes, and behavioural regulation. For opportunity, both environmental context and resources, as well as professional or social influences were found to affect SDM. For motivation, professional role and identity, beliefs about consequences, beliefs about capabilities, and emotions, influenced how clinicians participated in SDM with young people and parents.

Chapter 7 examined the barriers and facilitators to SDM from the perspectives of the young people and parents using the TDF (Cane et al., 2012). Here, 16 themes across eight theoretical domains were identified as factors which may help or hinder SDM. As in Chapter 6, these findings spanned all three areas of the COM-B model (Michie et al., 2014). For capability, the barriers and facilitators were related to the domains of knowledge, cognitive and interpersonal skills, and memory, attention and decision making processes. With regard to opportunity, environmental context and resources along with social influences affected SDM. For motivation, beliefs about consequences, capabilities and emotions influenced how and when the young people and parents participated in SDM.

Each empirical study in this thesis has contributed to knowledge around the practice of SDM in child and youth mental health. This was through an examination of the components of the interventions which affect participation in decision making, as well as the analysis of the perceived barriers and facilitators to SDM by different stakeholder groups. These findings will now be
critically examined and applied to the development of an intervention to facilitate SDM.

8.1.1 Aims of the present chapter

Drawing on the BCW (Michie et al., 2014) and previous findings, the present chapter outlines the process of developing an intervention to facilitate SDM in child and youth mental health.

8.2 Developing the intervention to facilitate SDM in child and youth mental health

Given the barriers and facilitators to SDM identified in Chapters 6 and 7, it was necessary to systematically discern which of these would form the basis of an intervention, as well as what the proposed intervention would look like. The next section draws on the BCW (Michie et al., 2014) and previous literature in order to outline the process of arriving at the key decisions related to the intervention’s design and content.

8.2.1 Change of sites

The two sites that took part in the qualitative interviews in Chapters 6 and 7 withdrew from the intervention development phase due to service pressures and ongoing transformation plans which required services to concentrate time and resources into their achievement. Consequently, three new sites were approached to develop and test the intervention. One site, which was based in London, agreed to take part in the development and testing of an SDM intervention. The development process is further outlined below.

8.2.2 Selecting IFs (Step 1)

Following the identification of the theoretical domains known to affect SDM,
each domain was mapped onto its possible IFs\textsuperscript{15} (Michie et al., 2014). As the theoretical domains spread across all three areas of the COM-B model (Michie et al., 2014), all nine IFs were considered as possibilities for the development of this proposed intervention. As behaviour change occurs within a wider social context, it was important that the many factors that might affect intervention delivery were considered (Michie et al., 2014). Therefore, each IF was assessed using the APEASE criteria (see Table 8-1) (Michie et al., 2014), which has been developed to help select which areas may be best suited for intervention development.

Table 8-1 APEASE criteria (Michie et al., 2014).

<table>
<thead>
<tr>
<th>Would the IF be considered:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affordable</td>
</tr>
<tr>
<td>Practical</td>
</tr>
<tr>
<td>Effective</td>
</tr>
<tr>
<td>Acceptable</td>
</tr>
<tr>
<td>Safe</td>
</tr>
<tr>
<td>Equitable</td>
</tr>
</tbody>
</table>

The APEASE assessment was conducted as a round table exercise with four individuals (the intervention development group) in May, 2016. This included the PhD candidate (DH), a researcher working in the field of SDM (RT), a young person with lived experience of mental health difficulties who had accessed services at the London clinic where the intervention would be implemented (JT) and a consultant psychiatrist and patient involvement lead working at the same clinic.

London clinic (EL). The young person and consultant psychiatrist provided important information about contextual aspects of the service which could affect the delivery of a proposed SDM intervention. This was considered particularly important as the barriers and facilitators to SDM (Chapters 6 and 7) were identified by stakeholders in different locations.

The intervention development group scored each IF using the APEASE criteria. It was decided by the PhD candidate that all six criteria needed to be met to determine which IFs would be suitable. Any disagreements by members in the development group were resolved through discussion. This exercise resulted in the identification of two IFs: ‘education’ and ‘enablement’ which met all six APEASE criteria. Thus, these were deemed to be appropriate for a proposed intervention that aimed to increase SDM (see Appendix 8a for the table breakdown of what each IF scored).

Results were then compared to the findings from Chapter 4 in which IFs were examined in the context of SDM. From this chapter, ‘education’ and ‘enablement’ were identified as two IFs which may increase the participation of parents in decision making, whilst ‘enablement’ was a potential IF for young people. For clinicians, the findings indicated that ‘education’ and ‘training’ were IFs that showed evidence of increase participation in decision making. As ‘training’ for clinicians was identified as a potential IF in Chapter 4, this was considered by the intervention development group to be important. However, ‘training’ would focus on clinicians being trained with regard to the developed intervention (if applicable), rather than addressing the barriers and facilitators outlined in Chapters 6 and 7 (e.g. becoming skilled in negotiation and

16 ‘Enablement’ is defined as increasing the means to carry out the behaviour (SDM) (Michie et al., 2014).
8.2.3 Applying IFs to the identified barriers and facilitators (Step 2)

Education and enablement were applied to each relevant identified theoretical domain and barrier and facilitator to ascertain which could be incorporated into an SDM intervention (see Appendix 8b). The intervention development group then used the APEASE criteria to identify with which barriers and facilitators to progress. As within the previous round, all six APEASE criteria needed to be met. Table 8-2 lists the IFs and associated barriers and facilitators that were identified for inclusion (see Appendix 8b for the table breakdown of what each barrier and facilitator scored).

Table 8-2 IFs aimed at increasing SDM

<table>
<thead>
<tr>
<th>‘Education’</th>
<th>‘Enablement’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinicians</td>
<td>Clinicians</td>
</tr>
<tr>
<td>About care and treatment options in and out of services</td>
<td>To present all options to young people and parents</td>
</tr>
<tr>
<td>About the disparity between clinicians’ experiences of SDM when compared to the experiences of young people and parents.</td>
<td>To have access to more knowledge to help with confidence when discussing options</td>
</tr>
<tr>
<td>About the positive and negative consequences of SDM</td>
<td></td>
</tr>
<tr>
<td>Young people and parents</td>
<td>Young people and parents</td>
</tr>
<tr>
<td>About how they can be involved in decision making from the beginning (young people only)</td>
<td>To have appropriate information resources so they can be involved in decision making</td>
</tr>
<tr>
<td></td>
<td>To ask questions and remember information discussed and agreed during appointments</td>
</tr>
</tbody>
</table>
8.2.4 Selecting BCTs and approaches (Step 3)

Behaviour change techniques were then examined using the BCW (Michie et al., 2014), which maps the BCTs onto possible IFs. The findings from Chapter 4 were also consulted, as the BCTs linked to increased participation in decision making were explored. An additional factor, the approach to facilitating SDM, was also considered at this stage as this could affect the BCTs that could be used (e.g. a DA would require the BCT ‘adding objects to the environment’ to be present). The six overarching approaches in the Cheng et al. (2017) review were used as a guideline to possible approaches for the proposed intervention development17.

Iterative round table exercises were conducted with the intervention development group. Each possible BCT was mapped onto known IFs. These were then examined in relation to the barriers and facilitators around SDM outlined in Table 8-2, as well as possible approaches to delivery. This resulted in the selection of two approaches and 10 different BCTs which were then considered for the proposed intervention. One approach was a DA for young people, parents and clinicians to use within the appointment18. This included four BCTs: ‘prompts/cues’, ‘adding objects to the environment’, ‘information about health consequences’ and ‘pros/cons’. The second approach was a joint educational and training package aimed at increasing the knowledge around SDM along with skills regarding how to use the DA. The educational element consisted of six BCTs: ‘information about social and environmental

17 Therapeutic techniques, psychoeducational information, decision aids, action planning or goal setting, discussion prompts and mobilising patients to engage.

18 As a DA formed part of the intervention, this also meant that the IF ‘environmental restructuring’, as well as ‘enablement’ was also being utilised.
consequences’, information on health consequences’, ‘credible source’, ‘pros/cons’, ‘information about others approval’ and ‘information about emotional consequences’. The training section included two BCTs: ‘instructions on how to perform the behaviour’ and ‘demonstration of the behaviour’. The results from this exercise were then shown to a research psychologist who works in behaviour change (EV). No changes were made as a result of this. The findings from this exercise are outlined in Table 8-3.

Following this, a logic model was created to understand the proposed intervention in the context of the London site. This included the target audiences, the proposed mechanisms of change, the outcomes that would be associated with the success of the intervention, as well as the potential moderators. This is outlined in Figure 8-1.
<table>
<thead>
<tr>
<th>IF and linked barrier/facilitator</th>
<th>Method/mode of delivery</th>
<th>Associated BCTs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educate clinicians about the positive and negative consequences of SDM</td>
<td>Presentation outlining the literature on this</td>
<td>• Information about social and environmental consequences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Information on health consequences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Credible source</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Pros/cons</td>
</tr>
<tr>
<td>Educate clinicians about the disparity of clinicians’ experiences of SDM when compared to the experiences of young people and parents</td>
<td>Presentation outlining the literature on this</td>
<td>• Information about others approval</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Information about emotional consequences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Credible source</td>
</tr>
<tr>
<td>Educate clinicians about care and treatment options available in and out of services</td>
<td>Presentation outlining the literature on this, supplemented by a DA which contains information on this</td>
<td>• Adding objects to the environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Prompts/cues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Credible source</td>
</tr>
<tr>
<td>Enable and train clinicians to present all options to young people and parents (through the developed DA)</td>
<td>Instruct and train clinicians after the presentation on how to use the DA</td>
<td>• Adding objects to the environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Prompts/cues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Instructions on how to perform behaviour</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Demonstration of behaviour</td>
</tr>
<tr>
<td>Enable clinicians to have access to more knowledge of treatment options (through the developed DA) which will help with confidence when discussing options</td>
<td>The DA will provide a brief overview of information, as well as links to resources for further information</td>
<td>• Adding objects to the environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Prompts/cues</td>
</tr>
<tr>
<td>Educate young people that they can be involved in decision making (through the developed DA)</td>
<td>The DA will outline that it is a tool that should be used to help the young person (and other stakeholders) make decisions about treatment</td>
<td>• Adding objects to the environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Prompts/cues</td>
</tr>
<tr>
<td>Enable young people and parents to ask questions and remember decisions (through the developed DA)</td>
<td>The DA will contain the most frequently asked questions, and it will be paper-based so that it can be written on and taken away after the appointment</td>
<td>• Adding objects to the environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Prompts/cues</td>
</tr>
<tr>
<td>Enable young people and parents to have the appropriate resources to be involved in decision making (through the developed DA)</td>
<td>The DA will be co-developed with service users to make it accessible, relevant and comprehensible</td>
<td>• Adding objects to the environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Prompts/cues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Information about health consequences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Pros/cons</td>
</tr>
</tbody>
</table>
Figure 8-1 A logic model outlining the proposed intervention for SDM
8.3 The inclusion of THRIVE and i-THRIVE

The London site developing the proposed intervention subsequently co-won a bid to develop DAs as part of a wider service transformation initiative known as i-THRIVE (Moore, 2016). As part of this project, the site sought a project manager to oversee this work. It was agreed that the PhD candidate was well-placed to carry out this work. This role allowed for a great deal of creativity and flexibility; however, it was necessary to abide by some stipulations determined by the bid. For example, a requirement was that the development of this tool would follow the process of creating Option Grid™ DAs (Elwyn et al., 2015). It was also stipulated that the DA should be aligned with the THRIVE conceptual framework (Wolpert, Harris, et al., 2016), which is discussed in further detail below. These stipulations were not incompatible with the work already undertaken by the PhD candidate, and provided an excellent opportunity to refine and implement the SDM intervention as part of this project. A brief discussion of i-THRIVE follows.

8.3.1 THRIVE and i-THRIVE

The THRIVE conceptual framework (Wolpert, Harris, et al., 2016) was developed through a collaboration between authors from the AFNCCF and the Tavistock and Portman NHS Foundation Trust. THRIVE is an integrated, person-centred and needs-led approach to delivering mental health services for children, young people and families. It conceptualises needs into five categories: Thriving, Getting Advice, Getting Help, Getting More Help and Getting Risk Support. Figure 8-2 displays the THRIVE conceptual framework.

Each section of the model is unique in terms of 1) the needs and choices of patients, 2) the skill mix required by professionals who help and support young people, 3) the language used to describe need, and 4) the resources required
to meet the needs and choices of patients. Central to THRIVE is the concept of SDM. The segments are not distinguished by severity but rather focus on the needs and types of structures or activities that could be put in place to support young people and families.

![Figure 8-2 The THRIVE conceptual framework (Wolpert, Harris et al., 2016)](image)

i-THRIVE (Moore, 2016) is the implementation of the THRIVE conceptual framework (Wolpert, Harris, et al., 2016). Using an evidence-based approach to implementation, i-THRIVE aims to translate the principles of THRIVE into models of care that fit within local contexts. i-THRIVE has been designed to enable the provision of services that move towards delivery of a population health model for child and youth mental health. This approach strives to ensure the continuous quality improvement of services by drawing from evidence-based implementation science to ensure that children, young people and families achieve the best possible outcomes. i-THRIVE is delivered in partnership with the Tavistock and Portman NHS Foundation Trust, the
AFNCCF, the Dartmouth Institute for Health Policy and Clinical Practice and UCLPartners.

8.3.2 The i-THRIVE team for improving SDM

The i-THRIVE team for improving SDM was composed of a project manager (PhD candidate – DH), an implementation lead (AM), a research assistant (RT) and a clinical lead (EL). The PhD candidate was responsible, alongside the team, for the development of i-THRIVE DAs and the implementation of the DAs at a London i-THRIVE site.

8.4 Specific considerations for the DA as well as the educational and training package

8.4.1 What is the target age for the DA?

To date, most DAs in the realm of child and adolescent mental health have been developed only for the parents of young people with mental health difficulties (Cheng et al., 2017). Only two DAs have been created specifically for young people. One of these tools, which was created as part of a wider suite of tools to improve SDM (Evidence Based Practice Unit, 2015), scored poorly on a DA quality assessment due to its lack of specificity. The other DA was developed for use with young people with depression (Simmons, 2011; Simmons et al., 2016).

Two evaluations of the depression DA demonstrated positive results, although they were only conducted with older adolescents ($M = 17$ and $18.5$ years respectively) (Simmons, 2011; Simmons et al., 2016). The reading age of the DA was suitable for young people aged 12 years and above (Simmons, 2011; Simmons et al., 2016), which is in accordance with research suggesting that young people with mental health difficulties aged 12 years and above still have sufficient understanding to participate in treatment decisions (Billick et al., 1998; Schachter et al., 2011). However, this research also highlights that it is
important to take into account individual numeracy and literacy when making decisions about treatment, as information may not be presented in ways that are congruent with the individual’s understanding (Billick et al., 1998; Schachter et al., 2011). Given that DAs have not been developed for use with young people aged under 12 years, and existing evaluations have not focused on the younger section of the 12-18 age group, it was decided that the proposed DA should be designed for young people aged 12-18 years, along with their parents and clinicians.

8.4.2 Should the DA be designed for specific presenting difficulties, and if so, which ones?

Quality assessments of DAs highlight that these tools should contain enough information to help individuals make preference-sensitive decisions (Elwyn et al., 2006; O’Connor et al., 2005). They should include a statement outlining the presenting difficulty for which the DA is designed, as well as a list of the risks and side effects that are specific to the individual options for treatment or support for that presenting difficulty. As such, it was decided that the proposed DA needed to focus on specific presenting difficulties to meet quality assessment criteria, as well as to present the full range of difficulty-specific options that were available.

As the THRIVE conceptual framework (Wolpert, Harris, et al., 2016) was developed from the Child and Adolescent Mental Health Payment Systems Project (Wolpert, Vostanis, et al., 2015), which outlines the frequency of different presenting difficulties, the report was consulted in order to identify the potential focus of the proposed DA. Estimated percentages for each presenting difficulty in the report indicated that the most frequent were: signposting and self-management (27.7%), difficulties not covered by other groupings (16.08%), ADHD (6.96%), depression (5.76%) and self-harm (5.68%). As increased internalising difficulties lower the odds of parents and young people receiving
gold-standard SDM (as outlined in Chapter 5), depression and self-harm were selected as potentially useful areas for the focus of a DA. Moreover, as depression had a slightly higher prevalence rate in the Child and Adolescent Mental Health Payment Systems Project, and as previous DA research has focused on older adolescents with depression (Simmons, 2011; Simmons et al., 2016), it was decided that the first DA would focus on depression and low mood.  

8.4.3 How should the DA be designed?  

Whilst there are many types of DAs for SDM in child and youth mental health (Cheng et al., 2017), the stipulations of the bid required this project to follow the development process of an Option Grid™ DA. Option Grids™ have several advantages; they follow a set procedure for development involving co-production and they are brief and easy to read (Elwyn, Lloyd, et al., 2013). Existing Option Grid™ DAs provide information needed by patients to make a preference-sensitive decision in a one-page tabular layout (Elwyn, Lloyd, et al., 2013). The care and treatment options form the top row of the table, whilst the left-hand column lists the most frequently asked questions (FAQs) by patients when making a preference-sensitive decision about the presenting difficulty. The remaining matrix is filled in with the best available scientific evidence in order to answer each question, or when there is no evidence, expert consensus is consulted. The content is reviewed and agreed upon by the Option Grid™ Core Management Team at the Dartmouth Institute for Health  

As part of the wider i-THRIVE programme (Moore, 2016), decision aids were made for ADHD and self-harm.  

A preference-sensitive decision is one in which there is no one right approach to care and treatment (Elwyn, Lloyd, et al., 2013).
Policy and Clinical Practice. Option Grids™ are designed to be simple to use and to fit into clinical sessions without adding extra time (Elwyn et al., 2016). Studies indicate that Option Grids™ can facilitate SDM and increase patient knowledge, and that they are viewed as useful by clinicians (Elwyn et al., 2016; Elwyn, Lloyd, et al., 2013; Tsulukidze, Grande, & Gionfriddo, 2015).

Despite this, there are also some limitations to Option Grids™. One study indicated that Option Grids™ are unlikely to be useful when interpreters are needed, as language barriers can cause patients to be less active in discussions (Wood, Phillips, Edwards, & Elwyn, 2017). Moreover, whilst Option Grids™ do appear to increase SDM, their use does not guarantee that patients’ preferences will be elicited or integrated into decisions during discussions about treatment or care (Tsulukidze et al., 2015).

Only one Option Grid™ DA, which covers complex behavioural difficulties, is available in the field of child and adolescent mental health (Barnett et al., 2017). As is the case with many other SDM approaches in this field, this Option Grid™ was developed for use solely with parents rather than with young people. Although user testing with parents and clinicians indicated that Option Grids™ were well-liked and easy to use, clinicians felt that further training and support would be required to embed the Option Grids™ within clinics (Barnett et al., 2017).

8.4.4 How should the joint educational and training package be structured?

A recent review identified that the provision of education and training for clinicians on SDM has become more frequent over the last ten years (Diouf et al., 2016). The modes of delivery for education and training identified in this review included online videos, webinars, presentations and lectures. The length of these packages ranged from 30 minutes to 30 hours. In conjunction with increasing frequency, the review also found that such programmes are now
beginning to target inter-professional practice, as well as trainee clinicians (Diouf et al., 2016). An investigation of the effectiveness of these programmes found that less than a quarter (23.4%) had been evaluated. Moreover, due to the heterogeneity of approaches, the people targeted and the programme content, the authors of the review could not determine whether there were particular types of interventions which would help to increase SDM. However, three resources that focused specifically on mental health and child mental health were identified as part of this review. Given their close proximity to the proposed intervention, each is explored below.

The first programme is based in the UK and hosted on the Royal College of Psychiatrists’ website. It is called ‘How person-centred are you?’ and consists of online education and training that aims to increase SDM in psychiatric practice, with an emphasis on psychosis (Chaplin & Quirk, 2016). Four modules are required to complete this training. They include such topics as SDM in medical and psychiatric practice, keeping patients informed, engaging patients’ concerns and making shared decisions. There is also an introduction, a summary and an additional resources section. However, this approach has not been evaluated to determine whether it affects psychiatrists’ practice of SDM (Diouf et al., 2016).

The second mental health resource included in the review, which was also developed in the UK, was an educational video about SDM and depression (Flynn, 2015). The video takes individuals on the journey of a fictional character named John who has depression. In the video, John shares his experiences of the services and describes the support he receives from his friends and his GP in making decisions about his care and treatment. This intervention is aimed at clinicians as well as patients, and the developers state that it can also be used as an educational resource for people wanting to understand SDM. However, whether this resource affects clinicians’ practice of SDM has yet to be evaluated (Diouf et al., 2016).
The last resource is an educational and training package called ‘Promoting Active Choices Together’ (PACT) aimed at clinicians who work in child and youth mental health services. Developed by the EBPU, PACT lasts one-day and is delivered via PowerPoint, focusing on a model of SDM and how to use and incorporate SDM tools into practice. A pre-post evaluation of the training found that clinicians’ attitudes towards SDM positively increased after training. However, no changes were demonstrated related to clinicians’ attitudes regarding whether they should give young people more information, or in their confidence in supporting SDM (Wolpert, Page, & Edbrooke-Childs, 2015).

Promoting Active Choices Together, which combines educational aspects with a focus on tools, was most closely related to the proposed intervention in this thesis in terms of its mechanisms for change and its target population. It also demonstrated some positive outcomes related to attitudes around SDM (Wolpert, Page, et al., 2015). Thus, it was decided that the proposed educational and training package would consist of a PowerPoint presentation containing educational information followed by work with clinicians concerning using the DAs. However, unlike the full-day format of PACT, the proposed package would be time-limited in order to engage clinicians. The team leader of the service where the proposed intervention would be delivered outlined that it would need to take place in a team meeting and be no more than 30 minutes long. To consolidate the training element into this, the Brinkman et al. (2013) study was consulted, in which clinicians received brief training on how to use a DA for ADHD. The same amount of training was delivered in this study, which

---

21 The PhD candidate was not involved in the development or evaluation of these tools.
resulted in a successful increase in SDM with parents. Thus, it was deemed feasible to build the educational and training package into a 30-minute meeting.

8.5 Developing the intervention content

8.5.1 The DA

Development of the DA followed a manualised process which was created by the Dartmouth Institute (Elwyn et al., 2015). An editorial team was gathered and three expert reference groups (ERGs) were created. These ERGs consisted of health care professionals, children and young people and parents. The process of developing the DA is outlined below in Figure 8.3. The ERGs provided input into which FAQs should be selected and which options should go into the DAs, as well as providing input on the content and design.

Figure 8-3 Description of the DA ERGs and editorial team
8.5.1.1 Identifying options for treatment or care and FAQs about those options

Two scoping exercises were carried out to identify: First the options available for treatment or care for low mood and depression, and second, the FAQs about these options that could result in a preference-sensitive decision.

For treatment or care options, the following resources were consulted: *What Works for Whom 2nd Edition* (Fonagy et al., 2016), the NICE guidelines for depression in young people (NICE, 2007), and the Youth Wellbeing Directory, which is a website listing organisations that provide help or support to young people (Anna Freud National Centre for Children and Families, 2014). Information was collated for each type of help or support, including the modality of care, where the help or support could be accessed and any research evidence that supported the effectiveness of the intervention.

Several resources were consulted to identify questions that could elicit a preference-sensitive decision. These resources included the FAQs on pre-existing Option Grid™ DAs and pre-existing literature on preference-sensitive decisions for depression (Barr et al., 2016). Message boards from websites were also reviewed, including Childline, Big White Wall, Samaritans, Young SANE, MIND and Young Minds. Message posts on peer support Facebook groups specialising in depression were also reviewed, as well as other DAs for depression (Simmons, 2011; Simmons et al., 2016). In addition, three participation officers at the AFNCCF (NM, EO) and Common Room Consulting (MH) provided input. Preliminary results from this review generated 73 preference-sensitive questions. Questions with overlapping content were subsequently condensed, and any questions which were not related to
preferences concerning different options for treatment or care were removed. This resulted in 35 FAQs (see Appendix 8c for the full list).

Following this, ethical approval to seek views from young people and parents about which FAQs were most important to them when considering treatment or care was obtained through UCL Ethics Committee (UCL ethics reference: 6735/006) (see Appendix 8d for approval letter). Participants were asked to rate each FAQ in order of importance on a five-point Likert scale which ranged from 0 (‘very unimportant’) to 5 (‘very important’). A sixth option (‘don’t know’) was also included.

8.5.1.2 Survey results for the FAQs

Information about the survey was sent to charities and peer support groups for young people with depression and their parents (both in the community and online). The information that was given to parents contained the survey link for them to access. However, for the young people, the contact details of the PhD candidate were provided, as parental consent was needed before the survey could be completed. Overall, five young people (three females and two males) with a mean age of 18.60 years (SD = 2.30) completed the survey. Two identified as White or White British, two as Asian or Asian British and one as Mixed Race. Conversely, 25 parents (24 female and one ‘prefer not to disclose’) with a mean age of 42.08 years (SD = 9.19) completed the survey. Twenty-three parents identified as White or White British, one as Black or Black British, and one as Asian or Asian British.

The young people’s most important FAQs regarding treatment for depression in descending order were as follows: ‘Is it safe?’ (m = 4.8), ‘How will this help me get better?’ (m = 4.6), ‘What will this involve for me?’ (m = 4.6), and ‘Will I see the same people for the duration of this help or support?’ (m = 4.6). For parents, the most important FAQs were: ‘Is it safe?’ (m = 4.56), ‘Are there risks or side
effects associated with this type of help or support?’ \((m = 4.56)\), ‘How will this help my child or young person get better?’ \((m = 4.52)\), and ‘What will happen?’ \((m = 4.52)\). As safety was a top priority identified by both the young people and parents, risks and side effects were explored in more detail in the survey. The same top three side effects were viewed as the most important by both the young people and parents. These included an increased risk of suicide (100% of the young people and 84% of parents), sleep issues (80% of both the young people and parents) and concentration issues (80% of the young people and 68% of the parents).

8.5.1.3 Drafting of the initial DAs

The top FAQs and options for treatment or care were presented to the ERGs for comments and feedback.Alternative mock-up versions of the DAs were created to facilitate discussion and critiquing. An example is provided in Figure 8-4.

<table>
<thead>
<tr>
<th>Frequently asked questions</th>
<th>Watchful waiting</th>
<th>Self-management (e.g. bibliotherapy, online self harm)</th>
<th>Peer and community support (e.g. playing football, gardening, community theatre)</th>
<th>Brief psychosocial intervention/structured clinical care</th>
<th>Talking Therapies (e.g. Cognitive Behavioral Therapy, IPT-A, Family therapy, Psychodynamic therapy)</th>
<th>Medication (e.g. SSRIs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it safe?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How will this help me get better?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What will this involve?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Will I see the same people for the duration of this help or support?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are there risks or side effects from this type of help or support?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What will happen during this type of help or support?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which modalities of care would you be interested in?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual Group Digital/Online School-based</td>
<td>Individual Group Digital/Online School-based</td>
<td>Individual Group Digital/Online School-based</td>
<td>Individual Group Digital/Online School-Based</td>
<td>Individual Group Digital/Online School-Based</td>
<td>Individual Group Digital/Online School-Based</td>
<td>Individual Group Digital/Online School-Based</td>
</tr>
</tbody>
</table>

Figure 8-4 Early example of a mock-up DA
The DAs were reviewed and refined over a four-month period following feedback from the ERGs. The changes that were made during this time are outlined below.

The first alteration involved reducing the number of FAQs. Participants across all ERGs felt there were too many on the mock-up DAs. As a result, the FAQs were collapsed into four questions: ‘What will this involve?’, ‘How will this help me get better?’, ‘Will I see the same people for the duration of this help or support?’ and ‘Are there risks or side effects from this type of help or support?’ Specifically, answers to the question ‘Is this safe?’ were combined with ‘Are there any risks or side effects from this type of help or support’, and ‘What will happen?’ was combined with ‘What will this involve?’

The second change that resulted from the ERGs involved the overarching categories of treatment or care. The healthcare professionals in the ERG stated that certain options, such as IPT-A, were not available at their service. Some practitioners felt that presenting an unavailable treatment could be discouraging, as they felt the DAs would not be representative of the available forms of treatment or care unless the categories were broader (i.e. ‘talking therapies’ instead of ‘psychodynamic psychotherapy’). Moreover, the young people and parents highlighted that having too many options felt overwhelming. They also pointed out that the category ‘watchful waiting’ might be unhelpfully viewed as being placed back on a waiting list (rather than being offered a treatment option) and all had already waited weeks to access services. As a result of these comments, a top-down approach was applied to the categories of treatment or care, and broad overarching categories were adapted from combinations of specific forms of treatment or care. These options were divided across two DAs based on where young people and parents could access the treatment or care. This distinction was labelled ‘Inside the NHS’ (i.e. specialist CAMHS) and ‘Outside the NHS’ (i.e. schools, community or third sector organisations).
The third change involved altering the graphic design of the DAs so that they were appealing to the target demographic. Most stakeholders outlined that DAs needed to be attractive if they were to be successfully implemented in child and youth mental health services. Although this resulted in a deviation from the traditional Option Grids™ format, it was considered important in the unique context of young people’s mental health and wellbeing. It was agreed that the graphic design of the DAs should form an essential part of their progressive development.

8.5.1.4 Completing the matrices of the DAs

The matrices of the DAs were filled out according to the best available evidence. For the ‘Inside the NHS’ DA, the following resources were accessed: NICE guidelines for depression in children and young people (NICE, 2007), What Works for Whom 2nd Edition (Fonagy et al., 2016), the Electronic Medicines Compendium (Electronic Medicines Compendium, 2017), the results of the IMPACT study (Goodyer et al., 2017), and Headmeds (Young Minds, 2017). For the ‘Outside the NHS’ DA, information was collated from NICE guidelines (NICE, 2007), What Works for Whom 2nd edition (Fonagy et al., 2016), and expert consensus.

Readability was also taken into consideration. The DAs were assessed using the Flesch Reading Ease and Grade Level test. For the ‘Inside the NHS’ DA, the reading ease was measured at 48.9, which corresponds to US grade level 9.5 (approximately 14 years of age). For the ‘Outside the NHS’ aid, the reading ease was measured at 85.9, which corresponds to US grade level 3.9 (approximately 9 years of age). Further work with the young people and parent ERGs to simplify the wording bought the ‘Inside the NHS’ DA’s reading ease score up to 64.9, which corresponds to US grade level 7 (approximately 12 years of age). The final versions of the DAs are presented below in Figures 8-5 and 8-6.
Figure 8-5 Decision aid for depression/low mood ‘inside the NHS’ version 1
**Figure 8-6 Decision for depression/low mood, 'outside the NHS' version 1**

<table>
<thead>
<tr>
<th>Common Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What will this involve?</strong></td>
</tr>
<tr>
<td>This involves reading information about depression/low mood and understanding more about your difficulties.</td>
</tr>
<tr>
<td>This involves activities like drama, sport or art. Families can sometimes also be a part of these activities.</td>
</tr>
<tr>
<td>This involves calling a telephone number and speaking with someone who can listen to you and provide you with information and advice.</td>
</tr>
<tr>
<td>This involves working through a computer programme either on your own or with a therapist.</td>
</tr>
</tbody>
</table>

| **How will this help me feel better?** |
| You may learn tips to feel less stressed, worried or sad. You might also find out new ways to understand your thoughts and feelings. |
| You may meet other people at these events who are experiencing similar difficulties. This could help you make new friends and learn strategies to tackle challenges in your life. |
| Talking to someone about your difficulties may help you to work through your worries and/or sadness. This may also help you see things more clearly and think about what your options are. |
| Meeting with a counsellor in a safe and regular space may help you to talk about, better cope with, and eventually overcome your difficulties. It might take more than one session to start feeling better. |

| **Will I see the same people for the duration of this support?** |
| This support can usually be done on your own or your parent or carer may be able to help you. |
| These groups are usually run by the same person. |
| There will probably be a different person on the line each time you call. |
| It is likely that you will see the same person for this support. |

| **Are there risks or side effects from this type of support?** |
| There is not enough evidence to know for sure if these types of support will have side effects. Talking, reading or thinking about your difficulties might cause worry or stress. Making changes in the way you think about things or do things may also be hard, and you might feel worse before you start to feel better. |
| Someone if you are having these feelings. If you are finding it too hard to use this support on your own, it may be a sign that you should ask for more support. |

| **Where can I get this support?** |
| Online or through reading material/ books (See back of page.) |
| At community or faith centres, online, or at school (See back of page.) |
| On the phone (See back of page.) |
| In person or online (See back of page.) |
| Online or at a venue that offers this type of support (See back of page.) |
8.5.2 The educational and training package

To inform the content and development of the educational and training package, an ERG was created that consisted of clinicians working in the clinic where it would be delivered (see Figure 8-7).

![Diagram of ERG and Editorial Team]

**Figure 8-7 Outline of the ERG and the editorial team for the training and educational package**

As the educational content was specific to the barriers and facilitators identified in Chapters 6 and 7, literature pertinent to these points was explored. PowerPoint slides from PACT were also consulted, although no additional resources which could aid educational content were identified. Several resources were drawn on as evidence to educate clinicians on the identified barriers and facilitators to SDM. This is further outlined below.
For the positive and negative consequences of SDM, empirical research from this thesis was used, as well as findings from a review of approaches to SDM (Cheng et al., 2017). A Cochrane Review on DAs was also consulted (Stacey et al., 2014), as were studies of young people’s experiences of SDM (e.g. Simmons 2011), and findings in Chapters 1 and 2 (e.g. Andersen, Mooney, & McPherson, 1990; Kyrke-Smith & Edbrooke-Childs, 2014). Particular care was taken to emphasise both the positive aspects of SDM (e.g. empowerment) and the negative consequences (e.g. clinicians believing it can take more time).

The disparity of the experiences of SDM between clinicians, young people and parents was emphasised with a presentation of the results from the CYP-IAPT rapid internal audit. These findings suggested that whilst most clinicians felt they involved young people in SDM, only 30% of young people and half of parents felt they were given enough information to make a choice about treatment (Edbrooke-Childs, Calderon, et al., 2015). Knowledge regarding care and treatment options was derived from the findings in Chapter 6, which suggested that clinicians may lack knowledge about the full range of treatment or care options both in and out of services. The ways in which DAs could help by providing references to further available resources were also highlighted. As the development of this DA was informed by THRIVE, the conceptual framework was also outlined in the educational and training package to provide context for this work (Wolpert, Harris, et al., 2016).

The training aspect of the package aimed to mirror the brief training on ADHD DA choice cards (Brinkman et al., 2013). Clinicians were provided with a demonstration of the target behaviour (in this case, engaging in SDM with young people and parents) acted out by members of the development team. Additionally, instructions on how to use the tool during a clinical session were provided, including how and when the DA should be introduced and how to explore the options in the DA with stakeholders. The package was delivered by
the PhD candidate (DH), the research assistant (RT) and the clinical lead (EL). As EL was a psychiatrist working within the London site, it was postulated that he would provide credibility. The slides for the package can be found in the Appendix (see Appendix 8e).

8.6 Discussion

This chapter outlines the development of two DAs for low mood/depression, as well as an educational and training package for clinicians. The BCW (Michie et al., 2014) provided useful guidance for selecting the salient aspects from the previous chapters and translating them into an intervention for SDM. The final intervention package contained solutions to the barriers to SDM that had been identified by young people, parents and clinicians. For young people and parents, these barriers were related to capability and opportunity, whilst for clinicians, barriers were related to capability and motivation. Four IFs were incorporated into the final intervention. These were ‘education’, ‘enablement’, ‘environmental restructuring’ and ‘training’. ‘Education’, ‘environmental restructuring’ and ‘enablement’ were applied to all of the stakeholders, whilst ‘training’ was applied only to the clinicians. Additionally, ten different BCTs were employed as part of this intervention. These included ‘information about social and environmental consequences’, ‘information about health consequences’, ‘credible source’, ‘pros/cons’, ‘information about others’ approval’, ‘information about emotional consequences’, ‘instructions on how to perform the behaviour’, ‘demonstration of behaviour’, ‘prompts/cues’ and ‘adding objects to the environment’. All ten of these were used with clinicians, whilst the following four were used with young people and parents: ‘adding objects to the environment’, ‘prompts/cues’, ‘pros/cons’ and ‘information about health consequences’.

Where possible, scientific evidence was used to guide intervention development. However, empirical findings for some interventions were not strong, particularly when it came to designing the educational and training
package, as well as the ‘outside the NHS’ DA. This resulted in some decisions being influenced by ERG consensus rather than scientific knowledge. Whilst drawing on other sources of support can be useful when there is a lack of evidence, there are some limitations to this process. It should be noted that the ERGs were not representative of all the healthcare professionals who would be using the DAs with young people or those who would receive the educational and training package. Importantly, not all of the 21 health care professionals attended all four ERGs, which meant that the attendees of a greater number of ERGs may also have had greater influence over the development of the DAs. Moreover, while some professionals from third sector or voluntary organisations were present at the ERGs, the majority of attendees were clinicians at NHS sites. This may have biased the DA content for this specific population.

There were also limitations to the young person and parent ERGs. For instance, both groups were female dominated. The parent ERG was composed only of female participants, whilst 80% of the participants in the young person ERG were female. This disparity was also reflected in the online survey concerning treatment preferences and FAQs. Whilst the majority of caregiving activities are undertaken by mothers (Bianchi, 2000; Fraser & Warr, 2009), it cannot be assumed that fathers would place the same importance on the options for treatment and FAQs. The same assertions may also be made about male young people compared to their female counterparts.

Despite these limitations, the ERGs were useful in shaping the DAs. The deliberate removal of ‘watchful waiting’ as an option was derived from ERG feedback from both the young people and parents. These stakeholders felt that lengthy waiting lists meant they had already been ‘watchfully waiting’ for long enough. The lack of ‘watchful waiting’ on these DAs differs from others currently available for young people with low mood/depression (Simmons, 2011; Simmons et al., 2016), as well as DAs for adults (Barr et al., 2016). This may
represent cultural differences between the UK, the US and Australia, as the UK is the only country of the three with a public healthcare service which the majority of individuals use. As access to private services may be faster than public services, watchful waiting may be more appropriate in a private healthcare setting.

The decision to add colour and icons to the DAs also resulted from feedback from the stakeholders. Young people and parents felt that the DAs, in their original format, were less accessible to young people. In collaboration with a graphic designer, the young people were instrumental in designing icons for the DAs. This appears to be the first time that icons have been used on a DA in order to increase accessibility and user friendliness. This alteration corresponds to the previous findings in Chapter 7 regarding the importance of making resources appropriate for young people. However, research should be undertaken to ascertain whether the icons have the potential to bias decisions due to their placement or attractiveness. Similarly, whilst the frequencies of side effects were presented in line with Option Grid™ DA recommendations (Elwyn et al., 2015), work should be undertaken to ascertain whether young people with depression and low mood have an accurate understanding and comprehension of these frequencies when they are presented in this format.

Challenges related to readability and language should also be noted. Whilst considerable work was undertaken to address the readability of the DAs, there is a disparity between the reading age of each. The ‘outside the NHS’ DA has a reading age of approximately nine years, while the ‘inside the NHS’ DA has a reading age of 12 years. The differences were due to the inclusion of medication and side effects on the ‘inside the NHS DA’, whereby certain words had to be included as there were no appropriate substitutes. While these ages fall within acceptable limits for the age range outlined in this thesis, this could have wider implications for the field of SDM with children.
8.6.1 Conclusion

This chapter outlined the development process for a proposed intervention package to facilitate SDM. The BCW (Michie et al., 2014) guided intervention development and created transparency around how decisions were made. This included defining which IFs and BCTs were appropriate for the intervention and how these would be incorporated into it. Once specific IFs and BCTs were chosen, there was flexibility around the specific content. The DAs followed a manualised process developed by the Dartmouth Institute for Health Policy and Clinical Practice. The education element of the overall package was developed in accordance with the barriers and facilitators to SDM and literature. Finally, the training aspect of the package mirrored aspects of the Brinkman et al. (2013) DA training. The next chapter outlines the testing of this newly developed intervention.
Chapter 9  Testing of the DAs and educational and training package to facilitate SDM in child and youth mental health
9.1 Introduction

Prior to the formal evaluation of an intervention’s processes and effectiveness, it is important to consider pilot testing in order to determine aspects such as acceptability (Craig et al., 2008; Craig & Petticrew, 2013). Previous reviews have suggested that the majority of DAs do not undergo testing prior to their implementation or release (Durand et al., 2008). Similarly, a review of training programmes does not appear to indicate pilot testing, and few programmes have an accompanying evaluation (Diouf et al., 2016). Whilst all aspects of the developed intervention received stakeholder input regarding format and content, it is still necessary to pilot the intervention in the ‘real world setting’ for which it has been designed.

9.1.1 Aims

The aim of this chapter was to gain feedback on the usefulness and acceptability22 of the DAs from clinicians, young people and parents, as well as for the training and educational package with clinicians.

9.1.2 Research questions

1) What do young people, parents and clinicians think about the DAs in terms of their acceptability and usefulness?

22 Acceptability is defined as whether stakeholders felt that the format, design, and content of the intervention were acceptable. Usefulness is defined as whether and how individuals felt the intervention facilitated SDM.
2) What do clinicians think about the educational and training package in terms of its acceptability and usefulness?

9.2 Methods

9.2.1 Setting

One multidisciplinary, outpatient mental health team based in London took part in testing the intervention. The team was made up of psychiatrists, psychologists, nurses, psychotherapists, family therapists and social workers. These practitioners worked with a wide range of presenting difficulties, including depression and low mood. Assessment clinics were held weekly, and an average of five new assessment cases were seen, in total, each week.

9.2.2 Participants

Clinicians who had received the educational and training package during a team meeting and who were involved in assessment clinics were eligible to take part in this study. Young people with low mood or depression aged 12-18 years and their parents who had attended an assessment appointment and used the DAs were also eligible to take part. Young people and parents who required an interpreter were excluded due to previous findings related to DAs that indicate that patients with an interpreter tend to have little involvement in SDM (Wood et al., 2017).

9.2.3 Procedure

The brief educational and training package (see Appendix 8e) was delivered during a weekly team meeting in February, 2017. The presentation began with an outline of the THRIVE framework (Wolpert, Harris, et al., 2016) and i-THRIVE (Moore, 2016). This was followed by information on the disparities between young people and parents’ experiences of SDM when compared to
clinicians’ experiences, as well as the possible positive and negative consequences of engaging in SDM. A justification for the use of DAs was presented to the participants, and it was explained how DAs could help with SDM. Instructions on how to use the DAs and an example of how they may be used in practice were presented. After the presentation, clinicians were encouraged to ask questions.

To test the usefulness and acceptability of the training, an audit survey was emailed to clinicians. This survey asked clinicians what they thought about the training, which aspects they found useful, which aspects they found less useful and whether there were any changes they would make in the future (see Appendix 9a).

Following the delivery of the educational and training package, the DAs were implemented in the assessment clinic. The clinicians were asked by the i-THRIVE team to use the DAs during the assessment of cases where low mood or depression was the primary presenting difficulty. To test their usefulness and acceptability, the PhD candidates requested feedback from the clinicians after each appointment. This included feedback related to whether the DAs were used, what went well or what did not go well, the barriers or facilitators to using the DAs and any aspects of the DAs that the clinician would like to be different (see Appendix 9b for the feedback sheet). This information was collated and reviewed by the i-THRIVE team (DH, RT, EL, AM) on a monthly basis.

The changes incorporated into the DAs were examined using ‘Plan-Do-Study-Act (PDSA) cycles’. These feedback loops are a quality improvement technique which test planned changes on a small scale and develop learning prior to a full-scale implementation (NHS Improvement, 2014). This was followed by qualitative interviews with the clinicians in July, 2017 to gain additional feedback after the DAs had been implemented in the clinics.
9.2.3.1 Materials

Materials in this study included the two DAs (see Figures 8-5 and 8-6) and a feedback form (see Appendix 9b) administered by a researcher after the clinician had used the DA(s). For follow-up interviews with the stakeholders, an interview schedule was developed according to Dartmouth’s approach to field testing Option Grid™ DAs (see Appendix for interview schedule 9c).

9.2.4 Ethical considerations

Ethical considerations fell under existing approval from the London Hampstead NRES Committee (REC ref: 15/LO/0997). Accordingly, the participants were reminded that they could withdraw at any time during the interview process and that their care and treatment would not be affected. In addition, the participants were informed that the results would not identify individuals and that all data would be processed in accordance with the Data Protection Act (1998) as well as the Information Governance Policies at the AFNCCF.

9.2.5 Analysis

Refinements to the DAs and survey feedback were analysed using content analysis (Krippendorff, 1980). This is a technique used to describe and quantify a topic of interest which is often used in the field of healthcare (Elo & Kyngäs, 2008; Krippendorff, 1980). Content analysis allows for valid inferences to be made from data in relation to their context, with the purpose of providing knowledge, new insights, a representation of facts and a practical guide to action (Krippendorff 1980). Similarly to thematic analysis, content analysis may be inductive or deductive in nature (Elo & Kyngäs, 2008). As there is little information available on the refinement of DAs prior to field testing, an inductive approach was taken in which feedback collected from the researchers was coded and quantified based on the themes that were identified in the data.
For follow-up interviews on DA usefulness and acceptability, thematic analysis (Braun & Clarke, 2006) was employed (see section 6.2.5 for a detailed outline of the steps). A deductive, top-down approach was applied to the data, in which the interview schedule was used to identify the themes which fit into the core categories related to the DAs: usefulness and acceptability.

9.3 Results

9.3.1 Refining the DAs using the PDSA cycles

March PDSA cycle: Removing diagnosis from the DAs

They’re too diagnostic and medicalising. I wouldn’t use them with words like “depression” across the top (Clinician A).

The change implemented as part of the first PDSA cycle was to remove the diagnostic language on the DAs. Five clinicians highlighted that having the word ‘depression’ on the DAs hindered or stopped them from using the DA during clinical assessments. Specifically, the clinicians explained that they felt uncomfortable giving a young person without a formal diagnosis of depression a DA with ‘depression’ written across the top. The clinicians suggested that the language should be more symptomology-based in order to ensure that the DAs would be applicable for young people with or without a diagnosis. They also felt this change in language would be less stigmatising for young people and parents. Therefore, ‘depression’ was replaced with ‘low mood’ on both DAs.

Following on from this, the five clinicians highlighted they would consider using the DAs as this barrier had now been removed. Between this change and the next PDSA cycle, four eligible cases of depression and low mood presented at the clinic in March. However, only one clinician used the DAs with a young person and parent (25%).
April PDSA cycle: Further training on how to use the DAs and edits to the side effects section of the ‘inside the NHS’ DA

I don’t feel like I really know how to use the grids. Do I just give them out [to young people and parents]? (Clinician B)

The next PDSA cycle revealed that some clinicians were unsure how to use the DAs during appointments. Further exploration revealed that the clinicians ‘didn’t really feel comfortable’ (Clinician C) using the DAs or that they did not know how to incorporate them into a clinical session.

Sometimes there just isn’t a good time to introduce them (Clinician D).

To overcome this, further training was provided to all the team members. This included a ‘refresher’ course on the earlier training, which emphasised how to use the DAs and described previous research suggesting that SDM interventions could be challenging to incorporate into clinical practice at the beginning of implementation (Abrines-Jaume et al., 2016). Furthermore, the clinicians within the team who had successfully used the DAs gave testimonials and examples to other group members of how they had used the DAs and found them helpful.

Further alterations that were made as part of this cycle were changes to the text and formatting the medication section of the ‘inside the NHS’ DA.

It would be good to highlight the names of the medications on the grids to make them clearer (Clinician E).

23 Grids refer to the decision aids
Adding how common all the side effects are would be helpful (Clinician F).

The clinicians explained that it was important to put both the medication name (in this case, fluoxetine) and the side effect frequency labels in bold. This would ensure that young people and parents understood the different types of medication and the probability of the side effects occurring for each one. Whilst fluoxetine is recommended as the first line of medication for depression (NICE, 2007), young people and parents may be familiar with other types of medication that are available. Therefore, bolding ‘fluoxetine’ ensured that the type of medication that was being discussed was clear. Similarly, stating and bolding the different frequencies of the side effects ensured that this important information was clear to young people and families. After these changes were implemented, three eligible cases of depression and low mood presented prior to the May PDSA cycle. The DAs were used with two of these cases (67%).

May PDSA cycle: Adding side effect frequencies to the reverse of the DAs and creating and implementing the ‘You said, we did’ poster

The decision aids, whilst good, need to be clearer in terms of side effects, I don’t know what ‘common’ means and neither do young people and parents … I might think common means 1 in 5, whilst a young person may think it’s 1 in 3 – that’s a huge difference (Clinician G).

The third PDSA cycle focused on the medication section of the ‘inside the NHS’ DA. Three clinicians outlined that listing the frequencies of side effects (e.g. ‘rare’, ‘common’), whilst useful, was left open to interpretation by individuals. It was agreed that this needed to be clarified. However, due to limited space on the front of the DAs, it was decided that the frequency table should be placed on the reverse of the DAs so that clinicians, young people and parents could refer to it if needed. The data that informed this table were gathered from the electronic Medicines Compendium (eMC), a database of UK medicine.
information, which is checked and approved by the UK Medicines and Healthcare Products Regulatory Authority and the European Medicines Agency (Electronic Medicines Compendium, 2017).

The clinicians also stated that they wanted to be kept up-to-date with changes that were made to the DAs. To keep clinicians informed, a ‘You said, we did’ poster was created and incorporated into the third PDSA cycle. The ‘You said’ section contained comments from the clinicians about what changes they thought would be helpful to the DAs, whilst the ‘we did’ section contained responses from the development team as to whether the changes were made and the rationale behind this. This was placed in a shared staff working area of the clinic next to a THRIVE poster, and printed copies of the DAs were placed below it. After these changes were implemented, three eligible cases of low mood presented at the clinic in May and the DAs were used with all the young people and parents involved (100%).

After the third PDSA cycle, there were no more substantial changes raised by clinicians. Figures 9-1 and 9-2 depict the finalised DAs after the third and final PDSA cycle.
Low mood: Help or support available for low mood. Use this tool to help you, your parent or carer and a professional decide about getting help or support.

**Practical support**
- This can involve learning practical strategies that may help you feel better. You will usually meet weekly with a therapist who can help you understand your difficulties, set goals, create an action plan, and give you activities to complete. This can include support with schoolwork, social skills, family events, or things personal to you.

**Talking therapies**
- This can involve focusing on your thoughts and feelings. You will usually meet weekly with a therapist who can offer you a space to talk about and understand your feelings and the difficulties in your life. Each session is usually about an hour long and may involve other family members.

**Anti-depressants**
- This can involve taking medication to treat your symptoms. You will usually meet with a psychiatrist who can give you a prescription for medication. The most common medication for depression is called an SSRI. There is evidence that the SSRI Fluoxetine can help you feel better, although there is not enough evidence about this to be sure.

**Common questions**

**What will this involve?**
- This support may help you learn a lot about your mood. You will be given practical strategies for managing your feelings that may help you feel better.

**How will this help me feel better?**
- Talking therapies can help you think differently about situations in your life and improve how you feel. Different types of talking therapy focus on different things in your life like your relationships with others, your past experiences, or negative thoughts you might be having.

**Will I see the same people for the duration of this help or support?**
- You will usually see one person for this support. This may not be the same person you see for your assessment.

**Are there risks or side effects from this type of help or support?**
- Talking about your difficulties can sometimes cause discomfort, anxiety or stress. Tell the person you are talking to if you are experiencing these feelings.

**Very common side effects of Fluoxetine:**
- Insomnia, headache, diarrhoea, nausea and fatigue.
- Uncommon: Suicidal thoughts and behaviour. Rare: Hostility.
- If you have suicidal thoughts, you or your parent or carer should immediately contact your doctor.

**Note:** You may want to try other types of help or support alongside the ones that are listed here. There is evidence that combining CBT with medication is more likely to help than either talking therapy or medication alone. Changes to diet, exercise and lifestyle could also help to improve your symptoms, although there is not enough evidence about this to be sure.

---

Version 1.5 (last updated 01/07/2017) Editors: Daniel Hayes MSc, Rosa Town MSc, Emilios Lemoniatis MBBS, Anna Moore MBBS

This decision aid does not constitute medical advice, diagnosis or treatment. The authors of this decision aid do not stand to gain or lose anything by the choices people make after using this tool.

*See back of page for information about likelihood of side effects

---

Figure 9-1 Decision aid for low mood, ‘inside the NHS’, after the final PDSA cycle

337
Figure 9-2 Decision aid for low mood, ‘outside the NHS’, after the final PDSA cycle
9.3.2 Interviews to explore the usefulness and acceptability of the DAs

After the PDSA cycles were complete, the clinicians were given two months to use the DAs within their practice. Follow-up interviews with the clinicians were then conducted in July, 2017. All the clinicians in the team were asked whether they would like to participate in the interviews regardless of whether they had used the DAs. Six of 28 clinicians (21%) agreed to take part. Five of the six clinicians had used the DAs during an assessment appointment. Amongst the participants were two consultant psychiatrists (33%), two clinical psychologists (33%), a trainee psychologist (17%) and a child psychotherapist (17%). Five participants identified as ‘White British’ (83%), and one identified as ‘White Other’ (16%). Four clinicians were female (67%) and two were male (33%). Ages ranged from 29 to 52 years ($M = 40.5$, $SD = 8.53$).

9.3.2.1 Clinician interviews

Acceptability

Acceptability was examined in terms of the following subthemes: format and design, and the language of the DAs. Each of these is explored below.

Format and design

The clinicians highlighted that the icons and colours on the DAs were ‘appropriate’ (Clinician 2) for young people and parents and helped to make the DAs ‘approachable’ (Clinician 2). The clinicians also highlighted that they liked that the colours on the DAs linked to the different THRIVE groupings.

*I like it that it links with the THRIVE categories, so that I can see at a glance that the green is the ‘getting advice and signposting’, and...*
‘getting help’ and ‘getting more help’ is the blue and purple (Clinician 5).

This helped with the clinician’s clarification and understanding of THRIVE and its categories, which were needed to complete the information related to THRIVE on the patient records system.

Other clinicians also described liking the layout of the DAs in relation to the way in which the options were presented.

*It was really helpful for me to have the information [around options] set out logically, and I think then once you’ve got it all in front of you, you can then let the patient know* (Clinician 1).

Expanding on this further, two clinicians stated that they liked the way in which the DAs were divided into what was available in CAMHS and what was available outside of specialist services.

*What I quite like about them as a clinician is the distinction between the support in the NHS and outside the NHS* (Clinician 5).

This allowed clinicians to offer options across both NHS and non-NHS settings and to remember all of the available options. One clinician highlighted that this was particularly important as a young person they had seen for an assessment chose an option in the NHS which had a waiting list, and it was decided that community resources could supplement this whilst she waited.

*The young person made a very clear decision to have CBT, so I used the non-NHS one, just to support her while she was awaiting the clinician making contact* (Clinician 5).

Whilst clinicians were positive about the DAs overall, some format and design issues were raised. The first consideration centred around how the information was presented on the back of the DAs. For one clinician, the fact that the back
of the DAs lacked colour and design made them look unattractive and as if the back was an afterthought.

*The front side is very user-friendly, or more user-friendly than the support list on the back* (Clinician 6).

The second consideration was related to how the DAs were accessed. Two clinicians suggested that the DAs should be available electronically. This would allow the tools to be downloaded and printed whenever they were needed, rather than clinicians having to search for paper copies.

*If I could have a copy on my desktop, then I could use it whenever* (Clinician 5).

**Language**

In terms of the options and the language, the content of the DAs was well-liked. The language of the DAs was described by clinicians as *‘clear, simple…non-leading’* (Clinician 1). Another clinician reflected favourably on the way the FAQs were worded, *‘because they’re from the clients’ point of view’* (Clinician 3). This made it easier for young people to contextualise and recognise that the DAs were designed for them. Similarly, Clinician 2 liked the wording of the answers to the FAQs, as they reflected that clinicians cannot know for certain whether a treatment will help or not.

*I like the wording of what is written within the grid. I like the tentative language because we don’t always know if something might help people to feel better or not* (Clinician 2).

Particular attention was paid to the risks and side effects which the DAs displayed in an *‘open’* manner (Clinician 2). The side effect section was liked by clinicians, as the alternative to this was the *‘complicated’* information leaflet that accompanies the medication.
The [side effects] are described in quite a kind of simple way… they’re not overly complicated the way that they are if you read the packet (Clinician 3).

However, it was noted that the content of the DAs may not be appropriate for individuals with co-morbid difficulties, as the content was based on one presenting difficulty.

[When patients present with complex or co-morbid difficulties], things don’t always neatly fit into these boxes. So that’s an issue (Clinician 4).

Another limitation noted by one clinician related to the ‘word-heavy’ language of the DAs. As a result, the clinicians highlighted that the DAs may not be useful ‘when an interpreter was needed’ (Clinician 5). To overcome this, it was suggested that the developers should consider whether they should ‘create [the DAs] in different languages’ (Clinician 5).

Usefulness

The usefulness of the DAs focused around the following three subthemes: knowing what options were available, a useful resource for young people and parents to take away, and its applicability outside assessment appointments. Each subtheme is explored below and examples provided.

Knowing the available options

The clinicians explained that they needed up-to-date information on the resources available in order to support children and young people. They stated how the DAs helpfully provided this information.

We’re often sort of wanting to guide people to useful sources, you know, good, reliable sources of information, and it’s helpful to have that to hand about a specific issue (Clinician 4).
All five clinicians who had used the DAs with young people and parents stated that they found them useful. They outlined how the DAs depicted all of the options and opened up a conversation so that young people could feel that they were involved.

_I think it is useful to have the information clearly there with their options, and I think it’s good for the young people to sort of feel that they’re part of the decision-making process rather than things just being done to them_ (Clinician 4).

Specifically, for the ‘outside the NHS’ DA, Clinician 2 highlighted how this reminded them of options they might have otherwise forgotten within the session.

_For some families with particular difficulties, all they might need is some kind of self-help. I think [the grids are] useful in bringing attention to things that, that as a [clinician] you are more likely to forget about. For me, that would be likely reading support_ (Clinician 2).

This was also echoed by another clinician, who described how they discussed reading support with a young person after using the ‘outside the NHS’ DA. They stated that this was something they did not normally discuss.

_Well, with [showing them] the low mood grid … yeah, it did trigger them to ask about supported… reading support_ (Clinician 3).

**A useful resource for young people and parents to take away**

The clinicians commented on how they found it reassuring that they could give families something tangible to take home and consult following the assessment. This would ensure that the information discussed in the session, such as their options, would not be forgotten.

_Within the context of the meeting with the family, you can verbally explain things but often they are really highly aroused and anxious in_
the moment. We always do try and explain what something might involve, but it’s nice that when they walk away they have something where it’s written down when they might not have fully taken in what you’ve said (Clinician 2).

The same clinician then went on to describe one family’s experience of using the DAs, in which the family found the DAs so useful that they asked for more to take away.

I think what I was struck by is that the family specifically requested more grids. The dad wanted a grid, and I thought that was indicative that it was something that they thought was a useful component of the conversation that we had (Clinician 2).

Clinician 3 also provided similar examples of how the DAs were a useful resource for young people and families to take away and reflect on.

I think it’s hard for people to take in all the information that they’re given in an initial consultation because it’s stressful for them, and I think it’s nice for them to have something to take away, to remind them what was talked about. But also, it means if anything was missed, then they can come back and ask questions (Clinician 3).

Whilst Clinician 5 expressed similar views, they also outlined that a consequence of providing more options was that more time was needed to allow the young person and parents ‘breathing space’ prior to making a decision.

They weren’t sure of what treatment intervention they wanted to opt for, and they wanted to take home the information they’d been given and discuss it with Dad. And so I then arranged a follow-up appointment (Clinician 5).

This meant that an additional appointment was added into the clinician’s diary for this young person and family, which was something that the clinician had not initially planned for.

Applicability outside assessment appointments
Whilst the DAs were not intended for use outside the assessment clinic during this testing period, it was mentioned by a few clinicians that they had successfully used the DAs in other appointments and settings. For example, one clinician highlighted that they had used one of the DAs within a school context.

*I used one in schools…with a mum who was concerned about low mood* (Clinician 5).

Another clinician also commented on the potential usefulness of the DAs outside of the assessment clinic, as options for treatment could be reviews at different points along the pathway.

*There’s always going to be different times when you want to bring the grids in, I think, not just the initial assessment* (Clinician 3).

### 9.3.2.2 Interviews with the young people and parents who used the DAs

The clinicians were asked to invite all the young people and parents who had used the DAs to feed back to the researchers in an interview or focus group. The clinicians asked four parents and six young people whether they would like to participate. All four parents declined and cited issues with time. One young person agreed to take part. However, the young person did not arrive for their scheduled interview. All of the other young people declined. Two young people stated to the clinicians that they did not want their parents to be contacted for consent, two explained that they were about to start exams and the remaining one did not give a reason for declining to participate. As a result, no interviews were conducted with the young people or parents.
9.3.3 Examining feedback from clinicians on the educational and training package

An electronic audit survey was emailed to all the clinicians at the end of the project (late June and early July 2017) in order to understand the acceptability and usefulness of the educational and training package. The link to the survey was emailed to clinicians three times over the period of one month to encourage individuals to complete it. Seven out of 28 clinicians (25%) completed the survey. This included one psychiatrist, two clinical psychologists, one psychotherapist, one family therapist, one trainee psychotherapist and one educational psychologist. Six participants were female, and one was male. Information about age and ethnicity were not requested.

The responses to the educational and training package varied in terms of what clinicians liked about the content and how they incorporated aspects of the educational and training package into their clinical practice.

Acceptability

Three clinicians stated that they found the content of the educational and training package to be acceptable, whilst three stated that they did not. One other clinician outlined that they were not present at the sessions and therefore could not comment further.

In terms of positive responses, one clinician liked that the educational session provided ‘the rationale behind the grids and why they were implemented’ (Clinician 1). Clinician 2 also agreed with this.

*Good to know how decision aids can improve SDM in different ways* (Clinician 2).

A further point raised by a clinician was that the length of the training and the mix between educational and training aspects worked well.
The length of the package and combination of info was good (Clinician 3).

However, other responses indicated that some clinicians felt that ‘nothing new was covered’ (Clinician 5) in the educational and training package, and that SDM was something they already did.

I think that clinicians across the trust have had to engage in SDM with clients. This is the foundation of engagement. I always explore options with patients in every session (Clinician 6).

Lastly, another clinician stated that the training was too ‘static’ and needed to be ‘more interactive’ (Clinician 5).

Usefulness

Three clinicians felt that the training and educational package were useful in enhancing SDM with young people. One clinician stated that it was useful to see an example of how SDM could work in practice ‘when tools were involved’, and that the example provided a reference point to ‘try [the decision aids] with a young person’ (Clinician 1). This comment was echoed by another clinician who felt that the package helped them to broach the topic of treatment options.

[It was] useful for helping segway into an options conversation (Clinician 2).

Clinician 3 highlighted that knowing about the disparity between experiences of SDM was useful as it made them reflect on their own practice. As a result, they now made more of an effort to ensure young people were included.

The disparity between young people and clinician experiences made me think whether I am doing SDM. I am much more mindful of this now and check in with young people more (Clinician 3).

To increase the usefulness of the package to facilitate SDM in clinical practice, two clinicians suggested that ‘more specific role plays’ (Clinician 5 and 3) would
be useful. It was also highlighted by one clinician that it would be helpful to get further support on how to engage young people who had ‘disengaged’ and did not want to be involved in decision making (Clinician 4).

9.4 Discussion

This chapter examined the stakeholders’ views on the intervention package that was developed to facilitate SDM. As part of the wider scope of the i-THRIVE project, two newly developed DAs were refined in a child and youth mental health clinic to ensure they were fit for use in clinical practice. Three PDSA cycles were conducted with clinicians and resulted in changes to the diagnostic language, medication frequencies and side effects depicted on the DAs. They also resulted in the delivery of additional training to clinicians on how to use the DAs in practice.

Although the clinicians requested further follow-up training on how to use the DAs in this study, this was not reported by Brinkman et al. (2013) when using DAs with parents of young people with ADHD. The findings of the present study do, however, align with the findings for user testing of an Option Grid™ DA for complex behaviour difficulties, during which clinical staff indicated that they would find further training beneficial (Barnett et al., 2017). The reasons for this may be ascertained from other research into SDM tools which demonstrate that clinicians feel apprehensive about their use, as well as feeling ‘clunky’ when using them at first (Abrines-Jaume et al., 2016). Thus, training with an emphasis on the demonstration of SDM with tools and roleplays could help to embed such tools in practice.

The follow-up interviews on acceptability and usefulness indicated that the clinicians generally found the DAs useful and acceptable in their practice. Whilst interviews did not explicitly cover the barriers and facilitators that were identified in previous chapters (see Chapters 6 and 7), some of these barriers and
facilitators were nonetheless highlighted by the clinicians when discussing the DAs. For example, the content was highlighted as helpful in reminding the clinicians of all the options that were available, as well as providing information about other services to which they could signpost. This addresses the barrier related to clinicians not knowing what treatment options are available both inside and outside of their service. Moreover, the clinicians found the DAs to be ‘containing’ and accessible for young people and families, as well as a useful resource that young people and families could take home and reflect upon. This addresses the barriers related to young people and parents having a lack of appropriate resources and having something to remind them of what was discussed in appointments.

Further refinements could focus on the usefulness of the back of the DAs. Expert reference groups should be convened to gain input regarding the content, icons and colour with the explicit goal of making the back of the DAs more user-friendly. Additionally, clinicians should be provided with electronic copies of the DAs so that they are able to print them to use with young people and families as needed. For the purposes of refinement and testing during the project, only paper DAs were allowed so that researchers could make sure that the most up-to-date versions were being used. To address this issue in the future, the project aims to make the DAs electronically available through the i-THRIVE website. As the clinicians highlighted that they did not know how to use the DAs in practice, it would also be useful to have an online educational and training package accompanying any existing training.

In contrast to the positive clinician responses to the DAs, the educational and training package received a mixed response from clinicians. Whilst some felt that it enhanced their understanding of SDM, DA research and the DAs that had been developed, other clinicians stated that they thought the package did not have any impact. Interestingly, as part of the wider work in i-THRIVE, teams at the London site were using the questionnaire CollaboRATE (Elwyn, Barr, et al.,
2013) to measure SDM. The high scores observed across teams at the London site support the clinicians’ assertions that they were already engaging in SDM and that education and training may not have been necessary. The London site was considered to be an i-THRIVE accelerator site\textsuperscript{24} and employed clinicians who were involved in the development of the THRIVE conceptual framework (Wolpert, Harris, et al., 2016). Therefore, substantial work implementing i-THRIVE principles such as SDM may have already occurred within this Trust.

9.4.1 Strengths and limitations

A strength of this study is that the two DAs underwent extensive testing in a clinic and were refined using feedback from a diverse range of professionals. This contrasts with previous research which suggests that most DAs do not undergo testing prior to their release (Durand et al., 2008). Only one DA in child and youth mental health has reported user feedback as part of its development process (Simmons, 2011). However, in the Simmons (2011) study views were only sought from medics rather than other professional groupings. Therefore, the DA may not be as useful for professionals whose knowledge and skillsets are different to those who have had medical training. From a UK perspective, mental health assessment clinics can be staffed by a range of individuals. Thus, having DAs which can be used by different professional groups are essential.

The use of PDSA cycles to make iterative changes to the DAs is another strength of the present study. Multiple rounds of testing allowed intervention developers to establish what clinicians identified to be the major limitations

\textsuperscript{24} i-THRIVE accelerator sites are Trusts that have been implementing THRIVE as part of their CAMHS transformation plans since October, 2015.
preventing or stopping use of the DAs in the clinical setting. After one round of user testing, the overarching comment from the clinicians was related to the diagnostic language at the top of the DAs. The subsequent rounds allowed for more nuanced and detailed aspects of the DAs to be improved. However, it should be noted that the ‘study’ part of the PDSA cycle, which examined uptake of the DAs, is a crude measure of clinical acceptance into practice and subject to high variability due to small sample sizes. As a result, this was instead used with specific clinicians to explore why DAs had or had not been used and to ascertain where further refinements were needed.

There are also some limitations to this study. Interviews on usefulness and acceptability were not conducted with young people and parents. A lack of feedback from these stakeholders means that there is no information about how they viewed the DAs and whether further refinements were needed to increase their usefulness and acceptability. Whilst some of the clinicians reported that young people and parents found the DAs useful, this may differ from their actual experience. As such, there is an urgent need to investigate these views to ascertain whether further refinements are needed. In a similar vein, it was not possible to observe DAs being used in clinical practice. Consequently, it is not known exactly how the DAs were being used in the assessment clinics and whether there were differences between the ways in which clinicians were using them with young people and how they were being used with parents. To address this, future research could involve video recordings of sessions so that it is possible to ascertain how the DAs are being used and how this may affect the experience of SDM.

In relation to the lack of interviews with the young people and parents, the time of year appeared to be a barrier to both the young people and parent interviews. Some potential interviewees were about to start the school exam period and were unable to commit to an interview during this time. This was followed by the six weeks holiday, during which many young people left London
and were out of contact with services and the researchers. Similarly, parents stated that they felt too busy to be interviewed due to childcare demands during this period. Future research might benefit from avoiding data collection just before or during the summer holidays.

An additional difficulty encountered was that a considerable amount of time had passed between when some individuals had used the DAs and when they were invited for an interview. This meant that many of these families were no longer in contact with the service and were difficult to contact. Henceforward, it would be worth considering whether young people and parents could have provided feedback shortly after using the DAs, or immediately after a subsequent clinical appointment. This would have kept families from having to return to the clinic or arrange a time to meet with a researcher in order to be interviewed. This would have the additional benefit of the researchers not having to rely upon the clinicians as gatekeepers to those who had used the DAs. Relying on the clinicians to ask the young people and parents meant that it was possible that clinicians would only ask young people and families to participate who they felt had a good SDM experience with them, so as not to reflect poorly upon their clinical practice, which could result in distorted views towards the SDM experience and DA.

A further limitation was the poor response rate by the clinicians to both invitations to interview and complete the audit questionnaire. Whilst the clinicians who were interviewed expressed positive opinions about the DAs, the sample that were interviewed only represents 21% of the clinicians in the service. It is possible that other clinicians who did not use the DAs felt that they were not usable or that some aspects needed to be improved before they could be used. However, it is also possible that not all the clinicians had a chance to use the DAs due to the small number of assessment cases per week. To try and counteract this bias, all the clinicians in the service were invited to an interview regardless of whether they had used the DAs or not. Only one
clinician who had not used the DAs accepted. All the clinicians stated that they liked the DAs, and although had not used them as they were currently only working with young people under five years due to CYP IAPT, they did state that if this changed they would use the DAs in the future.

Similarly, a poor response rate was also obtained for audit feedback. This was despite the fact that the audit questionnaire was designed to be short and not burdensome. This means that it is not known what the majority of clinicians in the service thought about the educational and training package. Even for those clinicians who did complete the questionnaire, findings suggested a mixed response related to its acceptability and usefulness. Moreover, the short text responses given by the clinicians to the open-ended questions limited what changes can be made without further information. For example, some clinicians highlighted that specific roleplays would be useful, but they did not specify what they would like the focus of these to be upon. Follow-up interviews regarding the educational and training package would help provide further rich and detailed information about the acceptability and usefulness of the educational and training package.

9.4.2 Conclusion

This chapter sought to obtain views from the stakeholders regarding a theory-led SDM intervention developed in line with the BCW (Michie et al., 2014). The findings from the interviews suggested that clinicians felt that the DAs could enhance their practice, as they reminded them of options for treatment or care that young people and parents might want to try. The clinicians also highlighted that the young people and parents seemed to find the DAs helpful in clinical sessions, and that they liked the fact that the DAs could be taken away and referred back to as needed. However, some further changes, such as making the DAs available electronically and altering the reverse side of the DAs to
make them more user friendly, should be employed to improve usefulness and acceptability.

With regard to the educational and training package, the feedback from the clinicians produced a mixed picture. Some clinicians stated that they did not like the content of the educational and training and that they already practiced SDM. However, other clinicians found some aspects, such as the background research on DAs and the length of the training, helpful. For some clinicians, aspects of the training changed their practice as they used things they learnt as a basis for their interactions with young people. The responses related to improvements to the educational and training package suggest the need to make the package more practical, that is, by incorporating roleplays.

Further work on acceptability and usefulness needs to be undertaken with a wider range of clinicians than those who were included in this sample (e.g. nurses and social workers). The same work also needs to be undertaken with young people with low mood or depression and their parents. As clinicians are gatekeepers to services and ultimately decide whether to use the DAs with young people, their suggestions that the DAs should be electronically available and that the reverse side of the DAs need improving should be acted upon. The educational and training package requires further work to establish what individuals find useful and how to better establish SDM principles and tools within clinical practice.
10.1 Introduction

The overall aim of this thesis is to contribute to the understanding of SDM in child and youth mental health, as well as to develop a theory-led intervention for young people, parents and clinicians. As part of the initial development process for this intervention, a systematic review, a quantitative study and two qualitative studies were undertaken. The findings from these studies were used to develop an intervention that followed the development process outlined in the BCW (Michie et al., 2014). This was followed by a final empirical study in which the intervention was tested in a London CAMHS clinic.

This chapter begins by summarising the previous chapters. For the chapters without an empirical focus, previous research is presented in order to provide a rationale for the subsequent empirical work. Within the empirical chapters, findings are explored in relation to how they contribute to the field of SDM in child and youth mental health. This is followed by an exploration of the strengths and limitations of this thesis and a discussion of the implications of this work. Next, the working definition outlined in Chapter 3 is explored, along with reflections on the methodologies used within this thesis and the role of parents and young people in the research process. The chapter concludes with a discussion of future directions for this work and the main suppositions that can be drawn from this thesis.

10.2 Chapter summaries and exploration of their contribution to knowledge about SDM

Chapter 1 explored SDM in adult health. The contributions of three drivers (clinical, resource and service use, and ethical) to the rise of SDM were discussed (Coulter & Collins, 2011; Slade, 2017). The research evidence related to these drivers has produced mixed results. For example, only half of the RCTs investigating SDM and clinical outcomes demonstrate a positive outcome (Clayman et al., 2016; Shay & Lafata, 2015). With regard to service
use and resources, a small number of existing studies suggest findings which are similarly mixed (Walsh et al., 2014).

An examination of the concept of SDM indicated that a broad range of descriptions of SDM exist (Makoul & Clayman, 2006). This was reflected in a division between the established models of SDM. The models either defined the concept of SDM in terms of its key characteristics (Charles et al., 1999; Makoul & Clayman, 2006), or in terms of the skills or competencies needed to facilitate SDM (Elwyn, Edwards, Gwyn, & Grol, 1999; Towle & Godolphin, 1999). However, six commonalities were found across the models. These included: ‘pros and cons’, ‘options’, ‘preferences’, ‘role definition’, ‘making (or in some cases deferring) a decision’, and ‘process/stages’ (Makoul & Clayman, 2006). A critique followed of how these topics translate to healthcare environments outside of general or acute settings (Entwistle & Watt, 2006, 2016), with a specific focus on mental health. A study comparing physical and mental health settings demonstrated subtle differences in SDM. In mental health, more emphasis was placed upon the initial steps within the consultation, and there was also greater variation in whether patients felt involved in all stages of SDM (De las Cuevas et al., 2013). The concept of capacity was also examined, as it is relevant to the translation of SDM from physical to mental health settings. Research indicates that people with mental health difficulties are often assumed to lack capacity (Hamann et al., 2009, 2016; Seale et al., 2006), which clinicians believe may affect the SDM process. However, research has demonstrated that even individuals with severe mental health difficulties can be involved in SDM (e.g. Loh et al., 2007).

Chapter 1 concluded with an exploration of the SDM evidence base in adult mental health. Since the last Cochrane Review (Duncan et al., 2010), a greater number of studies have been conducted examining the effect of different SDM interventions on outcomes (e.g. van der Krieke et al., 2013). Similarly to the studies conducted in physical health settings (Clayman et al., 2016), the
findings indicated that the positive outcomes associated with SDM varied. These differences in findings may have been the result of design limitations, or, alternatively, they may have been due to differences within the interventions themselves. The interventions varied in terms of their specific components, length, intensity and the amount of participation required by the stakeholders.

Chapter 2 began with an exploration of SDM with children and young people. It highlighted how changes in thinking around rights for other marginalised groups (Farson, 1974; Gottlieb, 1973), as well as scientific advances related to how children interact with the world (James & Prout, 1990) and understand rights (Nucci, 2001), have helped to initiate a discourse around young people’s involvement in care and treatment decisions. The development and ratification of the CRC (United Nations, 1989) has further aided the involvement of children and young people in decision making. Articles 12 and 13 of the CRC outline that young people should have their views taken seriously and given consideration consistent with their age and maturity. With regard to drivers, no research is yet available for service or resource outcomes. However, for patient outcomes, a review focused on young people identified some positive results, although these results varied by intervention (Feenstra et al., 2014). A subsequent review with a wider scope and a meta-analysis of the findings found that SDM interventions increased parental knowledge and reduced parental decisional conflict (Wyatt et al., 2015).

This was followed by an exploration of the ethical concerns regarding the capacity of young people to be involved in decision making. Research suggests that young people in physical health settings are able to make decisions deemed acceptable by adults (e.g. Alderson 1993). There is also evidence that young people demonstrate measurable aspects of capacity, such as an understanding of their illness, knowledge of how to manage it and an understanding of how decisions can affect the outcome of their illness (Alderson, 1993; Alderson et al., 2006; Sutcliffe et al., 2004). This chapter then
discussed whether young people with mental health difficulties are able to be involved in treatment decisions, given that they may be ‘doubly incapacitated’ (Coppock, 2005; LeFrançois, 2008). Research on this topic has mainly focused upon consent to inpatient treatment, and the findings are mixed and often conflicting (Billick et al., 1998; Casimir & Billick, 1994; Kaltiala-Heino, 2010; Lurie et al., 2009). However, in outpatient clinics, research suggests that young people with ADHD have a level of understanding and knowledge comparable to that of their parents (Schachter et al., 2011). This led the researchers to suggest that children and young people should be involved in care and treatment decisions, although they cautioned that the numeracy and literacy levels of the child should also be taken into account.

Models of SDM in child and youth mental health were then examined. Six models were identified. These differed in terms of the types of decisions that were being made and who the decision maker was. A comparison of the characteristics of each model resulted in the identification of two elements which were present across all the models. These were ‘presenting options’ and ‘arranging follow-up’. Two additional elements were present in the majority of the models. These were ‘patient values/preferences’ and ‘making (or deferring a) decision’. Importantly, the frequency of all four elements in this setting differed from their frequency in adult physical health settings. Therefore, these characteristics may be unique to the context of SDM in mental health settings.

Chapter 2 then discussed the empirical research related to SDM in child and youth mental health. Observational studies have indicated that increased severity in symptomology are associated with lower SDM (Butler, 2014; Butler et al., 2015; Fiks et al., 2010). However, all of these studies were limited by being focused solely on parental experiences of SDM. They were also all conducted in the US which has a substantially different healthcare system to the UK. Following this, an exploration of experimental studies identified a number of different SDM interventions that have been developed and
evaluated. As previous reviews have suggested (Bowen et al., 2006; Durand et al., 2008; Sheehan & Sherman, 2012), DAs appeared to be the most widely used intervention. Moreover, in line with previous research (Clayman et al., 2016), some positive outcomes were found, although these findings varied by study and intervention. Compared with adult mental health settings, it was noted that the studies tended to be of a lower methodological quality, and many relied on pre-post testing or were conducted without a control group (e.g. Simmons et al., 2016). Lastly, barriers and facilitators were explored in relation to SDM. Whilst barriers and facilitators were identified across different levels of the healthcare system, many of these studies were conducted outside the UK (Simmons et al., 2011) or did not set out to explicitly explore barriers and facilitators (e.g. Offord et al., 2006), which means that key areas may have been missed.

Chapter 3 provided an overview of the intervention development and thesis methodology. The MRC guidelines, a prominent framework for intervention development, were explored. This was followed by an outline of the limitations of this framework, which included a focus on the lack of guidance in intervention development and a lack of information on how to select theory (Correy et al., 2013). Research conducted in relation to intervention developments across different settings highlighted that theory was often omitted or used poorly (Davis et al., 2015; Painter et al., 2008; Prestwich et al., 2014). In fact, these researchers found that interventions often relied on one of a few key theories, which meant that the chosen theory may not have been the best to address the difficulty for which the intervention was developed. Similarly, an investigation of theory specific to SDM interventions found that many either omitted theory entirely or also focused only on one of a few key theories (Bowen et al., 2006; Durand et al., 2008; Sheehan & Sherman, 2012). Consequently, a theory-practice gap in SDM interventions has been highlighted by researchers (Elwyn et al., 2011). These authors suggest two possible reasons for this gap. Firstly,
singular theories are unlikely to be sufficient, as they omit key characteristics related to design or content. Secondly, the majority of theories currently used in decision support interventions focus on how individuals cognitively make decisions, rather than how decision support tools and other factors such as the environment influence decision making.

The BCW (Michie et al., 2014) was chosen by the PhD candidate as a solution to the issues identified above in developing an SDM intervention. The rationale behind this was twofold. Firstly, the BCW provides step-by-step guidance on developing an intervention, which is a current limitation of the MRC guidelines (Correy et al., 2013). The BCW is compatible with the MRC guidelines (Sinnott et al., 2015), and it allows for an understanding of how interventions work by breaking them down into their mechanisms of change (IFs) and active units of change (BCTs). Secondly, the BCW addresses the theory-practice gap which has previously been identified in SDM intervention development (Elwyn et al., 2011), as it contains the TDF (Cane et al., 2012). The TDF is an amalgamation of 33 behaviour change theories and 128 behaviour change constructs. The use of the TDF in intervention development ensures that multiple theories and constructs will be utilised, and that important contextual aspects, such as the environment, will be taken into account if relevant.

Chapter 4 presented the first empirical study in this thesis. It consisted of an updated review of SDM interventions in child and youth mental health. This study aimed to address the limitations of a previous review of SDM interventions within this context (Cheng et al., 2017). Specifically, the earlier review did not explore theory in SDM interventions, and grouped interventions by their approaches rather than by their mechanisms of change. Within this chapter, interventions with a control group were examined in relation to theory, and they were broken down into IFs and BCTs. Whether particular IFs and BCTs could be linked with increased participation and outcomes were then examined. Four studies met the final inclusion criteria for this review. In line with
previous SDM literature (Bowen et al., 2006; Durand et al., 2008; Sheehan & Sherman, 2012), the findings from this study indicated that there was a lack of explicit theory within the SDM interventions in child and youth mental health. Five different IFs were identified that were being used with the aim of improving SDM. These were: ‘enablement’, ‘education’, ‘training’, ‘environmental restructuring’ and ‘modelling’. The IFs ‘education’ and ‘enablement’ showed promise with regard to increasing SDM with parents, whilst for young people, ‘enablement’, was found to be potentially useful for increasing SDM. Intervention functions for clinicians identified ‘training’, and ‘education’ and as showing the most evidence for increasing SDM. Other IFs (e.g. environmental restructuring) may also be considered potentially relevant though a lack of studies makes this difficult to discern.

Overall, fifteen BCTs were found across the interventions. For young people and clinicians, each BCT only appeared once. On the other hand, for parents, commonly used BCTs which increased participation included ‘credible source’, ‘goal setting (outcome)’, ‘information about health consequences’, and ‘pros/cons’. Most BCTs were found to be possible candidates for increasing participation, however, the BCTs ‘behavioural practice and rehearsal’ and ‘habit formation’ did not increase participation when they were used without any other BCTs in one study with young people. Compared to previous literature (Bartlett et al., 2014; Golley et al., 2011; van der Kruk et al., 2013), there was little overlap between the BCTs used here and in other patient interventions. This is likely to be due to differences in the types of behaviour being targeted, as interventions aiming to improve SDM are substantially different to those aiming to help patients increase healthy behaviours. However, some of the BCTs identified here overlap with clinician-designed behaviour change interventions, such as ‘demonstration of behaviour’ and ‘behavioural practice and rehearsal’ (Cadogan et al., 2016; Craig et al., 2017; McSharry, Murphy, & Byrne, 2016; Sinnott et al., 2015). This was the first time in the SDM literature that BCTs and
IFs had been used with regard to examining their impact on SDM. Whilst not conclusive, these findings provide some direction regarding the possible IFs and BCTs which could be employed to increase participation in decision making.

Chapter 5 examined service-level variation in experiences of SDM, as well as the association between patient demographics, case characteristics and experiences of SDM. Previous studies have focused solely on the parental perspective and have not examined the SDM predictors in a UK population (e.g. Butler 2015). High levels of variation in reported experiences of SDM were found for both young people and parents. An examination of the predictors for young people found that a lower age and having increased internalising difficulties were associated with the reduced likelihood of experiencing gold standard SDM. For parents, if their young person was ‘non-white’ or had increased internalising or externalising difficulties, then the parents had a reduced likelihood of experiencing gold standard SDM.

When examined in relation to previous literature, service-level variation was slightly higher in this study of SDM when compared to service-level variation in studies of overlapping constructs, such as goal-based outcomes (Jacob et al., 2017). The influence of the demographic factors of age (for young people) and the ethnicity of the young person (for parents) were novel findings (Butler, 2014; Butler et al., 2015; Fiks et al., 2010). For case characteristics, previous studies also indicated that the increased severity of a young person’s internalising and externalising difficulties predicted the reduced likelihood of their parent experiencing high SDM (Butler, 2014; Butler et al., 2015; Fiks et al., 2010).

25 Gold standard SDM means that young people or parents scored the top score of 9 across all areas on THE SDM tool CollaboRATE (Elwyn et al., 2013)
However, for young people, this finding was only supported in the current study in relation to the increased severity of internalising difficulties. The impact of difficulties was also not found to predict gold standard SDM for either young people or parents, which contrasted with previous findings (Butler, 2014; Butler et al., 2015; Fiks et al., 2010). This study was the first time that predictors of young people’s experiences of SDM had been explored, along with the variation in the reported experiences of SDM for parents and young people. Whilst there was some overlap between the demographic and case characteristics that predict young person and parent-reported SDM, there were also some important differences. These primary differences included parents reporting externalising difficulties and the ethnicity of the young person as predictive of whether parents received gold standard SDM. Conversely, for young people, their age predicted whether they received gold standard SDM. These findings demonstrated the importance of gathering the perspectives of all the stakeholders involved in the decision making process, as different factors impact individuals’ reported experiences of SDM.

Given that the dataset was limited by the variables collected by CORC members, the aims of Chapters 6 and 7 were to explore the barriers and facilitators to SDM with clinicians, parents and young people. It was important to investigate this topic, as most qualitative research on SDM to date has either been conducted abroad (e.g. Simmons et al., 2013), with specific populations (e.g. Pycroft et al., 2013), or without explicitly exploring the barriers and facilitators to SDM (e.g. Offord et al., 2006). The TDF (Cane et al., 2012) guided the structure of the interview schedule and analysis within these chapters. The interview schedule was structured around the 14 domains of the TDF, whilst data were analysed using these domains to explore the barriers and facilitators to SDM. Chapter 6 focused on the barriers and facilitators to SDM from the perspective of clinicians working in the field of child and adolescent mental health. A thematic analysis of the interviews with the clinicians identified 21
barriers and facilitators across ten different domains. These barriers and facilitators were spread across all three areas of the COM-B model, which are capability, opportunity, and motivation. The identification of several factors that affect SDM, such as capacity, a lack of information sharing, and resource issues, corresponded with the findings from previous studies (e.g. Simmons et al., 2011, 2013). However, several novel findings were also identified. These included factors such as clinicians not knowing what options were available, some clinicians not being familiar with the term ‘SDM’ and clinicians not feeling comfortable discussing certain treatments.

Chapter 7 focused on the barriers and facilitators to SDM from the perspective of young people with internalising difficulties and their parents. A thematic analysis of the interviews with the young people and parents identified 16 barriers and facilitators across eight theoretical domains. Similarly to the study conducted with clinicians in Chapter 6, the barriers and facilitators identified for young people and parents spanned all three areas of the COM-B model. The barriers and facilitators that were consistent with previous research in SDM included the clinician’s ability to listen and the need for patient resources to be comprehensible (e.g. Iachini et al., 2015; Simmons et al., 2011, 2013). However, there were also some novel findings from this research. For example, whilst most parents knew they could be involved in care and treatment decisions, young people often did not. This was particularly true when it was the young person’s first time attending a service. Additionally, the ways in which rooms and clinics were arranged and the consequences of making the ‘wrong decision’ were highlighted as factors that could also affect SDM.

Chapter 8 outlined the development of an intervention to facilitate SDM. A psychiatrist and young person who were associated with the clinic in which the intervention would be implemented were included in the core development team. This ensured that contextual information from the site could be taken into account. The BCW was used to guide the intervention development (Michie et
al., 2014), along with the findings from previous chapters and the wider literature around SDM. Two DAs and an educational and training package were selected to be the components of the intervention designed to improve SDM.

The development of the DAs followed a manualised process which had been developed by the Dartmouth Institute for Health Policy and Clinical Practice (Elwyn, Durand, & Blaine, 2015). As part of this process, three ERGs were held consisting of the different stakeholders involved in SDM, comprised of clinicians, young people with a lived experience of low mood/depression and their parents. Once these groups were established, they were used to attain input and advice about the content and layout of the DAs. For the educational and training package, a separate clinician ERG was established with the individuals within the clinic in which the DAs would be piloted. The educational aspect of this package included information about the positive and negative consequences of SDM, the treatment options that are available for low mood/depression, the disparity in experiences of SDM between young people, clinicians and parents, and information on THRIVE (Wolpert, Harris, et al., 2016) and i-THRIVE (Moore, 2016). The training section involved showing clinicians the DAs, providing them with instructions on how to perform the behaviour (using the DAs) and demonstrating how they could be used in practice.

Chapter 9 aimed to test the intervention in a London CAMHS clinic. Initial feedback on the DAs was collected via PDSA cycles, and this resulted in changes to the diagnostic language, side effects and medication section, and the provision of further training to the clinicians on how to use the DAs. Following these alterations, the DAs were embedded in the service and the clinicians began to use them in their practice. Follow-up interviews with the clinicians indicated that they found the DAs acceptable. The clinicians stated that they liked the content, including the colours, icons and language. The decision to divide the DAs between help or support either ‘inside’ or ‘outside’ of
the NHS also received positive feedback. However, it was suggested that some changes could be made to further improve the DAs, including altering the reverse side to make them more user-friendly, providing electronic access to the DAs and making them less ‘word heavy’. The clinicians found the DAs useful in helping to remind them about the different options that are available. They also stated that the DAs were a useful item to give to parents and young people to take away from the session and utilise for reflection regarding decisions or discussions that had occurred. Some also asserted that the DAs would be useful outside of the assessment appointment. Previous research has indicated that most interventions do not undergo testing prior to their release (Durand et al., 2008). Indeed, only one DA in child and youth mental health described prior testing (Simmons, 2011), and in this instance, changes to medication were also discussed. The clinicians’ requests for further training in using the DAs also fits with previous research findings on Option Grid™ DAs for complex behavioural difficulties (Barnett et al., 2017).

The findings regarding the acceptability and usefulness of the educational and training package were mixed. Regarding the acceptability of the package, some clinicians found it helpful to learn how the DAs could be used and about the evidence base surrounding SDM. However, others felt that nothing new was presented and that the package would benefit from being more interactive. Regarding the usefulness of the package, the clinicians focused on how they might use the DAs in real-world settings. One clinician felt that the educational and training package would make them more mindful of partaking in SDM with young people. It was also suggested that the training could be improved by being provided with the opportunity to participate in roleplays using the DAs.
10.3 Strengths and limitations of these studies

The strengths and limitations of each chapter have been previously discussed. However, the next section addresses the overarching strengths and limitations of this thesis.

10.3.1 Limitations

One limitation throughout this thesis relates to the participant demographics. The qualitative chapter with young people and parents consisted of individuals who predominantly identified as ‘White’, as were individuals involved in the ERGs and FAQ surveys. Given that the parents of young people from a non-white background are 32% less likely to report experiencing gold standard SDM (Chapter 5), it would have been valuable to have interviewed a larger number of individuals from other ethnic backgrounds. This might have provided insight into what they perceived as the barriers and facilitators to SDM. In a similar vein, there were also a larger number of female participants than male participants involved in the interviews and the intervention development process. Although females do report higher rates of emotional or internalising difficulties when compared to males (McManus, Meltzer, Brugha, Bebbington, & Jenkins, 2009; Morrison Gutman, Joshi, Parsonage, & Schoon, 2015), the content of the DAs may be biased toward what female patients and their mothers deem important when making a preference-sensitive decision.

The change of sites that took place between the interviews and intervention development/testing was also a limitation. Contextual factors are known to be important when designing interventions (Craig et al., 2013), and the barriers and facilitators identified in the first two services may not have been applicable to the new site. Alternatively, other barriers and facilitators may have been missed. A psychiatrist (EL), who was also a patient and participant involvement lead, was included in the intervention development process in order to attempt to address the contextual factors. A young person who had previously attended
the service was also included for similar reasons. However, these were only the subjective opinions of two individuals regarding what they thought was important. It may have been more useful to have engaged more young people, parents and clinicians at the London site in order to better understand the specific barriers and facilitators within this context.

Limitations related to the BCW (Michie et al., 2014) should also be considered. The ways in which the BCTs explicitly link to theory is unclear. Work is currently being undertaken in this area (Johnston et al., 2017). However, findings have not yet been published in academic journals. Thus, the explicit theories that were drawn upon to develop the SDM package cannot be detailed. Moreover, whilst quantifying interventions in terms of their mechanisms for change and their smallest component parts can be useful, the BCT taxonomy is not able to account for certain aspects of SDM which may be important. These may include therapeutic alliance, cultural competence or trust. Furthermore, some specific strategies which may be useful in SDM, such as motivational interviewing (Elwyn et al., 2014), are not currently included. Although further work on the taxonomy is being undertaken (Cane, Richardson, Johnston, Ladha, & Michie, 2015), version two has yet to be released.

10.3.2 Strengths

A strength of this thesis was the range of methodologies it used to investigate SDM in child and youth mental health, which is still a field in its infancy. The systematic review at the beginning of this thesis provided insight into the theory, IFs, and BCTs in SDM interventions. The CORC dataset enabled the predictors around demographic and case characteristics to be examined for both parent-reported and young person-reported SDM. The qualitative chapters built on these findings and provided rich data related to the barriers and facilitators of SDM from the perspectives of young people with internalising difficulties, their parents and clinicians. The findings were examined in the context of the BCW
(Michie et al, 2014) to produce a theory-led SDM intervention. Finally, the use of PDSA cycles and quality improvement methodology allowed for the DAs to be refined in the London assessment clinic in collaboration with clinicians.

The use of mixed-effect logistic regressions when examining the predictors of SDM can be considered a particular strength of this thesis. This allowed for correct inferences to be drawn through recognising the nesting of young people and families within services (Rabash, 2012). Prior research (Butler, 2014; Butler et al., 2015; Fiks et al., 2010) has failed to take nesting into consideration, instead treating each unit of analysis as an independent observation. Importantly, using techniques which omit nesting structures can produce different results to those that do (Jones, Wright, & Bell, 2012). Given the high level of service variation found in reports of SDM in this study, researchers may wish to consider examining service variation within their own data. When the variation is high, they may wish to consider using this technique.

The use of the TDF (Cane et al., 2012) to inform intervention development can also be considered a strength of this thesis. This was utilised in an attempt to address the theory-practice gap (Elwyn et al., 2011). The use of the TDF allowed for 33 behaviour change theories to be amalgamated and examined with the stakeholders involved in the SDM process. This could be argued to provide the most comprehensive account of factors underpinned by theory to date. Given that the only other theory-laden framework, the ODSF (O'Connor, 2006), contains only seven theories, the TDF may have considerable advantages and address a wider range of the barriers and facilitators that may affect SDM.

10.4 Revisiting the working model of SDM for child and youth mental health

The term, SDM has been outlined as conceptually broad (Charles et al., 1997; Makoul & Clayman, 2006). Thus, a working model was developed. This
contained four steps. Firstly, that young people (and parents) should be involved in care and treatment decisions. Secondly, that options should be presented around care and treatment. Thirdly, that young people (and parents) should examine these options in light of their values and preferences. Lastly, that decisions should be made or deferred, and follow-up appointments should be arranged. This working definition is now reviewed in light of the findings from this thesis.

1. Young people (and parents) are involved in care and treatment decisions

The review in Chapter 4 highlighted that the primary stakeholders in SDM differed according to the study under examination. For example, two studies focused only on parents participating in SDM with clinicians (Brinkman et al., 2013; He et al., 2016), whilst two other studies either focused solely on young people (Adelman et al., 1990) or on both parents and young people (Hogue et al., 2016). Interestingly, the studies that included only parents as the decision makers involved children with a mean age of 7.5 years and 8.4 years respectively (Brinkman et al., 2013; He et al., 2016), which although young, is analogous to research conducted by Alderson (1993) and Sutcliff et al., (2004) demonstrating that children can be involved in decision making. As age, maturity and mental health difficulties (in all but the most severe cases) have been argued as not presenting barriers to inclusion in decision making (Shaw, 1999), more effort should be made to include young people rather than just their parents in SDM. Accordingly, future SDM training for clinicians may benefit from a focus on the fact that the inclusion of young people in SDM is not a binary outcome between being involved in SDM or not, but a ‘stepped’ approach within which there are different levels of involvement (Alderson & Montgomery, 1996, p. 66).
One study of an intervention that included the BCT ‘goal setting’ found that this intervention increased the participation of young people and parents in SDM. ‘Goal setting’ may promote the inclusion of young people in creating a shared language with clinicians (Law & Jacob, 2015). This may help young people understand why they have come to services and what they want to achieve. In Chapter 7, young people highlighted that they did not know they could be involved in decision making. This contrasted with parents’ perceptions of SDM, as parents were usually aware that they could be involved. The reasons behind the barriers to involvement are broad, but an examination of the factors may point toward aspects such as clinician time constraints, parents dominating the session and clinicians being worried about risks or safeguarding issues (Chapter 6). Further work with clinicians, such as additional training in containment and negotiation, may help to address some of these barriers. Training may also help clinicians enable young people to be more active partners in their own care.

2. Options are presented around care and treatment

In line with previous models and research, the role of options was prominent in this thesis. The results from Chapter 4 highlighted that three of the included approaches to improving SDM focused on options. These approaches involved parents using a DA for ADHD (Brinkman et al., 2013), parents specifically choosing a treatment option for their child’s behaviour difficulty (He et al., 2016) and young people and parents choosing whether to take medication for ADHD. Behaviour change techniques that provide ‘information’ to the young person or parent may be closely related to this area. From Chapter 4, these BCTs may specifically include ‘information about health consequences’, ‘information about emotional consequences’ and ‘information about social and environmental consequences’.
In Chapters 6 and 7, the young people, parents and clinicians all viewed options as an important part of SDM. For the young people and parents, options were described as a barrier to SDM when there were not many. This could be the case when parents or young people were only allowed to choose between one treatment option or receiving nothing, or being offered a treatment for which there was a long waiting list. The clinicians highlighted that they sometimes did not know which options were available, particularly outside of services, and felt that there was a lack of choice within their own service. This had a ‘knock-on effect’, as some clinicians would only present the options that they knew were available within their service. Additionally, the clinicians stated that they did not know much about some treatments, which could lead them to be less likely to present them to the young person or parent. It was also noted by some clinicians that they might forget to offer different care and treatment choices if they were feeling stressed or overwhelmed.

Several aspects of this work were expanded upon to form the basis of the intervention that was developed. These aspects included educating clinicians around treatment options, enabling clinicians to present all the options to young people and parents and providing clinicians with information about each option to increase their confidence. The results from the interviews with the clinicians indicated that they found the DAs to be both acceptable in their practice and useful as they reminded them about aspects of treatment which they may have forgotten to discuss.

3. Young people (and parents) examine the options in light of their values and preferences

Once options for treatment have been presented, the next step is to examine these in light of the values and preferences of the young person and parent. This relates to the BCT ‘pros/cons’, as stakeholders are invited to assess the options which are presented. In Chapter 4, ‘pros/cons’ was present in two of the
three interventions in which a decision needed to be made (Brinkman et al., 2013; Hogue et al., 2016). In the Brinkman et al. (2013) intervention, the BCT ‘problem solving’ was also present. Problem solving may relate to choosing an option for treatment, but its presence in this intervention could also suggest that this BCT is useful in addressing multiple stakeholder views beyond the traditional doctor-patient dyad.

In their interviews, the clinicians mentioned that SDM requires them to take the preferences of the young person and family into account, and that they felt that the young people and parents were experts in themselves (Chapter 6). As part of their duty as practitioners in the field of child and youth mental health, the clinicians felt that they needed to elicit the preferences of the young people and parents and incorporate them into their treatment plans. In the interviews, the young people expressed that if they did not feel comfortable with a new clinician, it could be difficult for them to express their values and preferences (Chapter 7). Some young people also suggested that having time alone with the clinician could be helpful, as this would give the young person the opportunity to express opinions which they would not state if a parent were present.

Preference-sensitive decisions were built into the DAs through the use of the FAQs. The questions which were included on the DAs were derived from what young people and parents considered most important to address when making preference-sensitive decisions. However, the selected questions were limited to those that the survey respondents deemed most important, which may not be applicable to all young people with low mood and their parents. The findings from a study that used the same approach to develop a DA concluded that the use of FAQs does not guarantee that patients’ preferences will be elicited or integrated into decisions (Tsulukidze et al., 2015). Future research may benefit from identifying better methods for eliciting young people and parents’ preferences that can then be included in DAs.
4. Decisions are made or deferred, and follow-up appointments are arranged

After the above steps have been undertaken, the last actions are to either make or defer the decision and to arrange a follow-up appointment. The BCT ‘problem solving’ may also be useful here, particularly if decisions cannot be reached. ‘Problem solving’ may facilitate discussions around whether the decision should be deferred or an option is selected with which to proceed. However, more guidance about how to navigate this process is needed. At follow-up appointments, clinicians should incorporate two BCTs. These are ‘review (behavioural) goals’ and ‘review (outcome) goals’. These BCTs could be used to revisit the decision and ascertain whether any changes are needed in light of values, preferences and goals. Both of these BCTs were used in one study in which increased involvement in the process of decision making was observed (Hogue et al, 2016).

Exploring the BCTs around goals, the clinicians in Chapter 6 acknowledged that although reviewing goals was important, this was often done sporadically and depended on different pressures within the service. Clinicians and services may wish to consider more formal and concrete methods for reviewing goals, such as electronic reminders, to ensure that they check in with individuals once a treatment has been chosen. Additionally, clinicians also spoke about the difficulty of having dominating parents in the room and how this could influence the decisions that were made. To overcome this, clinicians should explore young people’s goals for therapy alone with the young person.

In Chapter 7, young people and parents did not overtly mention deferring or making decisions or speaking about follow-up appointments. However, young people spoke about sometimes not having the capacity or being in the ‘right headspace’ to make decisions, in which cases parents became more involved. Not being involved in a decision is a decision within itself, although clinicians
should always explore with young people the reasons for a young person not wanting to be involved in a decision, rather than automatically deferring it to the parent. Additionally, some individuals mentioned that they were worried they would make the ‘wrong decision’ and that there would be consequences associated with this. In such circumstances, clinicians may wish to outline the evidence base of the options. It is also important for young people and parents to remember that there is no ‘wrong’ decision, as long as they are not put in extreme danger or harm as a result of the decision they make (Paul, 2004).

10.5 Reflection

SDM in the research context

Upon reflecting on my thesis as a whole and the importance of including young people and parents in care and treatment decisions, I was struck by the limited degree to which I had actively encouraged young people and parents to participate in the research process. When young people and parents were the participants in my research (Chapters 6 and 7), they were ‘studied’ and asked to answer the questions I had developed. Young people and parents were only ‘equal partners’ in involvement during the development of the SDM intervention (Chapter 8). In this instance, they led the DA design and development. This led to changes in the language of the DAs, improvement in their design and the selection of the options which were ultimately included on the DAs.

Looking back on this work, it struck me that I had been conveying an inconsistent message to services and clinicians. I was in a similar position to clinicians in terms of having the opportunity to actively involve young people, however, I did so only to a limited degree. It was possible that I was a ‘paternalistic researcher’ who only engaged with and included young people and parents when it was easy and convenient. I believe that young people and parents should take a more active role in research. However, this belief mirrors
clinicians’ beliefs that SDM is the right thing to do, although they do not always engage young people in it.

There are many ways in which young people and parents could be included in the research process. In the early stages, young people and parents could help to identify the research questions they feel to be important. They could also be involved in data collection, which might involve conducting interviews or collecting survey data with other young people and parents. Young people and parents could also analyse data and write reports. However, it is important to have the resources to be able to fully include young people and parents throughout the research timeline. This requires early planning at the bid stages to make sure that young people and parents are adequately compensated to carry out such tasks. It is also important that they are given enough time and supervision to develop their skills and feel properly supported.

Organisations such as the NIHR are increasingly emphasising the need for patients and the public to be involved in the research process (Research Design Service, 2014). Whilst this is seen as positive by many, there are significant and ongoing challenges related to how to best incorporate patients and the public into research (Wilson et al., 2018). An important first step may be to have designated PPI leads within all research institutions, as well as to emphasise the importance of PPI at the undergraduate, master’s and PhD level. This will allow researchers to better understand the importance of and methods to actively involve young people and parents in the future.

10.6 Implications

The next section examines the implications of the findings from this thesis.

Shared decision making with children and young people with mental health difficulties is now emphasised in policy documentation (Department of Health, 2015; NICE, 2007), and it can also be found within new service improvement
initiatives and transformation programmes such as CYP IAPT and THRIVE (NHS England, 2016; Wolpert, Harris, et al., 2016). Whilst emphasis on SDM is important, this thesis has identified a number of barriers to the implementation of SDM in practice. For clinicians, the barriers included factors such as already believing they were engaging young people and parents in SDM or not feeling they had enough time to do SDM properly (Chapter 6). For parents and young people, the barriers included not being provided with the appropriate resources, not feeling listened to and young people not knowing they could be involved in SDM (Chapter 7). The intervention package that was developed as part of this thesis, consisting of two DAs and an educational and training package for clinicians, provides an approach to overcoming such barriers.

Most DAs to date have either focused on only one stakeholder, usually the parent (e.g. Brinkman et al., 2013); included CBT as the only talking therapy (Simmons, 2011; Simmons et al., 2016); or have missed some essential criteria which is necessary for the tool to be classified as a DA (Evidence Based Practice Unit, 2015). The two DAs developed as part of this thesis address all of these limitations. Importantly, these DAs have evidence of acceptability and usefulness with the clinicians that have used them. The clinicians also stated that young people and parents found the DAs to be beneficial. It should also be noted that whilst these DAs fit with the THRIVE conceptual framework, they can be used by any service regardless of whether they adhere to THRIVE principles or not.

In September 2017, both DAs were submitted for consideration of endorsement by the National Institute for Health and Care Excellence (NICE). The endorsement confers that the DAs contain information aligned with NICE guidelines, recommendations and quality standards, and that they address an area yet to be covered by any existing resources (NICE, 2015). Feedback from the endorsement team on 16 criteria used to assess resources for depression with children and young people highlighted that two further changes were
needed to the DAs. Both of these changes were to the medication section on the ‘in NHS’ DA (see Appendix 10a). The first change requested was to add ‘before your treatment starts’ to the activities that needed to be undertaken (e.g. height and weight assessments) prior to fluoxetine being prescribed. The second change, also in the same section, was to alter the phrase ‘a member of the team will usually meet with you once every six months’ to ‘a member of the team will regularly check with you’. The requested changes were taken to the i-THRIVE partnership board where they were subsequently approved. Thus, as of November 2017, the DAs have received endorsement by NICE and are cited on the NICE endorsement page. They are also embedded within the NICE guidelines for treatment options for young people with low mood or depression. This endorsement may help to raise the profile of these resources and help clinicians to engage in SDM with young people through having accessible, trusted interventions. The final grids are shown in Appendix 10b.

From the perspective of research and intervention development, this is the first time that the BCW (Michie et al., 2014) has been used to create an intervention which is intended to be received by more than one stakeholder group. Although previous research has triangulated findings from different individuals, it has always aimed at targeting a specific group to receive the intervention. For example, both professionals in public health and parents were interviewed in order to develop an app for health food portions (Curtis, 2016), but the target population for the app was parents. This also appears to be the first time that the BCW has been used to design an intervention with young people aged 12

26 https://www.nice.org.uk/about/what-we-do/into-practice/endorsement

years and older, as other studies have tended to focus on adults (e.g. Curtis, 2016; Sinnott et al., 2015) or young people in mid-to-late adolescence (Murtagh, Barnes, McMullen, & Morgan, 2018). The findings from this thesis suggest that young people can answer questions around the barriers and facilitators to SDM in reference to the TDF (Cane et al., 2012). Thus, this thesis can act as a framework for researchers and intervention developers who wish to involve young people in intervention design using the TDF, or when developers want to target multiple stakeholders as the recipients of an intervention.

10.7 Future directions

This thesis aimed to provide a richer understanding of SDM in the context of child and youth mental health and to develop an intervention to promote SDM within this setting. Throughout the thesis, some topics have arisen which warrant further investigation. There are also some outstanding questions which need to be addressed. The next section explores the most pressing or relevant unanswered questions.

Further research may wish to explore SDM in under-represented groups and other populations where it may be less likely to occur. Particular attention in future research should be given to non-white individuals, as the findings from Chapter 5 indicated that non-white parents were less likely to report receiving gold standard SDM. It would be useful to explore the reasons behind this finding by interviewing individuals within this group about their experiences, barriers and facilitators to SDM. Individuals who lack capacity to a greater degree than explored within this thesis may be another marginalised group that is less likely to experience SDM. This could include young people with learning difficulties and those in inpatient settings. There is already some ongoing research being conducted in these areas. For example, an app ‘Power Up +’ has been created for individuals with learning difficulties in order to support SDM and self-management (Edbrooke-Childs & Martin, 2017). In addition,
experiences of SDM in inpatient settings are currently being studied as part of a doctoral research project at the Institute of Education (Martin, 2018).

As part of future intervention development work, views on the acceptability and usability of the DAs should be sought from the young people and parents who have used them in assessment appointments in services. Whilst all the stakeholders were involved in the development of the DAs in this thesis, feedback from the clinicians during the implementation process identified further changes that needed to be made to the DAs in order for them to be both acceptable and useful. The same steps should also be undertaken with young people and parents during the implementation process. In a similar vein, further work should also focus on testing the acceptability and usefulness of the ‘outside of the NHS’ DA with individuals in the community (e.g. nurses, GPs and faith healers) to make sure they are fit for purpose. This work is ongoing, as the DAs are currently being implemented in a new London site, and feedback from young people and parents is planned as part of this. Additionally, training has been delivered to Child Wellbeing Practitioners who are based both in schools and CAMHS and who provide advice and signposting.

Acceptability and usefulness are just two of the aspects outlined by the MRC guidelines that should be considered when testing an intervention (Craig & Petticrew, 2013). If, following further testing with young people and parents, the DAs are still found to be acceptable and useful, then a pilot feasibility study may be conducted. This would allow for the testing of several features of the intervention, including the procedures, the acceptability of measures, the fidelity to the intervention, rates of recruitment and retention, and sample size (Craig & Petticrew, 2013). Results could then be used to establish whether an RCT is needed.

Research should also examine whether the components of the intervention have the effect they intend to produce. For example, it may be useful to test the
knowledge of clinicians, young people and parents around treatment options after the DAs have been introduced and used (see Fig 8-1 for the logic model describing the mechanisms of change and outcomes). This may allow for further refinement of the IFs and BCTs used in the intervention. However, one ongoing issue is that the measures that have been created to capture this information have yet to be used and validated with children and young people (Cheng et al. 2017). This is an important area which needs to be addressed for progress in this field to occur.

10.8 Overall conclusion

This thesis set out to explore SDM in child and youth mental health and to develop a theory-led intervention intended to facilitate SDM with young people, parents and clinicians. Together, the studies in this thesis clarify that not all young people and parents experience SDM in the same way. It also illuminates the barriers and facilitators to SDM for young people with internalising difficulties and their parents, and highlights how this group is less likely to experience gold standard SDM. The use of the TDF and BCW in developing an educational and training package, as well as two DAs, directly addresses the theory-practice gap in SDM interventions. The DAs developed as part of this work were found to be useful and acceptable by clinicians, although the training and educational package received mixed responses.

Whilst there is a need for further work to understand how young people and parents experienced the DAs, there are some clinical applications resulting from the work undertaken. Greater focus should be placed upon individuals who are less likely to report receiving gold standard SDM. Services may wish to investigate their own barriers and facilitators to SDM utilising the framework tested in this thesis. Given that the DAs received good feedback from the clinicians in this study and, in the wider literature, demonstrate positive outcomes (Stacey et al., 2014) services may wish to draw upon additional DAs.
developed as part of the i-THRIVE programme (Moore, 2016) which have followed the same development process outlined in this thesis.
References


Arterburn, D., Wellman, R., Westbrook, E., Rutter, C., Ross, T., Mcculloch, D., … Jung, C. (2012). Introducing decision aids at group health was linked to


393


De las Cuevas, C., Peñate, W., Perestelo-Pérez, L., & Serrano-Aguilar, P. (2013). Shared decision making in psychiatric practice and the primary care
setting is unique, as measured using a 9-item Shared Decision Making Questionnaire (SDM-Q-9). *Neuropsychiatric Disease and Treatment*, 9(March), 1045–1052. https://doi.org/10.2147/NDT.S49021


London.


https://doi.org/10.1016/j.pec.2007.12.004

https://doi.org/10.1177/1359104515591226


Hwang, W. C. (2006). Acculturative family distancing: Theory, research, and


Kennedy, I. A. (2010). Getting it right for children and young people:
Overcoming cultural barriers in the NHS so as to meet their needs. London.


McCaffery, K. J., Smith, S., Shepherd, H. L., Sze, M., Dhillon, H., Jansen, J., ...


Morrow, V., & Richards, M. (1996). The ethics of social research with children:


NHS Improvement. (2014). *Plan, do, study, act (PDSA) cycles and the model*


theory in health behavior research from 2000 to 2005: A systematic review. 


Rightcare. (2012). *NHS atlas of variation in healthcare for children and young*


Scotland, J. (2012). Exploring the philosophical underpinnings of research: Relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. *English Language Teaching, 5*(9), 9–16.


StataCorp. (2015). Stata statistical software. College Station, Texas: StataCorp LP.


https://doi.org/10.1177/1077558707299479


decision-making behaviours in health professionals: A systematic review of studies based on the theory of planned behaviour. *Health Expectations, 18*(5), 754774.


431


Williams, S. L., & French, D. P. (2011). What are the most effective intervention techniques for changing physical activity self-efficacy and physical activity behaviour - and are they the same? *Health Education Research, 26*(2), 308–322.

Wilson, P., Mathie, E., Poland, F., Keenan, J., Howe, A., Munday, D., ..., &


https://doi.org/10.1037/0022-006X.69.6.1018


Appendices

Appendix 4a: PRISMA checklist

<table>
<thead>
<tr>
<th>Section/topic</th>
<th>#</th>
<th>Checklist item</th>
<th>Reported on page #</th>
</tr>
</thead>
<tbody>
<tr>
<td>TITLE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Title</td>
<td>1</td>
<td>Identify the report as a systematic review, meta-analysis, or both.</td>
<td>153</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structured summary</td>
<td>2</td>
<td>Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.</td>
<td>n/a – this will be applicable for the paper</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rationale</td>
<td>3</td>
<td>Describe the rationale for the review in the context of what is already known.</td>
<td>154-155</td>
</tr>
<tr>
<td>Objectives</td>
<td>4</td>
<td>Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).</td>
<td>155-156</td>
</tr>
<tr>
<td>METHODS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protocol and registration</td>
<td>5</td>
<td>Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.</td>
<td>156</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>6</td>
<td>Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.</td>
<td>156</td>
</tr>
<tr>
<td>Information sources</td>
<td>7</td>
<td>Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.</td>
<td>157-158</td>
</tr>
<tr>
<td>Section/topic</td>
<td>#</td>
<td>Checklist item</td>
<td>Reported on page #</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-----</td>
<td>-------------------------------------------------------------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Search</td>
<td>8</td>
<td>Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.</td>
<td>69-70</td>
</tr>
<tr>
<td>Study selection</td>
<td>9</td>
<td>State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).</td>
<td>158-159</td>
</tr>
<tr>
<td>Data collection process</td>
<td>10</td>
<td>Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.</td>
<td>159</td>
</tr>
<tr>
<td>Data items</td>
<td>11</td>
<td>List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.</td>
<td>159-160</td>
</tr>
<tr>
<td>Risk of bias in individual studies</td>
<td>12</td>
<td>Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.</td>
<td>160</td>
</tr>
<tr>
<td>Summary measures</td>
<td>13</td>
<td>State the principal summary measures (e.g., risk ratio, difference in means).</td>
<td>n/a</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>14</td>
<td>Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$) for each meta-analysis.</td>
<td>n/a</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>15</td>
<td>Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).</td>
<td>160</td>
</tr>
<tr>
<td>Additional analyses</td>
<td>16</td>
<td>Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.</td>
<td>n/a</td>
</tr>
</tbody>
</table>

**RESULTS**

<p>| Section/topic                  | #   | Checklist item                                                                 | Reported on page # |
| Study selection               | 17  | Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram. | 161                |
| Study characteristics         | 18  | For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations. | 164-168            |</p>
<table>
<thead>
<tr>
<th>Risk of bias within studies</th>
<th>19</th>
<th>Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).</th>
<th>169, 178-179</th>
</tr>
</thead>
<tbody>
<tr>
<td>Results of individual studies</td>
<td>20</td>
<td>For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.</td>
<td>170-177</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>21</td>
<td>Present results of each meta-analysis done, including confidence intervals and measures of consistency.</td>
<td>n/a</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>22</td>
<td>Present results of any assessment of risk of bias across studies (see Item 15).</td>
<td>169</td>
</tr>
<tr>
<td>Additional analysis</td>
<td>23</td>
<td>Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).</td>
<td>n/a</td>
</tr>
</tbody>
</table>

**DISCUSSION**

| Summary of evidence | 24 | Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers). | 179-185 |
| Limitations | 25 | Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias). | 185-187 |
| Conclusions | 26 | Provide a general interpretation of the results in the context of other evidence, and implications for future research. | 187-188 |

**FUNDING**

| Funding | 27 | Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review. | 6 |
Appendix 4b: Components and rating criteria for EPHPP Quality Assessment Method (Thomas, 2004).

<table>
<thead>
<tr>
<th>Quality Assessment Method Components</th>
<th>Strong</th>
<th>Moderate</th>
<th>Weak</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Selection bias</strong></td>
<td>Very likely to be representative of the target population and greater than 80% participation rate</td>
<td>Somewhat likely to be representative of the target population and 60–79% participation rate</td>
<td>All other responses or not stated</td>
</tr>
<tr>
<td><strong>Study design</strong></td>
<td>Randomised Control Trial or Controlled Clinical Trial</td>
<td>Cohort analytic, case-control, cohort, or an interrupted time series</td>
<td>All other designs or design not stated</td>
</tr>
<tr>
<td><strong>Confounders</strong></td>
<td>Controlled for at least 80% of confounders</td>
<td>Controlled for 60–79% of confounders</td>
<td>Confounders not controlled for, or not stated</td>
</tr>
<tr>
<td><strong>Blinding</strong></td>
<td>Blinding of outcome assessor and study participants to intervention status and/or research question</td>
<td>Blinding of either outcome assessor or study participants</td>
<td>Outcome assessor and study participants are aware of intervention status and/or research question</td>
</tr>
<tr>
<td><strong>Data collection method</strong></td>
<td>Tools are valid and reliable</td>
<td>Tools are valid but reliability not described</td>
<td>No evidence of validity or reliability</td>
</tr>
<tr>
<td><strong>Withdrawals and drop-out</strong></td>
<td>Follow-up rate of &gt;80% of participants</td>
<td>Follow-up rate of 60–79% of participants</td>
<td>Follow-up rate of &lt;60% of participants or withdrawals and dropouts not described</td>
</tr>
</tbody>
</table>
Appendix 5a: CORC board approval

RE: Request for use of CORC dataset FINAL v5 04/07/16

Hi Dan,

Your research request has now been approved by the CORC senior management team.

The next step will be for us to prepare the dataset for access, and for IT to configure some computers to allow secure access to the data. We anticipate that this may take up to several weeks.

We will be in touch as soon as the data is ready to access, should you have any questions in the meantime please let us know

Best Wishes

REDACTED

Research Officer
Child Outcomes Research Consortium (CORC) | 4-8 Rodney Street, London, N1 9JH | T: 020 7443 2225 | E: CORC@annafreud.org | www.corc.uk.net

Appendix 6a: Expression of Interest Form

Expression of Interest Form: Piloting ‘Power Up’ a tool for Shared Decision Making in CAMHS

I would be interested in hearing more information about being involved in research piloting a tool to aid shared decision making in child and adolescent mental health services (CAMHS)

Name: __________________________
Email: __________________________
Phone Number: ____________________

Daniel Hayes: Researcher
Email: daniel.hayes@annafreud.org
Telephone: 020 7443 2220
Version 1, 25/05/15
Appendix 6b: Clinicians – TDF interview schedule

Introductions
- Introduce self
- Talk about organisation and research
- Data protection
- Safeguarding information

Demographic information
- What is your role – can you tell me about the range of work you do in this role?
- How long have you been at [service]?
- How long have you worked in CAMHS?
- Gender
- Age
- Ethnicity

Aim of the project is to look at SDM between 11-16 year olds with internalising difficulties, please bear this in mind when answering the questions

1) Knowledge
- Are you familiar with the term shared decision making?
- If so, can you tell me how you came to become familiar about SDM - does your team talk about it, have you had training on it, have you read about it?

2) Skills
- In your experience, what skills are needed by young people and parents/guardians to engage with healthcare professionals in decision making?
- In your experience, what skills are needed by clinicians to engage young people and parents/guardians in decision making?

3) Memory/attention/decision making processes
- In your experience, do you ever forget to ask questions or offer care and treatment options?
- In there anything that would help this?
- Do you find it easy or difficult to pay attention fully or hold in mind what has been discussed by young people and parents? Can you tell me more?

4) Behavioural regulation
- In your experience, how do you make sure/monitor you involve young people and parents in decision making?
- Are there any set standards?

5) Environmental context and resources
- What types of environments are conducive to shared decision making
- Who need to be there? Where? Time allocated?

6) Social Influences
- Do other people ever affect your ability to undertake shared decision making?
  In what ways?
- What do you think of the communication about care between HCPs and families/young people?
- How do you think clinicians feel about decision making with young people and parents?

7) Social/Professional Role
- Whose responsibility is it to make decisions about a young person’s care?
- In your experiences, do you think that certain healthcare professionals are better suited to shared decision making, can you tell me more

8) Beliefs about capabilities
- Do you feel capable of being involved in shared decision making with young people and parents? Can you tell me more
- What would help you feel more comfortable/confident?
- What would make it easier?

9) Optimism
- How confident/optimistic are you that you are able to initiate/implement shared decision making?
- How confident/optimistic are you that services are able to initiate/implement shared decision making?

10) Beliefs about consequences
- What do you think are the benefits/disadvantages of young people and families engaging in decisions about their care, do you have examples from the care you received, can you tell me more?
- What do you think happens when young people and families are more involved/not involved in their care?

11) Intentions
- Do you intend to involved young people and parents in decision making? Can you tell me more? What influences this?

12) Reinforcement
- What incentives are there for you to engage in shared decision making with young people and parents? Personal/financial?

13) Motivation and Goals
- Do you want to engage in shared decision making with young people and parents, what effects this?

14) Emotions
- In your experience, do you think emotions affect the ability to engage in shared decision making? In what ways? What kind of emotions?

Thank you.
- Outline how data will be processed, how they can contact the researcher
Appendix 6c: Clinician Information Sheet

INFORMATION SHEET (Clinicians)
Developing ‘Power Up’: A tool for Shared Decision Making in CAMHS

We would like to invite you to take part in this research. Before you decide, we would like you to understand why the research is being done and what it involves. A researcher will go through this information sheet with you and answer any questions you may have. This should take about 30 minutes. Talk to others, if you wish, and ask us if there is anything that is not clear.

What is the purpose of the study?
We want to develop a tool to enable shared decision making in mental health settings between young people, their parents and clinicians.

Why have I been invited to take part?
The Child and Adolescent Mental Health Service (CAMHS) you work in is part of the project, and you have filled out a form saying that you would like to speak about your experiences, views and beliefs. We will also talk to other young people, parents/guardians and healthcare professionals too.

Do I have to take part?
It is up to you to decide whether you are willing to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect your employment or legal rights.

If, after you have taken part, you decide that you want us to remove your responses, you can contact us and ask us to delete it.

What will happen if I take part?
If you decide to take part, we would like to hear your views and experiences about shared decision making (i.e. what constitutes good/bad shared decision making) and also show you existing decision aids to get your opinion on them so that we can develop one further. This can be done in one of two ways.

1) You could take part in an interview. This can take place over the phone or face to face (whatever you prefer) and will last up to an hour. We will conduct the interview at a time convenient for you.

2) You could take part in a focus group. Here you will discuss your experiences and views with others (children and/or clinicians and/or parents). The focus group will last up to two hours. Focus groups will be dependent on other people wanting to take part as well. If you agree to take part in a focus group, we will find out yours,
theirs and others’ availability to find the most convenient time for everybody. Everybody that attends the focus group will be asked to keep everything strictly confidential to protect everyone’s views and opinions.

Both the interviews and focus groups will be recorded so that we may type up the conversations.

**What will I have to do?**
If you want to share your views with us, the first thing we will ask you to do is sign a consent form saying that you wish to take part.

If you want to be interviewed, we will then find out when would be a convenient time for us to conduct the interview with you, and how you would like to be interviewed (over the phone or in person).

If you want to take part in a focus group, we will ask about your availability and see how this fits in with other participants’ availability to try and find a convenient time for everyone. If we are running a focus group which you are unable to attend, we will ask your permission to keep your details on file to let you know about upcoming focus groups.

After, we have analysed the data we may ask to contact you to get feedback to see if you think what we found matches your experiences. However, this is optional and you don’t have to do this if you don’t want to.

**What are the possible disadvantages of taking part?**
There are no known risks to taking part in these interviews or focus groups. If any risks become known during the research, you will be informed straight away.

**What are the possible benefits of taking part?**
There is no guaranteed benefit in taking part. One advantage is that you will get to help shape a shared decision making tool that clinicians, young people and their families may use in future. Most people find taking part in research rewarding, as they contribute to the development of knowledge that may benefit other people in the future.

**Will my taking part in the study be kept confidential?**
All information we collect from participants is strictly confidential, though we may have to break confidentiality if you tell us something that puts you or others at risk. We will assign you a unique code, and this will appear on any data we collect from you. Consent forms will be kept in their own locked filing cabinet, and transcribed interviews will be identified only by the unique code we assign to you. Only members of the research team will have access to full transcribed data. Quotations from interviews and focus groups will be provided to the Anna Freud Centre (AFC), however any information that may identify a participant will be redacted (e.g. if job title is mentioned).

**What will happen of the results of the study?**
The anonymised results will be published in project reports, scientific journals, presented at conferences and disseminated on the AFC website. The results will be shared once the last person completes the research and the results have been analysed.

Who is organising and funding the research?
This research is being carried out by researchers at the Anna Freud Centre/University College London. The research is funded by a UCL/AFC IMPACT studentship.

What happens if something goes wrong?
If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor’s (University College London) or the hospital’s negligence then you may be able to claim compensation. After discussing with Mr. Daniel Hayes or Dr. Julian Edbrooke-Childs, please make the claim in writing to the Dr Julian Edbrooke-Childs who is the Chief Investigator for the research and is based at Evidence Based Practice Unit (EBPU), 21 Maresfield Gardens, London, NW3 5SU. The Chief Investigator will then pass the claim to the Sponsor’s Insurers, via the Sponsor’s office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Who has reviewed the study?
All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given a favourable outcome by London Hampstead Research Ethics Committee

Contact details:
If you have any questions about research in general, this research in particular, your rights as a participant, or would like to report any problem or complaint arising from this research, please contact either of the following staff members of the Anna Freud Centre:

this research is insured by University College London.
Appendix 6d: Clinician consent form

Centre Number:

CONSENT FORM (Clinicians)
Developing ‘Power Up’: a tool for Shared Decision Making in CAMHS

Please initial box

1. I confirm that I have read and understand the information sheet dated ................. (version.............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my employment or legal rights being affected.

3. I consent to the storage and processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

4. I agree to take part in the above study.

Name of Participant     Date     Signature

Name of Person taking consent     Date     Signature

e-mail: daniel.hayes@annafreud.org Tel: 020 7443 2220
NHS ethics reference: 15/LQ/0997 Page 1 Version 1 01/12/2014
Appendix 6e: REC Approval Letter

Health Research Authority
National Research Ethics Service
NRES Committee London - Hampstead
Barbette House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

07 July 2015
Dr Julian Edbrooke-Childs
Evidence Based Practice Unit (EBPU)
University College London and Anna Freud Centre
21 Maresfield Gardens
NW3 5BU

Dear Dr Edbrooke-Childs

Study title: The development and trialling of 'Power Up': A tool for young people with internalising/emotional disorders to make shared decisions in Child and Adolescent Mental Health Services (CAMHS)

REC reference: 15/LO/0997
IRAS project ID: 166102

Thank you for your letter of 03 July 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Dr Ashley Totenhofe, nrescommittee.london-hampstead@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the
Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.ntrforum.nhs.uk](http://www.ntrforum.nhs.uk).

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra_studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.
### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering letter on headed paper</td>
<td></td>
<td>03 July 2015</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants [Young Person Aged 11+]</td>
<td>1</td>
<td>13 May 2015</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants [Parent/Guardian]</td>
<td>1</td>
<td>13 May 2015</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants [Clinician]</td>
<td>1</td>
<td>13 May 2015</td>
</tr>
<tr>
<td>Letter from statistician</td>
<td></td>
<td>24 April 2014</td>
</tr>
<tr>
<td>Non-validated questionnaire [CollaboRATE]</td>
<td>1</td>
<td>25 May 2015</td>
</tr>
<tr>
<td>Participant consent form [Assent 16- Development]</td>
<td>V2</td>
<td>29 June 2015</td>
</tr>
<tr>
<td>Participant information sheet (PIS) [PIS 11-15 Development]</td>
<td>2</td>
<td>29 June 2015</td>
</tr>
<tr>
<td>Participant information sheet (PIS) [PIS 16+ Development]</td>
<td>V4</td>
<td>29 June 2015</td>
</tr>
<tr>
<td>Participant information sheet (PIS) [PIS Clinicians]</td>
<td>V4</td>
<td>29 June 2015</td>
</tr>
<tr>
<td>REC Application Form</td>
<td>4.0.0</td>
<td>03 July 2015</td>
</tr>
<tr>
<td>Research protocol or project proposal</td>
<td>4.0</td>
<td>29 June 2015</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>03 July 2015</td>
</tr>
<tr>
<td>Summary CV for Chief Investigator (Clj) Enjoybrooke-Childs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summary CV for student [Daniel Hayes]</td>
<td></td>
<td>13 May 2015</td>
</tr>
<tr>
<td>Summary CV for supervisor (student research) [Nick Midgley]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validated questionnaire [OPTION Scale]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validated questionnaire [ESQ Aged 9-11]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validated questionnaire [ESQ Aged 12-18]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validated questionnaire [RCADS]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validated questionnaire [SDQ]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validated questionnaire [Session Rating Scale Aged 6-12]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validated questionnaire [Session Rating Scale Aged 13+]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Validated questionnaire [Ottawa Family Decision Guide]</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
• Adding new sites and investigators
• Notification of serious breaches of the protocol
• Progress and safety reports
• Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/LO/0997 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

Email: nrescommittee.london-hampstead@nhs.net

Enclosures: “After ethical review – guidance for researchers”

Copy to: Mr Dave Wilson – UCL
Dr Bonnie Teague - Norfolk & Suffolk NHS Foundation Trust (Norfolk & Waveney Mental Health)
Mr Daniel Hayes – UCL
Appendix 7a: Recruitment poster

Young people with anxiety or depression, and/or their caregivers needed for interviews and focus groups

We are looking for people to take part in a research study telling us about their experiences of decision making in child mental health centres, as well as what they think is important when it comes to decision making. We are looking for:

Young people
Aged between 11-16 years of age
With anxiety or depression

AND/OR

Caregivers (Parents/Guardians)
Who look after a young person aged 11-16 with anxiety or depression

This study is carried out by the Evidence Base Practice Unit (EBPU) which is part of the Anna Freud Centre and University College London. This study has been approved by Hampstead Ethics Committee (ref: 15/LO/0997) who look after participants rights. Taking part is voluntary and the study is confidential and covered by the Data Protection Act (1998).

If you are interested ask your clinician for an expression of interest form. If you would like to know more, contact the research team on: 0207 443 2220 or via email: daniel.hayes@annafreud.org
Appendix 7b: CYP/parents – TDF interview schedule

Introductions
- Introduce self
- Talk about organisation and research
- Data protection
- Safeguarding information

Demographic information
- Can you tell me about why you went to CAMHS (diagnosis)?
- Can you tell me how long you have been in CAMHS (length)?
- Gender
- Age
- Ethnicity

General
- In your experience of attending CAMHS, how often have you been involved in decisions about your/your child’s care/treatment?
- Can you give me examples? (If have)
- How does this make you feel?
- What types of decisions would you like to be involved in?
- If I used the term shared decision making, what do you think it means?

1) Knowledge
- From your experience, did you know that you/your child could be involved in decisions about your care and treatment?
- If so, how did you know about this, do you have examples?

2) Skills
- In your experience, what skills are needed by young people and parents to engage with healthcare professionals in decision making?
- In your experience, what skills are needed by clinicians to engage young people and parents/guardians in decision making?

3) Memory/attention/decision making processes
- In your experience, do you ever forget to ask questions or remember decisions about your/your child’s care and treatment?
- Is there anything that would help this?
- Do you find it easy or difficult to pay attention fully or hold in mind what has been discussed about your/your child’s care? Can you tell me more?

4) Behavioural regulation
- In your experience, how do you monitor if you have been involved in shared decision making? Can you tell me more?

5) Environmental context and resources
- What types of environments are conducive to shared decision making?
- Who needs to be there? Where? Time allocated?
6) **Social Influences**
   - Do other people ever affect your decision making about your/your child’s care? In what ways?
   - Have you experienced any conflict with health professionals over decisions about care?
   - What do you think of the communication about care between clinicians and families/young people?
   - How do you think clinicians feel about decision making with young people and parents/guardians?

7) **Social Role**
   - Whose responsibility is it to make decisions about a young person’s care?
   - In your experiences, do you think that certain healthcare professionals are better suited to shared decision making, can you tell me more?

8) **Beliefs about capabilities**
   - Do you feel that you are able to be involved in decisions about your/your child’s care? Can you tell me more?
   - What would help you feel more comfortable/confident in making decisions about your care?
   - What would make it easier to make decisions in your/your child’s care?

9) **Optimism**
   - How confident/optimistic are you that you are able to initiate/implement shared decision making?
   - How confident/optimistic are you that services are able to initiate/implement shared decision making?

10) **Beliefs about consequences**
    - What do you think are the benefits/disadvantages of young people and families engaging in decisions about their care, do you have examples of from the care you received, can you tell me more?
    - What do you think happens when young people and families are more involved/not involved in their care?

11) **Intentions**
    - Do you/your child intend to be involved in decision making? Can you tell me more?

12) **Reinforcement**
    - What incentives are there for you/your child to engage in shared decision making? Personal/financial?

13) **Motivation and Goals**
    - From your experience, why do you think yourself/young people would like more of a say in their care?
From your experience, are there any particular decisions that you feel are more important for young people and parents/guardians to be involved in?

From your experience, are there any particular decisions that you feel are less important for young people and parents/guardians to be involved in?

14) Emotions

- In your experience, do you think yours or your child's emotions affect decisions about your care? In what ways? What kind of emotions?

**Thank you.**

- Outline how data will be processed,
- What will be done with the data
- How they can contact the researcher for more information
Appendix 7c: Information sheet for parents

INFORMATION SHEET (Parents/Guardians)
Developing ‘Power Up’: A tool for Shared Decision Making in CAMHS

We would like to invite the young person you are a parent/guardian to, to take part in this research. Before you decide, we would like you to understand why the research is being done and what it involves. A researcher will go through this information sheet with you and answer any questions you may have. This should take about 10 minutes. Talk to others, if you wish, and ask us if there is anything that is not clear.

What is the purpose of the study?
We want to develop a tool to enable shared decision making in mental health settings between young people, their parents and clinicians.

Why has my young person been invited to take part?
We are looking for young people with emotional/internalising difficulties to take part in this project – this means that their behaviours or difficulties are turned ‘inwards’ or on themselves and includes things such as feeling sad, worrying, fear, self-injury, and not wanting to go out. The Child and Adolescent Mental Health Service (CAMHS) your young person has attended is taking part in this project, and you or your young person have filled out an evaluation form given to you by a member of staff at a CAMHS service indicating that you are willing to be contacted to take part in an interview/focus group.

Does my young person have to take part?
It is up to you to decide whether you are willing for them to join the study. We will also ask for their permission too. We will describe the study and go through this information sheet with you (and an age appropriate information sheet with them). If you agree for them to take part, we will then ask both of you to sign a consent form. Either of you can withdraw at any time, without giving a reason. This would not affect your/their medical care or legal rights.

If, after you have taken part, you decide that you want us to remove your young person’s responses, you can contact us and ask us to delete them.

What will happen if I agree for my young person to take part?
If you decide that your young person can take part, we would like to hear their views and experiences about shared decision making (i.e. what constitutes good/bad shared decision making) and show them potential decision aids that we plan to develop. This can be done in one of two ways:

1) They could take part in an interview. This will take place face to face at a time to suit them. You can be there if you would like or we will provide an age appropriate adult
(whatever you prefer). The interview will last up to an hour.

2) They could take part in a focus group. Here they will discuss their experiences and views with others (children and/or clinicians and/or parents). The focus group will last about up to two hours. Focus groups will be dependent on other people wanting to take part as well. If you agree for your young person to take part in a focus group, we will find out yours, theirs and others availability to find the most convenient time for everybody. Everybody that attends the focus group will be asked to keep everything strictly confidential to protect everyone’s views and opinions.

Both the interviews and focus groups will be recorded so that we may type up the conversations.

What will my young person and I have to do?
If you agree for your young person to share their views with us, the first thing we will ask you to do is to both sign a consent form saying that you wish to take part.

If your young person agrees to be interviewed, we will then find out when would be a convenient time for us to conduct the interview with them, arrange a suitable place, and find out if you want to be there (or another appropriate adult from the University College London or Anna Freud Centre, or one suggested by you).

If your young person wants to take part in a focus group, we will ask your/their availability and see how this fits in with other participants’ availability to try and find a convenient time for everyone. If we are running a focus group that you/your young person is unable to attend, we will ask your permission to keep their details on file to let you and them know about upcoming focus groups.

After, we have analysed the data we may ask to contact you/your young person to get feedback to see if you/they think what we found matches your/their experiences. However, this is optional and you/they don’t have to do this if you don’t want to.

What are the possible disadvantages of taking part?
There are no known risks to taking part in these interviews or focus groups. If any risks become known during the research, you and your young person will be informed straight away.

What are the possible benefits of taking part?
There is no guaranteed benefit in taking part. One advantage is that your young person will get to help shape a shared decision making tool that clinicians, young people, and their families may use in future. Most people find taking part in research rewarding, as they contribute to the development of knowledge that may benefit other people in the future.

Will my young person’s participation in the study be kept confidential?
All information we collect from participants is strictly confidential, though we may have to
break confidentiality if your young person tells us something that puts them or others at risk from harm. We will assign your young person a unique code, and this will appear on any data we collect from them. Consent forms will be kept in their own locked filing cabinet, and transcribed interviews will be identified only by the unique code we assign to you. Only members of the research team will have access to full transcribed data. Quotations from interviews and focus groups will be provided to the Anna Freud Centre (AFC), however any information that may identify a participant will be redacted (e.g. if your child’s name is mentioned).

What will happen of the results of the study?
The anonymised results will be published in project reports, scientific journals, presented at conferences and disseminated on the AFC website. The results will be shared once the last person completes the research and the results have been analysed. Your young person will not be identified in any report or publication.

What happens if something goes wrong?
If you wish to complain, or have any concerns about any aspect of the way you or your child have been approached or treated by members of staff they may have experienced due to their participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask the research doctor if you would like more information on this. In the unlikely event that you or your child are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor’s (University College London) or the hospital’s negligence then you may be able to claim compensation. After discussing with Mr. Daniel Hayes or Dr. Julian Edbrooke-Childs, please make the claim in writing to the Dr Julian Edbrooke-Childs who is the Chief Investigator for the research and is based at Evidence Based Practice Unit (EBPU), 21 Maresfield Gardens, London, NW3 5SU. The Chief Investigator will then pass the claim to the Sponsor’s Insurers, via the Sponsor’s office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Who is organising and funding the research?
This research is being carried out by researchers at the Anna Freud Centre/University College London. The research is funded by a UCL/AFC IMPACT studentship.

Who has reviewed the study?
All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given a favourable outcome by London Hampstead Research Ethics Committee. Contact details:
If you have any questions about research in general, this research in particular, your rights as a participant, or would like to report any problem or complaint arising from this research, please contact either of the following staff members of the Anna Freud Centre:
Appendix 7d: Information sheets for young people 11-15

INFORMATION SHEET (11-15)
Developing ‘Power Up’: A tool for Shared Decision Making in CAMHS

We are asking if you would like to join in a research project to hear your experiences of making decisions about your care/treatment, and to help us make a tool for shared decision making between young people in mental health services, their parents and clinicians.

Why are we doing this research?
We want to help young people be more involved in their care and treatment. To do this we want to hear what young people think of shared decision making, and hear their thoughts on what are the best tools/ways to do this.

Why have I been invited to take part?
We are looking for young people who may be feeling sad, worrying, fear, self-injury, and not wanting to go out. The Child and Adolescent Mental Health Service (CAMHS) you go to is part of the project, and you have filled out a form saying that you would like to speak about your experiences, views and beliefs. We will also talk to other young people, parents/guardians and clinicians too.

Do I have to take part?
No! It is up to you whether or not you take part, if you decide now, or at a later date, that you do not wish to take part in this research you are free to stop at any time. If you choose not to take part you will not be disadvantaged... Even if you start to take part and then change your mind that is ok.

What will happen if I take part?
If you decide to take part, we would like to hear your views and experiences about shared decision making. You could do this in one of two ways:

1) You could take part in an interview. This will involve talking to a researcher and will take place at a time that works for you and will last up to an hour. We will ask your parent/guardian if it is ok for you to take part, and for them (or another appropriate adult) to be there.

2) You could take part in a focus group. Here you will discuss your experiences and views with other people, and it will last up to two hours. Focus groups will be dependent on other people wanting to take part as well.

NHS ethics reference: 15/LO/0997
Page 1
Version 2
29/06/15
Both the interviews and focus groups will be recorded so that we may type up the conversations so we can study them later on.

**What will I be asked to do?**
If you want to share your views with us, the first thing we will ask you to do is sign a form saying that you agree to take part. We will also ask your parent/guardian to sign a consent form saying they agree for you to take part.

We will then want to hear what you think about shared decision making. This is not a test and there are no right or wrong answers. If you want to take part in a group discussion, we will try and arrange a time and place that everyone can do. After we have looked at the data we may ask to speak to you to see if what we found matched your experiences – however this is optional and you don’t have to tell us anything if you don’t want to.

**What are the possible disadvantages of taking part?**
There are no known risks to taking part in these interviews or focus groups. If any risks become known during the research, we will tell you straight away.

**What are the possible benefits of taking part?**
You may not get any benefits from taking part. One advantage is that what you tell us will help us make a tool to help other young people make decisions about their treatment. Most people find they get something positive out of taking part in research, as they can help researchers find out more information that may help other people in the future.

**Will anyone else know what is spoken about?**
If you take part in the group discussion, the other people in the group with you will know what you say. However, everything that is said during the group discussion will be kept private, and everyone in the group will agree not to share what is talked about with other people.

If you take part in an interview, it will be the researchers in the project and the other adult in the room that will know what you have said.

The only time we may have to tell someone outside of the group is if you tell us that you or someone else is in danger, or if something bad was going to happen.

**What happens when the research stops?**
When the research finishes, we will write a short report and present this to services involved in this project. This will include things you have told us about your experiences. We will not write your name or other things that show it was you who said it, so no one will know it was you.

**What happens if something goes wrong during the research?**
It is unlikely that taking part in the research will harm you in any way; if it does there are things in place to protect you and look after you. If something happens that you don’t like,
and you want us to know, contact Dr. Julian Edbrooke-Childs or Mr. Daniel Hayes, or speak to your parent/guardian. We will make sure what you have told us is acted upon.

Who has reviewed the study?
All research is looked at by a group of people, called a Research Ethics Committee, to look after people in the research. This research has been reviewed and given a favourable outcome by London Hampstead Research Ethics Committee.

If you have any questions about research, or what you will be asked to do, you or your parent can contact the people below:

This research is insured by University College London.
Appendix 7e: Information sheet for those aged 16 and over (parents and young people)
views with others (children and/or clinicians and/or parents). The focus group will last about up to two hours. Focus groups will be dependent on other people wanting to take part as well. If you agree to take part in a focus group, we will find out yours, theirs and others’ availability to find the most convenient time for everybody. Everybody that attends the focus group will be asked to keep everything strictly confidential to protect everyone’s views and opinions.

Both the interviews and focus groups will be recorded so that we may type up the conversations.

What will I have to do?
If you want to share your views with us, the first thing we will ask you to do is sign a consent form saying that you wish to take part.

If you want to be interviewed, we will then find out when would be a convenient time for us to conduct the interview with you, and how you would like to be interviewed (over the phone or in person).

If you want to take part in a focus group, we will ask about your availability and see how this fits in with other participants’ availability to try and find a convenient time for everyone. If we are running a focus group which you are unable to attend, we will ask your permission to keep your details on file to let you know about upcoming focus groups.

After, we have analysed the data we may ask to contact you to get feedback to see if you think what we found matches your experiences. However, this is optional and you don’t have to do this if you don’t want to.

What are the possible disadvantages of taking part?
There are no known risks to taking part in these interviews or focus groups. If any risks become known during the research, you will be informed straight away.

What are the possible benefits of taking part?
There is no guaranteed benefit in taking part. One advantage is that you will get to help shape a shared decision making tool that clinicians, young people, and their families may use in future. Most people find taking part in research rewarding, as they contribute to the development of knowledge that may benefit other people in the future.

Will my taking part in the study be kept confidential?
All information we collect from participants is strictly confidential, though we may have to break confidentiality if you tell us something that puts you or others at risk. We will assign you a unique code, and this will appear on any data we collect from you. Consent forms will be kept in their own locked filing cabinet, and transcribed interviews will be identified only by the unique code we assign to you. Only members of the research team will have access to full transcribed data. Quotations from interviews and focus groups will be provided to the Anna Freud Centre (AFC), however any information that may identify a participant will be redacted (e.g. if your name is mentioned).
What will happen of the results of the study?
The anonymised results will be published in project reports for CAMHS sites, scientific journals, presented at conferences and disseminated on the AFC website. The results will be shared once the last person completes the research and the results have been analysed. You will not be identified in any report or publication.

What happens if something goes wrong?
If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor’s (University College London) or the hospital’s negligence then you may be able to claim compensation. After discussing with Mr. Daniel Hayes or Dr. Julian Edbrooke-Childs, please make the claim in writing to the Dr Julian Edbrooke-Childs who is the Chief Investigator for the research and is based at Evidence Based Practice Unit (EBPU), 21 Maresfield Gardens, London, NW3 5SU. The Chief Investigator will then pass the claim to the Sponsor’s Insurers, via the Sponsor’s office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Who is organising and funding the research?
This research is being carried out by researchers at the Anna Freud Centre/University College London. The research is funded by a UCL/AFC IMPACT studentship.

Who has reviewed the study?
All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given a favourable outcome by London Hampstead Research Ethics Committee.

Contact details:
If you have any questions about research in general, this research in particular, your rights as a participant, or would like to report any problem or complaint arising from this research, please contact either of the following staff members of the Anna Freud Centre:
Appendix 7f: Parent/guardian consent

CONSENT FORM (PARENT/GUARDIAN)
Developing “Power Up”; a tool for Shared Decision Making in CAMHS

Please initial box

1. I confirm that I have read and understand the information sheet dated .
   (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that participation is voluntary and that I am free to withdraw my young person at any time without giving any reason, and without my young person’s medical care or legal rights being affected.

3. I consent to the storage and processing of my young person’s personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998

4. I agree for my young person to take part in the above study.

Name of Parent: ________________________________ Date: __________________ Signature: __________________

Name of Young Person: ________________________________

Name of Person taking consent: ________________________________ Date: __________________ Signature: __________________
Appendix 7g Assent form for young person

Centre Number:

ASSENT FORM (11-15)
Developing ‘Power Up’: A tool for Shared Decision Making in CAMHS

You are agreeing that:

- You are happy to be interviewed or take part in a group discussion
- We will record today’s discussion and type this up
- We will write up your views in a report which will be read by people outside of this study but your name will not be mentioned.

We are agreeing that:

- These consent forms with any personal details (such as your name) on them will be kept in a locked drawer.

Please initial each box below if you agree with the sentences below:

1) Somebody has explained this project to you
2) You understand what this project is about
3) You have asked all the questions you want
4) Your questions were answered in a way you understand
5) You understand that it is OK to stop taking part at any time
6) You are happy to take part

If don’t want to take part, don’t sign your name!
If you do want to take part, you can write your name below

My name ___________________________ Date __________
Name of researcher ___________________________ Date __________ Signature __________

e-mail: daniel.hayes@annafrued.org Tel: 020 7443 2220
NHS ethics reference 15/LO/0997 Page 1 Version 2 29/06/15
Appendix 7h: Consent form for those aged 16 and over (parents and young people)

Centre Number:

CONSENT FORM (16+)
Developing “Power Up”: A tool for Shared Decision Making in CAMHS

Please initial box

1. I confirm that I have read and understand the information sheet dated __________________ (version __________) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I consent to the storage and processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998

4. I agree to take part in the above study.

Name of Participant________________________Date________________________Signature________________________

Name of Person taking consent________________________Date________________________Signature________________________

e-mail: daniel.hayes@anna Freud.org Tel: 020 7443 2220
NHS ethics reference: 15/LQ/0997 Page 1 Version 1 01/12/2014
Appendix 8a: Table breakdown for IF exercise for clinicians, parents and young people

<table>
<thead>
<tr>
<th>Candidate intervention function</th>
<th>APEASE criteria for interventions aimed at clinicians to increase shared decision making</th>
<th>APEASE criteria for interventions aimed at young people and parents to increase shared decision making</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Affordable</td>
<td>Practical</td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Persuasion</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Incentivisation</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Coercion</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Training</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Restriction</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Environmental restructuring</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Modelling</td>
<td>?</td>
<td>0</td>
</tr>
<tr>
<td>Enablement</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

468
### Appendix 8b: Table breakdown for round 2

<table>
<thead>
<tr>
<th>COM 2</th>
<th>BRF</th>
<th>Potential solutions</th>
<th>Possible intervention function mapped into each TDF category</th>
<th>Rational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capability</td>
<td>Knowledge</td>
<td>Educating clinicians on the time shared decision making</td>
<td>1. Education</td>
<td>Not likely to be seen as effective or acceptable (4/6)</td>
</tr>
<tr>
<td></td>
<td>Memory, attention and decision making processes</td>
<td>Educating clinicians on care and treatment options</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enabling clinicians to present all options to parents and young people</td>
<td>1. Education</td>
<td></td>
</tr>
<tr>
<td>Opportunity</td>
<td>Excess emotional and social influences</td>
<td>Enable clinicians access to better tools to aid shared decision making</td>
<td>1. Enablement</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enable clinicians to have access to more psychological interventions</td>
<td>1. Education 2. Enablement</td>
<td>Not likely to be practical, effective or acceptable (4/6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enable clinicians to have less administration and time constraints</td>
<td>Not likely to be affordable or practical (4/6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social influences</td>
<td>Enable teams members to not negatively influence decisions or positively influence decisions</td>
<td>1. Enablement</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enabling procedural influences to facilitate shared decision making</td>
<td>Not likely to be affordable, practical, effective or acceptable (4/6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Motivation</td>
<td>Educate young people to have the ability to participate and understand shared decision making</td>
<td>Not already happens (N/A)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Professional role and identity</td>
<td>Educate clinicians of the dignity between the young people and parents experience of shared decision making</td>
<td>1. Education</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Educate clinicians of professional standards and shared decision making</td>
<td>1. Enablement</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Educate clinicians of the positive and negative consequences of engaging in shared decision making</td>
<td>Not likely to be effective or acceptable (4/6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Beliefs about consequences</td>
<td>Enable clinicians to have access to more knowledge which will help with confidence</td>
<td>1. Enablement</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enable clinicians to not feel stressed or overwhelmed when impacts on decision making</td>
<td>1. Enablement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Beliefs about capabilities</td>
<td>Educate young people and parents around clinical equipoise and that there is no ‘wrong’ decision</td>
<td>1. Education</td>
<td>Not likely to be seen as effective or acceptable (4/6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enable young people and parents access to appropriate resources to facilitate shared decision making</td>
<td>1. Enablement</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enable parents to support young people, and advocate for them when they don’t want to/can’t be involved</td>
<td>3 (A/B)</td>
<td></td>
</tr>
<tr>
<td>Capabilities</td>
<td>Emotions</td>
<td>Enable those with enhanced emotional states to be involved in decision making</td>
<td>1. Enablement</td>
<td></td>
</tr>
</tbody>
</table>

---

**Note:** The table provides a breakdown of potential solutions and interventions mapped into relevant TDF categories based on clinical scenarios. The rational column indicates the likelihood and effectiveness of each intervention, with ratings from 1 (highly likely) to 6 (highly unlikely).
Appendix 8c: FAQs

1. How will this help me get better?
2. What will this involve for me?
3. What will happen?
4. Will this help improve my symptoms?
5. What people will be involved in this?
6. Will I see the same people for the duration of this help or support?
7. Who will need to know about this?
8. Will I be expected to tell the people helping or supporting me everything about me?
9. Do I have to come to a specific place?
10. How often will I need to come to this specific place?
11. Will I need to do this in person?
12. When can I start this help or support?
13. How quickly will this help me?
14. How long will I need this help or support for?
15. Will I need more help or support in the future if I use this?
16. Will this affect other physical/mental health conditions?
17. Are there any benefits from this type of help or support?
18. Can I use other types of help or support alongside this?
19. How many people get better using this help or support?
20. Can I stop if I don't like this help or support?
21. How many people stop this type of help or support?
22. When will we review if this type of help or support is working?
23. Is this help or support suitable for people who have felt this way before?
24. Will this help or support affect my social life/things I do on a daily basis?
25. Can I still go out with my friends?
26. Are there risks or side effects from this help or support?
27. Is it safe?
28. Is it addictive?
29. Will I need to change my exercise routine?
30. Will I need to change my diet?
31. Can I still go to school?
32. Can I drink alcohol?
33. Can I take drugs?
34. Will it change my personality?
35. How will this affect me over time?
Appendix 8d: Ethics approval letter

UCL RESEARCH ETHICS COMMITTEE
ACADEMIC SERVICES

Notification of Ethical Approval
Re: Ethics Application 6735/006: Understanding what are the frequently asked questions by young people and families with mental health conditions in order to make decisions about their care

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the REC until the 9th June 2017.

Approval is subject to the following conditions.

1. You must seek Chair’s approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the ‘Amendment Approval Request Form’: http://ethics.grad.ucl.ac.uk/responsibilities.php

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

3. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator (ethics@ucl.ac.uk) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

On completion of the research you must submit a brief report of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Yours sincerely
Appendix 9a: Survey questions

What did you think of the educational and training package? <open text box>
Please tell us any aspects of the educational and training you found helpful or useful? <open text box>
Please tell us any aspects of the educational and training you did not find helpful or useful? <open text box>
What changes would you make to the educational and training in the future? <open text box>
Appendix 9b: Feedback form

i-THRIVE Feedback form for decision aids

<table>
<thead>
<tr>
<th>Were the decision aids used? If so, which ones?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>How did you find using the decision aids?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Did anything go particularly well?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Did anything go not so well?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Were there any facilitators to using the grids?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Were there any barriers to using the grids?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>If you could change something about the grids, what would it be?</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

Appendix 9c: Interview schedule

Interview schedule draft – Clinicians

- Can you tell me about your experience of using (XXXX) grid/s?
  - What happened?
  - When during the session did you introduce the grid? Why?
  - How did you find using the grid with your client? What was your first impression?
  - What went well?
  - What was good about the grid?
  - In what ways did you find the grid helpful/not helpful?
  - Was there anything you did not understand about the grid?
    - If yes, please describe.
  - Did anything not go well?
    - If yes, please describe.
- Are there any changes you would make to the grids?
- What did you talk about related to the grid with your client?
- How did the session where you used the grid compare to sessions where you did not use the grids?
- What do you think about using grids like this in places like the Tavistock/other clinics?
  - Do you think other people would benefit from using grids like these? (Why/Why not)
Appendix 10a: Criteria used by NHS endorsement team

NICE Endorsement Analysis E153 ‘i-THRIVE Grids: low mood’

The full analysis leading to the endorsement decision is shown below.

1. **Scope and purpose criteria** - An analysis of the resource scope

<table>
<thead>
<tr>
<th>Criterion</th>
<th>1. Scope and purpose</th>
<th>Evidence of Meeting Criteria</th>
<th>Overall Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Does the resource producer specify the NICE guidance or quality standard that the resource relates to? Which NICE guideline recommendations and/or quality standard statements does the resource cover?</td>
<td>The resource comprises 2 patient consultation aids – one showing the help available through the NHS, the other showing support available outside the NHS. The resource producer states that the resource supports the following recommendations: CG28 Depression in children and young people: identification and management (updated 2017) 1.5.2.2, 1.6.1.2, 1.6.2.1, 1.6.4.3, 1.6.4.5</td>
<td>Criterion met</td>
</tr>
<tr>
<td>1.2</td>
<td>Does the producer indicate if content goes beyond what NICE says with a rationale for this?</td>
<td>The resource producer states that the resource includes information from other sources such as expert reference groups and community-based resources. These are referenced transparently and the resource producer stated this was to enable the tools to work outside a traditional tier-based system and be inclusive of a range of agencies.</td>
<td>Criterion met</td>
</tr>
<tr>
<td>1.3</td>
<td>Does the resource address recommendations and/or statements with (potentially) poor uptake, identified</td>
<td>CG28 identifies recommendation 1.6.1.2 as a priority for implementation. In addition, the resource was developed with a grant from the Health Foundation, suggesting there is a recognised need for the resource.</td>
<td>Criterion met</td>
</tr>
</tbody>
</table>
difficulties in implementation or involving a significant change to practice?

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Evidence of Meeting Criteria</th>
</tr>
</thead>
</table>

1.4 Does the majority of the resource relate to NICE guidance and/or quality standards? It is not sufficient for just a small part of the resource to support implementation of guidance.

The majority of the resource relates to NICE guidance. Both parts of the resource concentrate on what support is available for young people, which is one of the areas covered by CG28. **Criterion met**

1.5 Is the intended user of the resource clear? If the intended users include patients has the resource been produced by an Information Standard certified producer?

The intended user of the resource is clear – young people and their parents or carers in consultation with a professional. **Criterion met**

---

### 2. Resource properties criteria - An analysis of the generic resource properties

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Evidence of Meeting Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Is there a process for handling resource updates including when they would happen aside of guidance recommendations or quality standard statements updates?</td>
<td>Supporting documentation provides that they should be updated in two years, but this will need board/clinical lead sign off</td>
</tr>
<tr>
<td>2.2</td>
<td>Can the resource be used in a UK health setting with no amendments required? If amendments are needed can they be made?</td>
</tr>
<tr>
<td>2.3</td>
<td>Can the resource be used as is or does it need other things to function, such as specific software, licensing or a fee paid?</td>
</tr>
<tr>
<td>2.4</td>
<td>Does the resource address potential sources of bias, such as using other sources of information, sponsorship or focus?</td>
</tr>
<tr>
<td>2.5</td>
<td>Did the producer involve relevant stakeholders/intended users in developing the resource? If not does the producer explain why not?</td>
</tr>
</tbody>
</table>

### 3. Recommendations criteria

Does the resource output align to the recommendations in the guideline/statements in the quality standard? Is the wording used in the resource consistent with NICE guidance/quality standard and not in conflict with it?

<table>
<thead>
<tr>
<th>Criterion</th>
<th>3. Recommendations</th>
<th>Evidence of Meeting</th>
<th>Overall Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1</td>
<td>Do any aspects of the resource contradict NICE guidance and/or quality standards</td>
<td>The resource doesn’t include all the details of the recommendations (see below) but these may not all be appropriate as it is intended for use by children and young people rather than</td>
<td>Criterion met</td>
</tr>
<tr>
<td>Section</td>
<td>Description</td>
<td>Evaluation</td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
<td>------------</td>
<td></td>
</tr>
<tr>
<td>3.2</td>
<td>1.5.2.2 Following a period of up to 4 weeks of watchful waiting, offer all children and young people with continuing mild depression and without significant comorbid problems or signs of suicidal ideation individual non-directive supportive therapy, group cognitive behavioural therapy (CBT) or guided self-help for a limited period (approximately 2 to 3 months). This could be provided by appropriately trained professionals in primary care, schools, social services and the voluntary sector or in tier 2 Child and Adolescent Mental Health Services (CAMHS). The resource covers types of treatment for children and young people with depression and describes what they can expect in terms of practical support, talking therapy and antidepressants. It includes information that is not in the recommendation. For example, practical support is likely to involve meeting with a therapist once a week and talking therapy usually lasts about an hour. The resource for the NHS doesn’t specify guided self-help but this is included in the resource for use outside the NHS. The resource does not include the extra information from the recommendation that psychological treatment should be offered after a period of up to 4 weeks of watchful waiting and should last for a limited period of about 2 to 3 months. It doesn’t mention that psychological treatments are not for children and young people with comorbid problems or signs of suicidal ideation. However, most of these extra points (with the possible exception of the duration of the treatment) are for healthcare professionals. The resource covers points that professionals will share with children and young people and so the points excluded may not be relevant. The resource is a clear summary of what children and young people can expect from treatment for depression and for the most part meets the recommendation.</td>
<td>Criterion met</td>
<td></td>
</tr>
<tr>
<td>3.3</td>
<td>1.6.1.2 Offer children and young people with moderate to severe depression a specific psychological therapy (individual CBT, interpersonal therapy, family therapy, or psychodynamic psychotherapy) that runs for at least 3 months. The resource describes talking therapies for children and young people with depression. It doesn’t specify the types of therapy but does mention that sessions may involve other family members (so covering family therapy). It describes the types of issues that might be covered by different talking therapies and so probably covers the range of therapies mentioned in the recommendation. The resource for use outside the NHS goes into quite a lot of detail about types of support, counselling and CBT. There is no mention of the severity of the depression but this may be because this information is for the healthcare professional rather than for the professional to share with the child or young person. Again, the duration of the therapy (at least 3 months) isn’t mentioned. This could perhaps be added to the resource as it might be</td>
<td>Criterion met</td>
<td></td>
</tr>
</tbody>
</table>
helpful for children and young people to know. The resource for the most part meets this recommendation.

| 3.4 | 1.6.2.1 Consider combined therapy (fluoxetine[2] and psychological therapy) for initial treatment of moderate to severe depression in young people (12–18 years), as an alternative to psychological therapy followed by combined therapy and to recommendations 1.6.2.2–1.6.2.4. | The resource for use in the NHS says that fluoxetine is often prescribed after or with a course of therapy. It doesn’t specify age for receiving fluoxetine but does say that fluoxetine can help young people with low mood (rather than children). The resource meets this recommendation. | Criterion met |
| 3.5 | 1.6.4.3 When an antidepressant is prescribed to a child or young person with moderate to severe depression, it should be fluoxetine[4] as this is the only antidepressant for which clinical trial evidence shows that the benefits outweigh the risks. | Fluoxetine is the only medication mentioned in the resource for use in the NHS. The resource says that there is evidence the SSRI fluoxetine can help young people with low mood. The resource meets this recommendation. | Criterion met |
| 3.6 | 1.6.4.5 A child or young person prescribed an antidepressant should be closely monitored for the appearance of suicidal behaviour, self-harm or hostility, particularly at the beginning of treatment, by the prescribing doctor and the healthcare professional delivering the psychological therapy. Unless it is felt that medication needs to be started immediately, symptoms that might be | The resource for use in the NHS says that you will usually have height, weight, blood pressure, pulse and mental health assessment. It doesn’t specify that this will be before treatment is started. It would be helpful to add these details to the resource. It says that a member of the team will regularly check for side effects but it doesn’t tell children and young people that they or their parents or carers should make urgent contact with the prescribing doctor if certain mental health symptoms develop. This is an important part of the recommendation and should be added to the resource because knowledge of this could avoid serious harms. The resource needs to have some more detail added before it can fully meet the recommendation. | Criterion not fully met |
| subsequently interpreted as side effects should be monitored for 7 days before prescribing. Once medication is started the patient and their parent(s) or carer(s) should be informed that if there is any sign of new symptoms of these kinds, urgent contact should be made with the prescribing doctor. |  |