

**What approaches for promoting shared decision making are used in child mental health? A scoping review.**

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**Conflicts of interest**

Daniel Hayes, Julian Edbrooke-Childs, Louise Chapman and Miranda Wolpert work at the Evidence Based Practice Unit (EBPU) which, alongside Kate Martin, has developed and evaluated, in-house, some of the approaches (My CAMHS Choices, IncludeME/PACT, Choosing What's Best for You) included in the scoping review.

## **Abstract**

**Objective:** Whilst the benefits of shared decision making (SDM) have been promoted across different health settings, its implementation is complex, particularly for children and young people with mental health difficulties. The aim of this scoping review was to identify and describe SDM approaches (tools, techniques, and technologies) used in child and youth mental health.

**Method:** Electronic databases and grey literature were searched. Papers were included if they satisfied these criteria: English language; described an SDM approach (tool, technique, or technology); included sufficient detail on the SDM approach for quality assessment; did not use only a questionnaire to provide feedback on SDM or related concepts (e.g., therapeutic alliance) without another SDM approach; child or adolescent population (up to 18 years); carers of children or adolescents; and mental health setting. Screening and data extraction were performed by two co-authors and each included record was quality assessed against a set of essential ingredients of SDM identified by previous studies

**Results:** Of the 8,153 initial results, 22 were eligible for final inclusion. These could be grouped into six approaches: therapeutic techniques, psychoeducational information, decision aids, action planning or goal setting, discussion prompts, and mobilising patients to engage. The quality of approaches identified ranged from one to seven of the nine essential elements of SDM.

**Conclusion:** Evidence suggests that a range of approaches are being developed to support SDM in child and youth mental health. Rigorous research evaluating the effectiveness of these approaches is urgently needed, particularly from the perspective of children and young people.

**Keywords:** SDM Approaches; Mental Health; Children; Adolescents

## **What approaches for promoting shared decision making are used in child and youth mental health? A scoping review**

Shared decision making (SDM) is defined as a process in which patients and clinicians work in partnership to make decisions about care and treatment (Coulter & Collins, 2011; The Health Foundation, 2014). These decisions may focus on, but not be limited to: tests for screening, undergoing procedures, participating in self-help or psychological interventions, whether or not to take medication, and whether to make changes to the patient's lifestyle (Coulter & Collins, 2011). The last 15 years have seen a rapid expansion of research and policy documentation related to SDM (Makoul & Clayman, 2006), and increasingly SDM is seen as the hallmark of excellent healthcare (The Health Foundation, 2012). Internationally, bodies such as the United Nations and the World Health Organisation have called for the inclusion of young people in decisions when it comes to their care and treatment (United Nations Convention on the Rights of the Child, 1989; World Health Organization, 2012), and specific recommendations to include young people with mental health difficulties at a national level can be seen in countries such as the USA (SAMHSA, 2008), Australia (Australian Health Disaster Management Policy Committee, 2009), and the UK (British Psychological Society Division of Clinical Psychology, 2001; Department of Health, 2012).

There are a number of different approaches to implementing SDM within healthcare settings, which lie on a continuum of participation ranging from passive to active participation (Da Silva, 2012, p. V). Passive approaches to SDM focus on information provision rather than supporting the patient in making decisions (Da Silva, 2012, p. V). Such approaches include prompts for professionals, printed and electronic information, and patient-held records. Conversely, more active approaches include action planning and goal setting, mobilising patients to engage, and training professionals to engage. Unlike passive

approaches, active ones focus on a constructive and interactive dialogue between the clinicians and patients where clinicians encourage and support the patient (Da Silva, 2012, p. V). However, whilst these approaches have been classified on this continuum, it is not known whether certain approaches are related to better child mental health outcomes.

Implementing and using SDM within child and youth mental health raises a number of challenges, and can be complex (Légaré, Ratté, Gravel, & Graham, 2008). Challenges include whether young people have the skills to be able to make decisions about their care and treatment (Ruhe, Wangmo, Badarau, Elger, & Niggli, 2014), and whether this is further compounded by a mental health difficulty (Fonagy, Steele, Steele, Moran, & Higgitt, 1991). SDM can also cause clinicians to feel apprehensive about the consequences of changing their practice, the possible risks, or to be conscious of why the approaches may not work (Abrines-Jaume et al., 2014). A recent review of barriers and facilitators around involving young people in care and treatment identified 23 studies, and concluded that barriers were roughly equivalent across different child and youth mental health settings. Importantly, barriers were identified at all levels of care, including the professional level, relationship level, service user/carer level, service level, and context level (Gondek et al., 2017)<sup>1</sup>. Despite these barriers, there is increasing commitment to implementing and embedding SDM in routine practice (Richter, Halliday, Grømer, & Dybdahl, 2009; Soffe, Read, & Frude, 2004). Evidence from routinely collected data suggests that higher levels of both child- and parent-reported experience of SDM are associated with higher levels of child- and parent-reported improvement in psychosocial difficulties (Edbrooke-Childs et al., 2015).

There have been two recent reviews of SDM interventions in child health (Feenstra et al., 2014; Wyatt et al., 2015). The first review identified five papers, with the SDM components being either decisional coaching or an educational workshop, supported by

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<sup>1</sup> Frequent mentioned factors influencing care included: information sharing, feeling listened to, respected, validated, the quality of the relationship and support given, parental involvement, a shortage of resources, having choice and autonomy, and flexibility over options.

computer programmes, workbooks, follow-up sessions, and information provision (Feenstra, et al., 2014). Findings suggested that interventions were associated with higher levels of congruence between the child and parent, child-reported satisfaction with the decision, and decision-making quality (Feenstra, et al., 2014). The second review identified 54 interventions consisting of a variety of approaches including, but not limited to, information provision and decision aids in paper, electronic and online formats, workshops, and structured family interventions (Wyatt, et al., 2015). Results from the meta-analysis found that SDM interventions were associated with lower levels of decisional conflict and higher levels of knowledge (Wyatt, et al., 2015). Still, the majority of included studies were from child physical (not mental) health settings. In addition, as SDM in child and youth mental health is a recent, emerging field, many relevant approaches may be published in the grey literature, making them harder to locate and include in systematic reviews. To develop effective interventions and approaches to support SDM in child and youth mental health, we need to understand what the existing approaches are, and their quality in terms of incorporating essential elements of SDM. Therefore, the aim of the present study was to conduct a scoping review to identify and describe SDM approaches (tools, techniques, and technologies) used in child and youth mental health.

### **Method**

A scoping review was conducted drawing on systematic review methods using a protocol (available from authors), which was developed and based on previous reviews (Feenstra, et al., 2014; Wyatt, et al., 2015) and adhered to PRISMA (Moher et al., 2015; Shamseer et al., 2015). It has been described as a process of mapping the existing literature more qualitatively, and typically not quantitatively (Arksey & O'Malley, 2005). Based on best practice guidelines (Higgins & Green, 2008), the review involved the stages described below; an overview of the stages is presented in Figure 1.

## **Search strategy**

A search strategy was developed, which included three concepts: 1) SDM and related terms (e.g., client/patient choice, informed choice, client participation, decision aids, therapeutic alliance, common goals); 2) child, young person, adolescent, or parent/carer; 3) mental health (e.g., anxiety, depression, behavioural problems). Search terms were included for each concept using the Boolean operator ‘OR’, and concepts were combined using the operator ‘AND’; search terms for each database were mapped using database bibliography tools and a mixture of key word and subject headings (The preliminary search terms and the final search terms are listed in Appendix A and Appendix B respectively).

Searches were conducted in a variety of databases: PsycINFO (1806 to September 2016), Ovid MEDLINE (1946 to September 2016), EMBASE (1980 to September 2016), PubMed, Web of Science (1900 to September 2016), and the Cochrane Libraries (Central and Reviews). Extracted records from each of the above mentioned databases were exported to Endnote, through which the duplicated records were identified and excluded. In addition, grey literature was searched, including key websites (e.g., the Cochrane database of patient decision aids, Health Foundation, King’s Fund). A Facebook group of SDM experts was consulted for any additional resources. Reference lists of included articles were hand searched, and articles citing included references were tracked. Google Scholar was also searched using key words from the search strategy.

## **Inclusion criteria and search flow (see Figure 1 for details)**

The following criteria was used for inclusion in this scoping review: 1) Record written in English language, 2) Described an SDM approach (tool, technique, or technology), 3) Included sufficient detail on the SDM approach for quality assessment, 4) Did not use only a questionnaire to provide feedback on SDM or related concepts (e.g., therapeutic alliance) without another SDM approach, 5) Included a child or adolescent population (up to 18 years),

or, 6) Included carers of children or adolescents , 7) Facilitated SDM within a child and youth mental health service or setting .

The search identified 8,153 potentially relevant records and 30 additional records through hand searching and grey literature (Step 1: Identification). After excluding duplicates, 6,876 records were identified for the screening of titles and abstracts by the joint first co-authors (first stage screening). One (HC) screened all records at this stage, with the second (DH) screening 20% (n = 1,400) of the total records title and abstracts. Interrater reliability between the two co-authors was computed for first stage screening (Kappa = .76, which demonstrates a high level of agreement). The exclusion of records at this stage was based on three criteria (did not describe an SDM approach but merely used the term “SDM” in the record; adult population not in the context of caring for children or adolescents; and were not based in mental health services or settings). A substantial amount of records (n = 6,482) were excluded with records pertaining to physical health and adult populations..

Following this, 394 records underwent a full-text screening (second stage screening in which they were assessed for eligibility). The most frequent reason for exclusion at this stage were that the record did not include a SDM approach or tool (n = 370). In total, 12 retrieved records and 10 hand-searched records met the inclusion criteria. The full text records of included articles were retrieved and screened for final inclusion by both reviewers (HC and DH) and any disagreements were resolved by discussion. Both reviewers then independently extracted data from included articles. Fields extracted included: author, year, country, study design, sample size, gender and age of participants, description of the SDM approach included, category of SDM approach (i.e., tool, technique, or technology), and evidence of evaluation of the approach (if applicable). For irretrievable papers, two attempts were made to contact the first two co-authors. For records/tools that had no obvious evaluation attached,

two attempts were made to contact authors or organisations who developed or owned the tool to see if any evaluation was available.

[INSERT FIGURE 1 HERE]

### **Data synthesis and quality assessment**

The heterogeneity in approaches of the included papers, study design, methods, and measures used precluded the pooling of results for meta-analysis. In line with the research question and scoping review method (Arksey & O'Malley, 2005), meta-analysis was also not seen as appropriate, as the primary aim was not to investigate effectiveness. A narrative synthesis (Popay et al., 2006) was conducted summarising the similarities and differences between the approaches found.

Following this, each of the approaches included was quality assessed against the nine essential elements of SDM. These are: patient values/preferences, options, professional knowledge/recommendations, make or explicitly defer a decision, define/explain the problem, check/clarify understanding, benefits/risks, discuss patient ability/self-efficacy, and arrange follow up (Makoul & Clayman, 2006).

### **Results**

The 22 records that met inclusion criteria are presented in Tables 1 and 2.

[INSERT TABLES 1 and 2 HERE]

Table 1 shows the descriptive information of the included studies and SDM approaches. Overall, six approaches of SDM were classified among the 22 records. They are:



therapeutic techniques, decision aids, psychoeducational information, action planning or goal setting, discussion prompts, and mobilising patients to engage.

Table 2 shows the results of the quality assessment agreed by two co-authors (DH and LC) against the nine elements of SDM synthesised (Makoul & Clayman, 2006).

### **Therapeutic techniques to support SDM**

Two retrieved records included distinct therapeutic techniques for facilitating SDM in child and youth mental health. These were a framework to support SDM in youth mental health medication treatment (Crickard, O'Brien, Rapp, & Holmes, 2010: *record 3*), and Counseling in Dialogue (Westermann, Verheij, Winkens, Verhulst, & Van Oort, 2013: *record 4*). The models and therapeutic approaches were diverse in target groups. The medication framework was aimed at young people aged 14–17 and their parents with clinicians (Crickard, et al., 2010), whilst Counseling in Dialogue (Westermann, et al., 2013) was aimed at parents and clinicians. None of these approaches were specific to a certain mental health diagnosis.

Examining these against essential elements of SDM (Makoul & Clayman, 2006), the medication framework (Crickard, et al., 2010) included four of the essential elements: 'expressing preferences', 'making or deferring a decision', 'defining or explaining a problem', and 'discussing risks and benefits'. No evaluation was available on the medication framework. Counseling in Dialogue (Westermann, et al., 2013) fulfilled six of the essential elements: 'presenting options', 'making or deferring a decision', 'defining or explaining a problem', 'discussing risks and benefits', 'discussing efficacy', and 'arranging follow up'. An evaluation of Counseling in Dialogue (Westermann, et al., 2013) found that parents who were randomly assigned to receive the intervention reported significantly less decisional conflict and were more likely to accept the recommended treatment option.

## Decisions aids

Ten retrieved records included decision aids to promote and support SDM. Split into diagnostic categories, three were aimed at populations with a diagnosis of depression (Healthwise 2015a: *record 8*; Simmons, 2011: *record 13*; Simmons, Elmes, Trevena, & Hetrick, 2016: *record 18*), three aimed at attention deficit hyperactivity disorder (ADHD) (Brinkman et al., 2013: *record 2*; Healthwise 2015b: *record 7*; Ossebaard, van Gemert-Pijnen, Sorbi, & Seydel, 2010: *record 16*), three aimed at autism spectrum disorder (ASD) (Grant, 2016: *record 21*; Autism Speaks, 2011: *record 5*; AHRQ, 2014: *record 22*), and one which was not diagnosis specific (Evidence Based Practice Unit, 2015: *record 6*).

Of the decision aids aimed at depression, two were aimed at young people with a diagnosis of depression, one for moderate/severe depression (Simmons, 2011), and one for all types of severity (Simmons, et al., 2016). The other decision aid was aimed at parents of young people around medication (Healthwise, 2015a). Of the decision aids aimed at depression, two were aimed at young people with a diagnosis of depression, one for moderate/severe depression (Simmons, 2011), and one for all types of severity (Simmons, Elmes, Trevena, & Hetrick, 2016). The other decision aid was aimed at parents of young people around medication (Healthwise, 2015a). The decision aids aimed at young people with moderate/severe depression (Simmons, 2011) contained seven of the essential elements of SDM including: ‘expression of preferences/values’, ‘presenting options’, ‘professional recommendations’, ‘defining or explaining a problem’ ‘check/clarify understanding’, ‘discussing risks and benefits’, and ‘arranging follow up’. A pilot feasibility study of the decision aids for young people with moderate/severe depression suggested they found the decision aid to be useful and acceptable, that it helped them know the risks and benefits, and that it helped them make an informed choice (Simmons, 2011). The decision aid for all types

of depression severity (Simmons, et al., 2016) scored five of the essential elements of SDM, as we were only able to judge from the paper. These included: ‘expression of preferences/values’, ‘presenting options’, ‘professional recommendations’, ‘make or defer a decision’, and ‘define/explain a problem’. It was found that young people who used it were more satisfied with their decision, had reduced decisional conflict, and were more able to make a decision (Simmons, et al., 2016). The decision aid aimed at parents of children with depression considering medication (Healthwise, 2015a) contained seven of the essential elements of SDM: ‘expression of preferences/values’, ‘presenting options’, ‘professional recommendations’, ‘making or deferring a decision’, ‘check/clarify understanding’, ‘discussing risks and benefits’ and ‘discussing efficacy’. No evaluation was available.

All ADHD decision aids were aimed at parents of young people with this diagnosis (Brinkman, et al., 2013; Healthwise, 2015b; Ossebaard, et al., 2010). The first ADHD decision aid consisted of a series of choice cards from America. It included seven of the essential elements of SDM: ‘expression of preferences/values’, ‘presenting options’, ‘professional recommendations’, ‘making or deferring a decision’, ‘defining or explaining a problem’, ‘check/clarify understanding’ and ‘discussing risks and benefits’. Findings from an evaluation of choice cards suggested parents who used them were more involved in shared decision making, were more knowledgeable, and less conflicted about treatment options. The second decision aid, an online tool from Canada (Healthwise, 2015b), contained seven of the essential elements of SDM: ‘expression of preferences/values’, ‘presenting options’, ‘professional recommendations’, ‘making or deferring a decision’, ‘check/clarify understanding’, ‘discussing risks and benefits’ and ‘discussing efficacy’. No evaluation was available. The last ADHD decision aid, an online tool from the Netherlands (Ossebaard, van Gemert-Pijnen, Sorbi, & Seydel, 2010), contained four of the essential elements of SDM: ‘presenting options’, ‘professional recommendations’, ‘make or defer decision’, and

‘discussing risks or benefits’. A small scale evaluation found no difference in decisional outcome.

All ASD decision aids were aimed at parents of young people with this diagnosis (AHRQ, 2014; Grant, 2016; Autism Speaks, 2011). The first decision aid specifically addressed whether medication was necessary to manage challenging behaviour (Autism Speaks, 2011). When assessed against the essential elements of SDM, the decision aid was found to have seven essential elements of SDM: ‘expression of preferences/values’, ‘presenting options’, ‘professional recommendations’, ‘making or deferring a decision’, ‘define/explain a problem’, ‘check/clarify understanding’, and ‘discussing risks and benefits’. An evaluation found that parents who were randomised to use the decision aid were more involved in SDM, had lower decisional conflict, and were more likely to have their priorities for their child’s behaviour addressed than those in the control condition (Anixt, 2015). The second decision aid outlined a number of early intervention (non-medication) options for ASD (Grant, 2016). It contained four of the essential elements of SDM, including ‘expressing values’, ‘presenting options’, ‘professional recommendations’, and ‘discussing risks or benefits’. A pilot RCT found no significant difference on decisional conflict or self-efficacy between parents who used the decision aid and those who did not (Grant, 2016). The last decision aid outlined intervention options, including medication, for ASD (AHRQ, 2014). It contained six of the essential elements of SDM: ‘expressing values’, ‘presenting options’, ‘professional recommendations’, ‘define/explain problem’, ‘check or clarify understanding’, and ‘discussing risks or benefits’. No evaluation was available.

The last decision aid, IncludeMe /PACT (Evidence Based Practice Unit, 2015) (note some authors of this paper were involved in the development of this tool; see COI), was not diagnosis specific. It also spanned both the approaches ‘action planning/goal setting’ and ‘information’. In terms of quality assessment, it contained six of the essential elements of

SDM: ‘patient values’, ‘presenting options’, ‘professional recommendations’, ‘making or deferring a decision’, ‘discussing risks and benefits’, and ‘discussing efficacy’. A questionnaire study of young people who used the decision aid found that young people felt it helped them open up and encouraged communication with clinicians (Ellis, Wolpert, Kay, & White, 2016).

### **Psychoeducational information**

Provision of information to assist SDM was identified in four of the retrieved records (Evidence Based Practice Unit, 2014: *record 9*; Murphy, Gardner, Kutcher, Davidson, & Manion, 2010: *record 11*; Evidence Based Practice Unit, 2007: *record 14*; Evans, Armstrong, Thompson, & Lee, 1994: *record 15*).

My CAMHS Choices (Evidence Based Practice Unit 2014) (note some authors of this paper were involved in the development of this tool; see COI) is an online resource providing information to young people aged 10–18 years and their families about what to expect at CAMHS, with the explicit aim of promoting greater collaboration in decision making. In terms of quality assessment, My CAMHS Choices (Evidence Based Practice Unit 2014) included two of the essential elements of SDM: ‘presenting options’ and ‘professional recommendations’. In terms of evaluation, it was found that the website was likely to have a direct influence on young people’s likelihood to attend appointments, to express opinions, and ask questions (Kyrke-Smith & Edbrooke-Childs, 2014). Clinicians were also able to identify the direct use of My CAMHS Choices in supporting informed choice (Kyrke-Smith & Edbrooke-Childs, 2014).

The Med Ed passport (Murphy, Gardner, Kutcher, Davidson, & Manion, 2010) is an information booklet aimed at young people needing to make decisions on medication. It also contains a list of discussion prompts that young people may want to ask clinicians. The Med

Ed passport (Murphy, et al., 2010) contained five essential elements of SDM: ‘presenting options’, ‘professional recommendations’, ‘check/clarify understanding’, ‘discussing risks and benefits’ and ‘discussing efficacy’. Findings from the evaluation suggest it may be useful in conversations with clinicians about medication, but the small sample size included ( $n = 3$ ) makes findings tentative (The Provincial Centre of Excellence for Child and Youth Mental Health at CHEO, 2009).

Choosing What’s Best for You (Evidence Based Practice Unit, 2007) (note some authors of this paper were involved in the development of this tool; see COI) is a booklet aimed at young people and their families outlining different treatment options. It is based on the evidence outlined in What Works For Whom (Fonagy, Target, Cottrell, Phillips, & Kurtz, 2002). Choosing What’s Best for You (Evidence Based Practice Unit, 2007) contained two of the essential elements of SDM: ‘presenting options’ and ‘professional recommendations’. No evaluation was available.

The last record identifying information provision as part of SDM focused on a service improvement initiative for parents of young people with emotional and behavioural disorders (Evans, Armstrong, Thompson, & Lee, 1994). It included information, both written and in video format, on diagnosis, treatment, parenting support and groups, and special education for young people (Evans, et al., 1994). It contained three of the essential elements of SDM: ‘expressing values’, ‘professional recommendations’, and ‘define/explain problem’. No evaluation was available.

### **Action planning and goal setting**

Action planning and goal setting were a feature of three retrieved records (Cheshire and Wirral NHS Foundation Trust, 2012: *record 12*; Fiks et al., 2012: *record 10*; Law, 2006: *record 9*). Goal Based Outcomes (Law, 2006) are a way to promote and evaluate progress

towards goals in clinical work with children, young people, and their families. In terms of the quality assessment (Makoul & Clayman, 2006), Goal Based Outcomes scored two of the essential elements: ‘patient values’ and ‘professional recommendations’. Whilst no individual study was available, a meta-analysis into goal-based outcomes concluded that outcomes improve the more that clients and therapists agree on goals and methods, and form collaborative working relationships to implement those agreements (Tryon & Winograd, 2011)

Next Step Cards (Cheshire and Wirral Partnership NHS Foundation Trust, 2012) are a set of cards which help young people and their families in setting and achieving their own mental health goals. In terms of quality assessment against Makoul and Clayman’s essential elements (Makoul & Clayman, 2006), Next Step Cards (Cheshire and Wirral Partnership NHS Foundation Trust, 2012) scored two: ‘patient values’ and ‘presenting options’. No evaluation was available.

The last approach using goals and action planning was a tool containing questions used to examine parents’ concerns of treatment, beliefs about treatment and goals of therapy (Fiks et al., 2012). The tool helps parents of young people with ADHD to decide what to focus on in treatment. In terms of quality assessment against Makoul and Clayman’s essential elements (Makoul & Clayman, 2006) it contained four of the essential elements of SDM: ‘expressing values’, ‘presenting options’, ‘professional recommendations’, and ‘discussing risks or benefits’. An evaluation of the tool/questionnaire to ascertain treatment preferences found that parents of young people who initiated medication or behavioural treatment had decreased academic and behavioural goals at six months (Fiks, Mayne, Debartolo, Power, & Guevara, 2013).

## **Discussion prompts**

Discussion prompts were a feature of four retrieved records (Ahmed, McCaffery, & Aslani, 2015: *record 1*; Chesire and Wirral Partnership NHS Foundation Trust, 2012: *record 10*; Law, 2006: *record 12*; Murphy, et al., 2010: *record 11*). Three of these have been covered previously (see *information* for the Med Ed Passport (Murphy, et al., 2010), and *action planning and goal setting* for the Goal Based Outcomes resources Goal setting and Next Step Cards (Chesire and Wirral Partnership NHS Foundation Trust, 2012; Law, 2006)). The fourth approach was a question prompt list (QPL) which covered a list of questions relating to ADHD care, treatment, and support for parents.

Examining discussion prompts against the key elements of SDM, the QPL (Ahmed, et al., 2015) fulfilled six essential elements: ‘presenting options’, ‘professional recommendations’, ‘defining or explaining a problem’, ‘check/clarify understanding’, ‘discussing risks and benefits’, and ‘arranging follow up’. A pilot evaluation of the QPL found that, when used, parents asked more questions and found the QPL easy to understand (Ahmed et al., 2016).

### **Mobilising patients (or parents) to engage**

Mobilising patients to engage was a feature of two retrieved records: an approach aimed at increasing motivational readiness of young people to engage in decision making (Adelman, MacDonald, Nelson, Smith, & Taylor, 1990: *record 20*); and a parent training programme for parents of young people with conduct disorder, in which parents explicitly picked the treatment they wanted (He, Gewirtz, Lee, Morrell, & August, 2016: *record 19*). The approach aimed at increasing motivational readiness for decision making contained one of the essential elements of SDM: ‘expressing values’. An evaluation found that there were no differences in motivational readiness, ability to participate, or participation between participants who received the intervention and those that did not (Adelman, et al., 1990). The



parent training programme contained three of the essential elements of SDM: ‘expressing values’, ‘presenting options’, and ‘make or defer decision’. An evaluation found that those in the intervention condition were more likely to stay in treatment than those that had no choice (He, et al., 2016).

## **Discussion**

Due to the increasing emphasis on SDM in child and youth mental health both nationally and internationally, the aim of this paper was to conduct a scoping review into approaches used to facilitate SDM in this context. Research into this area is needed as SDM in child and youth mental health is relatively new, and whilst reviews have been conducted in child health and paediatrics (Feenstra, et al., 2014; Wyatt, et al., 2015), they may have missed more recent studies, as well as approaches in grey literature.

Overall this scoping review found six approaches across 22 retrieved records. In terms of approaches, this review is the first to categorise and outline different approaches as suggested by The Health Foundation (Da Silva, 2012). A previous review looking at approaches to child engagement (Feenstra, et al., 2014) identified two types of approaches: coaching (which we would categorise as ‘mobilising patients to engage’) and education (which we would categorise as ‘psychoeducational information’). However, this review highlights the broad nature of interventions and approaches, which may be used to facilitate SDM in child and youth mental health.

Of the records included in this review, 12 were aimed at parents (Ahmed, et al., 2015; AHRQ, 2014; Brinkman, et al., 2013; Evans, et al., 1994; Fiks, et al., 2012; Grant, 2016; He, et al., 2016; Healthwise 2015a; Healthwise 2015b; Ossebaard, et al., 2010; Autism Speaks, 2011; Westermann, et al., 2013), eight were aimed at children or young people (Cheshire and Wirral Partnership NHS Foundation Trust, 2012; Crickard, et al., 2010; Evidence Based

Practice Unit, 2007; Evidence Based Practice Unit 2014; Evidence Based Practice Unit, 2015; Murphy, et al., 2010; Simmons, 2011; Simmons, et al., 2016), and two were aimed at both parents and young people (Evidence Based Practice Unit, 2007; Law, 2006). In line with previous research (Wyatt, et al., 2015), the majority of records included in this review were conducted solely with parents. However, the number of retrieved records outlining an approach including only young people was substantially higher than the 7% identified by Wyatt (Wyatt, et al., 2015) (36% in this review).

With regard to evaluation, it was found that seven (32%) of the included records had no type of formal evaluation attached to them. This again is less than the review by Wyatt (Wyatt, et al., 2015) which found that around half of included studies had no evaluation. In addition, the number of RCTs was lower than those found by Wyatt (Wyatt, et al., 2015) (25% vs 18% respectively). This review is also the first that uses the nine essential elements of the Makoul and Clayman's (2006) integrative model, an acknowledged set of criteria in the SDM area which are used in other studies (Bouniols, Leclère, & Moret, 2016). These criteria evaluate the six SDM approaches used in child and youth mental health, in order to make the strengths and weaknesses of these approaches qualitatively comparable. However, as mentioned above, although the importance of SDM involving children and their carers is increasingly recognised in clinical settings, rigorous evaluation of such approaches is largely lacking.

Approaches that scored higher on the quality assessment framework tended to be decision aids. One possible reason for this may be because developers of decision aids can use the International Patient Decision Aid Standards (IPDAS) checklist which provides information on content, development and effectiveness, meaning that areas are less likely to be missed. In contrast, goal-based outcomes and information provision tended to score lower. For information provision, a possible explanation could be the passive way information is

shared with the patient (Da Silva, 2012). However, goal setting is defined as an active approach (Da Silva, 2012), suggesting other reasons may also contribute to lower scores. Alternatively, certain approaches, particularly those that are seen as more flexible and patient led, may not lend themselves well to this type of quality assessment.

In the original review of conceptual definitions of SDM by Makoul and Clayman (Makoul & Clayman, 2006), the most prevalent essential elements were ‘patient values/preferences’, ‘presenting options’, and ‘discussing risks/benefits. In this scoping review, the most common elements were ‘presenting options’, ‘professional recommendations’ and ‘patient values’. This subtle difference of risks/benefits versus professional recommendations could highlight clinician challenges in discussing the risks and benefits to parents and young people, instead preferring to make professional recommendations. It should also be considered that concepts of SDM may be different in child and youth mental health, and that the essential elements by Makoul and Clayman (Makoul & Clayman, 2006) may be less relevant as they draw on a largely adult, physical health literature base.

Findings from this review provide preliminary support for the argument that SDM can have some favourable outcomes in certain circumstances. Three of four RCTs included suggest that parents who engage in approaches to facilitate SDM were more likely to stick to the intervention provided (He, et al., 2016), have lower decisional conflict and continue engaging with the recommended treatment (Westermann, et al., 2013). Parents were also more likely to experience less decisional conflict and have their priorities addressed in the treatment plan (Anixt, 2015). In particular, the findings of reduced decisional conflict are consistent with the meta-analysis conducted by Wyatt (Wyatt, et al., 2015). However, the last RCT (Grant, 2016) found no difference in outcomes between control and intervention groups for self-efficacy and decisional conflict. A possible reason for no difference being found

could be that, unlike other tools, this decision aid was not used in the presence of a healthcare professional or healthcare setting. This could lead to less opportunity for parents to seek clarification from a healthcare professional when questions arise and when support is needed. Thus, such parents may be similar to those in the control arm who are searching for options for help and support. Differences in outcomes could suggest a more complex picture between SDM approaches, presenting problems, and outcomes, particularly as most of these studies utilised different approaches (mobilising patients to engage, model or therapeutic approach, and use of decision aids).

Findings from other included records suggested that young people and parents found interventions useful. However, as highlighted by authors in previous reviews (Feenstra, et al., 2014; Wyatt, et al., 2015), many studies around SDM are focused on small non-randomised pilot, feasibility, or acceptability studies which could lead to biases in selection and reporting. Moreover, some evaluations gathered as part of this review have not been subject to peer review in academic journals (Anixt, 2015; Ellis, et al., 2016; Kyrke-Smith & Edbrooke-Childs, 2014; The Provincial Centre of Excellence for Child and Youth Mental Health at CHEO, 2009). In this respect, whilst many of the findings look favourable, these must be treated cautiously and more rigorous methodologies employed to understand whether this is actually the case. The impact of SDM approaches on clinical outcomes has also not been examined, supporting previous reviews that little, if any, research exists within child and youth mental health (Feenstra, et al., 2014; Wyatt, et al., 2015). Nevertheless, the current study may serve as a useful guideline for those institutions and health service organisations that are keen to implement an SDM approach for children and young people in their care. However, further research is needed to establish the effect of SDM on clinical outcomes, as well as whether such approaches are cost effective.

Limitations should be considered when interpreting the findings of the present research. Firstly, only 20% of records were reviewed by both reviewers (DH and HC) at first screening, meaning that differences of opinion could have affected the inclusion of some studies for full text screening. Secondly, due to a lack of empirical papers from controlled trials examining the effectiveness of SDM approaches with young people in child mental health, there were insufficient data to perform a meta-analysis or draw concrete conclusions about the impact of SDM approaches. With no measures validated for use with young people around SDM, the ability to draw conclusions from the perspective of the young person may still be a way off. As such, the authors put forward the urgent need to develop measures for young people so that SDM approaches in such populations can be evaluated. A further limitation of the research is a lack of commonly used definitions of the concept of SDM (Wyatt, et al., 2015), particularly when three or more parties are involved. Further work needs to be undertaken to understand what SDM means in this context in order to make meaningful comparisons between approaches as the evidence base continues to grow.

Despite these limitations, evidence from the present review suggests that six different approaches are being implemented to facilitate SDM in child and youth mental health. These consist of: therapeutic techniques, decision aids, psychoeducational information, action planning or goal setting, discussion prompts, and mobilising patients to engage. Using such approaches to facilitate SDM has been shown to help redress the power balance between young people and clinicians, clarify different aspects of the treatment and decision-making process for both young people and clinicians, as well as helping with engagement (Abrines-Jaume, et al., 2014).

However, in order to be most effective, clinicians must also engage in positive behaviours to facilitate shared decision making, namely trust, flexibility and extra effort (Abrines-Jaume, et al., 2014). Trust between clinicians, young people and parents is seen as

a crucial factor for shared decision making to happen. This includes being open and honest about options, engaging in conversations around difficult decisions, and the need to compromise on aspects of care, such as who is involved, and agreeing what problems to focus on. Effort was also seen as another important behaviour needed by clinicians to engage in shared decision making, with young people requiring more time to understand options and being able to reflect on their own views and preferences. Lastly, the need to be flexible with SDM approaches was highlighted as important due to the range of ages, developmental abilities, and presenting problems seen in child and youth mental health. This often meant adapting existing approaches so that they were suitable for the individual in question.

Given the above, possible ways to help engrain SDM in practice could include further training for professionals and healthcare students on decision making, particularly around difficult decisions, resource databases of tools to help facilitate SDM, and longer assessment appointments, particularly for young people with ASD or learning difficulties.

As such, this review may serve to provide examples and guidelines for professionals to improve collaboration and decision making with young people and parents/carers in mental health settings. It may also provide professionals and practitioners with a range of approaches that they may wish to build and expand on within their own countries and communities, particularly in non-western countries where no approaches in this review were located. Flexibility in how to use approaches in clinical practice is required, including an understanding that approaches may not always be useful and may have to be used differently with patients in order to be meaningful. The flexibility to adapt approaches to the specific needs of children, young people, and families is essential.

[INSERT TABLE 3]

## Contributions

MW is the guarantor. HC, DH and JC drafted the manuscript. All authors contributed to the development of the selection criteria, the risk of bias assessment strategy and data extraction criteria. HC and DH developed the search strategy and HC conducted the initial search. DH screened 20% of the initial search, and 100% of the full-text eligible records. DH conducted the quality assessment against essential elements of SDM and LC and HC re-evaluated the results. JC provided guidance for the SDM review. MW, DH, KM and JC provided expertise on SDM literature in clinical settings. KM contributed to the section on SDM implementation. All authors read, provided feedback and approved the final manuscript

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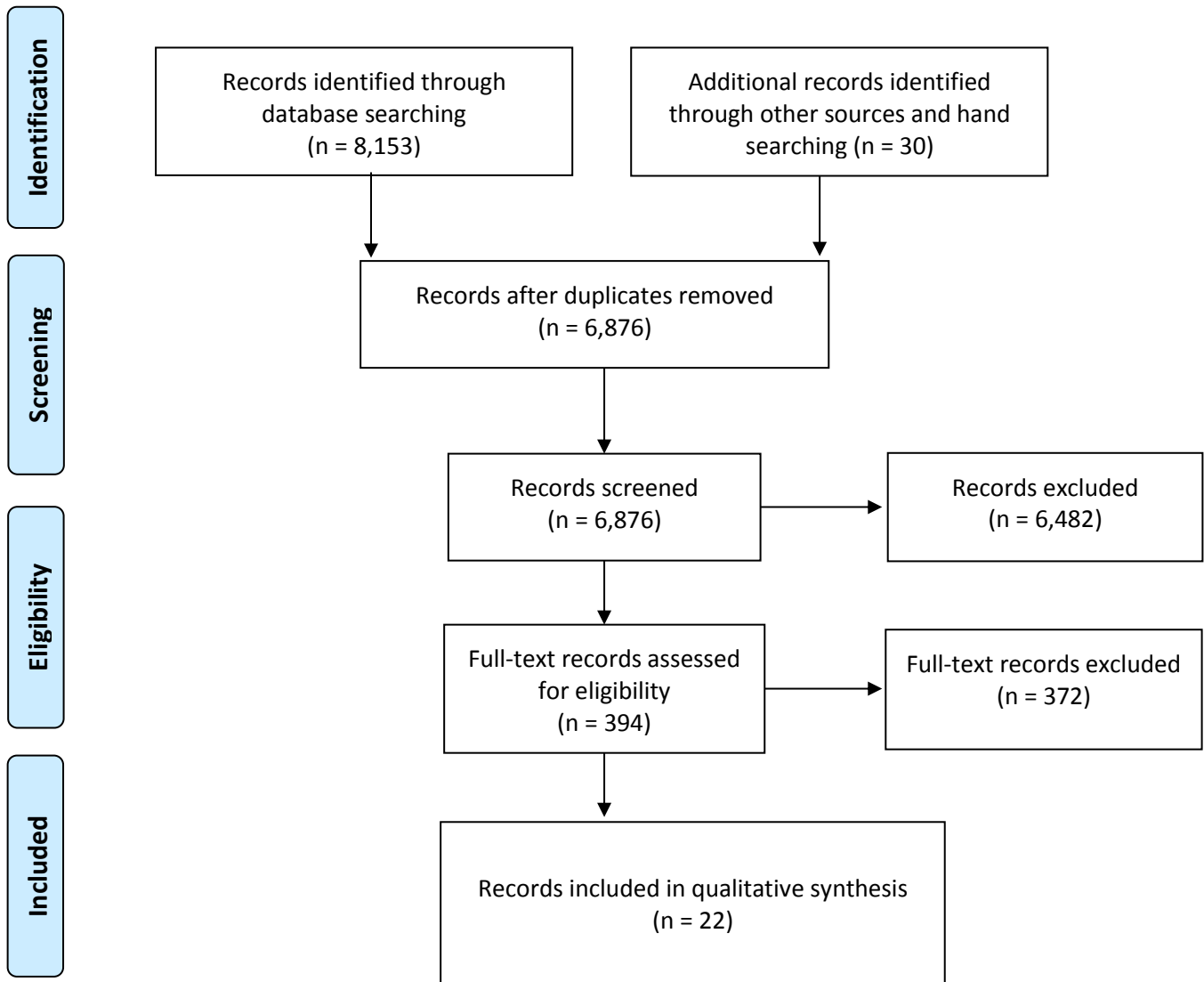


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Figure 1. Search flow chart.



**Table 1. Characteristics of papers on shared decision making (SDM) in child and youth mental health.**

	Author and Country	Intervention target audience	Intervention	Approach	Tools/techniques/technologies	Study design, and sample size*	Evaluation results
1	Ahmed et al. (2015). Australia	M/F Parents of children with ADHD.	A Question prompt list (QPL) intended to encourage parent question-asking during consultations with clinicians around ADHD.	Discussion prompt	88 questions covered key topics including diagnosis, understanding ADHD, treatment, health-care team, monitoring ADHD, managing ADHD, future expectations, and support and information.	Ahmed et al., (2016): Pre/post questionnaire study. Sample size 17 parents and 3 paediatricians.	Parents reported the QPL led them to ask more questions, was easy to use, and easy to understand.
2	Brinkman et al. (2013). USA.	M/F Parents of children (age 6–10) with ADHD.	Decision cards detailing information related to ADHD medication with five domains: cost, duration, improvement, daily routine, and side effects.	Decision aid	ADHD medication choice cards: Adaption from an established issue card format that facilitates SDM. The issue cards convey the attributes of ADHD medications that are important to consider, namely: <ul style="list-style-type: none"> <li>- Improvement</li> <li>- Side Effects</li> <li>- Duration</li> <li>- Daily Routine</li> <li>- Cost</li> </ul> Card are reviewed and discussed before arrival at a decision about what would work best for the family.	Brinkman et al., (2013): A pre/post open trial of decision aids. Sample size: 54 parents/carers of young people with ADHD.	Parents in the intervention group were more involved in shared decision making, more knowledgeable, less conflicted about treatment options. Proportion of young people medication titration, treatment response and visit length and follow-up sessions were unchanged.
3	Crickard et al. (2010). USA.	M/F Young people aged 14–17 years and parents.	A framework for youth SDM around medication. This included three functional areas: 1) Setting the stage for youth SDM, 2) Facilitating youth SDM, and 3) Supporting youth	Model or therapeutic approach	<i>Tools and methods of the framework for youth SDM:</i> 1) Orientation sessions for various youth participants (orientation sessions for providers, including prescribers, case managers, and parent support specialists; orientation for youth and parents that introduces families to youth SDM, describes the youth SDM tools, and allows youth and parents to determine if they want to be involved in the process);	No Evaluation <sup>1</sup>	N/A

			SDM. Under each functional area, further details are provided about what should happen.		<p>2) Worksheets for youth and parents. The Goal Sheet with separate versions for youth and parents. The worksheets are intended to be used in conjunction with face-to-face discussions during medication clinic appointments in order to support open dialogue; and the Shared Decision Worksheet. The purpose of this tool is to help identify pressing topics for discussion at the medication clinic appointment from both the parent and youth perspectives.</p> <p>3) Staff support roles. To introduce youth and parents to SDM, help them identify goals and self-care activities, revisit goal information on a quarterly basis, and prepare for medication clinic appointments if desired by youth and parents (Crickard et al., 2010).</p>		
4	Westermann et al. (2013). The Netherlands	M/F Parents of children and young people aged 2–12 years	An approach aimed at facilitating conversation through a three steps: 1) Retrospection, 2) Discussion of diagnostic findings, 3) Treatment plans and treatment policy arrangements. The approach is guided by the Ottawa Decision Support Framework	Model or therapeutic approach	<p><i>Differences of the characteristics of CD/Control group</i></p> <ul style="list-style-type: none"> <li>- Preparation by therapist: by standard form/no standard format</li> <li>- Preparation by parents: by standard invitation/no standard format</li> <li>- Duration counselling session: 1 h/1 h</li> <li>- Structure of counselling session: semi-structured/no standard format, at choice of therapist</li> <li>- Topics of counselling: defined/variable, preference of therapist</li> <li>- Communication style: dialogue/variable, preference of therapist</li> <li>- Informed consent: intrinsic aspect/ not standardised, optional</li> <li>- Empowerment: intrinsic aspect/ not standardised, optional</li> <li>- SDM: intrinsic aspect/ not standardised, optional</li> <li>- Communication and decision aid:</li> </ul>	Westermann et al., (2013): Randomised Control Trial Sample size: 94 parents of young people with a mental health difficulty.	Parents randomised to CD reported lower decisional conflict, and accepted the recommendations of treatment. Decisional conflict for therapists between CD and control was not significant.

					visualization tool/not standardised, optional - Report of counselling session: by standard form/no standard format		
5	Autism Speaks (2011) (DA). USA.	M/F Parents of children and young people with Autism.	An online decision aid to help parents of children with Autism Spectrum Disorder (ASD) around whether their child should take medication.	Decision aid	An online decision aid to help parents of children with Autism Spectrum Disorder (ASD) around whether their child should take medication, including: information on autism and common problem behaviours, and the possible benefits and possible risks of medicine.	Anixt et al., (2015) <sup>^</sup> : Randomised Control Trial. Sample size 46 parents of young people with ASD.	Parents randomised to use the DA were more involved in SDM during visits, less conflicted about treatment decisions, and more likely to have their priorities addressed by the care plan.
6	Evidence Based Practice Unit (2015) (IncludeME/PACT – DA and support materials) UK. <sup>s</sup>	M/F Children and young people aged 10–18.	An online, interactive platform containing a variety of tools to support collaborative practice and SDM with children and young people.	Decision aid, goal setting/action planning, and information.	IncludeME contains a set of child decision aids and SDM tools (brief questions, doodles, drawings etc.) developed by EBPU for children and young people with mental health problems.  PACT contains clinician training materials to support knowledge and skills building around SDM and IncludeMe.	Ellis et al., (2016) <sup>^</sup> : Qualitative interviews and questionnaire. Sample size: 3 young people (interviews) and 126 young people (surveys).	Young people reported being positive about IncludeMe as it helped them talk and open up and encouraged communication, survey responses indicated 80% of young people rated the platform as 3 or more out of 5.
7	Healthwise (2015) (DA for depression). Canada.	M/F Parents of young people with depression.	An online decision aid for parents of children with depression around whether their child should take medication.	Decision aid	An online decision aid for parents of children with depression around whether their child should take medication, including: information on facts of depression; treatment options and whether parents want to have a say in a given decision or simply want to follow their doctors' recommendation.	Unknown <sup>2</sup>	N/A
8	Healthwise (2015) (DA for ADHD). Canada.	M/F Parents of young people with ADHD.	An online decision aid for parents of children with ADHD around whether their child should take medication.	Decision aid	An online decision aid for parents of children with ADHD around whether their child should take medication: including: information on facts of depression; treatment options and whether parents want to have a say in a given decision or simply want to	Unknown <sup>2</sup>	N/A

					follow their doctors' recommendation.		
9	Evidence Based Practice Unit (2014). UK. <sup>§</sup>	M/F Children and young people 10–18	A website to help young people and their families who will, or may, be accessing CAMHS, to understand the process and pathways in CAMHS.	Information	My CAMHS Choices contains information and videos from clinicians and service users detailing information on therapy, privacy and confidentiality, feeling stuck, diagnosis, my therapist, and moving on.	Kyrke-Smith et al., (2014) <sup>^</sup> Online questionnaire. Sample size: 22 young people	The majority of young people liked the website (n = 20). It was found that the website was likely to have an influence on young people's probability to attend appointments, to express opinions and to ask questions.
10	Cheshire and Wirral NHS Foundation Trust (2012). UK.	M/F Children and young people aged ≤ 18 years.	A pack of cards used to facilitate the use of Goal Based Outcomes in CAMHS.	Goal Setting/action planning and discussion prompt	Next Step Cards are 52 reversible cards containing drawings and/or words that may be useful to help focus on goals and measurement of goals during CAMHS appointments. The cards are split into the following categories: life cards, position cards, level cards, and step cards.	Unknown <sup>2</sup>	N/A
11.	Murphy et al. (2010). Canada.	M/F Young people aged 12–24.	A booklet for young people making decisions about medication, including frequently asked questions, a medication overview, and paper-based decision aid.	Information and discussion prompt	Med Ed is a booklet which has 88 pages covering eight main sections including: 1. 26 frequently asked questions (FAQs) with concise bulleted responses 2. Psychotropic information on the major psychotropic drug classes 3. Monitoring tools ("trackers") for symptoms, activities, and side effects 4. Checklists of questions to ask doctors and pharmacists, and one about blood monitoring 5. A medication log/list 6. An appointment log 7. A notes section 8. A glossary	The Provincial Centre of Excellence for Child and Youth Mental Health at CHEO, (2009). Online survey. Sample size: 3 (2 parents, 1 young person) <sup>^</sup> .	Med Ed useful in monitoring, and may be useful in conversations with clinicians about medication.



					A 56-page Med Ed Passport was also developed, which mirrors the booklet but is populated with trackers, condensed checklists and FAQs, a notes section, and logs for appointments and medications		
12.	Law et al. (2006). UK.	M/F Parents and young people (age unspecified)	An approach to evaluate progress towards a goal in clinical work with children and young people and their families and carers.	Goal Setting/action planning and discussion prompt	A 0–10 Likert scale to assess where children and their parents feel they are making progress towards achieving their goal during therapeutic work.	Tryon and Winograd (2011), Meta-analysis Sample size: 1,302	There was indication of better outcomes when patients and therapists agree on goals and process.
13.	Simmons et al., (2011). Australia	M/F. Children and young people with moderate-severe depression aged 12–25	An electronic decision aid for young people and children with depression to make decisions about treatment.	Decision aid	An electronic decision aid to help making decisions about treatment for young people with depression including: a home page, treatment options, getting better, side effects, what matters to you, and deciding.	Simmons et al., (2011). Questionnaire study. Sample size 5 young people and 3 clinicians	All participants found the DA acceptable, and most (n = 4) found it useful. All participants agreed that the DA helped them know the benefits and risks, and felt that they had enough information and advice to make an informed choice.
14.	Evidence Based Practice Unit. (2007). UK. <sup>§</sup>	M/F Parents and young people (age unspecified)	A booklet aimed at young people and their families who will, or may, be accessing CAMHS, to understand the treatment options available.	Information	<i>Choosing What's Best For You</i> is a 40-page booklet outlining the different treatment options available for each mental health diagnosis from a review of the research literature captured in <i>What Works for Whom</i> (Fonagy, et al., 2002).	Unknown <sup>2</sup>	N/A
15.	Evans et al., (1994). USA	M/F Parents of young people with serious emotional difficulties	A parent- and professional-led service for young people with serious emotional difficulties, includes a wide range of activities.	Information	A wide range of parent and professional co-led initiatives including books and tapes on: mental health problems, diagnosis, treatment, services, parenting, and special education. Parent led support groups.	Evans et al., (1994): Quasi-experimental design. Sample size: unknown as evaluation was said to be ongoing	No Evaluation <sup>1</sup>

16.	Ossebaard et al., (2010). Netherlands	M/F Parents of young people with ADHD.	An online decision aid for parents of children with ADHD to make decision around treatment.	Decision aid	An online decision aid containing information on different treatment options for young people with ADHD.	Ossebaard et al., (2010): Pre-post questionnaire study. Sample size: 12 parents.	No difference was found on decisional outcome measures
17.	Fiks et al., (2012). USA	M/F Parents of young people aged 6–12 with ADHD	A scale developed for clinicians to gather information on parents' views on ADHD treatment	Action planning/goal setting	The scales examine parents' concerns for ADHD treatment options, beliefs in effectiveness of treatment (behavioral therapy or medication), barriers and facilitators, and goals for treatment.	Fiks et al., (2013) Logistic regression Sample size: 148 parents/guardians of young people with ADHD	Parents of young people who initiated medication or behavioural treatment had decreased academic and behavioural goals at 6 months
18.	Simmons et al., (2016). Australia	M/F young people aged 12–25 with mild-severe depression	An electronic decision aid for young people and children with depression to make decisions about treatment.	Decision aid	An electronic decision aid to help making decisions about treatment for young people with depression including: a home page, treatment options, getting better, side effects, what matters to you, and deciding.	Simmons et al., (2016): An uncontrolled cohort study. Sample size: 66 young people	Young people who used the decision aid were more able to make a decision, had reduced decisional conflict, and were more satisfied with their decision. At follow up client had reduced symptoms and were adherent to treatment.
19.	He et al., (2016). USA.	M/F Parents of young people with child conduct disorder	Services giving a choice between different therapeutic modalities, with the parent choosing their preferred treatment, or being allocated a treatment with no choice	Mobilising patients to engage	Patients were given options of preferred choice of treatment or services choice.	He et al., (2016): Randomised Control Trial. Sample size: 129 parents of young people with ADHD	Families assigned to having a choice in therapy were more likely to stay in treatment.
20.	Adelmann et al. (1990). USA.	M/F young people aged 5–18 with learning and behavior difficulties	An approach aimed enhancing motivational readiness for decision making.	Mobilising patients to engage	Enhancing motivational readiness to engage in decision making, including: giving young people permission and encouragement to participate, discuss and rehearse participation, and to induce feelings of personal responsibility	Adelmann et al. (1990): Participants assigned to condition (randomisation not mentioned). Sample size: 85	No significant difference in outcomes specific to the intervention
21.	Grant et al.,	M/F Parents	An online decision aid	Decision aid	An online decision aid to help parents	Grant et al., (2016):	No statistically

	(2016). Australia	of young aged <7 people with ASD.	for parents of children with ASD to make decisions about treatment.		make decision about ASD interventions, including: information about ASD, interventions that are available, questions to ask healthcare professionals and links to additional information.	Pilot Randomised Control Trial. Sample size: 71 parents.	significant differences on decisional conflict or self-efficacy between groups.
22.	AHRQ (2014). USA	M/F Parents/ Carers of young people aged 0–12 with ASD	A decision aid for parents/carers of young people and children with ASD to make decisions about treatment	Decision aid	A decision aid to help parents make decisions about treatment for young people with ASD including: who this is for, understanding your child's condition, understanding your options, making a decision.	No Evaluation <sup>1</sup>	N/A

*Notes.*<sup>1</sup>Authors/organisations were contacted and no evaluation was conducted, <sup>2</sup>Authors/organisations were contacted but no answer was received, \*sample size at last time point/follow up, \$Developed and evaluated by authors of this manuscript, ^Did not come from a peer reviewed journal

SDM = shared decision making. DA = Decision Aid. CD = Counseling in Dialogue.

**Table 2. Quality Assessment against essential elements of SDM**

		Expressing Values	Presenting Options	Professional Recommendations	Make or Defer Decision	Define/Explain Problem	Check or Clarify Understanding	Discussing Risks or Benefits	Discussing Efficacy	Arrange Follow Up	Total Elements
1.	Ahmed et al. (2015)	N	Y	Y	N	Y	Y	Y	N	Y	6
2.	Brinkman et al., (2013)	Y	Y	Y	Y	Y	Y	Y	?	N	7
3.	Crickard et al., (2010)	Y	?	?	Y	Y	?	Y	?	?	4
4.	Westermann (2013)	?	Y	?	Y	Y	?	Y	Y	Y	6
5.	Autism speaks (2011)	Y	Y	Y	Y	Y	Y	Y	?	?	7
6.	Evidence Based Practice Unit (2015)	Y	Y	Y	Y	?	N	Y	Y	?	6
7.	Healthwise (2015a) DA for depression:	Y	Y	Y	Y	?	Y	Y	Y	?	7
8.	Healthwise (2015b) DA for ADHD	Y	Y	Y	Y	?	Y	Y	Y	?	7
9.	Evidence Based Practice Unit (2014)	N	Y	Y	N	N	N	N	N	N	2
10.	Cheshire and Wirral NHS Foundation Trust (2012)	Y	Y	N	N	N	N	N	?	N	2
11.	Murphy et al. (2010)	N	Y	Y	N	?	Y	Y	Y	N	5
12.	Law (2006)	Y	N	Y	N	N	N	N	N	N	2
13.	Simmons (2011)	Y	Y	Y	N	Y	Y	Y	N	Y	7
14.	Evidence Based Practice Unit (2007)	N	Y	Y	N	?	N	N	N	N	2
15.	Evans et al., (1994).	Y	N	Y	N	Y	N	N	N	N	3
16.	Ossebaard et al., (2010)	?	Y	Y	Y	N	N	Y	N	N	4
17.	Fiks et al., (2013)	Y	Y	Y	N	N	N	Y	N	N	4
18.	Simmons et al., (2016)	Y	Y	Y	Y	Y	N	?	?	N	5
19.	He et al., (2016).	Y	Y	?	Y	N	N	N	N	?	3
20.	Adelmann et al. (1990)	Y	N	N	N	N	N	N	N	N	1
21.	Grant et al., (2016)	Y	Y	Y	N	N	N	Y	?	N	4
22.	AHQR (2014)	Y	Y	Y	N	Y	Y	Y	N	N	6

**Table 3. Implications**

<b>What is known</b>	<b>Future directions</b>
<ol style="list-style-type: none"> <li>1. A number of heterogeneous approaches are being developed to facilitate SDM in child and youth mental health.</li> <li>2. There is some evidence that SDM approaches improve parental knowledge and decisional conflict.</li> <li>3. Preliminary evidence suggests some SDM approaches are seen as positive by parents and young people, or have an effect on certain outcomes. Yet, findings must be treated with caution due to a risk of bias in included records.</li> <li>4. Decision aids were the most frequent approach found in this review. This prominence may be explained by the fact that there are specific, international guidelines for decision aid creation (see the International Patient Decision Aid Standards).</li> <li>5. There does not appear to be one superior approach in terms of better outcomes. Whatever approach is being used, flexibility to adapt it to specific populations is seen as important (Abrines-Jaume, 2015). This may mean that some decision aids, as well as approaches to goal setting, which allow for specific tailoring by clinicians and young people, could be more beneficial for young people and parents.</li> </ol>	<ol style="list-style-type: none"> <li>1. Little is known on how SDM approaches affect outcomes for young people as there is a lack of high quality research studies, such as RCTs, conducted on SDM approaches with children and young people.</li> <li>2. This may be further complicated by the fact that there is a lack of validated SDM measures for this population. Possible measures for development, which have included some testing and consultation with young people, parents and clinicians may include the SDM-Q-9 (Kriston et al., 2010) which has been used with young people with depression in Australia (Simmons, et al., 2016) or CollaboRATE (Elwyn et al., 2013) which is currently being trialed in the UK in child and youth mental health services (Hayes et al., 2016).</li> <li>3. Rather than overarching ‘approaches’ to facilitate SDM, future research may wish to identify the active units of change, known as behavior change techniques (BCTs), within each approach. For example, ‘adding objects to the environment’ is a frequent BCT used in records found in this review, yet is this enough on its own to facilitate SDM, or are other BCTs needed alongside this?</li> <li>4. Research and implementation has been primarily concentrated in the affluent countries of Western Europe and the United States. More studies in populations of greater cultural diversity are needed to strengthen the evidence base and understanding of SDM in mental health settings.</li> </ol>

**Appendix A: Preliminary search terms**

**Concept 1: SDM**

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  
Common goals  
Value oriented care  
Personalisation /personalization

**Concept 2: Child, young person, or parent/carer**

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  
Pre-school

**Concept 3: Mental health**

Mental health  
Mental illness  
Mental disorder  
Chronic mental illness  
Community mental health  
Community mental health centers (centres)  
Community mental health services

**Appendix B: Final search terms (combined) <sup>‡</sup>**

MEDLINE search – Ovid

("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 (Child\* OR "young person\* " OR teen\* OR adolescen\* 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 ) 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 "Behavio\*r disorders" OR "Behavio\*r problem\* " OR "child psychopathology\*" OR Psychosis OR (Neurosis or neuroses) OR "Cognitive behaviour therapy" OR depression OR Psychology OR Therapy OR Counselling).mp.

*Note:* <sup>‡</sup> The combined search terms were the final search terms obtained on MEDLINE after numerical trials designed to validate and ensure that the MEDLINE strategy retrieves a high proportion of eligible studies found through any means but indexed in MEDLINE. The combined search terms subsequently used in other databases listed in Method with minor modifications (e.g. add or delete a bracket or a quotation mark).