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Antipsychotic Medication Management In Primary Care - Using Realist Informed Synthesis To Develop Recommendations For Policy And Practice.

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Declaration

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

21May2022

Date Signature

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I would like to thank my supervisors, Joanna Moncrieff, Nadia Crellin and Richard Byng for their invaluable support, advice, and expertise. I would also like to thank Claire Duddy, Louise Marston, Maria Long, Nicola Morant and Mark Horowitz for their insightful feedback and advice on my work. Thank you also to Dr Siddiqui and Dr Pizzo for their invaluable contribution to the Realist Review and GP survey.

Abstract

Introduction: Increasing numbers of service users with a severe mental health (SMI) diagnosis are discharged from secondary care services back to their General Practitioner (GP). Recent estimates suggest that this affects between 30-50% of people with a SMI diagnosis, most of whom are prescribed long term antipsychotic medication. Given the wide range of associated adverse effects, and lack of efficacy of antipsychotic medication in some people, this medication needs to be reviewed, and potentially adjusted, regularly. It is unclear to which extent antipsychotic medication reviews are completed in primary care and what potential barriers and facilitators may be, and what GPs and service users' views and experiences of primary care reviews are. It is also unclear if service users in primary care have particular needs in comparison to those service users still under specialist secondary care services, which may have treatment implications.

Method: A realist informed synthesis was conducted: An initial programme theory was developed as part of a realist review (Chapter 2). This was further refined through an analysis of Service User interviews (Chapter 3) and a GP survey (Chapter 4). Chapter 3 analyses quantitative and qualitative data from semi-structured interviews of N=269 service users from a range of secondary and primary care services. This allowed a between groups comparison on a range of demographic and clinical variables. It also explores service user views on long term antipsychotic medication, reducing and stopping antipsychotics. The data were analysed using univariate statistical tests and thematic analysis. The GP survey was developed based on the initial programme theory and included GPs (N=103) views on long term antipsychotics, primary care only medication reviews, and explores barriers and facilitators of medication reviews, with the GP – Service User relationship at its core.

Results: The realist review identified 5 CMOCs, indicating why meaningful antipsychotic medication reviews may not occur for people with a SMI diagnosis in primary care. The literature suggests a lack of hope and trust between GPs and service users. This manifests in low expectations of recovery for service users with a diagnosis of SMI, for which the GP survey also provided some evidence. The review also suggested that Service Users are perceived as lacking capacity to understand and participate in medication reviews, linked with a lack of mutual information sharing regarding mental wellbeing and rationale for medication. Research also suggests that GPs may feel at risk in consultations, for which the GP survey also provided some evidence. The most pervasive evidence was collated on the topic of uncertainty. Uncertainty regarding antipsychotic dose and illness trajectory meant that reviews may not occur. Little published data was identified, however the service user interviews highlighted that primary care service users are more reluctant to reduce their medication, despite increased age, than secondary care service users. Primary Care service users were most concerned with fears of relapse. Key considerations included effects on employment if medication is changed, older age as a barrier to reduction, and it being part of their role to take medication lifelong. Similarly, GPs listed uncertainty regarding relapses, a lack of knowledge and confidence, paired with lack of secondary care support as their reason for not reviewing or reducing medication. GPs highlighted the lack of “exit plans” upon discharge, detailing the proposed strategy for antipsychotic medication dose adjustment in the long term.

Conclusions: Meaningful antipsychotic medication reviews may not occur in primary care. This PhD identifies key considerations to help explain why this might be the case and summarises these in a list of recommendations, which carry important implications for policy and practice. Further research is required to identify evidence-based means of addressing these issues.

Impact Statement

My role:

This PhD has been funded by the North East London NHS Foundation Trust. I completed my PhD part-time, working on the RADAR (Research into Antipsychotic Discontinuation and Reduction) Trial, a 6-year National Institute for Health Research (NIHR) funded programme grant between 2017-2020 as a Researcher and was involved in recruitment, data collection and management. Chapter 3 is a secondary analysis of interviews conducted as part of the RADAR programme. For this study, I supported with site set up, data queries and data management and I was involved in the analysis and write-up of the overall project. I independently developed the analysis plan for the current project, transcribed the interviews and conducted the analysis and write up. Chapters 2 and 4 are not related to the RADAR trial: The realist review (Chapter 2) was independently completed as part of this PhD, and for the GP survey (Chapter 4) I designed the survey, applied for ethical approval, recruited all participants, and analysed the data under supervision. Outside of the supervisory team, chapters of the PhD were supported by Claire Duddy (Chapter 2), Nicola Morant, Louise Marston and Mark Horowitz and Maria Long (Chapter 3). Dr Pizzo and Dr Siddiqui piloted the survey in Chapter 4.

Who will benefit from this work?

The PhD’s findings are of crucial importance to service users with an SMI diagnosis and their clinicians, as well as policy makers, Clinical Commissioning Groups (CCGs) and academics. Detailed recommendations can be found in Chapter 6. In summary, primary care only service users are currently at risk of having their physical and mental health needs neglected. Improvements are required at the GP practice, CCG and policy level to ensure that primary care only service receive adequate support. The PhD forms a basis for recommendations to improve practice.

1. **Impact on people with SMI**

- The PhD clarifies key considerations service users have when considering long term antipsychotic medication, reduction and discontinuation.
- Key differences in clinical and demographic variables between primary and secondary care service users were identified, suggesting approaches to management should be tailored to each individual, taking each of their concerns into account.
- The Realist Review explored the relationship service users may have with their GPs; it also shone a light on stable, long-term service who may be on antipsychotics without thorough review and at risk of falling between cracks. It goes on to suggest improvements to overcome barriers associated with thorough medication reviews.
- It highlights the role of trust and hope in consultations, and outlines why genuine Shared Decision Making may not be possible in consultations at the moment. It suggests ways to empower service users, to ensure their concerns are addressed, and that they play an equal role in the decision-making process.

2. **Clinician and health service impact**
    - The PhD explored the level of medication reviews currently conducted for long term stable Service users on long term antipsychotics. It also explored the level of guidance currently available to GPs.
    - It theorised the interactions between GPs and Service User in the current NHS context.

- It explored GP views on long term antipsychotics, reducing and stopping antipsychotics. GPs have many concerns regarding long term antipsychotic treatment, feel uncomfortable to reduce and/or stop the medication, however.
- PhD highlights suggestions of improving communication between GP and service user with the view to increase GP and service user satisfaction and improve treatment. It also highlights the importance of increased communication with secondary care services. This may result in better use of resources.

3. **Policy impact**

- The Community Mental Health Framework for Adult and Older Adults (NHSE, 2019) highlights the need for improved service provision and communication between primary and secondary care services, especially data linkage between services. This PhD suggests implementable changes which may improve this.
- Chapter 5 outlines an array of policy implications.

4. **Academic impact**

- This PhD is the first in depth study exploring the care and treatment of people with an SMI diagnosis, on long term antipsychotics, who no longer have access to secondary care.
- The programme theory offers a useful starting point to understanding the status quo and highlights the need for further research in this area. A full list of research recommendations can be found in Chapter 5.
- It sets a research agenda for future research to ensure that primary care mental health is evidence based, is suitable to those who use the services and prioritises shared decision making, in the current context.

Publication and Dissemination Plan:

Publications associated with the PhD:

1. **Grünwald, L. M.,** Duddy, C., Byng, R., Crellin, N., & Moncrieff, J. (2021). The Role of Trust and Hope in Antipsychotic Medication Reviews in Primary Care Settings: A Realist Review. *BMC Psychiatry 21, 390.*
2. **Grünwald,L.M,** Crellin,N., Moncrieff, J. (2021). ANTIPSYCHOTIC MEDICATION REVIEWS IN PRIMARY CARE – SEARCHING FOR BEST PRACTICE.BJGP Life, posted 10th Feb 2021, URL: https://bjgplife.com/2021/02/10/antipsychotic-medication-reviews-in-primary-care-searching-for-best-practice/
3. **Grünwald,L.M,** Duddy, C., Moncrieff, M., Crellin, N., Byng, R. (2020). Antipsychotic Medication Reviews in Primary Care. Presentation at the RADAR conference, July 2020
4. **Grünwald,L.M,** Duddy, C., Moncrieff, M., Crellin, N., Byng, R. (2020). How do stereotypes impact the healthcare of people with severe mental illness in primary care? Oral presentation at Realist2020, March 24th-26th 2020 in Dublin (rescheduled for 16-18th February 2021)

Other publications during the PhD:

1. Crellin NE, Priebe S, Morant N, Lewis G, Freemantle N, Johnson S, Horne R, Pinfold V, Kent L, Smith R, Darton K, Cooper RE, Long M, Thompson J, **Gruenwald L**, Freudenthal R, Stansfeld JL, Moncrieff J. An analysis of views about supported reduction or discontinuation of antipsychotic treatment among people with schizophrenia and other psychotic disorders. BMC Psychiatry. 2022 Mar 15;22(1):185. doi: 10.1186/s12888-022-03822-5. PMID: 35291964; PMCID: PMC8925064.
2. **Grünwald,L.M** & Thompson, J. (2021) Re-starting the conversation: improving shared decision making in antipsychotic prescribing. *Psychosis*, 1-5.
3. Johnson, S., Dalton-Locke, C., Vera San Juan, N. *[…]* **The Covid -19 Mental Health Policy Research Unit Group**. Impact on mental health care and on mental health service users of the COVID-19 pandemic: a mixed methods survey of UK mental health care staff. *Soc Psychiatry Psychiatr Epidemiol* (2020).
4. Sheridan Rains, L., Johnson, S., Barnett, P. *[…]* **The Covid -19 Mental Health Policy Research Unit Group**. Early impacts of the COVID-19 pandemic on mental health care and on people with mental health conditions: framework synthesis of

international experiences and responses. *Soc Psychiatry Psychiatr Epidemiol* (2020)

5. Cooper, R.E, **Grünwald,L.M,** Horowitz, M. (2020): The Case for Including Antipsychotics in the UK NICE Guideline: 'Medicines Associated with Dependence or Withdrawal Symptoms: Safe Prescribing and Withdrawal Management for Adults'. *Psychosis*
6. **Grünwald,L.M,** Haime, Z., Aworinde, J., Moncrieff, J. (2018): An Outline for "Research into Antipsychotic Discontinuation and Reduction" (RADAR): A randomised controlled trial. – Poster presented at North East London NHS Foundation Trust Research and Development Conference. 2nd Place in poster competition.

Planned publications:

1. **Gruenwald, L.M** & Thompson, J. Is genuine informed consent possible in antipsychotic medication management for people diagnosed with psychosis? A systematic review on the effects of previous coercion and stigma on informed consent.
2. **Gruenwald, L.M**, Crellin, N., Byng, R., Moncrieff, J. GP views on antipsychotic treatment and medication reviews in primary care. A survey of UK General practitioners treating people diagnosed with psychosis and schizophrenia.
3. **Gruenwald, L.M**, Crellin, N., Byng, R., Horowitz, M., Moncrieff, J. Important differences in views on antipsychotic medication management. A comparison between primary care and secondary service users

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Table 1: Glossary

Attribution Theory	a theory which supposes that people attempt to understand the behaviour of others by attributing feelings, beliefs, and intentions to them.
Context (C)	Elements outside the parameters of the formal programme architecture, that have causal impact, e.g. norms and values, economic conditions, participant characteristics
Context Mechanism Outcome Configuration (CMOC)	A theme, combining the contexts, which trigger a mechanism, which results in an outcome.
Mechanism (M)	M is the underpinning generative force that leads to outcomes, triggers by Context
Medication review	For the purposes of the PhD, medication review refers to antipsychotic medication reviews. As defined by NICE, a structured medication review should include: 1) Shared Decision Making – taking the service users' views, concerns, and questions about medication into account, as well as their families and carers' views. 2) Assessment of risk factors which may interfere with current medications 3) Required drug monitoring Leucht et al. (2018) further suggests that the aim of antipsychotic medication reviews should also be: 1) to assess if medication is prescribed according to prescribing guidelines (such as the British National Formulary (BNF) guidelines in the UK) 2) ensure that medication is reduced to a maintenance dose following crisis 3) after a period of stability, to review if a lower dose of medication is possible.
Outcome (O)	O is the result of a programme or study, can be intended or unintended, expected or unexpected
Primary care only service users	People who are discharged from secondary care services, and are no longer seen by a psychiatrist, making their GP their main health care contact.
Programme Theory (PT)	A hypothesised framework, made up of CMOCs, developed throughout the review (initial programme theory to refined

	programme theory)
Realist And MEta-narrative Evidence Syntheses: Evolving Standards (RAMESES)	Funded by the National Institute of Health Research (NIHR) Health Services and Delivery Research Programme. The projects goals are to produce quality and publication standards and training materials for realist research approaches.
Shared Decision Making	“A collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care. [..]It involves choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values. It means making sure the person understands the risks, benefits and possible consequences of different options through discussion and information sharing. This joint process empowers people to make decisions about the care that is right for them at that time (with the options of choosing to have no treatment or not changing what they are currently doing always included)” (p.16, NICE, 2021)
Substantive Theory	A higher-level conceptual theory that is not directly about the programme, but introduces a concept that increases the explanatory power of the programme theory

TABLE 1 GLOSSARY

TABLE 2 ABBREVIATIONS

Accident and Emergency	A&E
Antipsychotic	AP
British Journal of General Practice	BJGP
Body Mass Index	BMI
British National Formulary	BNF
Critical Appraisal Skills Programme	CASP
Clinical Commissioning Group	CCG
Cardiovascular Disease	CVD
Confidence interval	CI
Community Mental Health Team	CMHT
Context-Mechanism-Outcome Connection	CMOC
Chlorpromazine Equivalent	CPZE
Clinical Research Network	CRN
Drug Attitudes Inventory	DAI

Electronic Health Records	EHR
General Medical Services	GMS
General Practitioner	GP
Improving Access to Psychological Therapies	IAPT
Lived Experiences Advisory Panel	LEAP
Mixed Methods Appraisal Tool	MMAT
National Health Service England	NHSE
National Institute for Clinical Excellence	NICE
National Institute of Health Research	NIHR
Odds Ratio	OR
Primary Care	PC
Primary care Mental Health	PCMH
Quality Outcome Framework	QOF
Research into Antipsychotic Discontinuation and Reduction	RADAR
Realist And MEta-narrative Evidence Syntheses: Evolving Standards	RAMESES
Randomised Controlled Trial	RCT
Shared Decision Making	SDM
Severe or Serious Mental Illness	SMI
Service User	SU
United Kingdom	UK
World Health Organisation	WHO

Chapter 1 - Introduction

This chapter sets out the context for my thesis, providing an overview of long-term antipsychotic treatment for people with a diagnosis of schizophrenia or psychosis and the importance of regular medication reviews. It goes on to outline the barriers to facilitating these in primary care, with the GP – service user relationship at the core of the issue. Finally, I discuss key research gaps and the rationale for the PhD. Aims and objectives to address these are outlined for each study conducted as part of the PhD.

1.1 Psychosis/Schizophrenia SMI

Serious Mental Illness (SMI) includes schizophrenia, bipolar disorder and other psychoses. It affects approximately 300,000 people in the UK (Royal College of Psychiatrists, 2014). Schizophrenia and related disorders are associated with many debilitating symptoms, including hallucinations, like hearing voices, unusual beliefs, and disorganized thinking, as well as lack of motivation, anhedonia, avolition and social withdrawal. Whilst these symptoms are not always distressing, most people with these diagnoses will require treatment. Current NICE (National Institute for Clinical Excellence) Guidelines recommend medication (‘antipsychotics’ or ‘neuroleptics’) and psychological therapies as treatment (NICE, 2014).

1.2 Treatment with Antipsychotic medication

Antipsychotic medication is the most common treatment: In a sample of 5091 service users with a SMI diagnosis, 94.8% were prescribed at least one antipsychotic (Patel et al., 2014). There are two functions to antipsychotic medication treatment: firstly, to treat distressing symptoms during an acute episode. Once symptoms have improved, antipsychotic medication is mainly used to prevent a relapse - the “maintenance phase” (Harris, 2002).

NICE guidance recommends antipsychotic treatment for one to two years initially (NICE, 2014). Should symptoms persist or re-appear, if relapses occur or the person be considered at risk to harm to themselves, then they may be advised to remain on maintenance treatment long term, in some cases indefinitely (Burns & Kendrick, 1997; Geyt et al., 2017; Happell et al., 2004; Johnson & Rasmussen, 1997; Lester et al., 2005; Pereira & Pinto, 1997). Given the length of antipsychotic treatment, it is crucial that the benefits of the medication are weighed up with potential risks on an ongoing basis.

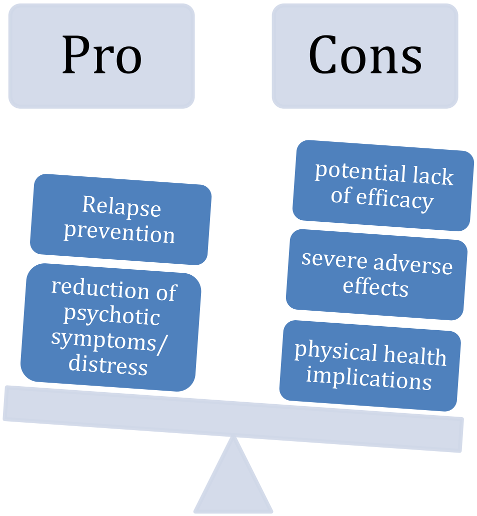


FIGURE 1 KEY CONSIDERATIONS FOR LONG TERM ANTIPSYCHOTIC MEDICATION TREATMENT

1.3 Considerations regarding antipsychotic treatment

There are key considerations to antipsychotic medication treatment, which must be weighed up. These include the benefits of antipsychotics, such as reduction of psychological distress and relapse prevention, as well as the risks, including severe adverse effects, physical health implications of antipsychotics and a reported lack of efficacy observed by service users (see Figure 1). The next section will discuss the available evidence for these key considerations and subsequent implications for clinicians and service users.

1.3.1 Relapse prevention

A rationale for long term antipsychotic medication is reduction or prevention of relapses. Recent meta-analyses suggested that maintenance medication in schizophrenia can prevent relapse (Leucht et al., 2021; Leucht & Davis, 2017). Questions have been raised about the available evidence for the use of long-term antipsychotic medication however (Moncrieff, 2015; Morrison, Hutton, Shiers, & Turkington, 2012; Murray et al., 2016). In particular, there are very few studies with a follow up period of more than six months, yet people remain on antipsychotics for years (Leucht et al, 2018; Crellin et al., 2022). Moreover, differences between antipsychotics and placebo in existing relapse prevention trials may be inflated by withdrawal effects (Brandt et al., 2022). There are now several ongoing studies assessing the impact of reducing antipsychotic medication, such as the HAMLETT trial (Begemann et al., 2020) and RADAR trial (Moncrieff et al., 2019). Findings from one such discontinuation trial showed significant improvement in social functioning in the discontinuation group (versus maintenance treatment) after 2.5 years of discontinuing medication and comparable levels of relapses and psychotic symptoms in both groups after seven years. This indicated that discontinuing medication did not lead to an increase in psychotic symptoms or relapse over the long-term, even though there was an increased rate of relapse in the shorter-term follow-up at 18 months (Wunderink et al, 2013). This questions whether antipsychotic treatment continues to be beneficial in the long term for everyone.

1.3.2 Efficacy of antipsychotic medication

People with a SMI diagnosis may experience psychotic symptoms and/or severe psychological distress. The aim of antipsychotic medication is to ease these symptoms. Quantitative studies showed a reduction in overall psychotic symptom scores (Haddad& Correll, 2018, Leucht et al, 2009). Qualitative evidence showed that medication can reduce psychotic symptoms and other psychological difficulties such as insomnia, and that it can aid peoples' subjective wellbeing and provide a sense of normality. (Thompson et al., 2020). A service user described '*I can see a change in my thinking, I used to have some…oh, you know, some funny thoughts… this medication helps me in a way that I can think…and see that it's not right (thinking)…it has offered me hope again for a normal life' (p. 148, Usher et al., 2001)*.

However, research has been criticised for overstating the benefits of antipsychotic medications (Goetzsche, Young & Crace, 2015). Studies, especially those funded by the pharmaceutical industry have also been criticised of selective reporting and bias (Turner et al., 2022; Leucht et al 2008; Lexchin et al., 2003). Research found that between 5% and 25% of those with a diagnosis of schizophrenia respond little or not at all to antipsychotic medication (Brenner et al., 1990; Conley & Buchanan, 1997). More recent evidence suggests that potentially up to 60% of service users do not respond (or only partially) to antipsychotic medication, even if medication is taken reliably (Lindenmayer & Khan, 2010).

A recent survey of 650 people taking antipsychotics showed that only 14.3% experienced only positive effects from the medication and 58.7% experienced adverse events from taking the medication (Read & Sacia, 2020). The survey may suffer from sampling bias; service users who experience adverse effects may be more likely to take part in a survey regarding experiences of antipsychotics, than those who are content with their medication. However other studies support some of the findings: In a meta-analysis, 40% of people did not experience specific benefits from taking medication (Leucht et al., 2009) and the medication has been shown to lead to significant adverse effects, reduced social functioning and quality of life (Wunderink et al, 2013; Wykes et al 2017). This is supported by qualitative studies, illustrating that service users may experience cognitive slowing, emotional blunting, and reduced motivation, as well as a loss of their sense of autonomy as a consequence of taking antipsychotic medication (Thompson et al., 2020).

1.3.3 Physical health considerations

Physical health issues are a particular concern in this population (Reilly et al., 2021). A diagnosis of Serious Mental Illness is associated with a reduced life expectancy of up to 25 years (Laursen, 2011; Osborn et al 2007). Whilst previous evidence attributed this partially to suicide and accidents (Brown, 1997), more recent evidence found that suicide was relatively rare (Hayes et al., 2017). More serious concerns relate to cardiovascular and respiratory disorders (Brown, 1997; Hayes et al., 2017). Hayes et al. (2017) found that both all-cause mortality and cardiovascular disease death rates are decreasing less quickly than the general population, leading the authors to conclude that the mortality gap between individuals with SMI and the general population continues to widen.

Referencing Hayes et al.'s (2017) findings, Siddiqui et al. (2017) referred to the increased mortality gap as a 'scandal' (p.131) and calls for immediate action to address this. An NHS England report concluded in 2016 that two out of three deaths would be preventable for people with an SMI diagnosis, if physical health screening and treatment for illnesses like cardiovascular disease or diabetes were to be improved. The Kings Fund suggests that multiple factors, including adverse effects of antipsychotic medication, can be attributed to worsened physical health in this population (Naylor et al., 2020).

In the UK, regular physical health assessments are therefore required for this population. The Quality Outcomes Framework (QOF) mandates a yearly review for people with a diagnosis of schizophrenia or psychosis. The QOF is "a system designed to remunerate general practices for providing good quality care to their patients, and to help fund work to further improve the quality of health care delivered. It is a fundamental part of the General Medical Services (GMS) Contract, introduced in 2004" (Department of Health,2022). The review includes a review of weight, BMI, Cardiovascular Disease (CDV) monitoring, and blood glucose and lipids. Whereas the reviews are mandated for everyone with an SMI diagnosis, research suggests that reviews either do not occur or are not thoroughly conducted:

In 1997, Burns & Kendrick found a high rate of undetected health problems, some of which may be due to use of long-term antipsychotics. They noted that "*GPs are usually aware of these risk factors, but do not appear to intervene very often, judged by patients' accounts and medical records*" (p.515). The authors did not discuss reasons for this lack of action. They proposed that service users may also not discuss their physical health issues due to lack of self-confidence, negative symptoms of schizophrenia or may be generally reluctant to discuss their physical health issues with their GP (Burns & Kendrick, 1997).

Whereas some of these earlier findings may relate to pre-QOF mandated physical health checks (it was introduced in 2013), a 2016 report concluded that less than a third of people with schizophrenia received appropriate cardiovascular risk assessments in the last 12 months (NHS England, 2016). Further evidence highlights a lack of physical health monitoring for people with a diagnosis of schizophrenia:

In an audit of 5091 electronic health care records of people with a SMI diagnosis, only 21.6% had all nine audit measures, including BMI, blood pressure, blood glucose and lipids, recorded. The range of service users, who had all nine measures collected was between 5% and 65% across GP practices (Crawford et al., 2014). These audit measures are key to monitoring people's physical health to prevent a range of physical health issues, including CVD. Mitchell et al (2012) found concerningly low levels of metabolic monitoring in a meta-analysis of 48 studies. This mirrors more recent findings, as a study by Black and Held (2017) showed: in their sample of 1036 participants, 61.1% had a reported CVD history, however only 56% (N = 575) participants were screened for all three CVD screening measures (defined as blood pressure, glucose and cholesterol). Khawagi et al (2021) reported a prevalence of 91.6% (91.4 to 91.9 CI) for their audit criteria of "antipsychotic prescribed for at least 12 months without monitoring glucose, weight or lipid profile in the previous year" and a 54.9% prevalence (54.4 to 55.4 CI) for lack of recorded weight in this population. They also found high rates of variation between GP practices in monitoring physical health and prescribing (Khawagi et al, 2021).

1.3.4 Adverse effects

Antipsychotic mediation itself has been associated with adverse effects, including cardiovascular and metabolic effects, neurological effects, psychological effects, and other effects. Common side effects include agitation, constipation, dizziness, drowsiness, sexual dysfunction, fatigue, hyperglycaemia, insomnia, movement disorders, weight gain, vomiting and seizures and metabolic effects (British National Formulary (BNF)). Weight gain can increase the risk of risk of diabetes, stroke, and heart disease (MIND, 2020). According to the BNF, uncommon side effects include confusion, embolism, and thrombosis, as well as neuroleptic malignant syndrome (which is possibly fatal). Rare or very rare side effects include sudden death. Research has also indicated that antipsychotic use is associated with decreased brain volume (Moncrieff & Leo, 2010).

Service users have described the impact of this on their quality of life: "*[The medication] makes me put on weight actually, reduces my motivation, changes other people's attitudes towards me for the worse, makes me feel depressed, sometimes I'm restless sometimes, has a negative effect on my day-to-day living*" (Morant et al., 2018).

In summary, many may not experience a reduction in distressing symptoms when taking antipsychotic medication and may also be impacted negatively in other areas of their mental wellbeing, thus questioning if medication continues to be appropriate over time. It is possible that some may benefit from reducing their antipsychotics, or even discontinuing them altogether, potentially alongside non-pharmacological interventions like psychological therapy. Recent evidence calls for increasing the offer of such alternatives (Cooper et al., 2021). The next section discusses the treatment pathway for people with a SMI diagnosis.

1.4 Treatment pathway and medication reviews

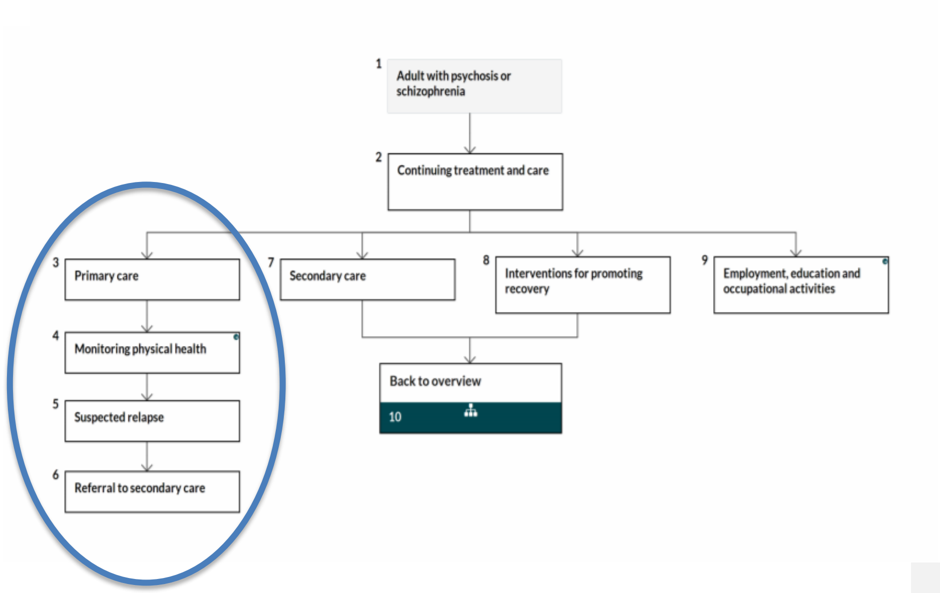


FIGURE 2 CARE PATHWAY (NICE,2016)

Figure 2 illustrates the Care pathway for adults diagnosed with psychosis or schizophrenia in the UK. Acute episodes can occur suddenly and may be associated with sectioning under the Mental Health Act and admission to an inpatient ward. This can also include forced administration of antipsychotic medication when the person is deemed to lack capacity about their care.

Following discharge from an inpatient ward, a specialist, secondary care, community mental health team will usually take over the care. This involves regular medications reviews with a psychiatrist and potentially meetings with a care coordinator. Following a period of stability, and in the absence of any other difficulties such as housing or significant risk, people may be discharged from their specialist mental health team to the care of their GP (NICE, 2014; NICE 2016). Unlike countries such as Italy or the US, GPs act as a gatekeeper service in the UK: GPs can refer back to specialist mental health services, should a relapse occur; service users cannot refer themselves.

Whilst the person is considered stable, and if they are only seen in primary care, it is thus the GPs' responsibility to conduct the annually mandated Quality Outcomes Framework Review, during which antipsychotic medication, mental state and adverse effects should be reviewed. The focus of this PhD is the care and treatment of people with a SMI diagnosis, who have been discharged from specialist secondary care services, who present as stable and who are on long term antipsychotic medication. For the purpose of the PhD, "primary care only service users" refers to people who have been discharged from secondary care services.

1.5 Treatment for Primary Care Only service users.

It is not possible to determine exactly how many people with SMI are solely under the care of their GP without involvement of secondary mental health services: Research has shown that between 25-40% of service users diagnosed with schizophrenia lose contact with or are discharged from secondary care mental health services, leaving the GP as the person they are most likely to see (Burns & Kendrick, 1997). This is in line with a study by Reilly et al (2012), which suggest that approx. 31% of service users with a diagnosis of SMI do not have access to specialist secondary care services. A recent Kings fund publication estimates that this may have increased further: the primary care only population may make up to 50% of people with a SMI diagnosis, as discussions with commissioners suggest (Kings Fund, 2020). These figures were published before the Covid-19 pandemic. During the pandemic, the percentage is likely to have increased again due to NHS Trusts asking their psychiatrists to discharge an additional 20% of their caseload due to increased pressures on services (Personal Communication, 2020). This indicates that a large proportion of service users may currently only see their GP for medication reviews.

Accurate figures for people solely under primary care cannot be given, due to a lack of linkage of Electronic Health Records (EHR) systems between primary and secondary care. In the UK, mental health trusts use different EHR systems from primary care services, thus records between services cannot be reconciled. Previous studies have calculated percentages by either following up a representative number of people in a community mental health team, investigating the percentage of people who were discharged and by looking through GP referrals, or by manually investigating GP records:

People with a diagnosis of schizophrenia and/or psychosis are captured on the "SMI register" (which also triggers the yearly QOF review). By looking through each person's health record on the SMI register, researchers can identify who has been discharged by searching for discharge letters or letters from psychiatrists to confirm that they are still under secondary care. The percentages listed above are thus still an estimate, as research has also shown that discharge letters may not always be received or filed appropriately (Hampson et al, 1996; Reilly et al., 2012). Some service users may also still be under secondary care, but only attend yearly or two-yearly reviews, giving the impression that they may have been discharged. Although likely not a large factor, some people may also choose to see a private GP or psychiatrist, further hindering reliable communication between secondary and primary care. Given the complexity of assessing whether a person is still under secondary care or not, and the lack of precision in doing so, it is likely that GPs will also struggle to identify those who are no longer being reviewed by secondary care in their own caseload. This has important treatment implications (Khawagi et al., 2021), including being able to tailor reviews to those who no longer receive regular, in-depth medication reviews by their psychiatrist.

1.6 Primary Care Medication Reviews and Quality Outcomes Framework

From the data available, it is apparent that GPs play an integral part in the prescribing of antipsychotics and prescribing levels are increasing (Ilyas & Moncrieff, 2012; Kaye, Bradbury, & Jick, 2003; Marston, Nazareth, Petersen, Walters, & Osborn, 2014). With increasing numbers of service users being seen in primary care only (Siddiqui et al, 2017), GPs thus have increased responsibilities in monitoring and reviewing this medication. Given the high adverse effect burden of antipsychotics, potential lack of efficacy and poor physical health in this population, adequate monitoring and prescribing is crucial.

There are no agreed criteria for what an antipsychotic medication review in primary care should consist of, aside from the required physical health review criteria outlined in the QOF (see above). The Pharmaceutical Care Network Europe published a consensus paper in 2018, defining medication reviews in general as "*a structured evaluation of a patient's medicines with the aim of optimising medicines use and improving health outcomes. This entails detecting drug-related problems and recommending interventions*" (p. 1199, Griese-Mammen et al, 2018).

NICE (2016) differentiates between a “medication review” and “structured medication review”. Structured medication reviews are recommended for adults taking multiple medications and people with chronic or long-term conditions. According to NICE (2016), the medication review should include:

1) Shared Decision Making – taking the service users’ views, concerns, and questions about medication into account, as well as their families and carers’ views. NICE (2021) defines Shared Decision Making as:

   > *“A collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care. [..]It involves choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values. It means making sure the person understands the risks, benefits and possible consequences of different options through discussion and information sharing. This joint process empowers people to make decisions about the care that is right for them at that time (with the options of choosing to have no treatment or not changing what they are currently doing always included)” (p.16)*

2) Assessment of risk factors which may interfere with current medications
3) Required drug monitoring

Leucht et al. (2018) further suggests that the aim of antipsychotic medication reviews should also be:

4) to assess if medication is prescribed according to prescribing guidelines (such as the British National Formulary (BNF) guidelines in the UK)
5) ensure that medication is reduced to a maintenance dose following crisis

6) after a period of stability, to review if a lower dose of medication is possible.

It is unclear to what degree medication reviews are currently conducted in primary care, and to what degree the above listed standards are met. As outlined above, the Quality Outcomes Framework mandates a yearly review, during which medication is also reviewed. We have already illustrated that QOF mandated physical health standards are not always met by the reviews. It is therefore possible, that the mental health and antipsychotic medication part of the review is also not adequate or may not occur at all. A study found that 11.3% of service users were not seen in the last year (Reilly et al., 2012), thus suggesting that a review may not have taken place. Even for those reviews that are happening, they may do so on a superficial level. Kendrick et al (1994) reported that mental state examinations were only recorded in 32% of cases, and 29.1% reported superficial changes, like “doing fine”.

One of the reasons why service users may not be reviewed as part of their yearly physical health check, is due to the aforementioned lack of data linkage between primary and secondary care services. It is therefore possible that some service users have had their physical health assessed twice (once in primary and once in secondary care) and others not at all. The QOF mandated review is also not thoroughly operationalised, and GPs can choose to what degree they document the medication review. This allows a level of flexibility, but also means that there is likely a large variation in how thorough the reviews are between GP practices, as the QOF does not differentiate between primary care only and secondary care service users. Mental health and physical health reviews are also not integrated well for those no longer receiving in depth mental health reviews by their psychiatrist, primary care health reviews likely focus on physical health reviews only.

1.7 Evidence based prescribing in primary care

Research has assessed the quality of antipsychotic prescribing in primary care. Mortimer et al (2005) conducted an audit of primary care prescribing and found that 54% of cases failed at least one audit criteria, including prescription without diagnosis and polypharmacy. Despite guidance to avoid polypharmacy due to a lack of efficacy and increased side effect burden (NICE, 2014; Royal College of Psychiatrists, 2014), high dose prescribing continues (Leucht et al., 2018). Following an in-depth review, 80% of health records screened as part of the audit, showed that medication changes were required (Mortimer et al., 2005).

Similarly, the City & Hackney GP Confederation published an antipsychotic prescribing audit in 2019, stating that for service users without a diagnosis of schizophrenia and psychosis, the majority had not received the mandatory physical health checks, and it concluded that *“a significant number of patients may benefit from having their medication reduced or coming off medication”* (p.2, Thomas, 2020).The implication is that without reviews, service users may remain on this medication unnecessarily, and others on unnecessarily high doses.

Current WHO guidance recommends that ‘the dose should be lowest possible for relief of symptoms and effective daily functioning’ (p. 55; Jenkins, 2004). This is in line with current NICE guidance (2014).

Medication should be prescribed in line with BNF guidelines; this includes a reduction or change of antipsychotic when significant side effects occur, and to avoid polypharmacy. Antipsychotic medication should also be reduced in older adults (Adler & Griffith, 1991; Uchida & Mamo, 2009). A UK cohort study of nearly fifty thousand people, Marston et al (2014) however found that people over the age of 80 years were more likely to be prescribed an antipsychotic than those below the age of 80.

In summary, antipsychotic medication should be regularly reviewed by GPs, for those service users no longer under secondary care services. For such reviews to be meaningful and to optimise patients’ health, there should be the possibility for medication to be changed, including reduction of doses. Research suggests that a significant percentage of antipsychotic prescribing is not in line with current guidelines, with difficulties in de-prescribing antipsychotics as a potential reason for this.

1.8 Deprescribing

The process of reducing or stopping antipsychotic medication can be defined as *“the planned and supervised process of dose reduction or stopping unnecessary or potentially harmful medications” (p.1, Coe et al, 2021).*

Deprescribing antipsychotic medication is a process required to address polypharmacy or prescriptions above BNF limits for example, however it is no straight forward task. There is no evidence available as to which service users can safely reduce or stop antipsychotics (Leucht et al., 2018), and no guidance to advise clinicians on how to safely reduce and/or stop antipsychotic medication in people with a SMI diagnosis. Horowitz, Murray & Taylor (2020) suggest gradual decreases in dose and slowing down tapering as the doses get smaller. This is not incorporated in clinical guidance yet. Research trials, which investigated medication reductions, have largely not specified how this has been completed (Cohen & Recalt, 2019). It is also unclear if GPs review and reduce antipsychotics when indicated. It is therefore possible that some stable service users, in primary care, may remain on antipsychotics indefinitely, as their medication is not reviewed or reduced over time.

The next section discusses barriers and facilitators of medication reviews in primary care.

1.9 GP – Service User relationship in primary care

1.9.1 Potential barriers to primary care medication reviews – GP perspective

Medication reviews are potentially well placed in primary care (Lester, Glasby, & Tylee, 2004). The authors argue that mental health care should be a core activity, as GPs provide a non-stigmatizing environment, in comparison to the attendance of outpatient clinics, mainly located by inpatient ward sites, which can deter service users from accessing services. On the other hand, there are obvious barriers to primary care reviews. GP surgeries may not be able to offer continuity of care, in that regular follow up appointments are not always possible, which is a requirement when medication is to be reduced gradually. Research suggests that many GPs may feel that they lack confidence or knowledge to reduce antipsychotic medication (Jones, Major & Fear, 2015). A lack of specialist mental health training may pose additional difficulties: Research by MIND (2017) found that less than 50% of GP trainees undertook a mental health training placement between 2013 and 2015, indicating that many GPs may not have adequate training in this area. Lester et al (2004) referring to the lack of training in GP practices, concluded that ‘it is therefore hardly surprising that “*many GPs are reluctant to open ‘Pandora’s Box’, worried about the skills, time, and resources required to support them and the patient if mental health problems are disclosed”* (p.286). Some GPs do not consider mental health reviews as part of their remit and may therefore only review physical health (Jones et al., 2015). Other factors which may contribute to this alongside a lack of confidence is a lack of specialist guidance and/or lack of attendance and engagement from service users themselves (Carr, 1997; Jones, Major, & Fear, 2015; H. Lester et al., 2004; Lester, Tritter, & England, 2003; Mortimer et al., 2005). It is not clear how GPs feel about long-term antipsychotic medication, reducing or stopping antipsychotics as part of the deprescribing process.

1.9.2 Barriers to primary care medication reviews – Service user perspective

Little is also known about service users’ views on medication reviews in primary care only and what changes they experience after losing access to secondary care services. Research conducted in secondary care services offers an insight; it is however unclear how service users, who are only under primary care feel about service provision, following discharge from secondary care services. Over the years, service users may have experienced coercion with forced administration of medication and may fear sectioning (LeGeyt et al, 2017; Morant et al, 2018; Maidment, Brown & Calnan, 2011). As nearly all service users with a diagnosis of SMI are prescribed antipsychotic medication (94.8%, Patel et al., 2014) and up to 50% of service users are under primary care only, it is important to understand their views. Qualitative research suggests that service users feel a lack of choice with regards to their treatment:

"Several of the interviewees felt that they had no control over, or ability to influence, their drug treatment. There are many examples in the interviews of situations where the choices of drugs and doses were made by the psychiatrist without prior discussion with the person about former experiences of the drugs or of his or her own preferences' (p. 824, Bülow et al., 2016)

This will likely affect their willingness to attend and openly discuss their mental and physical health with clinicians (Grünwald & Thompson, 2021). Research exploring service user views on antipsychotic prescribing found that clinicians and service user priorities may be at odds, with doctors favouring symptom reduction when considering treatment options, whereas service users favour overall quality of life when making treatment decisions (Happell, Manias & Rope, 2004; Morant et al, 2018).

Research conducted in mental health services also consistently reports that service users do not feel included in antipsychotic medication reviews, feel that their queries are dismissed and that they are not provided with sufficient information (Rogers et al., 1998, Usher, 2001, Morant et al., 2018; Happell et al., 2004). Service users report that little time is spent on assessing the appropriateness of antipsychotics, and feelthat a lack of efficacy is blamed on the service user (as it is assumed that they are not taking their medication) rather than an acknowledgement that antipsychotics may not be efficacious for everyone:

"*One of the first things that they (nurses and doctors) assume is that a person isn't taking their medication. and it's been my experience that often with that, you're actually sick before you stop taking medication … The loop has gone to the point where you might be disorganized in your thought processes. You get sick first and then you either forget, or you think that it's poison, or whatever reason that you might have for not taking your medication." (p. 246, Happell et al, 2004)*

Research exploring service users' experience of antipsychotic medication also suggests that service users adjust or even discontinue their medication altogether without consulting their clinician (leGeyt et al, 2017). This is potentially unsafe, and abrupt medication changes may result in relapses.

In combination, the outlined research describes a possibly strained relationship between clinicians and service users. It is unclear whether this applies to GPs as well as psychiatrists. It also illustrates that the principles of shared decision making (as outlined in 1.6) are not always met, suggesting that medication reviews may not meet agreed standards.

There is a lack of research specifically on the topic of GP and service user medication reviews, and whether similar mechanisms underlie the interaction in psychiatrist – service user interactions. Whereas most psychiatrists are involved in the use of the Mental Health Act to be able to admit people to hospital against their wishes, and sometimes to enforce the use of medication, GPs are not frequently involved in such procedures. This suggests that there may be less of a significant perceived power imbalance between service users and GPs, for example.

Given the uncertainty regarding antipsychotics, and the relatively unique issue of coercion in mental health care, increased trust and a good therapeutic relationship may play a crucial role to overcome this (Maidment et al., 2001; Morant et al., 2018). This may be difficult to achieve due poor continuity of care (Reilly et al., 2012; Reilly et al, 2021).

Research is desperately needed to establish primary care service users' thoughts on their interactions with GPs, their views antipsychotic medication, and potential reductions and discontinuation of medication.

Ethnicity and culturally appropriate care will also affect engagement with primary care services and medication reviews. The first step to understanding the influence of ethnicity on health care is by adequately recording ethnicity to allow research to gain a better understanding. A study by Hardoon at al (2013) explored the number of people with a SMI diagnosis in the UK via the THIN database of primary care records. They were unable to explore diagnosis by ethnicity due to a lack of data. Although Mathur, Hull, Boomla & Hobson (2012), using EMIS records, were able to investigate risk factors for CDV by ethnicity, they again highlighted the need for better recording of ethnicity to tackle inequalities.

It is well established that people from ethnic minority backgrounds receive less mental health care than their white counterparts (as discussed in Kohn-Wood & Hooper, 2014). Reasons for this may be differing perceptions of mental health difficulties, stigma, language barriers and structural barriers (McCabe & Priebe, 2004; Kohn-Wood & Hooper, 2014). Maura et al (2017) also highlight the importance of trust; a person's cultural background can effect their level of trust in services and health care practitioners, which can lead to decreased access. Primary care has been suggested as a good place to address some of these barriers, as many people access health services in general and they are arguably less stigmatising than secondary services (Lester et al., 2004).

It is important to consider mental and physical health by ethnicity. A study by Mathur et al (2012) for example, found that south Asians had better blood pressure control, were more likely on statins and more likely to achieve cholesterol goals than those people with a SMI diagnosis who were black or Caribbean. On the other hand, south Asians were more than twice as likely to be classified as obese, to which antipsychotics can contribute. As described above, physical health is one of the key considerations when prescribing antipsychotic medication. This highlights the need for tailored interventions to ensure improved physical health for all.

A study by Garcia et al (2019), in which specifically Chinese and Latino communities were interviewed in primary care about their mental health needs, they found that people with limited English proficiency, regardless of ethnicity, had higher unmet mental health needs than those with English proficiency, illustrating that language proficiency, in addition to ethnicity, must be considered by health services.

Kohn-Wood and Hooper (2014) argue for culturally informed services, interventions tailored to different communities and increased efforts to engage people from minority ethnic groups to ensure parity of access for all.

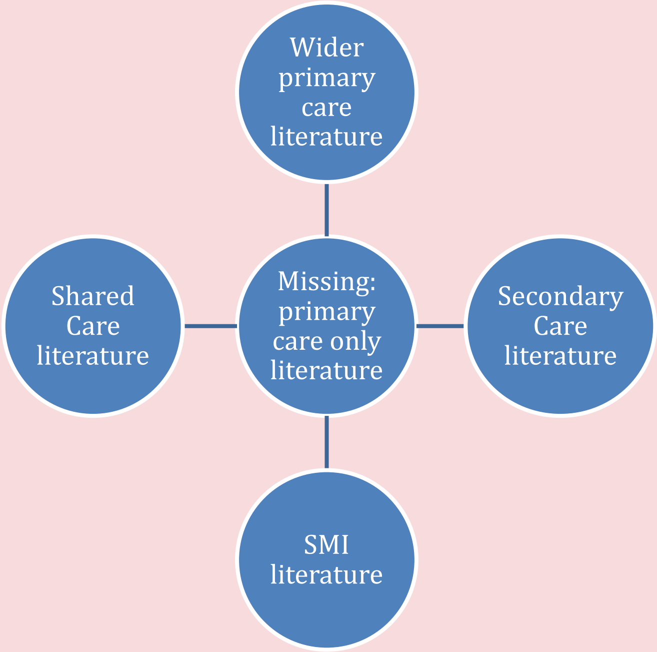
Person centred care, tailored to a person's needs based on their ethnicity and cultural needs is crucial to ensure diagnosis and treatment is appropriate. It is important to establish if there are difference between ethnicities in accessing primary care and secondary care services, and how this may be affect antipsychotic medication reviews.

1.10 Primary care only medication reviews: search for best practice

The onus is currently on individual GP practices to be proactive and to develop best practice guidelines (Byng, 2005), which may not always be possible given the lack of research in this area.

To the authors knowledge, there have been no trials which aimed to establish whether primary care medication reviews are acceptable to GPs and service users. No studies were identified which involved co-production in the current service design, and only one study assessed if service users were satisfied with GP services (Lester et al., 2005). Service users reported mixed levels of satisfaction, with some reporting that they felt “written off”. However, the study did not differentiate between service users who were just under primary care and those who were not, it merely recruited through GP practices and questioned service users on their interactions with their GP.

The available research largely focuses on four adjacent areas (figure 3): 1) wider SMI literature (diagnosis of SMI illnesses, efficacy of different antipsychotics), 2) literature regarding secondary care services (best practice in community mental health teams or inpatient services) , 3) wider primary care service provision (physical health reviews, number of prescriptions issued by primary care) and 4) the intersection between both: shared care literature (communication between primary care and secondary care with regards to physical health reviews, discharge letters, dividing responsibilities).



Commented [GL1]: Amended to illustrate all areas of literature carry the same weight

FIGURE 3 LITERATURE GAPS

The missing literature is highlighted in (Figure 3). Much literature is available on shared care, on diagnosis and treatment of SMI (Severe Mental Illness), on treatment in secondary care and wider primary care services. However little literature explores the care and treatment for those service users, who have been discharged from secondary care, and are only seen by their GP.To the authors knowledge, no studies have been conducted to investigate medication reviews for those who are no longer under secondary care, either from a clinician or service user point of view. It is unclear how those service users feel about their medication reviews, whether they feel their needs are addressed appropriately, how they feel about long-term antipsychotic treatment and about reducing or stopping their medication. Research is desperately needed to address this. King's fund (2020) suggests that current service design does not meet the full range of needs of clinicians and service users in the UK: GPs are left "*to pick up the pieces by supporting people with needs they may not have been trained to manage. [..]There has not been a clear national plan for improving mental health support in primary care for many years. NHS England's new Community Mental Health Framework is a notable step forward but there remains a need for greater clarity about what primary mental health care should look like in future*." (p.2)

1.11 Rationale for PhD

In summary, there are concerns regarding the evidence base for long-term use of antipsychotic medication, and research suggests that not everyone benefits from long-term use of these drugs. There are also significant adverse effects and physical health concerns in this population and concerns regarding the quality of antipsychotic prescribing in primary care. It appears likely that many service users remain on medication indefinitely, without a thorough review and without an appropriate assessment of whether the current medication dose is still appropriate. The GP – Service user relationship may play a crucial role in this. Thus, research is required to assess this. It is also not known, to which extent

GPs feel able to care for this population appropriately, and/or which resources need to be put in place to support the adequate delivery of care. It is also unknown whether “stable” primary care only service users have distinct needs to those still in secondary care, which may have treatment implications.

It is important to ensure that care is evidence-based for those service users who are discharged to primary care services. This could make a significant difference in the health and quality of life of service users in this area.

2. Methodology of the PhD

Given the lack of literature in this area, and thus a lack of understanding about what factors influence antipsychotic medication reviews primary care, a theory driven approach is required. An appropriate methodology is a realist informed synthesis.

2.1 What is a realist synthesis?

Realist methodology is a theory driven approach, used to assess complex evidence relating to the implementation of policy, programmes, services and interventions (Pawson, 2006). The aim of realist synthesis is to “…to articulate underlying programme theories and then to interrogate the existing evidence to find out whether and where these theories are pertinent and productive.” (p. 56; Pawson, 2006).

Realist ontology sits between positivism and constructivism (Sayer, 2000). It is concerned with understanding context in relation to underlying mechanisms of action (Pawson, 2006) and aims to address the key research question: what works, for whom, under what circumstances and how? (As opposed to simply, “does it work?”; Pawson, 2006). The approach has been used in this research area (Byng, 2005, Ford et al., 2019). Realist synthesis (or realist review) usually includes a synthesis of secondary data in the first instance. The synthesis results in an initial programme theory, or theorised idea of how an intervention occurs (a medication review in this case). The programme theory attempts to outline factors which affect medication reviews (Context) and the underlying mechanism of action (Mechanism). It aims to understand the outcome of interest, as well as possible alternative outcomes (Outcome).

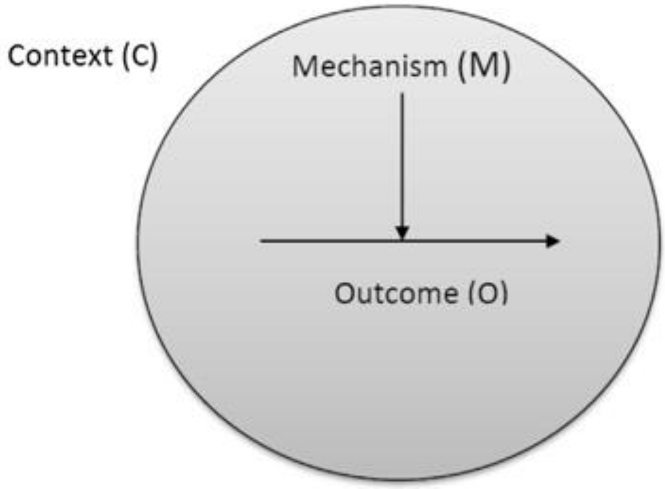


FIGURE 4 C-M-O CONFIGURATION (FIGURE 3.1 IN PAWSON & TILLEY, 2006)

CMO Configurations (CMOCs, Figure 4) are used to illustrate the theory. Each aspect in the programme theory is initially based on and tested against the literature identified in the realist review (Wong et al., 2013).

In addition to the realist review, primary data may be collected to confirm or deny the initial programme theory, as well as to collect further evidence where there are evidence gaps. Primary data collection can include interviews, with topic guides based on the theorised programme theory (Manzano, 2016). Less common data collection methods are realist surveys (Schoonenboom, 2017).

Analysis is based on key principles highlighted by Pawson & Tilley (1997); they include Context- Mechanisms- Outcome Configuration, ontological depth, inference sufficiency and approximation and accumulation. Data coding is retroductive and abductive. Retroduction is defined as "*the activity of theorizing and testing for hidden causal mechanisms responsible for manifesting the empirical, observable world*" (p.121. Jagosh, 2020), whereas abduction can be defined as "*the inventive thinking required to imagine the existence of such mechanisms*" (p.122, Jagosh, 2020). The additionally collected primary data will be used to juxtapose, reconcile and consolidate the initial programme theory, leading to a final programme theory.

Realist review versus systematic review

Conventional systematic reviews favour the logic of accumulation of evidence and find strength in the inclusion of large numbers of studies. Realist reviews instead aim to configure evidence to uncover hidden contexts and mechanisms, which influence outcomes. The focus is on synthesising evidence to explain *why* outcomes occur, not just whether they do or not (Pawson, 2006). The differences between conducting a systematic review and a realist synthesis are:

1. "The focus of the synthesis is derived from a negotiation between stakeholders and reviewers and therefore the extent of stakeholder involvement throughout the process is high.
2. The search and appraisal of evidence is purposive and theoretically driven with the aim of refining theory.
3. Multiple types of information and evidence can be included.

4. The process is iterative.
5. The findings from the synthesis focus on explaining to the reader why (or not) the intervention works and in what ways, to enable informed choices about further use and/or research" (p. 2, Rycroft-Malone et al., 2012).

Realist reviews are therefore inclusive of evidence from all forms of study design, as even 'anecdotal' evidence can give insights into hidden or implicit mechanisms ("nuggets"; Pawson, 2006). Realist reviews have been used extensively in primary care research (Ford et al.,2016) and prescribing (Papoutsi et al., 2018) and was therefore deemed an appropriate methodology to answer the research question posed here.

3. Objectives

The PhD aims to address seven key objectives.

3.1 Initial programme theory

A realist review, using only secondary data, will be conducted with the aim of theorising barriers to meaningful and shared conversations about antipsychotic medication in primary care and theorises how these barriers can be overcome. This includes outlining an initial programme theory (Chapter 2).

3.2 Refining the programme theory

To refine the initial programme theory, two separate studies will be conducted. The first study consists of service user interviews (Chapter 3), collecting key demographic and clinical variables, as well as exploring service user views on antipsychotic medication reviews, reduction, and discontinuation, with the aim to:

3. 2.1 To determine potentially unique demographic and clinical differences between primary care only and secondary care service users

3. 2.2 To determine primary care Service user views of long-term antipsychotic treatment, and how this might differ to secondary care service users.

3.2.3 To identify key considerations when discussing antipsychotic medication with service users, taking their concerns into account.

A second study will be conducted (Chapter 4). This will include designing a GP survey, based on the realist review, to:

3. 2.4

To determine if GPs are able to identify service users who are solely under primary care and whether there are any specific practice specific guidelines for this population?

3.2.5

To determine GPs' views on long term antipsychotic medication for service users with an SMI diagnosis.

3.2.6

To determine if primary care only antipsychotic medication reviews are occurring, and if so, how comfortable GPs are in reviewing, reducing and stopping (where appropriate) antipsychotic medication.

3.2.7

To collect data, specifically for those areas that lack literature in the Realist Review, to further refine the programme theory.

3. 3. Final programme theory (Chapter 5 and 6)

The findings of the Realist Review and additional collected data (GP and service user views) will be synthesised to propose a **final programme theory** with the aim of developing a core set of recommendations for primary care antipsychotic medication reviews, which also outlines key areas for future research.

4. The Realist Synthesis Process

Whereas each data collection chapter (2,3,4) has their own individual methodology section (which is described in depth in each chapter), the overarching methodology is that of a realist informed synthesis, based on Pawson & Tilley (1997, outlined in 2.1) and follows the standards outlined in the RAMESES guidelines (Wong et al, 2013). To illustrate this process more clearly, please see Figure 5 (taken from Salter and Kothari, 2014).

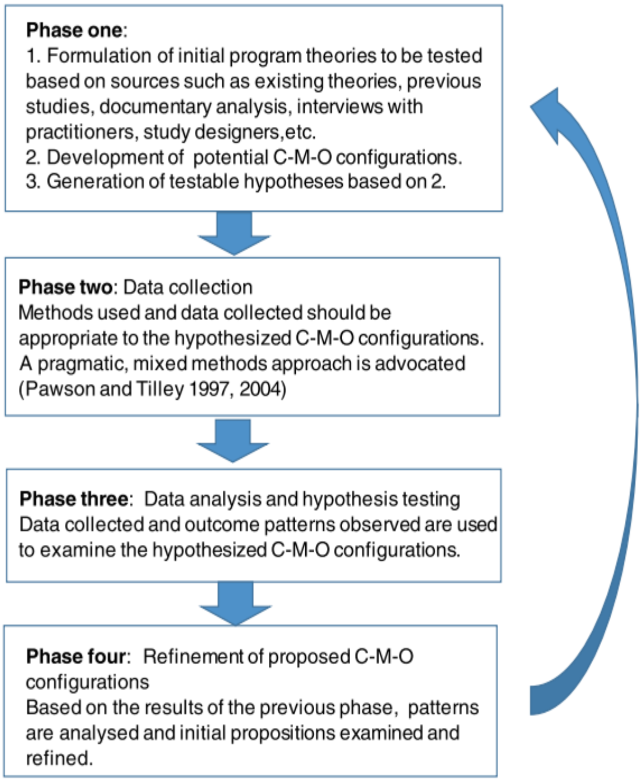


Figure 5 Phases of the realist synthesis (adapted from Salter and Kothari,2014)

The next chapter describes Phase 1, formulation of the initial programme theory using only secondary data (Chapter 2), which is followed by two data collection and data analysis chapters (Phase 2 and 3, outlined in Chapters 3 and 4). Chapter 5 will outline the refinement process (Phase 4), including the data synthesis and refinement of the programme theory. The refinement process was iterative throughout and is described in a linear way in this PhD to aid understanding of the research process. Chapter 6 discusses the results of the

PhD and will also outline to which degree each quality standard for realist synthesis (RAMESES, 2014) has been met by this realist informed synthesis, for the purposes of transparency.

Chapter 2 – Realist Review

This Realist review was published in BMC Psychiatry in February 2021 (please see Appendix for full publication) and was presented at the Realist2020 conference.

This chapter describes the realist review conducted on primary care antipsychotic medication reviews. The aim is to theorise barriers to meaningful and shared conversations about antipsychotic medication in primary care and theorises how these *barriers can be overcome. This includes developing an initial programme theory. It outlines briefly the background of what it known on the topic already relevant to this review, describes the methodology and the results of the review: five CMOCS and an initial programme theory. It goes on to explain the substantive theory and highlights recommendations for future research.*

1. Introduction/Background

As outlined in Chapter 1, an increasing number of Service Users diagnosed with serious mental illness, are being discharged from specialist services to primary care only (as discussed in (Byng, 2005; Siddiqi, Doran, Prady, & Taylor, 2017). Although exact numbers have not been reported, it is estimated that approximately 31% of people diagnosed with SMI are under primary care only in the UK (Burns & Kendrick, 1997; Kendrick et al., 1994; Reilly et al., 2012). In crisis, service users can be referred back to secondary care, but in all other cases, General Practitioners (GPs) are service users point of access to mental health care. To what extent GPs are able to provide adequate treatment for the stable, on long term medication part of the SMI population is unclear.

Antipsychotic medication deserves specific attention in this population, as it is the main treatment, and also has serious adverse effects, as discussed in Chapter 1. Research also found that service users under primary care only were prescribed significantly more medication than service users who were also seen in secondary care Reilly et al (2012). Given that up to 40% of service users do not show improvements from medication (NICE, 2014) and the presence of severe side effects resulting in long term health problems, medication should be reviewed regularly to ensure that it is prescribed appropriately. It is crucial to find a balance between the “lowest dose that affords protection while minimizing side-effects” (Burns & Kendrick, 1997). This needs to be reviewed on an ongoing basis, as the need for medication also changes across the lifetime, with guidance advising that older adults should be on lower doses (Adler & Griffith, 1991; Uchida & Mamo, 2009). This may be particularly pertinent to primary care only patients, who are on average older, and have been diagnosed with SMI for longer than service users still under secondary care (Kendrick et al., 1994; Reilly et al., 2012). Guidance also suggests for service users to “stop taking it gradually” when medication is no longer required (NICE, 2014), however it is unclear how this is to be executed, let alone in primary care. Little and vague guidance is available on medication reviews in primary care (Mortimer et al., 2004). It is clear that antipsychotic medication needs to be reviewed regularly; however it is unclear whether medication is reviewed for those service users no longer under secondary care services, and what potential barriers and facilitators to this area.

Due to the lack of research in this area, we conducted a realist review. Realist reviews allows researchers to explore the underlying factors which might influence medication reviews in primary care and to develop a testable, explanatory framework, which could guide further research in this area (Pawson, 2006).

2. Aim

The aim of this chapter is to explore “what works, for whom, in what respects, to what extent and in which context”, for medication reviews conducted in primary care for service users diagnosed with SMI.

The specific review questions were:

1) *What contexts and mechanisms facilitate or prevent antipsychotic medication reviews in primary care in patients diagnosed with psychosis ?*
2) *What contexts and mechanisms facilitate or prevent service users with SMI diagnoses from initiating effective and appropriate medication reviews?*
3) *Are there alternative outcomes from starting a medication review for GPs/service users/ other stakeholders?*

3. Flow diagram of the project

The review protocol was registered with PROSPERO (CRD42018107573). A realist review includes several, iterative literature searches. This chapter describes Phase 1 as outlined in the Introduction (4. Realist Synthesis). For this review, discussions with stakeholders and a scoping search informed the initial programme theory, which was refined following the main, systematic literature search. To refine the programme theory further, a citation search and additional, non-exhaustive search was completed. Refining the programme theory was an iterative process (Figure 1 Flow diagram)

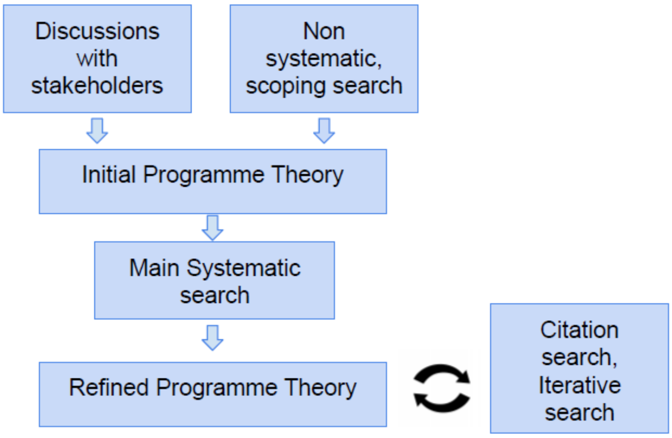


FIGURE 6 CHAPTER 2 REALIST REVIEW FLOW DIAGRAM

4. Initial Programme Theory Development

Following stakeholder discussions and a scoping review, local NHS guidance was also searched to shed light on potential mechanisms. Informal discussions were held with key stakeholders to increase understanding of current practice in medication reviews and identify any potentially relevant literature. This included discussions with GPs, members of the Lived Experience Advisory panel (LEAP)[1], psychiatrists and local Clinical Commissioning Group (CCGs). The aim was to identify how medication reviews are currently operationalised and which potential barriers and facilitators exist. Following

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[1] LEAP is made up of people with expertise in antipsychotic medication through personal use or as a carer for someone with psychosis. It meets regularly to discuss the progress of the RADAR study and to contribute to its development, for example, advising on the antipsychotic reduction strategy. RADAR is a 6-year NIHR funded programme, comparing the effects of antipsychotic reduction treatment with maintenance treatment, led by Dr Joanna Moncrieff. The LEAP were consulted on 4 separate occasions during the design stage, following the scoping searches and following initial CMOC coding.

these discussions, the topic area for this review was narrowed down, to focus on GP and primary care only patients' medication reviews, leaving out, for example, consideration of the factors affecting service users making or attending appointments, and communication with, or prescribing done prior by secondary care, as these do not directly influence the content of a medication review and are therefore considered beyond the remit of this review. Documents that included data relating to GP views of secondary care were still included, as early discussions indicated that these views may play a role in the conduct of medication reviews for primary care only service users.

These led to the development of very early stage "programme theories" (see Glossary), or theorised explanations of how medication reviews may operate (see Figure 4). These initial programme theories were discussed ongoingly with the research team (LG, CD, JM, NC, RB) and stakeholders.

5. Main, systematic search

Initial scoping searches indicated a paucity of specific papers discussing antipsychotic medication management in primary care, so the search terms for the main search were kept very broad to improve its sensitivity and reduce the risk of missing data related to any potential contexts or mechanisms ("Big Bang Approach"; (Booth et al., 2020). Some discussion papers explored antipsychotic prescribing without specifically using the term schizophrenia/psychosis or SMI (Marston et al., 2014; Mortimer et al., 2005) therefore this concept was left out of the main search. Search terms included variations describing antipsychotic medication (antipsychotics, major tranquilizers, neuroleptics), as well as variations describing primary care (general practitioners, primary care, GP). Following guidance from the LEAP group, terms describing pharmacists and nurse practitioners were also included in the search, as it had been suggested that these groups could play a potential role in the facilitation of medication reviews. The search terms and strategy can be found in Appendix 1.

Using papers identified in the initial scoping strategy as benchmarks, search terms were piloted and amended accordingly to ensure that highly relevant papers were retrieved.

Medline (via HDAS), EMBASE (via HDAS), The Cochrane Library, CINAHL (via HDAS), PsycINFO (via HDAS), PsycEXTRA, the Web of Science Core Collection, Scopus, IBSS, OpenGrey and PubMed (via HDAS) were searched in August 2018. The search terms and syntax were adapted as needed according to the database searched. The results were imported into Mendeley (version nr 1803). Papers from scoping searches were also included. Citation search and iterative search were run in April and August 2019 and the results were also added to Mendeley (Figure 3).

The inclusion criteria were:

- Adults (age 18 and above)
- Diagnosis of Psychosis, schizophrenia, psychosis like symptoms (SMI)
- Medication reviews, care and treatment of service users diagnosed with SMI
- Published after 1954 (year the first antipsychotic was introduced) to present day
- Published in English language
- All study methodologies
- Prescription of antipsychotic medication in primary care

Exclusion criteria

- Service users currently under section (Mental Health Act, Forensic, Community Treatment Order)
- Service users currently in crisis or studies discussing Crisis services (Home Treatment Team etc)
- Animal studies
- Physical health reviews only, which do not include factors around treating service users or have medication reviews alongside
- Studies discussing prescription of non-antipsychotic medications
- Studies from developing countries
- Studies discussing the prevalence and treatment of side effects by adding other (non-antipsychotic) medications
- Studies discussing the prevalence or validity of a diagnosis of severe mental illness
- Off – label prescribing

Excluded later

- Bipolar studies – too much coverage of affective mood states, and non – AP medication. Following reading a significant subsample of papers, it was decided that these did not add anything additional to the programme theories.
- Clozapine papers – as most service users who are prescribed clozapine, receive regular reviews at clozapine clinics and are prescribed clozapine there, these studies were not deemed to be “GP only” and therefore excluded.

LG first screened all results based on title. Following exclusion by title, the remaining papers were screened by abstract. A random 10% sample of references were screened in duplicate by LG and CD, to ensure the appropriateness of the inclusion and exclusion criteria, as well as consistency in their application. Following initial discussions, the main obstacles identified were due to the paucity of papers discussing the medication reviews directly, and vague abstracts. The disagreements were easily resolved following discussion, and this discussion guided the remaining screening. All remaining papers were screened by LG. LG and CD screened a 10% subsample of full text papers; full agreement was achieved following discussion. LG screened the remaining papers.

6. Additional searches

7.1 Citation Search

Backward citation searches were completed for all suitable papers identified upon full text screening. Citation searches were completed for those sections of the included documents from which relevant data was extracted and included in the review. This approach ensured that additional highly relevant data from cited documents that were not identified in the main search was considered for inclusion in the review.

7.2 Iterative searches

The synthesised data following the main and citation search pointed towards the importance of stereotypes and stigma. Therefore, an iterative search was conducted to further develop the programme theory. A Google Scholar search was completed to shed further light on the developing programme theory, using the search terms “GP”, “SMI” and “stereotypes” or “stigma”.

7. Extracting and organising data

All included papers from full text screening were added to NVivo (version 12.6.; qualitative data analysis software) and were initially coded into descriptive categories, which could shed light on potential Contexts, Mechanisms or Outcomes (C, M or O, see Glossary). The initial coding frame was very granular, to allow for nuanced details to be picked up by the analysis. CD coded a 10% subsample, in order to ensure consistency in coding. A consensus approach was used to deal with any potential discrepancies.

8. Synthesising the evidence and drawing conclusions

9.1 Quality appraisal - Assessing relevance, trustworthiness, and rigour

Further assessment of the relevance and rigour of the data available in the included papers was conducted at this stage. The quality appraisal process was completed in two stages: 1) overall quality appraisal 2) individual CMOC quality appraisal.

1) Overall quality appraisal:

The relevance of all included papers was assessed using a traffic light system, adapted from Jagosh et al. (2011) and Francis-Graham et al. (2019). Papers which contributed data relating to only an individual C, M or O, were classified as “red”, if it contributed to two of the criteria, as amber, and to all three (C,M,O) as “green”. They were also assessed according to relevance (low, moderate, high). Papers that had low relevance and only contributed to one of the C, M or O (therefore “red) were excluded, if this information was available in other, included papers. The quality of each included paper was then assessed using an appropriate critical appraisal tool. For empirical papers, the Mixed Methods Appraisal Tool (MMAT, version 2018) was used, for systematic reviews the Critical Appraisal Skills Programme for systematic reviews (CASP Systematic Review, 2018) was used to assess rigour. For the MMAT, scoring consisted of two screening questions, which were rated “yes”, “no” or “can’t tell”, followed by five questions dependent on the study design (qualitative, quantitative, mixed methods), again rated “yes”, “no” or “can’t tell”. For the CASP, all 11 questions were scored on a “yes” “no” “can’t tell” range. Non-systematic literature reviews were not quality assessed. Instead, for those sections in the paper used to refine the programme theories, references were double checked for credibility. This allows for the inclusion of “nuggets” of information, which otherwise might not meet rigour assessment but contribute greatly to relevance (Pawson, 2006).

A traditional quality assessment tool was included as part of the relevance, rigour and trustworthiness assessment for transparency purposes. The underpinnings of the realist approach were maintained, in that no papers were excluded based on quality appraisal assessment scores. Scores can however give the reader a clearer understanding of the sources which underlie each CMOC, as seen in Francis-Graham (2019) for example.

LG and CD completed a random 10% subsample of the quality appraisals to pilot this method and agreed that this was suitable for this project. Again, a consensus approach was used. Following a discussion, the remaining 90% were completed by LG. Please see Appendix 2 for overall quality appraisal.

2) Individual CMOC quality appraisal

Following the development of specific Context, Mechanism and Outcome Configurations (CMOCs, see Glossary), each was quality assessed (Table 1). The overall quality of the data included in the development of each CMOC was considered in relation to several criteria. For each CMOC, included data was first assessed in relation to its contribution of information relating to C, M or O (as above). Scores were given accordingly: A - papers providing evidence on C, M and O relevant to this CMOC, B - papers providing evidence on only two of the three (C, M, O) criteria or C - providing information only on one of C, M or O). Secondly, relevance was further assessed on a 3-point scale of A to C: A - papers of high relevance to the CMOC, B- papers of moderate relevance to the CMOC and C- low relevance. The closer the data was to discussing C, M or O in primary care, for people diagnosed with SMI and treated with antipsychotics, the higher the relevance. Reasons for each scoring was recorded for transparency (Appendix 3). Thirdly, the quality of the evidence was assessed, again on a A-C scale: A - evidence was derived directly through the studies' findings B -evidence was taken from the discussion, based on the study's findings (this allows for the inclusion of the authors suggestions on the nature of their findings) and C - taken from the introduction or from a non-systematic literature review, opinion or editorial. LG completed this assessment for each individual CMOC, any queries were discussed with CD and resolved by discussion.

	Contributes to C, M, O?	Relevance of contribution?	Quality of contribution
Scoring	A - provides evidence of all 3 (C, M, O) B - provides evidence on only 2 C - provides evidence on only one criterion	A - high B - moderate C - low	A - contribution taken from finding of a scientific study B - contribution taken from the discussion section C - taken from the introduction, or for non-systematic literature reviews, editorials and opinion

			papers

FIGURE 7 INDIVIDUAL QUALITY APPRAISAL

9. Synthesis & substantive theory

The process of refining the programme theory included appraising and juxtaposing data sources. This was done by extracting data into possible Contexts, Mechanisms and Outcomes. Codes were refined iteratively in NVIVo (Version 12.6), leading to the development of initial Context Mechanism Outcome Configurations. These were discussed with stakeholders and refined further. Alongside this quality appraisal were completed, which allowed researchers to assess the quality and compare and contrast the evidence available. The programme theory was tested and refined ongoingly through data triangulation. The programme theory and data codes were refined iteratively, as per the five steps (Pawson, 2006). Once the final programme theory was developed, another round of data extraction was completed to ensure that no data was missed. Retroductive reasoning was used to theorize the programme theory, based on available evidence.

During the process of developing and refining CMOCs, it became apparent that a common theme relating to the effect of stereotyping was common to multiple areas of the analysis. An iterative literature search was therefore conducted to explore this theory in more depth, with the aim of identifying relevant theoretical perspectives that could further explain the data and strengthen the overall programme theory.

10. Results

11.1 Agents considered to be playing a role:

Based on the records identified in the scoping search and stakeholder discussions, including the LEAP panel, the following groups of people are thought to influence directly or indirectly, the antipsychotic decision-making process in primary care in the UK (Figure 2). Whereas the interaction between GP and service users is crucial, these decisions are also influenced by the relationship GPs have other GPs in their practice, the practice nurses and with secondary care services, like community mental health psychiatrist and GP liaison services (where available). Medication reviews are also thought to be influenced by the wider NHS context and Quality Outcome Framework guidance. Service Users and GPs are further influenced by their family members, friends, and carers, as well as potentially by the media.

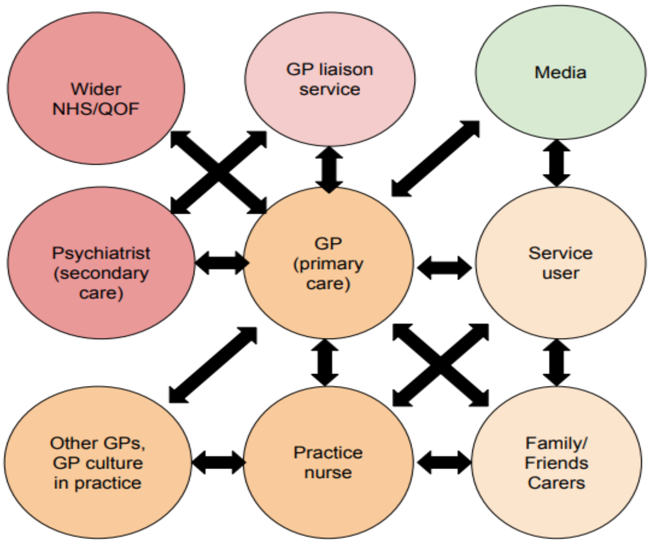


FIGURE 8 AGENTS THOUGHT TO BE INVOLVED IN THE MEDICATION DECISION MAKING PROCESS

11.2 Search

The main search was conducted in August 2018, in a total of 11 databases MEDLINE, EMBASE, The Cochrane Library, CINAHL, PsycINFO, PsycEXTRA, the Web of Science Core Collection, Scopus, IBSS, PubMed, OpenGrey. Papers identified in the earlier scoping searches were also added. Citation searches were run in May 2019. Iterative searches were conducted in September 2019 (Figure 1). Due to the broad search terms, a large number of references were excluded as they were not relevant to the research question. Applying the inclusion and exclusion criteria listed above, 5109 papers were found potentially suitable following title screening (see figure 3).

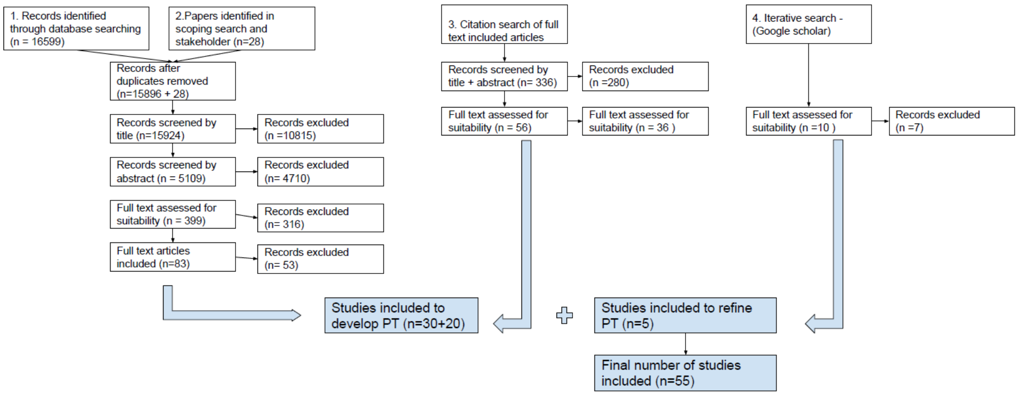


FIGURE 9 LITERATURE SEARCH

11.3 Initial programme theories and feedback

The initial focus of the review was on the content of antipsychotic medication reviews in primary care. The searches identified several studies conducted in primary care settings, but no studies focused on primary care only service users. Following on from this and GP stakeholder discussions, it became apparent that discussions around medication may not be happening in primary care at all. Therefore, the revised focus of this review was whether antipsychotic medication reviews occur (or not), rather than the quality and content of medication reviews. There is a paucity of studies discussing how often and in what depth medication reviews occur in primary care, especially for those service users who are under the care of their GP only (figure 4).

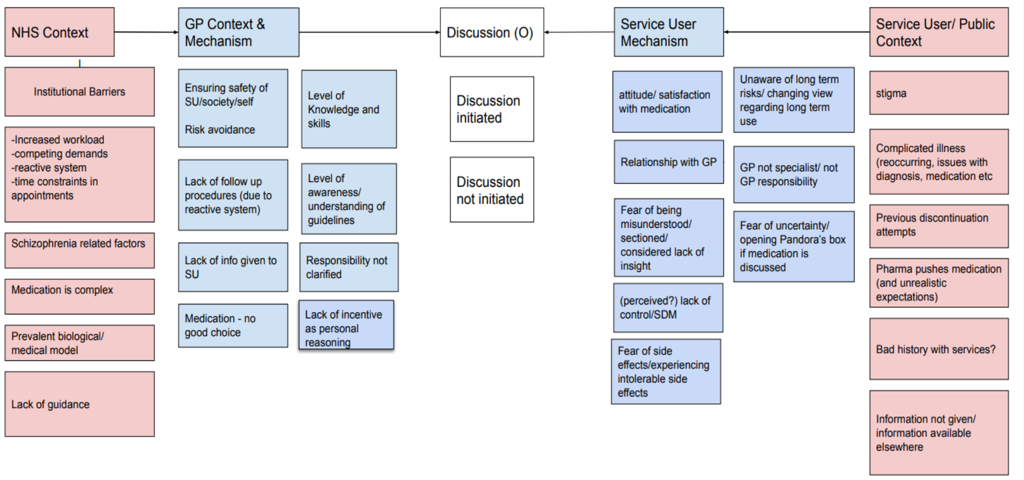


FIGURE 10 INITIAL PROGRAMME THEORIES

Initial programme theories (figure 3) focus heavily on GPs' lack of knowledge and training (Baker et al., 2019; Boardman, McCann & Clark, 2008; Rasmussen, 2006; Toews et al., 1996), however most service users know that GP has limited training and the important thing is to be heard and referred at the right time (Lester et al., 2005). Difficulties in adhering to standards were also noted in physical health (Burns & Kendrick, 1997; Feeney & Mooney, 2006; Jones et al., 2015; Lambert & Newcomer, 2009), suggesting that issues regarding medication reviews may possibly not be related to a lack of mental health knowledge and training alone. A lack of mental health guidance was also an initial factor, however even where there was guidance available, it was not well adhered to, as seen in rates of polypharmacy for example (Mortimer, 2004; Patel et al., 2014).

Other factors, like the low frequency of SMI diagnoses and complex medication regimes in this population were also excluded, as these are unlikely to change. Similarly, institutional barriers were considered to potentially play a role. Stakeholder discussions identified that GPs cannot easily identify which of their service users are primary care only, and which are also under secondary care. Although this is likely to influence the initiation of conversations about medication, it cannot be changed readily. Following the scoping searches, practice nurses were also excluded from the review, as they did not seem involved centrally (Reilly et al., 2012), although there should definitely be scope to be involved as recommended in the literature (Millar et al., 1999) and by the LEAP members.

11. Main Findings

In the end, a total of 55 papers were included, of which 30 were identified through the main search, 20 through the citation search, and 5 through the iterative search (Figure 3 Search Strategy). It included 34 empirical studies (of which N=15 questionnaires and N=15 qualitative interviews), 1 systematic review, 16 non-systematic literature reviews and N=4 other (e.g., NICE guidance and news reports).

The review consists of N=27 papers discussing the care and treatment of people diagnosed with SMI, including 10 articles on guidance for GPs and 7 GP surveys on the treatment and care of people diagnosed with SMI, N=21 papers discussing the experience of antipsychotic medication and treatment from the service user perspective, and N=7 on stigma and Shared Decision Making.

34 studies were empirical studies, which were assessed using the MMAT, 1 systematic review, which was assessed using the CASP for systematic reviews, and the remaining 20 were not quality assessed, as they were non-systematic literature reviews, guidance documents or opinion pieces. (For detailed quality assessment, please see Appendix 2). The overall quality of the papers was acceptable; however, no studies directly exploring

the care or needs of GPs or primary care only service users were found, despite a comprehensive search.

Through synthesis of the data, several Context, Mechanism and Outcome Configurations (CMOCs) were developed:

Barrier 1: Low expectations regarding recovery from mental illness

Barrier 2: Perceived lack of patients' capabilities to participate in medication reviews

Barrier 3: Lack of information sharing between GPs and patients

Barrier 4: Perceived risk of service users

Barrier 5: Uncertainty regarding medication and illness trajectory

Facilitators to antipsychotic medications reviews.

These CMOCs illustrate potential reasons for the lack of conversation or appropriate review of antipsychotic medication in SMI people diagnosed with schizophrenia or psychosis. They were theorised from a GP view and a service user view. They are not mutually exclusive, more than one or none may characterise any particular situation, and each may occur to a lesser or greater extent ("dimmer switch"; Dalkin et al., 2015). They were developed from the following papers:

TABLE 3 INCLUDED PAPERS

First author	Title	Country	Setting*	Aim	Study Design and data collection
Adams, 2007	Shared Decision-Making Preferences Of People With Severe Mental Illness	USA	G	Perceived roles and preferences were explored for shared decision making among persons with severe mental illnesses.	Questionnaire
Aref-Adib, 2016	A Qualitative Study Of Online Mental Health Information Seeking Behaviour By Those With Psychosis	UK	G	To explores the nature, extent and consequences of online mental health information seeking behaviour by people with psychosis and to investigate the acceptability of a mobile mental health application (app).	Qualitative interviews
BMJ News, 1995	Mental Health Law Obsolete, Says Inquiry.	UK	G	news report	News report

Boardman, 2008	Accessing Health Care Professionals About Antipsychotic Medication Related Concerns	Australia	G	To describe service users' access to and satisfaction with health care professionals, including nurses, as related to users' antipsychotic medication concerns.	Questionnaire
Britten, 2010	Resisting Psychotropic Medicines: A Synthesis Of Qualitative Studies Of Medicine - Taking	UK	G	Describe lay perspectives on prescribed psychotropic medicines.	Systematic review of qualitative studies
Burns, 1997	The Primary Care Of Patients With Schizophrenia: A Search For Good Practice	UK	PC	To develop practice for establishing a register and organizing regular reviews; comprehensive assessments; information and advice for patients and carers; indications for involving specialist services; and crisis management.	Consensus group developed good practice guidelines based on current literature

Carr, 2004	Attitudes And Roles Of General Practitioners In The Treatment Of Schizophrenia Compared With Community Mental Health Staff And Patients	Australia	PC	To examines the attitudes and roles of Australian GPs in the treatment of schizophrenia and their relationships with specialist services.	Questionnaires (completed by GPs, mental health staff and service users)
Carrick, 2004	The Quest For Well-Being: A Qualitative Study Of The Experience Of Taking Antipsychotic Medication	UK	G	To outline the experience of taking antipsychotic medication	Qualitative interviews + focus group
Corrigan, 2000	Mental Health Stigma as Social Attribution: Implications for Research Methods and Attitude Change	USA	n/a	To illustrate how attribution model advances research questions related to mental health stigma	Non- systematic literature review

Corrigan, 2013	Erasing the Stigma; Where Science Meets Advocacy	USA	n/a	Review of existing research regarding public stigma reduction, looking at approaches within mental health and other stigmatised communities.	Non- systematic literature review
Crawford, 2014	Assessment And Treatment Of Physical Health Problems Among People With Schizophrenia: National Cross-Sectional Study	UK	G	To examine the quality of assessment and treatment of physical health problems in people with schizophrenia.	Audit of routine data + questionnaire
Delman, 2015	Facilitators And Barriers To The Active Participation Of Clients With SMI In Medication Decision Making: The Perceptions Of Young Adult Clients	USA	G	To explore factors influencing active participation of young SU in psychotropic medication decision making	Qualitative interviews

Dixon, 2008	Medical Students' Attitudes To Psychiatric Illness In Primary Care	UK	PC	We describe a study of the attitudes and predicted behaviours of medical students towards patients with mental illness in primary care. To investigate the effects that level of undergraduate medical training and personal characteristics might have on responses.	Vignettes (either schizophrenia, depression, diabetes or no illness) and questionnaire
Donlon, 1987	"The Schizophrenias: Medical Diagnosis And Treatment By The Family Physician"	USA	PC	Overview of care of schizophrenia in primary care	Non – systematic literature review
Feeney, 2006	Atypical Antipsychotic Monitoring: A Survey Of Patient Knowledge And Experience	Ireland	G	To examine the knowledge and experiences of side-effects and their monitoring in patients prescribed atypical antipsychotic medications.	Questionnaire

Galon, 2012	Engagement In Primary Care Treatment By Persons With Severe And Persistent Mental Illness	USA	PC	To describe the social process of engagement in primary care treatment from the perspective of persons with SPMI.	Qualitative interviews
Happell, 2004	Wanting To Be Heard: Mental Health Consumers' Experiences Of Information About Medication	Australia	G	To examine the experiences of consumers, specifically in relation to education and decision making with regards to medication.	Focus group
Hustig, 1998	Managing Schizophrenia In The Community	Australia	PC	Overview of care of schizophrenia in primary care	MJA Practice Essentials (non systematic literature review)
Johnson, 1997	Professional Attitudes In The UK Towards Neuroleptic Maintenance Therapy In Schizophrenia	UK	G	To assess length of time considered suitable for treatment of schizophrenia	Teleconference between consultant psychiatrists, GPs, pharmacists and

					CPNs + Questionnaire + commentary
Jones, 1987	Educating Family Physicians To Care For The Chronically Mentally Ill	USA	PC	overview of care of schizophrenia in primary care	Non – systematic literature review
Jones, 2015	Schizophrenia In A Primary Care Setting	UK (but studies from all over)	PC	overview of care of schizophrenia in primary care	Non – systematic literature review
Katschnig, 2018	Psychiatry's Contribution To The Public Stereotype Of	Austria	G	To discuss the origins of the idea of a chronic brain disease, of the split personality concept derived from the term "schizophrenia" , and the craziness	Non – systematic literature review

	Schizophrenia: Historical Considerations			idea reflected in the “first rank symptoms”, which are all hallucinations and delusions .	
Kendrick, 1995	Randomised Controlled Trial Of Teaching General Practitioners To Carry Out Structured Assessments Of Their Long Term Mentally Ill Patients	UK	PC	To assess the impact of teaching general practitioners to carry out structured assessments of their long term mentally ill patients.	RCT of structured assessments vs TAU
Lambert, 2009	Are The Cardiometabolic Complications Of Schizophrenia Still Neglected? Barriers To Care	USA mostly	PC	barriers of physical health testing in primary care	Non systematic literature review
Lawrie, 1998	General Practitioners’ Attitudes To Psychiatric And Medical Illness	UK	PC	To examine the attitudes of general practitioners to patients with different psychiatric and medical illnesses.	Vignettes

LeGeyt, 2016	Personal Accounts Of Discontinuing Neuroleptic Medication For Psychosis	UK	G	To explore personal accounts of making choices about taking medication prescribed for the treatment of psychosis (neuroleptics).	Qualitative Interviews
Lester, 2003	Satisfaction With Primary Care: The Perspectives Of People With Schizophrenia	UK	PC	This study aimed to explore the elements of satisfaction with primary care for people with schizophrenia.	Qualitative interviews
Lester, 2005	Patients' And Health Professionals' Views On Primary Care For People With Serious Mental Illness: Focus Group Study	UK	PC	To explore the experience of providing and receiving primary care from the perspectives of primary care health professionals and patients with SMI respectively	Focus group
Magliano, 2017	Effects Of The Diagnostic Label 'Schizophrenia', Actively Used Or Passively Accepted, On General	Italy	PC	To investigate GPs' views of schizophrenia and whether they were influenced by a 'schizophrenia' label, passively accepted or actively used.	Vignette + Questionnaire

	Practitioners' Views Of This Disorder				
Maidment, 2011	An Exploratory Study Of The Role Of Trust In Medication Management Within Mental Health Services	UK	SC	To develop understandings of the nature and influence of trust in the safe management of medication within mental health services	Focus groups
McDonell, 2011	Barriers To Metabolic Care For Adults With Serious Mental Illness: Provider Perspectives	USA	PC	This study assessed barriers to metabolic care for persons with serious mental illness (SMI) by surveying experienced healthcare providers.	Questionnaire
Mitchel & Selmes, 2007	Why Don't Patients Take Their Medicine? Reasons And Solutions In Psychiatry	UK	G	To discuss patients' reasons for failure to concord with medical advice, and predictors of and solutions to the problem of nonadherence.	Non – systematic literature review
Morant, 2016	Shared Decision Making For Psychiatric Medication	UK	G	This conceptual review argues that several aspects of mental health care that differ from other health-	Conceptual review

	Management: Beyond The Micro-Social			care contexts may impact on processes and possibilities for SDM.	
Morrison, 2015	Living With Antipsychotic Medication Side-Effects: The Experience Of Australian Mental Health Consumers	Australia	G	The present study explores people's experience of living with antipsychotic medication side-effects	Qualitative interview
Mortimer 2004	Atypical Antipsychotics As First-Line Treatments For Schizophrenia Advantages For Stakeholders In The UK Healthcare System	UK	G	Review on antipsychotic prescribing	Non – systematic literature review
Mortimer 2005	Primary Care Use Of Antipsychotic Drugs: An Audit And Intervention Study	UK	PC	To audit and intervene in the suboptimal prescribing of antipsychotic drugs to primary care patients.	Audit + intervention study

NICE, 2014	PSYCHOSIS And Schizophrenia In Adults	UK	G	Guidelines on treatment and management	Evidence based guideline
Oud, 2009	Care For Patients With Severe Mental Illness: The General Practitioner's Role Perspective	UK	PC	Responsibility and nature of care for people with SMI was explored from a GP perspective	Questionnaire
Pereira, 1997	A Survey Of The Attitudes Of Chronic Psychiatric Patients Living In The Community Toward Their Medication	UK	G	To assess the acceptability of depot among those patients receiving medication via this route and, finally, to assess the views of subjects receiving oral medication about depot.	Questionnaire
Pilgrim, 1993	Mental Health Service Users' Views Of Medical Practitioners	UK	PC	positive and negative views about general practitioners (GPs) and psychiatrists are examined.	Questionnaire
Rasmussen	Improving Practice	UK	PC	Overview of care of people with SMI for GPs	Non – systematic literature review

2006					
Roe, 2009	Why And How People Decide To Stop Taking Prescribed Psychiatric Medication: Exploring The Subjective Process Of Choice	Israel	G	The purpose of the present study was to explore why and how people with a serious mental illness (SMI) choose to stop taking prescribed medication	Qualitative interviews
Rogers, 2002	Some National Service Frameworks Are More Equal Than Others: Implementing Clinical Governance For Mental Health In Primary Care Groups And Trusts	UK	PC	To reports on Primary Care Groups (PCGs) and Primary Care Trusts (PCTs) engaged with the Mental Health National Service Framework (NSF) as part of their remit to implement clinical governance.	Multiple case study
Rogers, 1998	The Meaning And Management Of Neuroleptic Medication: A Study Of	UK	G	To describe the meaning and management of neuroleptic medication by people who have received a diagnosis of schizophrenia.	Qualitative interviews

	Patients With A Diagnosis Of Schizophrenia				
Royal College of Psychiatrists	Mental Illness: Stigmatisation And Discrimination Within The Medical Profession	UK	SC	Report to combat and reduce stigmatisation of people with mental disorders.	Non – systematic literature review
Salomon, 2013	“All Roads Lead To Medication?” Qualitative Responses From An Australian First-Person Survey Of Antipsychotic Discontinuation	Australia	G	The purpose of the survey was to better understand the experiences of people who attempt antipsychotic discontinuation.	Questionnaire
Schachter 1999	Documenting Informed Consent For Antipsychotic Medication	Canada	PC	To educate about informed consent	Editorial

	What Family Physicians Should Know				
Schizophrenia Commission, 2012	The abandoned illness: a report from the Schizophrenia Commission	UK	G	To examine the provision of care for people living with psychotic illness.	Non-systematic literature review + survey + visits to services
Schulze, 2017	Stigma And Mental Health Professionals: A Review Of The Evidence On An Intricate Relationship	Switzerland	SC	To explore ways in which mental health professionals are 'entangled' in anti-stigma activities. It will outline the complex relationships between stigma and the psychiatric profession, presenting evidence on how its members can stigmatizers, stigma recipients and powerful agents of de-stigmatization.	Non – systematic literature review

Seale, 2007	Antipsychotic Medication, Sedation And Mental Clouding: An Observational Study Of Psychiatric Consultations	UK	SC	To explore how discussions about side effects are managed in practice	Observational study + Conversation Analysis
Toews, 1996	Improving The Management Of Patients With Schizophrenia In Primary Care: Assessing Learning Needs As A First Step	Canada	PC	To assess family physician learning needs related to the care of patients with schizophrenia.	Questionnaire
Tranulis, 2011	Becoming Adherent To Antipsychotics: A Qualitative Study Of Treatment Experienced Schizophrenia Patients	Canada	G	To explore views on illness and medication use and emphasized key turning points, such as periods of nonadherence and illness relapses.	Qualitative interviews

Usher, 2001	Taking Neuroleptic Medications As The Treatment For Schizophrenia: A Phenomenological Study	Australia	G	To explore the experience of taking neuroleptic medications from the individual’s perspective	Qualitative interviews
Viron, 2012	Schizophrenia For Primary Care Providers: How To Contribute To The Care Of A Vulnerable Patient Population	USA	PC	This review provides primary care providers with a general understanding of the psychiatric and medical issues specific to patients with schizophrenia and a clinically practical framework for engaging and assessing this vulnerable patient population	Non- systematic literature review
Younas, 2016	Mental Health Pharmacist’s Views On Shared Decision-Making For Antipsychotics In Serious Mental Illness	UK	G	To explore the views and experiences of UK mental health pharmacists regarding the use of SDM in antipsychotic prescribing in people diagnosed with SMI.	Qualitative Interviews

*PC =primary care, SC= secondary care, G = about care or treatment in general, without specifically looking at service provision in secondary or primary care services, n/a = setting unrelated to mental health

12.1 CMOC 1 Low expectations regarding recovery from mental illness

The first CMOC relates to low expectations regarding the recovery of mental illness. This CMOC was developed from 31 papers, largely empirical studies (N=21), including N=6 quantitative, cross-sectional studies, N=8 qualitative studies, and N=10 non-systematic reviews. The majority of these papers were set in primary care (N=16). Synthesising the literature available, it appears that low expectations about recovery for service users could be a potential barrier to commencing conversations around antipsychotic medication in primary care.

The GP and SU view are illustrated below (Figure 11 and 12).

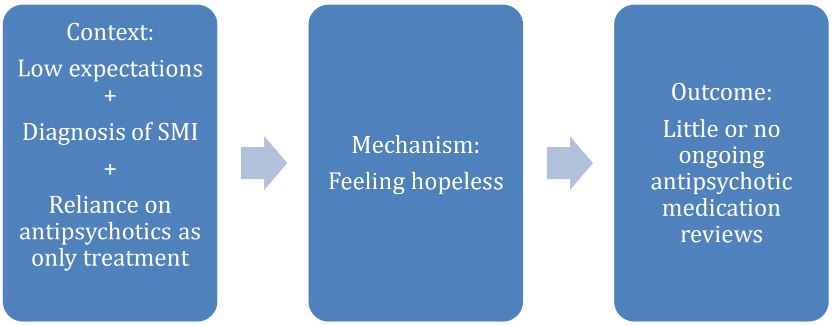


FIGURE 11 CMOC1 LOW EXPECTATIONS GP VIEW

Figure 12 CMOC1 Low Expectations SU View

CMOC1: Low expectations regarding recovery from mental illness

With ***a diagnosis of severe mental illness (C),*** *chances of recovery are seen as low. Antipsychotic medication is seen as the* ***only treatment option (C).*** *This notion appears to be communicated to service users* (Lester et al., 2005) *and their carers and family members* (Hustig & Norrie, 1998)*. Mental health professionals, alongside GPs, were found to* ***have low expectations (C)*** *of what service users can achieve* (Donlon, 1978; Hustig & Norrie, 1998; Lester et al., 2005)*, leaving GPs, as well as service users* ***feeling hopeless (M)*** (Lester et al., 2005; Morrison et al., 2015) *and* ***therefore little or no action is taken to change the status quo (O)***(Lawrie et al., 1998; Lester et al., 2003; Toews et al., 1996)*.*

Schizophrenia is considered a *lifelong condition*(Johnson & Rasmussen, 1997; Jones & Knopke, 1987; Lester et al., 2005; Lester et al., 2003). Several papers discuss the presence of “prevailing negative attitudes” (p. 183, (Jones & Knopke, 1987), and “therapeutic nihilism” in relation to this diagnosis

(Lambert & Newcomer, 2009; Viron et al., 2012). It has been described as a perceived "virtual death sentence" (Katschnig, 2018), illustrating that "[the] cultural response to schizophrenia remains relentlessly negative" (p.83, Jones et al., 2015). Most papers refer to a reluctance or pessimism in treating service users with this diagnosis (Lambert & Newcomer, 2009; Magliano et al., 2017; Maidment et al., 2011; Morant et al., 2016; Rasmussen, 2006; Rogers et al., 2002; Royal College of Psychiatrists, 2001; Toews et al., 1996; Viron et al., 2012). In a study comparing GPs responses to vignettes describing several chronic conditions, Lawrie et al. (1998) replicated their 1996 finding and illustrated that it is the illness GPs least like to treat, and that GPs tend to hold negative views about these patients, which do not necessarily reflect an accurate picture of nature of the illness (Dixon et al., 2008), despite recent findings that about one third of service users recover (as discussed in Katschnig, 2018). Pessimism about treatment and the possibility of recovery can also affect the recovery process. Hustig & Norrie (1998) suggest that GPs should be aware that families "will need help in coming to terms with the loss of aspirations that they had for the patient" and explains that "most patients with significant disability are unable to obtain open employment" (p.191).

In a sample of N=300 GPs, Magliano et al. (2017) found that 79.9% of GPs felt that people diagnosed with schizophrenia would have difficulty having a romantic relationship, 75.4% felt that they would have difficulty getting married or cohabitating, and 73.4% felt that it was not possible to completely recover from schizophrenia. To cope with GPs feeling of hopelessness, Jones (1987) specifically advise to reduce the amount of work with the "chronically mentally ill" to avoid burnout, as their "extensive need [..] can be self-defeating for the physician and may contribute to the processes leading to refusal to provide needed services for these patients" (p.182).

While Lawrie et al. (1998) state that this perception may be due to patients with schizophrenia being "intrinsically more difficult to look after "(p. 1466, Lawrie et al., 1998), it could also be due to the fact that GPs usually only see service users in crisis (Schulze, 2007). There is a prevailing view that medication is the only option for service users diagnosed with SMI and will be needed indefinitely (Burns & Kendrick, 1997; Geyt, Awenat, Tai, & Haddock, 2017; Happell, Manias, & Rope, 2004; Johnson & Rasmussen, 1997; Lester et al., 2005; Pereira & Pinto, 1997; Schulze, 2007) . The notion of a "chemical imbalance" in need of remedying with antipsychotics remains (Magliano et al., 2017; Tranulis et al., 2011) and is likely to contribute to feelings of hopelessness. Specifically, in primary care, a recent survey by Magliano et al (2017), showed that 50.4% of GPs thought that schizophrenia was due to a chemical imbalance. While medication is seen as main treatment option, GPs may feel that there is no more they can do, as described in a survey of service users views of medical practitioners: "…*just gives sick notes every 12 months. He wanted to give me an indefinite note so he wouldn't have to see me again"* (p.170, (Pilgrim & Rogers, 1993).

Additionally, GPs may not feel that medication reviews are useful in achieving change. A randomised controlled trial (RCT) comparing structured assessments with treatment as usual in primary care for people diagnosed with SMI showed that GPs felt that clinical reviews did not result in any changes despite prescription changes being shown in the study's findings (Kendrick et al., 1995). Even when medication changes are recommended, GPs encounter barriers to implementing any medication changes as illustrated by Mortimer et al. (2005): out of 32 medication reviews, medication changes were recommended for 26 (81%), however only one third were actioned. This illustrates the lack of incentive to engage in these "hopeless" tasks for time pressured GPs. Dixon et al (2008) also showed that even medical students felt like people diagnosed with psychosis would not follow GP treatment plans or that they do not value treatment (Galon & Heifner Graor, 2012), illustrating that this view exists even before commencing GP practice. This could lead to treatment not being offered to service users (as discussed in Viron et al., 2012).

Based on their survey findings, Magliano et al (2017) suggest that GPs' pessimism about recovery could be transferred to SUs, which could in turn prevent service users from actively trying to get better. Lester et al. (2005) conducted focus groups and found:

"When I approached my GP, he never gave me any hope that things could change. He said, 'Well, you'll be on these tablets for the rest of your life, and it's like diabetes, just take them for the rest of your life.' I remember the phrase. And I remember being told I'd never be able to work again, I'd never have an education, never have relationships, never have anything in my life. So, for a period of time I thought well, there's no hope—it's not worth living, is it really?" (Patient 9: male, Birmingham) "Write him off!" (Patient 10: female, Birmingham) "That's what they done, they'd written me off. But the thing is, people do recover, and they're never told there are people who do recover, so it's not a life sentence" (Patient 9: male, Birmingham) (p.4, Lester et al., 2005*).*

This illustrates that pessimism towards recovery is communicated directly to service users. Paired with the notion of indefinite medication use, Service users may be left feeling hopeless and helpless (Lester et al., 2003;

Rasmussen, 2006) in their recovery, as well as in coping with side effects (Morrison et al., 2015).

In summary, these prevalent and persistent negative views and low expectations may stop GPs from acting more proactively. This perception may be communicated to service users, which may in turn impede the recovery process, and potentially stop them from continuing to seek help from GPs. This in turn reinforce GPs' perception that recovery is not possible in schizophrenia.

12.2 CMOC 2 Perceived lack of capability to participate in medication reviews

This CMOC was developed using N=31 papers, including N=6 quantitative cross-sectional studies, N=13 qualitative studies and N=5 non-systematic literature reviews. N=7 papers were set specifically in primary care.

The GP view is illustrated in Figure 13:

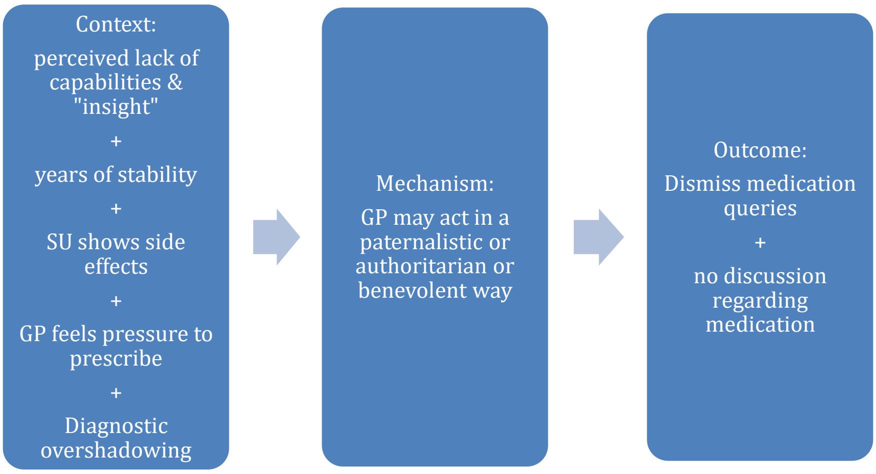


Figure 13 CMOC2 Perceived Lack Of Capabilities GP View

CMOC2 Lack of capabilities:

GPs may view people diagnosed with SMI as ***lacking in capabilities or insight*** *(C), despite years of stability (C) and therefore may* ***not always take their views seriously (M) and act in a more paternalistic way (M) or authoritarian way (M)***(Corrigan, 2000) ***leading to one-sided conversations about medication*** (**O)**(Delman et al., 2015) ***or none at all (O)***(Happell et al., 2004; Maidment et al., 2011; Morant et al., 2016; Roe et al., 2009; Royal College of Psychiatrists, 2001; Salomon & Hamilton, 2013). Additional contexts, which may impact this CMOC are:

- Where antipsychotic side effects are apparent in service users (cognitive impairment, apathy)
- Where GPs feel pressure to prescribe
- Diagnostic overshadowing (see Glossary)

A diagnosis of SMI has been associated with a perception of decreased capabilities (Rogers et al., 1998; Seale et al., 2007), which may be emphasised by a display of side effects of the medication: *"you're walking around like a zombie, and you're like sort of you can't join in with things, I wouldn't be talking to you like what I'm talking now. I know I might seem a bit high, but when you're on [antipsychotics] you can't even be bothered holding a conversation you know, you're just sat there saying yes and no*" (Rogers et al., 1998, p.1317). GPs have described perceived difficulties in effectively communicating with service users (Lester et al., 2005). For example, Lester et al. (2003) found that GPs might direct their questions and discussions at a carer or family member, rather than at the service user themselves, leaving service users feeling "*stupid and irrational*" (p.511). "Unwise decisions" by service users are often associated with a lack of capabilities in mental health conditions (Morant et al, 2016).

Furthermore, a diagnosis of schizophrenia has been associated with the notion of "split personality, implying unpredictability" (p. 1094, Katschnig, 2018) and symptoms such as hallucinations, delusions, and lack of "insight", requiring help from the doctor. However, this view seemed to prevail even after discharge from hospital and potentially years of stability (Britten et al., 2010; Lester et al., 2005; Morant et al., 2016). As noted above, the main treatment for schizophrenia is antipsychotic medication (see CMOC1). Many research studies have focused on ways to improve rates of medication adherence in this population (Britten et al., 2010).

Communication problems also may have their roots in the persistent focus on medication adherence. Doctors are pushed to prescribe to avoid the "*devasting effects of a relapse*" (Johnson & Rasmussen, 1997) – doctors not prescribing is labelled "physician noncompliance" (Johnson & Rasmussen, 1997). Service user initiated suggestions to change medication are questioned due to their "lack of insight". Much of the literature from primary care settings appears to emphasise that medication will not fail, and if it does, this will be due to service user non-adherence, as seen in Johnson & Rasmussen (1997): "*in the absence to the contrary, any acute schizophrenic relapse of a self-proclaimed, compliant patient should be taken prima facie as evidence of noncompliance*" (p.396). Medication nonadherence is further labelled as "failure to convince their patients of the overall benefits of such treatment", illustrating significant pressure on GPs (Johnson & Rasmussen, 1997).

The decision to question medication should be considered reasonable, given that service users might not benefit from medication (NICE, 2014; Pereira & Pinto, 1997), they experience serious side effects (Britten et al., 2010; Morant et al., 2016; Morrison et al., 2015; Seale et al., 2007; Tranulis et al., 2011;

Usher, 2001),given that doctor’s priorities might be different to those of service users (Carrick et al., 2004; Happell et al., 2004; Morant et al., 2016) and that medication is not always prescribed appropriately (Burns & Kendrick, 1997; Happell et al., 2004; Morant et al., 2016; Mortimer, 2004). The notion that service users cannot participate in discussions about medication, or cannot act in their own best interest, impedes open conversations about medication.

In summary, as medication is considered the only treatment option in this population, GPs are pressured to prescribe to avoid relapse. Therefore, criticism of medication would be seen as “irrational” by doctors, which is in line with stigmatising views of people with a SMI diagnosis lacking capabilities to understand and decide on their treatment. This would lead to service users’ concerns regarding medication being dismissed and conversations are not occurring or being one-sided.

CMOC2a – service user perspective

The Service User perspective is outlined in Figure 14:

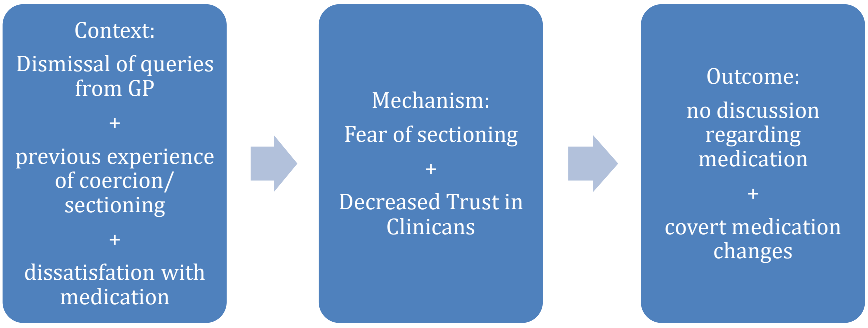


Figure 14 CMOC2 Perceived Lack of Capabilities SU View

In turn, service users *with a* ***history of coercion*** (**C)**, (Boardman et al., 2008; Britten et al., 2010; Happell et al., 2004; H. Lester et al., 2003; Maidment et al., 2011; Morant et al., 2016; Roe et al., 2009; Rogers et al., 1998; Salomon & Hamilton, 2013) *and* ***current (perceived or actual) coercion*** *in relation to their medication* ***(C)*** *and a history of being sectioned (C), which could evoke* ***fears of sectioning (M)****, could* ***feel decreased trust (M)*** (Maidment et al., 2011; Morant et al., 2016)*, and therefore lead them to* ***not starting a conversation about medication (O****) and potentially* ***covert medication changes (O),*** *if service users are* ***dissatisfied with their current medication (C).***

Previous experiences of not having their ***views taken seriously (C)****, can also lead to* ***decreased trust (M)*** *and leaves service users feeling like they have* ***no right to participate in discussions (M)*** *(as discussed in Delman et al., 2015), again leading to* ***no conversation started (O)*** (Mitchell & Selmes, 2007) ***and potentially covert medication changes (O).***

In response to GPs actions, service users have concerns about being viewed as lacking capabilities, if they were to start a conversation around medication (Britten et al., 2010), raise a potential dissatisfaction with medication, or express their wish to reduce medication (Lester et al.,2003, Seale et al., 2007). Raising queries may be entirely rational, especially for service users who have been stable for a long time and are able to actively participate in medication reviews (Schachter et al., 1999). Service users have reported a fear of sectioning and coercion, should physicians be alerted to their wish to reduce medication. (Carrick et al., 2004; Geyt et al., 2017; Rogers et al., 1998; Salomon & Hamilton, 2013). A survey reported that service users would prefer a more active role, especially with regards to psychotropic medication, but 71% of participants saw themselves in a passive role in primary care (Adams et al., 2007), this was also found in a more recent survey of pharmacists (Younas et al., 2016).

High rates of non-adherence, and service users tailoring their medication themselves to suit their needs illustrate how difficult it is to either start this conversation, or reach a shared decision (Britten et al., 2010; Geyt et al., 2017; Morant et al., 2016). In Happell et al.'s (2004) focus group, one participant reported: "*I think it's just a general disregard for they have for anything that people say, because they're mentally ill therefore you know, anything they say is questionable [..] and they say, well, I have a problem with chlorpromazine or something, they might override that, rather than listen to what the ...consumer is saying* " (p.4). Whereas this way of communicating might not be occurring regularly, it may lead to the same service user not returning to their GP practice or engaging with their GP in a meaningful way following on from this, as discussed in Magliano et al. (2017): "*GPs scepticism towards reliability and insight of people with psychosis may discourage clients themselves from help-seeking, with further negative effects on their health*" (p.230).

Diagnostic overshadowing has also been highlighted as a potential barrier for service users who seek to initiate a conversation about medication or its side effects (Happell et al., 2004; Pilgrim & Rogers, 1993) : "*I've had difficulty in getting full regular medical check-ups as every symptom is considered a sign for stress" - "I avoid my GP if at all possible as he has the tendency to see MH problems for everything*" (Pilgrim & Rogers, 1993, p.171) A lack of trust, or the perception that they are not able to engage in a meaningful conversation with their GP could partly explain why service users often do not seek help until illnesses have progressed significantly, or attend A&E rather than to their GP (Galon et al., 2012).

In summary, GPs may perceive that service users lack the capabilities to understand the effects and needs of medication and therefore dismiss their concerns. They may act in a more paternalistic way, which will deter service users from commencing a discussion. Not feeling heard, and fear of sectioning and coercion, may be further deterrents for service users to approach their GP to discuss their medication. This illustrates a potential barrier to communication between service users and their GPs.

12.3 CMOC 3 Lack of information sharing between GPs and service users

This CMOC was developed using data from N=20 papers, including N=8 quantitative, cross-sectional studies, N=7 qualitative studies and N=3 non-systematic reviews. N=5 studies specifically explored topics in primary care.

The lack of information sharing discussed here is twofold: 1) lack of information about medication and need for physical health checks, and 2) lack of information about side effects.

CMOC3a) Lack of information about the medication and need for physical health checks

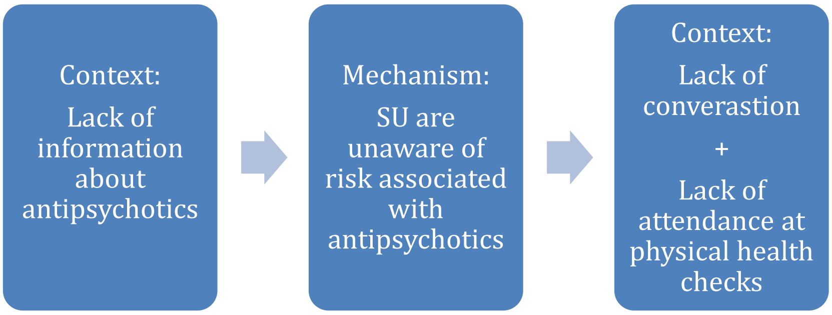


Figure 15 CMOC3a Lack of information – GP anD Service User view

*If **little information regarding medication is given to service users (C)** they may be **unaware of the risks (C)** associated with antipsychotic medication (Jones et al, 2015 and Feeney, 2006) and **need for annual reviews (M),** potentially leading them to not **commence discussions** around medication **(O)** or **attend yearly physical health checks (O)** (Crawford et al, 2014).*

Although Carrick et al (2004) note trends towards better informed consent, a significant number of studies report a lack of information being given to service users regarding their illness and medication (Aref-Adib et al., 2016; Boardman et al., 2008; Feeney & Mooney, 2006; Geyt et al., 2017; Happell et al., 2004; Maidment et al., 2011; Mitchell & Selmes, 2007; Salomon & Hamilton, 2013). Whereas there is difficulty in assessing whether information was not given or instead, not remembered (Seale, 2007), for the purposes of this review, both contexts may trigger the mechanism above. The only study to assess recall was Feeney (2006), who found that service user's recall of physical health examinations was accurate with what was recorded in the notes.

The problem is also illustrated in a study by Crawford et al (2014), who found that although service users felt that their physical health was well attended to, the majority of people "*with hypertension or dyslipidaemia had no record of being given appropriate treatment for these problems*".(p.475).Crawford (2014) recommend that more information is given to service users. Pilgrim & Rogers (1993) found that 41% of service users felt that they did not receive enough information regarding their medication: "*Doctor never says anything, has just given repeat prescriptions since 1954*" (p.171). Pereira et al. (1997) found that "[the] *great majority [of service users] would have liked to receive further information about both their illness (79%) and their medication (72%)*" (p.466). Lester et al (2003) found that most over 55-year-olds preferred to take a passive role in medication reviews. However, most others wanted to be involved: *"If I am taking tablets, I want to know about them, the side effects, things like that. I like to know what is going on. I should be part of that decision"* (p.511).

CMOC3b) Information regarding medication side effects

Not attending physical health checks can be detrimental to health. A second issue, however, is the discontinuation of medication without consultation, due to a lack of information about side effects.

Schachter et al (1999) reported only 84% of physicians explained the reasons for prescribing antipsychotics to service users and that they did not discuss all side effects. Similarly, service user interviews report a lack of information about side effects (LeGeyt et al, 2017, Maidment et al., 2011). In the same survey by Schachter et al (1999) looking at the use of consent forms for antipsychotic medication prescribing, 83% felt that using a consent form for antipsychotics would increase service user anxiety and 37% felt that it would impair the GP – service user relationship. This notion persists (Morant et al, 2016). GPs have also reported that providing full information is too stressful for service users (despite evidence to the contrary, as discussed in Burns & Kendrick, 1997; Happell et al 2004). Potential reasons for the lack of discussion are worries about service users stopping medication (Maidment 2011; Schachter et al 1999) if they knew the extent of side effects, as illustrated by Younas et al (2016): "At one time…it was…if you tell patients about side effects, they won't take the medication. (In03)" (p.1194).

Providing information on side effects to service users reduces the "shock" of experiencing them and gives service users the opportunity to seek help and advice and avoid stopping medication immediately. Salomon et al (2013) describe service users lactating and being so scared they stop medication immediately as they did not know that this was a potential side effect. Another service user reported increased weight gain of two stone in three months, and no action from her GP, which led her to reduce her medication herself (Salomon et al., 2013). While this is anecdotal evidence, it illustrates the potential effects of not providing a realistic expectation of antipsychotics. This could result in loss of trust and discontinuation of antipsychotic medication as service users may not want to attend the doctors again (Happell et al.,2004; figure 16 below).

Intended CMOC by health professionals

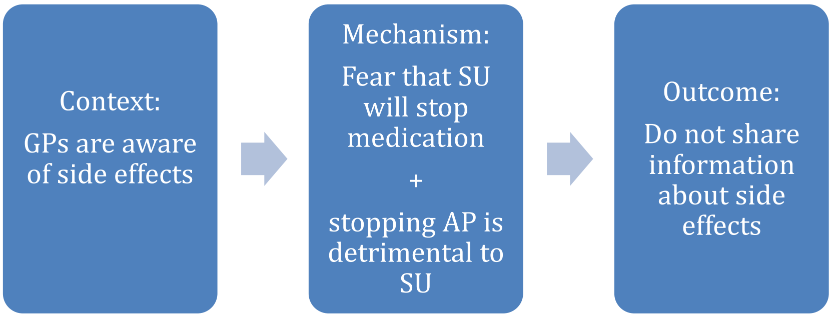


Figure 16 CMOC3b Lack of information – GP view

However, for Service users, this may result in:

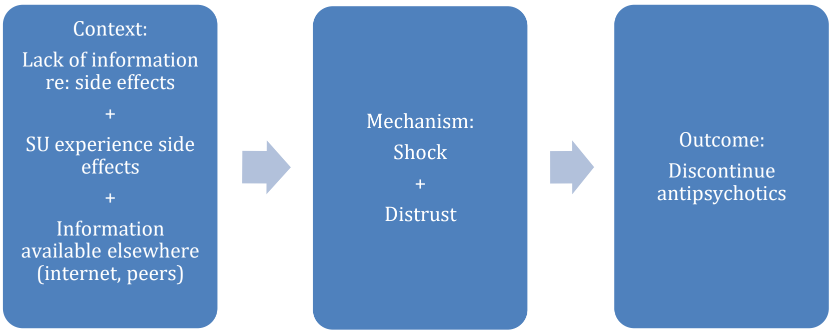


Figure 17 CMOC3b Lack of information – SU view

Where GPs are aware of side effects (C), they may fear (M) that service users will discontinue their medication (O) and feel that this is not in the service user’s best interest (M), therefore little or no information regarding side effects is shared with service users (O).

However, the data suggests that *if **insufficient information** is given about side effects (C), SU might be **scared or worried (M), lose trust (M)** when they experience these and therefore **discontinue medication abruptly themselves, without clinical support (O**).*

Paired with CMOC2, service user concerns are also not taken seriously, leading to no action from GP, which leads to a breakdown in communication and service user managing medication themselves.

CMOC3c Information accessed elsewhere

*Additionally, should service users **learn more about side effects of antipsychotic medication elsewhere (C)** (Aref-Adib et al., 2016; Delman et al., 2015), they may **feel misled by their GP** for not having been warned of the side effects (**M)**, therefore no **longer trusting the process (O)** potentially leading them to **discontinue the medication without further consultation (O)** (Aref-Adib et al., 2016,Britten et al).*

In summary, not sharing information appears to have the opposite effects as intended, in that a communication breakdown may be observed, when SU experience or otherwise find out about the adverse effects of medication. This may lead to a discontinuation of medication, without a consultation with the GP.

12.4 CMOC 4 Perceived risk of Service Users

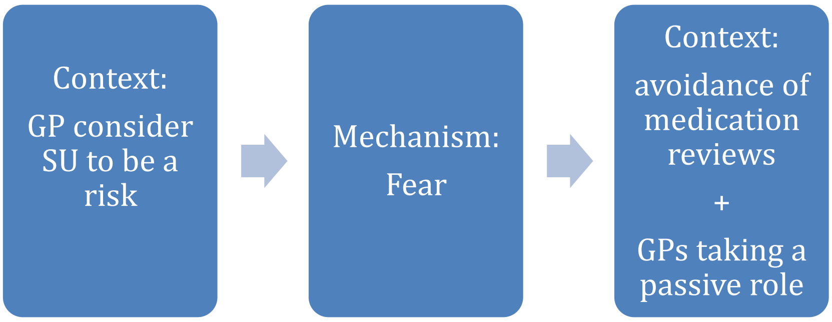


FIGURE 18 CMOC4 PERCEIVED RISK – GP VIEW

This CMOC was developed using 15 papers, including N=6 quantitative, cross-sectional studies, N=2 qualitative studies, and N=5 non-systematic literature reviews. N=7 were set in primary care.

Despite evidence to the contrary, GPs may ***perceive SU to be threatening, or a risk to others (C****; Oud et al, 2009, Rasmussen, 2006, Magliano et al, 2017) and are therefore fearful* ***(M),*** *leading GPs to avoidance and to take* ***a passive role, and may even result in GPs refusing to see SU altogether (O),*** *as illustrated by Corrigan (2000), McDonnell et al. (2011),Lester et al.*

(2003) and Pilgrim & Rogers, (1993). It is possible that *that* ***medication changes may not be made without secondary care support (O)*** *(Rasmussen, 2006).*

Views that people diagnosed with SMI are dangerous and violent have persisted over the years (Lawrie et al., 1998; Oud et al., 2009; Rasmussen, 2006). They are seen as more “irrational” (Katschnig, 2018) and “unpredictable” (Royal College of Psychiatrists, 2001). Symptoms of schizophrenia, like responding to voices or inappropriate affect have also been described as frightening to the public (Corrigan, 2000). A recent survey (Magliano et al, 2017) found that GPs endorsed either “partially true” or “completely true” for the following statements: people with schizophrenia are unpredictable (88.5%), people are frightened by them (93.9%), they are a danger to themselves (88.3%), and a danger to others and that they would become dangerous if they stopped their medication (73.9%). The study consisted of a vignette and a set of questions about the GPs beliefs about treatment of the patient described. When GPs were told that the patient in the vignette was diagnosed with schizophrenia, or made this diagnosis themselves based on patient characteristics, they were more restrictive about hospital treatment and felt the person was more dangerous (Magliano et al, 2017), illustrating the level of stigma associated with diagnosis.

Some of these views on risk in people with schizophrenia may be justified; for example, this population (statistically speaking) has higher rates of alcohol and substance abuse [as discussed in Lawrie et al, 1998], which could account for violent or dangerous behaviour, but this may also be due to personality types (Royal College of Psychiatrists et al 2001, Lawrie et al., 1998). Although people diagnosed with SMI may, on average, be more violent than people without this diagnosis, this group is much less violent than expected by the general public (as discussed in Corrigan, 2013). These views are likely to affect care and may prevent doctors from engaging in meaningful conversations with SU. SU recalled incidents were they "felt their GP was scared of them, ending a consultation quickly and suggesting they find a different GP" (Lester et al., 2003). Similarly, Pilgrim & Rogers (1993) found: "*at one time I went to see four different GPs who all turned me down because I had been to [local mental health hospital*]" *(p.170)*. In a survey by McDonnell et al (2011), being "scared of people with SMI" was the most endorsed item on the list of barriers to metabolic care in this population, illustrating that this view may also impede physical health care. Feeling that mental health care was not their responsibility and "not being paid enough" were endorsed least in the survey. Regardless of why and how often service users may present as "dangerous", Rasmussen (2006) described that GPs are overall apprehensive and take a passive role, which would negatively impact service users under primary care only. LeGeyt et al (2017) discussed how concerns regarding risk can affect decision making with regards to prescribing and recovery orientated approaches. Johnson & Rasmussen (1997) quoted recommendations in the British Medical Journal (BMJ News 1995), following homicides committed by people diagnosed with schizophrenia, to allow for "compulsory prophylactic medication for patients living in the community", as this would be "in the best interest of the great majority" (p.145).

Reasons for this stereotype of individuals with SMI diagnoses could originate from mistranslations of the word schizophrenia, which was initially supposed to describe split cognition, i.e., account for disorganised thinking, rather than the more well-known meaning of "split personality" (Rasmussen, 2006), which suggests irrational, unpredictable behaviour (Katschnig, 2018). Media reports further exaggerate this view (as discussed in Dixon et al., 2008 and Katschnig, 2018, Schulze, 2009, Corrigan, 2000, The Schizophrenia Commission, 2012).

In summary, perceived risks associated with service users diagnosed with SMI may prevent GPs from engaging with service users effectively and prevent medication reviews from happening.

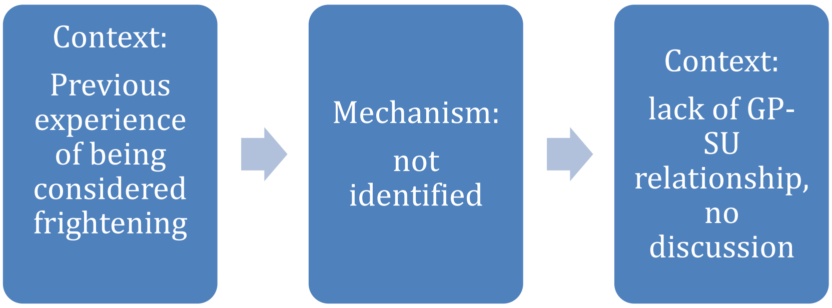


FIGURE 19 CMOC4 PERCEIVED RISK – SU VIEW

In turn, service users who were perceived to be frightening in the past, possibly due to stigma, may not have a good relationship with their GP and therefore do not attend appointments. SU "*felt their GP was scared of them, ending a consultation quickly and suggesting they find a different GP*" (Lester et al., 2003)

The literature did not provide any mechanisms here, but It could be theorized that a loss of trust, feeling disillusioned or feeling avoidant can play a role here. A possible additional context is the experience of stigma, which may prevent help seeking (Katschnig, 2018). Further research is required to understand the Service users' thoughts and experiences on this, to illicit a mechanism.

12.5 CMOC 5 Uncertainty regarding Medication and illness trajectory

This CMOC was developed using N=12 studies, including 2 quantitative, cross-sectional studies, N=3 qualitative studies, and 1 non-systematic literature review. N=5 were set in primary care. The least amount of evidence was found for this CMOC.

CMOC5 GP point of view

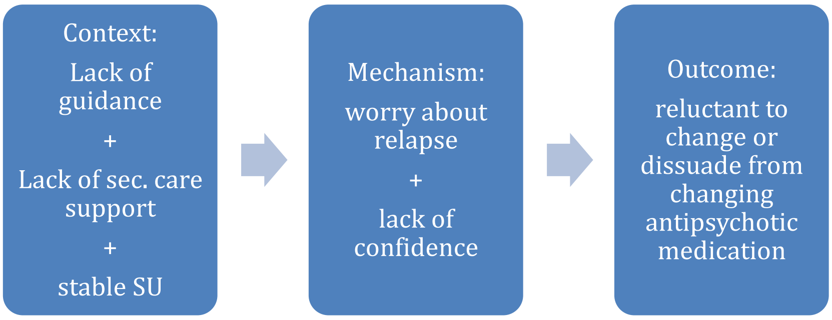


FIGURE 20 CMOC5 UNCERTAINTY REGARDING MEDICATION AND ILLNESS TRAJECTORY – GP VIEW

Conversations around medication for ***stable service usersI****) (Burns & Kendrick, 1997) are limited by the* ***unpredictable nature of schizophrenia & recurring relaI (C), the lack of guidance about medication and its eIcts (C) the (perceived) lack of secondary carIupport (C)****.*

*This may trigger one of two mechanisms****: GPs feel a lack confidence (M) or feel concerned (M), leading to avoidance*** *and* ***would therefore not consider reducing medication (O)*** *(as discussed in LeGeyt et al., 2017)* ***not commence a discussion (O)*** *or* ***dissuade from changing medication (O)*** *(Morrison et al., 2015).*

The notion that a change oI medication is not an option can hinder an open conversation about medication. The reason why GPs may be reluctant to change medication could be due to fact that illness trajectories vary, as does response to medication and its effects (Britten et al., 2010). Clear guidelines as to how to prescribe and for how long are missing. For example, there is no consensus as to what symptom free period warrants a medication discontinuation (Burns & Kendrick 1997). There is no clear guidance on how to deprescribe antipsychotic medication, and to date, there is no guarantee that relapse can be avoided while reducing. NICE (2004) guidance suggests prescribing medication at the lowest possible dose. To find this, medication would need to be prescribed below that to see which is the lowest tolerated dose. This could be destabilising for patients, leading to a recurrence of symptoms and potential admission to hospital. It is not yet possible to determine which SU can successfully live without medication (Johnson & Rasmussen, 1997), or even with a lower dose, as reducing the dose could trigger a relapse (Maidment et al., 2011). As non-mental health specialists, GPs may feel especially reluctant to make changes if they feel there is no secondary care support available (McDonell, et al., 2011; Mortimer et al., 2005).

“Many GPs are reluctant to reduce these without supervision, especially when the patient appears well. […] There is no clear agreement on the optimum frequency for reviewing maintenance treatment, nor is there consensus on what symptom-free period warrants consideration of discontinuation” [Burns & Kendrick, 1997].

It would furthermore seem reasonable to assume that the absence of the option to change medication may lead GPs to think that review of it might not be necessary, in the absence of severe side effects and/or physical health problems. GPs however may not enquire about physical health complaints due to a lack of confidence in managing mental health conditions (Carr et al., 2004; Jones et al., 2015; Kendrick et al., 1995). Therefore, it is possible that physical health complaints or severe side effects, which warrant a review of medication are occurring, but they are not picked up and therefore not addressed.

CMOC5 Service User point of view

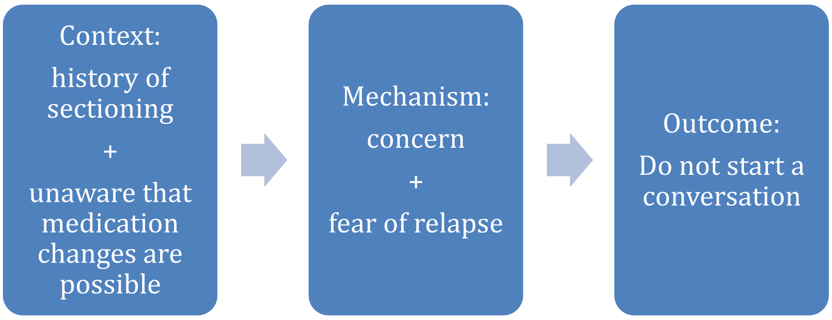


FIGURE 21 CMOC5 UNCERTAINTY REGARDING MEDICATION AND ILLNESS TRAJECTORY

Service users themselves are understandably wary of commencing discussions around medication, too.

SU may feel equally ***concerned (M)*** *to* ***start a conversation about medication (O)****, due to* ***fears of relapse (M)****, especially for those who have a* ***history Isectioning (C).*** *SU may* ***not even be aware*** *that medication chanI are possible (C).*

Fear of relapse is a concern for most service users, as it is usually associated with reoccurrence of distressing psychotic symptoms and potential hospital admissions. LeGeyt et al (2017) found this in their study conducting interviews with SU:

"This dynamic [power imbalance] resulted in some participants feeling coerced into taking medication and out of control. [..]When the option to discontinue neuroleptic medication was not explicit, participants were left with uncertainty

regarding the level of support they could expect from clinicians. […] All participants acknowledged the risks of withdrawing neuroleptic medication" (LeGeyt et al., 2017)

Mutual (understandable) anxiety around the fears of relapse (Britten et al., 2010), combined with individual illness trajectories and medication requirements (Britten et al., 2010), might be an obstacle to commence a medication review.

In summary, a lack of guidance and certainty with regards to medication and illness trajectories may lead to (understandable) anxieties in GP and SU, which can stop conversations medication.

3.7 12.6 Overall findings

In summary, there appears to be a form of communication breakdown between SU and GPs with regards to their antipsychotic medication. From a GP perspective, medication is seen as the only option for SUs and the notion prevails that there is little to be done, which is communicated to SU and their families, leading to hopelessness and a lack of ongoing conversations around medication (CMOC1). The perception that SU have not got the capabilities to understand the need for medication (CMOC2) means their concerns may be dismissed. Paired with a lack of information regarding the nature of the medication and its side effects (CMOC3), a lack of trust would result, which is a barrier to an open conversation about medication. It is also easy to see how a conversation may not be started, when GPs feel that people diagnosed with SMI are "dangerous" (CMOC4). Lastly, not feeling confident and potentially not supported by secondary care services to execute a change in medication, rendering the option of medication change moot, would also lead to a lack of conversation (CMOC5).

From a service user point of view, not being taken seriously (CMOC2), or even accused of lying with regards to medication adherence when they report relapses (CMOC2), not being given all the information (CMOC3) and seen as “dangerous” due to their diagnosis (CMOC4) will likely mean that a therapeutic relationship with the GP is difficult to build, especially in the light of previous coercion, history of sectioning and a power imbalance between doctors and SU (CMOC2). Experiencing the shock of severe side effects without prior knowledge that this could happen, will result in further loss of trust, especially when this information is access elsewhere (CMOC3). Furthermore, feeling hopeless due to “therapeutic nihilism” experienced in services and feeling “written off” by GPs (as discussed in CMOC1) will likely mean that SU will not seek support in services.

This communication breakdown would lead to SU not reporting health concerns, side effects and to discontinue medication without prior consultation. Although annual physical health checks are offered, it can be clearly seen why SU might not report side effects or medication changes, if they attend at all due to not having been told about the importance of regular checks (CMOC3).

Aspects of the therapeutic relationship, like the need for hope and trust, feature heavily across all CMOCs. Increased trust has been associated with a better therapeutic alliance (Delman et al., 2015; Geyt et al., 2017; Joseph-Williams et al., 2014; Lester et al., 2003; Maidment et al., 2011). Trust is especially important in this area, as there are many uncertainties regarding the diagnosis of SMI and antipsychotic mediation as treatment (Maidet al, 2011).

3.7 12.7 Attribution Theory and SMI

The data included in this review clearly indicates that potential and actual interactions between SU and GPs in primary care are affected by numerous stereotypes associated with SMI. For example, the perception that SU are dangerous or lack capabilities, and low expectations regarding recovery may be a barrier to starting a conversation about antipsychotic medication. Attribution theory offers a useful lens to better understand and explain the effect of these stereotypes, and potentially suggest how their effects may be reduced (Corrigan, 2000). Attribution theory assumes that people need to understand why events occur around them (Weiner, 1980). Weiner (1980) demonstrated in a series of experiments, that people were more likely to help a person who is falling, when they are told the person is appears ill, rather than drunk. The experiments suggest that if the person is in control (drunk being self-inflicted) rather than not in control (the perception that being “ill” means falling was not self-inflicted) will result in avoidance rather than helping behaviour (Weiner, 1980). Applying this to a mental health context, Corrigan proposes that “signals” like the label of “severe mental illness” and perceived skill deficits of mental illness can lead to a range of stereotypes, like authoritarianism and paternalism, which lead to discriminatory behaviour with regards to housing, employment, and treatment (figure 22).

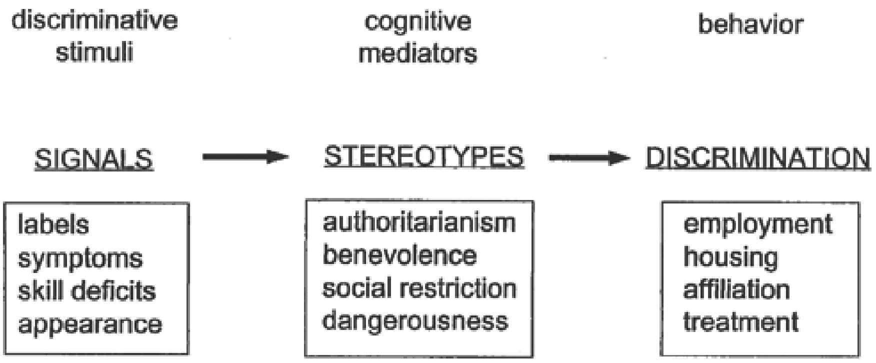


FIGURE 22 THE RELATIONSHIP BETWEEN STIGMA SIGNALS (CUES), STEREOTYPES (ATTITUDES) AND BEHAVIOURS (DISCRIMINATION). TAKEN FROM CORRIGAN (2000), P49.

This reflects the findings of the CMOCs above, like the perceived lack of capabilities (CMOC2), leading to authoritarian behaviour, meaning that SU are not involved in discussions about their treatment and dismissed. Equally, symptoms of SMI, and side effects of the medication (which contribute to the above listed signal “appearance”) can lead to the stereotype of “dangerousness” meaning that GPs may avoid SU, as seen in CMOC4. Whereas Corrigan (2000) proposes this as a theoretical framework, the findings of this review clearly show evidence for this. Contexts like the diagnosis of SMI are present in all CMOCs (1-5), authoritarian, as well as paternalistic behaviour have been identified as crucial mechanisms in CMOC 2-5, as well as dangerousness in CMOC4 specifically. These have had consequences on the provision of medication reviews in medication reviews, i.e. treatment, in all CMOCs.

Additionally, the review identified additional mechanisms to the ones proposed by Corrigan (2000), which may be specifically relevant in the GP and SU relationship, like hopelessness due to the associations with an SMI diagnosis and the lack of trust between both. As discussed, trust is especially important in mental health care, due to the added uncertainty around diagnosis of mental illness, and the effects of antipsychotic medication (Maidment et al., 2011). The implications of this are discussed below. Overall, attribution theory adds further strength to the Programme Theory identified above.

12.8 Initial programme theory

Using the findings of individual CMOCs, as well as the attribution theory as proposed by Corrigan (2000), the following programme theory was derived (figure 23) to counteract some of the mechanisms listed above, mainly hopelessness and mistrust, the following contexts have been identified as potentially counteracting the mechanism.

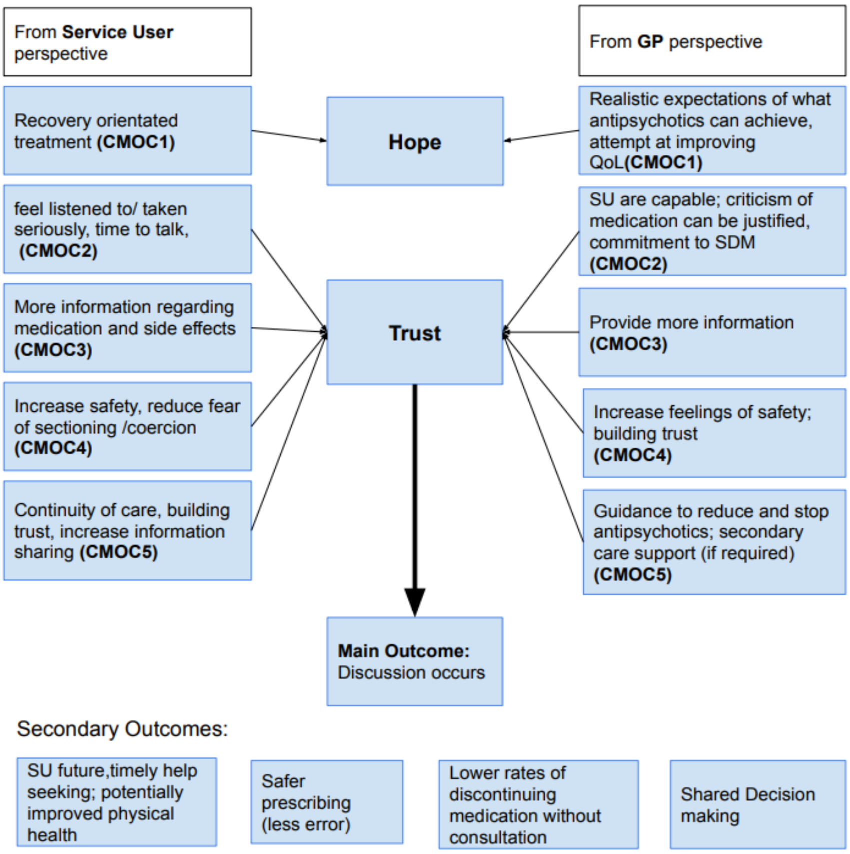


Figure 23 Programme Theory

In order to introduce hope with regards to a diagnosis of SMI, GPs should have realistic expectations of antipsychotics (Britten et al., 2010; Roe et al., 2009), communicate this to service users and be able to make reasonable changes to antipsychotic medication to alleviate adverse effects and improve functioning. Signposting to other interventions should be encouraged, like therapy (as recommended in NICE, 2014). More generally, increasing knowledge and education has been shown to tackle stereotypes associated with mental illness (Corrigan et al., 2001; Pettigrew & Trop, 2008). It is important that SU's are encouraged and advised that they can still gain employment and have meaningful relationships. This may instil hope, and potentially allow them to commence conversations easier, and to be more help seeking **(CMOC1**). As the title of a recent Schizophrenia commission publication showed ("the abandoned illness"), the importance of hope has been highlighted. Stigma is a barrier to help seeking (The Schizophrenia Commission, 2012). Being aware and able to discuss other approaches to care could reduce the sense of hopelessness associated with the treatment of long-term mental illness.

To counteract the communication breakdown illustrated in **CMOC2** (Perceived lack of capabilities), GPs would need to enable SU to express their views meaningfully (Annamalai & Tek, 2015; Joseph-Williams et al., 2014), and ensure that SU concerns are taken seriously (Happell et al., 2004). As seen above, SUs' complaints and queries regarding medication can be justified, and should be acted upon. The risk versus benefit ratio is individual to each person, and their views need to be considered. Every attempt should be made to be inclusive of SU and to ensure that they are included in the conversation (Royal College of Psychiatrists, 2001). Other facilitators include SUs being treated as equals and being encouraged to take part in the decision-making process (or not, if so preferred; Lester et al., 2003, Morant, 2016).

Allowing more time for discussions about medication, might also help increase trust and allow for an open and collaborative discussion to happen (Annamalai & Tek, 2015; Delman et al., 2015; Joseph-Williams et al., 2014). Even in secondary care services, where longer appointments may be possible, SU report "*there's really no time for me to give my opinion on medication*" (p. 248, Delman et al., 2015). Working with service users as part of the GP training has been suggested as a means to reduce possible stigma (Dixon et al., 2008; Royal College of Psychiatrists, 2001).

Included in the conversation should also be sufficient information about antipsychotic medication and its side effects and its benefits. Knowing potentially severe side effects has been associated with increased trust between SU and GP (Joseph-Williams et al., 2004, Maidment et al., 2011), which allow SU to prepare for side effects and return to the GP, should they persist, rather than discontinue medication without consultation. GPs may worry about non-adherence when too much information about the negative side effects is revealed, but as seen in **CMOC3** (Lack of information sharing), SU are also likely to discontinue when this information is not given, and side effects occur. Pharmacists can help to increase knowledge; they are seen as helpful by SU (Happell et al., 2004 and Younas et al., 2016). This would ease the pressure of time limited appointments. Pharmacists are further seen as independent, which may facilitate a more honest conversation (Younas et al, 2016). Sufficient information can increase SU confidence to commence a conversation (Delman et al., 2015), as well as improving adherence (Britten et al., 2010; Mitchell & Selmes, 2007), patient safety (McDonell et al., 2011) and facilitating Shared Decision Making (SDM; Roe & Goldenblatt, 2009).

Side effects of the antipsychotic medication can be dangerous and require regular monitoring. Ensuring that SU feel comfortable to return and discuss these, allows GPs to monitor their health more closely and potentially improve their physical health, as well as optimise their antipsychotic medication. It would also increase Shared Decision Making (SDM), a key recommendation for services.

Trust cannot be achieved when GPs feel at risk around people diagnosed with SMI (**CMOC4**). It is important that GPs feel safe and have a realistic understanding of the “risks” involved with the diagnosis. Given that SU who are only seen in primary care, the focus of the review, are most likely to be deemed as low risk (since they have been discharged from secondary care services), risk should be more of an exception rather than the rule. Equally, SU will feel concerned about opening up and starting conversations, due to their experience of stigma and previous experiences of sectioning and coercion. Decreasing anxiety and improving empathy between SU and GP, alongside increasing knowledge, has been shown to reducing stereotypes and stigma in mental illness (Corrigan et al., 2000; Pettigrew & Trop, 2008).

CMOC5 illustrated mutual anxieties around the change or reduction of antipsychotic medication. This may however be indicated to reduce side effects or after periods of stability. Guidance on how to reduce medication may be beneficial for GPs, as well as knowing that secondary care services are there to support (if required), as GPs do not seem to feel supported (Carr 2004, Bindman et al., 1997, Jones et al.,2015, Toews et al., 1996). It is also crucial to develop trust between GP and secondary care psychiatrists (Byng, 2004, Creed & Marks, 1989). Knowing that support is available may increase GP confidence. SU worries about relapse may be alleviated if they are reassured by the GP, and by seeing the same GP throughout a medication change process. Continuity of care has been highlighted as a crucial factor (Joseph-Williams et al. 2014; Lester, et al., 2003), as it would allow GPs to potentially spot a relapse in time (should they occur) and support it. Having this option might increase SU trust and may encourage the start of a discussion. Trust would also allow for safer prescribing (Maidment et al, 2011), as SU might feel able to discuss their actual dose of medication, rather than what they are prescribed. Research has found that due to a lack of conversations in services, SU tend to tailor their medication to their needs without consultation (Happell et al., 2004).

Application of the programme theory

Trust and hope were mechanisms proposed by the review, which may be especially relevant in the provision of mental health care in primary care. Considering Corrigan's (2000) framework, they potentially add an alternative step between stereotypes and discrimination to the model (Figure 15). The CMOCs clearly outline that this is an important factor in the relationship between GP and SU. A lack of trust and hope is a possible, unidentified mechanism between stereotypes and discriminatory behaviour.

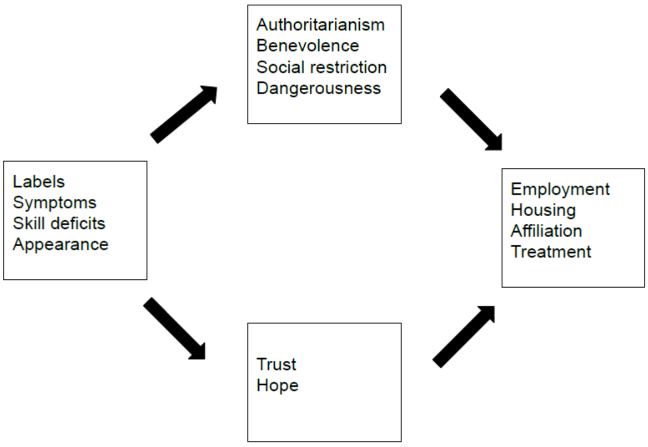


FIGURE 24 PROPOSED CHANGE TO CORRIGAN (2000) MODEL

Whereas labels, symptoms and appearance can lead to stereotypes and potentially discriminatory behaviour, making the recommended changes listed below could lead to a different outcome. Trust and hope would work against feelings of danger and need for authoritarian behaviour, which may result in a more equal relationship between SU and GP, which would allow for the start of conversations around medication, and therefore safer prescribing, increased help seeking, and increased Shared Decision Making.

13 Discussion

13.1 Summary of key findings

This review set out to determine which factors influence whether antipsychotic medication reviews in primary care occur or not. Using realist review methodology, an extensive search of the literature identified documents including data that was used to develop several CMOCs, which, taken together, indicate the presence of stereotypes which impede medication reviews. These include low expectations of people with serious mental illness and their recovery, a perceived lack of capabilities to manage their illness, a perceived risk or dangerousness and concerns regarding the change of antipsychotic medication due to a mutual (understandable) fear of relapse in GPs and service users. As seen in the overall programme theory, it appears likely that there is a lack of meaningful discussions regarding antipsychotic medication in primary care. This is concerning, due to the severe nature of side effects associated with antipsychotics, and the high rate of relapses experienced in SU discontinuing medication abruptly and the overall higher mortality rate in this population. We make recommendations to counteract some of the identified mechanisms. Trust and hope specifically can be crucial mechanisms in achieving this. Given the uncertainty with regards to antipsychotic medication, higher levels of trust between clinicians and service users are required (Maidment et al., 2011, Delman et al., 2015). Any history of coercion might make this more difficult, but a trusting relationship is key to Shared Decision Making (Boardman et al., 2008, Joseph Williams et al., 2014). Given the power imbalance, and the view that “doctor knows best” (Joseph-Williams et al., 2014) the onus might be on the GP to start the conversation. Several authors have highlighted the need for more proactive care (Kendrick et al.,1994, Kendrick et al., 1995, Oud et al., 2009, Lambert & Newcomer, 2009).

Improved outcomes may include the facilitating of open discussions about medication, and also improved help seeking and shared decision making, safer prescribing and less abrupt discontinuation of medication without medical consultation.

Additionally, negative symptoms like apathy and paranoia, as well as cognitive difficulties associated with a diagnosis of SMI, are frequently cited as a reason for lack of engagement with services in this population (Annamalai & Tek, 2015; Jones et al., 2015). The above listed CMOCs offer an alternative explanation, alongside potential solutions to improve engagement in the future.

13.2 Strengths and limitations

This review has benefited from the input of a diverse stakeholder group, including GPs, psychiatrists and the LEAP panel. This input helped ensure that the views of these groups informed the focus of the review, and the development and refinement of the programme theory. The data included in this review was found in documents identified by a comprehensive literature search strategy, including sensitive searches in a wide range of databases and the inclusion of additional material via citation chaining. The review has been conducted and reported following the RAMESES standards.

The review's findings are limited by the availability of data used to develop the CMOCs presented above. Many of the included studies focused mainly on specific contexts and outcomes, provided less data relating to mechanisms, or on why the outcomes they included were found. Although several included studies addressed the care of SU with a diagnosis of SMI in primary care specifically, none have researched a primary care only population. As a result, the findings are applied with caution to this population. For example, it is not clear to what extent the concepts of power imbalance and coercion are present in primary care. None of the papers assessed the level of (perceived) power imbalance and coercion between GPs and Service Users. It is possible that since GPs cannot section and are not seen as mental health specialists, service users do not perceive there to be a power imbalance (or at least not to the extent that they would with psychiatrists) and therefore feel more comfortable starting a conversation with their GP about medication, than with their psychiatrist.

13.3 Future research

The review found a complete lack of studies assessing the treatment and care of service users who are under primary care only. Future research is needed urgently to address our gap in knowledge regarding their individual needs and treatment, as well as how GPs can be supported better in looking after what is estimated to be approximately 30% of all service users with a diagnosis of schizophrenia or psychosis (Kendrick & Burns, 1994; Reilly et al., 2012). No studies thus far have linked primary care, patient level data to secondary care patient records, to establish exact figures, as well as compare the demographics and potentially unique needs of the primary care only population diagnosed with SMI. There is also a lack of literature on service user and GP views on long term antipsychotic medication, their views on reducing and stopping medication.

Further to this, there is a paucity of studies exploring GP and SU views regarding primary care only mental health care and antipsychotic medication, as well as studies exploring the level of care provided. The content of antipsychotic medication reviews, as well as their feasibility in primary care, have also not been investigated.

The findings of this review should also be seen as an initial model, in which several hypotheses have been identified that require further testing and refinement. The next chapter aims to collect data to further refine the initial programme theory by interviewing Service Users.

14 Conclusions

The findings of this review indicate communication difficulties, and to a certain extent a breakdown of trust between service users and health professionals. Several issues, which may impede the start of a discussion about medication have been identified. Misconceptions about doctors from the service user perspective, and vice versa, need to be addressed to improve care and treatment of people diagnosed with severe mental illness.

Chapter 3 – Service User Interviews

Following the introduction and the realist review, further data was collected to refine the initial programme theory. This chapter briefly outlines the existing evidence on primary care only service users, their (potentially) unique needs and views on long term antipsychotics, reduction, and discontinuation of medication. This chapter reports methods and results of a secondary analysis of a structured survey, conducted as part of the RADAR (Research into Antipsychotic Reduction and Discontinuation Study) programme. For full study results see Crellin et al. (2022).

1. Background

As outlined in the introduction increasing numbers of people diagnosed with severe mental illness (SMI) are discharged from specialist, secondary care services to primary care only. To date, few research studies have investigated the potentially unique needs and characteristics of this group. It is possible that this is a neglected group of SU, since they are likely stable in their mental health and therefore not being reviewed by secondary care. To the authors knowledge, the only three studies which have assessed this, are Reilly et al (2012), Kendrick et al (1994) and Kendrick et al (2000). As part of Reilly et al's (2012) study, researchers selected a representative number of GP practices and reviewed n=1150 primary care records to understand the differences between those who were no longer under secondary care and those who were. Reilly et al (2012) did not merge the data with the associated mental health community records, therefore relied on accurate and up to date secondary care information, including on number of psychiatrist visits and current dose of antipsychotics as documented in primary care records. They found that SU, who are under primary care only, were older than their secondary care counterparts (Reilly et al., 2012). This finding replicates Kendrick et al's (1994) findings, in which they reviewed N=440 GP health records for people with a SMI diagnosis and also found that those out of contact with secondary care services are older. It is important to understand the possibly unique needs and characteristics of primary care only service users, as they may have important treatment implications. As outlined in Chapter 1, there are concerns regarding the long-term effects of antipsychotic medication and there is a clear need to regularly review and potentially review medication, especially in older age (Adler & Griffith, 1991; Uchida & Mamo, 2009). This is particularly important for this sample then, given that the studies by Kendrick et al (1994) and Reilly et al (2012) found that the primary care only population is, on average, older than the secondary care counterpart (Kendrick et al., 1994; Reilly et al., 2012) and on more medication overall (Reilly et al., 2012) with the potential for harmful drug interactions.

Kendrick et al. completed a more in-depth study in 2000: they interviewed service users who were discharged from secondary care and those who were still under secondary care (N=70 and N=30 respectively), to estimate if there were any differences between groups. They did not find any significant differences between groups in age, gender, ethnicity or educational achievements, but were arguably limited by the small number of participants recruited from primary care only services. There was a statistically significant difference in marital status, with those under primary care less likely to be single. Participants under primary care only had less severe illness (as measured by the Comprehensive psychopathological rating scale), better social functioning (measured by the social role performance schedule) and quality of life (measured by the Lancashire quality of life schedule) than their secondary care counterparts. Primary care only service users were also more likely in employment and to live in their own homes, rather than community hostels or sheltered housing (Kendrick et al., 2000). These studies were conducted between ten and twenty-eight years ago, and neither explored service user views on long term antipsychotic medication and their views on reducing and stopping antipsychotics. Given recent increases in discharges back to primary care, it is important to collect data from current primary care only services, to understand service users' current views and reasons for making decisions about treatment, in order to provide person centred care.

To the authors knowledge, no further studies have investigated the potentially unique characteristics and needs of primary care only participants. Many demographic and clinical variables may be different to those people seen in secondary care. Treatment for primary care only patients may thus need to be adapted to include these needs. This would also need to be considered in any primary care only guidance or policy document relating to treatment for this population, to ensure that the best care possible can be provided.

1.1 Aim:

Therefore, the aim of this study was to compare SU in primary care only with those under secondary care on a range of factors (as outlined in Chapter 1):

1. To determine demographic and clinical differences between primary care only and secondary care SU
2. To determine primary care Service user views of long-term antipsychotic treatment, and how this might differ to secondary care service users.

3. To identify key considerations when discussing antipsychotic medication with service users, taking their concerns into account.

2. Method

2.1 Study design

As mentioned above, this is a secondary analysis of data collected as part of the RADAR feasibility study. The overall study design and findings are detailed in Crellin et al. (2022). The questionnaire, which was administered during face-to-face interviews, was designed to collect a range of demographic and clinical variables, and assess participants' views of long-term antipsychotic treatment, reducing and stopping antipsychotic medication. Where participants consented, their responses were audio recorded. This was done to allow the trial team to explore their reasons for selecting different answer options on the survey, rather than as part of an in-depth qualitative investigation.

Ethical approval was provided by the East of Scotland Research Ethics Service (REC reference: 15/ES/0163).

2.2 Participants

Participants were included if they met the following criteria:

- Inclusion criteria
    - Diagnosis of schizophrenia, schizoaffective disorder, or delusional disorder
    - A history of more than a single episode or a single episode lasting more than one year
    - Currently taking antipsychotics

  - Not having had contact with Home Treatment Team or inpatient admission in last 3 months
- Exclusion criteria
  - Lack of capacity to consent to the research
  - Being on Community Treatment Order or on any Mental Health Act Section
  - Considered a serious risk of causing harm to self or others
  - Requiring an interpreter

2.3 Setting & Participants

Participants were recruited from Community Mental Health Teams across London and nine GP practices in north and east London. In mental health services, staff were asked to identify potentially suitable participants form their caseloads. For primary care practices, a search syntax based on the eligibility criteria listed above, was run in the respective electronic patient records system. Clinical staff contacted eligible patients by letter or phone. If eligible patients consented, a member of the research team then contacted and arranged the interview.

2.4 Data collection

Written consent was received prior to the interview for all service users. Consent for audio recording was optional. The study consisted of a mixed methods survey, comprised of tick box questions and free text answers. The interviews lasted between 30-60 minutes.

The data collected included demographic data and clinical data including length of time with mental health services, length of time on medication and current medication dose and the Drug Attitudes Inventory (DAI), which is a short 10 item questionnaire exploring medication attitudes (Hogan et al, 1983).

It is scored between +10 and – 10, indicating a positive (+10) to negative (-10) attitude towards medication. There were also fixed format questions on views on long term antipsychotics, views on reducing antipsychotics and views on discontinuing antipsychotics, following a successful reduction. Participants were given five, mutually exclusive answer options to choose from and asked to elaborate on why they had chosen their answer option. For a detailed overview, please see Appendix 4. Participants were reimbursed for their time.

3. Analysis

The quantitative analysis was completed using the Statistical Package for Social Sciences (SPSS, Version 25.0). An exploratory analysis was undertaken to establish any differences between service users still in secondary care and those in primary care. Univariate statistical tests were used to conduct the comparison between secondary care and primary care service users. This included t-tests for continuous variables meeting normality assumptions, Mann- Whitney U tests for those which did not, and Chi Square tests for categorical variables. Logistic regression was performed to identify the Odds ratio for multi-level categorical data.

For those primary care participants who consented to audio recording, interviews were transcribed and uploaded to NVivo. Only audio recorded data was used for the qualitative data analysis. As this was a structured interview, and only data of limited depth was collected, framework analysis was used (Goldsmith, 2021). was completed using NVivo (Version 11) to explore primary care only SU reasons for their views on long term antipsychotic medication, reducing and stopping. LG and a second rater (ML) completed initial coding for N=5 interviews and conferred, to ensure good inter-rater reliability. Codes were compared and discussed to clarify any discrepancies. Initial themes were developed and shared with the supervisory team. Following discussion LG coded the remaining interviews independently, adding data to the existing themes and refining them further. Themes were then named and reviewed by all authors again and agreed upon. LG iteratively reviewed the themes and the raw data throughout the project, to ensure that the results adequately portrayed the key messages from the raw data.

4. Results

A total of 269 participants were recruited, N=41 were recruited from nine GP practices located in North London, and N=228 were recruited from four secondary care, mental health trusts, also located in London. Overall sample characteristics are described in Crellin et al. (2022).

4.2 Differences and commonalities in demographic variables

Demographic variables

Differences between primary and secondary care service users' demographics were explored:

TABLE 4 DEMOGRAPHIC VARIABLES COMPARED BETWEEN PRIMARY AND SECONDARY CARE

Variable	Primary care% (N)	Secondary care %(N)	Total %(N)	Mean difference/Odds ratio (95% CI)	p-value *
Age	M=50.49, SD=12.73	M= 45.42, SD=11.12	M = 46.0 SD=11.50	5.07 (1.26- 8.87)	.009
Gender -male -female	61.0% (25) 39.0% (16)	65.8% (150) 34.2% (78)	65.1% (175) 34.9% (94)	0.813 (0.41- 1.611)	0.5
Marital status					
Married/civil par/long term	22% (9)	20.2% (44)	20.5% (53)		0.62
Single/unmarried	61% (25)	69.3% (151)	68.0% (176)	.57 (.20-1.61)*	
Divorced/widow/ separated	17.1% (7)	10.6% (23)	11.6% (30)	.20 (.43-.93)* (*comp.against married)	
Ethnicity					.024

White	43.9% (18)	52.9% (119)	51.5% (137)		
Black	17.1% (7)	27.6% (62)	25.9% (69)	.76 (.26-2.22)**	
Asian	29.3% (12)	10.7% (24)	13.5% (36)	.44 (.16-1.23)**	
Mixed	7.3% (3)	5.3% (12)	5.6% (15)	.83 (.18-3.90)**	
Other	2.4% (1)	3.6% (8)	3.4% (9)	3.7(.32-42.04)**	
				(** comp. against white)	
Employment				2.68 (1.36 – 5.29)	.006
Employed	48.8% (20)	26.2% (59)	29.7% (79)		
Unemployed	51.2% (21)	73.8% (166)	70.3% (187)		
Living				0.96 (0 .46-2.01)	>0.99
Living alone	70.0% (28)	70.9% (146)	73.7%(174)		
Living with partner/family/friends	30.0% (12)	29.1% (60)	26.3% (72)		
Diagnosis				0.69 (0.34 – 1.37)	.378
- Schizophrenia	63.4% (26)	71.7% (162)	70.4% (188)		
- Other	36.6% (15)	28.3% (64)	29.6% (79)		
Age at diagnosis				0.37 (0.19-0.75)	.008
less than or equal to 30 years	47.4% (18)	70.7% (159)	75% (177)		
over 30 years	52.6% (20)	29.3% (66)	25% (86)		
Time in contact with MH services					.47
Up to 3 years	9.8% (4)	5.3% (12)	6% (16)		
4-15 years	43.9% (18)	41.6% (94)	41.9% (112)	.99 (.24-4.16)***	
More than 15 years	46.8% (19)	53.1% (120)	52.1% (139)	.65 (.15-2.8)***	
				(***comp against "up to 3 years")	

*p values are derived from t-tests for continuous variables and Chi squared tests for categorical variables

The primary care group were statistically significantly older than the secondary care group (Mean Difference = 5.07 years, p=.009) and included a statistically significantly higher proportion of employed patients (p=.006); almost half (49%) of the primary care sample were employed, compared with 26% of the secondary care population. Employment included any form of meaningful activity including volunteering, studying, part-time and full-time employment or a combination of those. There was also a statistically significant difference in ethnicity between groups (p=.024); the primary care group comprised a higher proportion of service users with asian ethnicity compared to the secondary care group. However participant numbers were very small for some categories, therefore results have to be interpreted with caution.

There were no statistically significant differences between the groups in gender, relationship status, living situation, diagnosis, and time in contact with mental health services.

There was a statistically significant difference in “age at diagnosis” between groups: service users in the secondary care sample were diagnosed earlier than the primary care sample, with 71% of the secondary sample diagnosed before the age of 30, in comparison to only 47.7% of primary care participants (p=.008). *Clinical variables compared between primary and secondary care*

A range of clinical variables were compared between primary care only and secondary care participants (see Table 5). There was a statistically significant difference between oral and depot medication: Only a few patients under primary care only were on only depot medication (9.8%) compared to 48% of the secondary care sample (p<0.001, see Table 5). There was also a statistically significant difference in type of antipsychotic medication (p<0.001): nearly 81% of primary care patients on second generation antipsychotics, with very few on first generation drugs or clozapine. In comparison, the secondary care patients showed a more equal split between types of medication, with 42% on second generation medication, 35% on first generation and 14% on clozapine. There were no statistically significant differences between groups for the DAI (Drug Attitudes Inventory), length of time taking antipsychotic medication, the overall dose of antipsychotic medication and the number of antipsychotics prescribed.

TABLE 5 CLINICAL VARIABLES COMPARED BETWEEN PRIMARY AND SECONDARY CARE.

Variable	**Primary care% (N)**	**Secondary care %(N)**	**Total %(N)**	**Mean difference/Odds ratio (95% CI)**	**p-value**
Drug Attitudes Inventory	N=37 Md = 4.00	N=202 Md = 4.00	N=239 Md=4.00	Minimum =-8.00 Maximum= +10.00 Mean = 2.71 (5.05 Std)	.13
Antipsychotic Dose (in chlorpromazine equivalent)	N=37 Md=266.68	N=181 Md=267.00	N= 218 Md=269.43	Min= 25 Max= 1033 Mean= 252.13 (18.24 Std.)	.97
Length of time taking antipsychotic medication (in years)	N=23 Md=15	N=186 Md=15	N= 209 Md = 15	Min =1 Max =49 Mean =16.5 (10.31 std)	.172
No of antipsychotics 1 2	82.9% (34) 17.1% (7)	84.3% (188) 15.7% (35)	84.5% (223) 15.5% (41)	.72 (.17-2.95)	.64
Form of AP Oral Depot both	87.8% (36) 9.8% (4) 2.4% (1)	42.6% (95) 48.0% (107) 9.4% (21)	49.6% (131) 42% (111) 8.3% (22)	7.85 (2.01-29.36) 21.50 (1.51-305.76)* (*comp to "oral")	<.001
Type of AP 1st gen 2nd gen Both Clozapine Clozapine+	7.3% (3) 80.5% (33) 4.9% (2) 4.9% (2) 2.4% (1)	35.3% (79) 42.2% (95) 14.3% (32) 5.4% (12) 2.7% (6)	30.9% (82) 48.3% 128) 12.8% (34) 5.4% (14) 2.6% (7)	.27 (.06-1.24) 2.14(.26-17.6)** .27 (.02-4.54)** 1.10 (.06-21.82)**	<.001

Variable	**Primary care% (N)**	**Secondary care %(N)**	**Total %(N)**	**Mean difference/Odds ratio (95% CI)**	**p-value**
other				(**comp to 1st gen)	

4.4 Views on long term antipsychotics, reducing and stopping antipsychotics

Participants were also asked about their views on long term medication, reducing long term medication and stopping long term antipsychotic medication. The findings are presented below.

4.4.1 Views on long term medication between primary and secondary care sample

In summary, our analysis found that secondary care and primary care participants are content to take long term antipsychotic medication (43.9% of primary care and 30.8% of secondary care participants; Table 6). We found a trend towards wanting to stay on antipsychotic medication in primary care patients, when compared to their secondary care counterparts, however the difference was not statistically significant. Similar proportions of participants do not want to take long term antipsychotic medication in both groups (14.6% vs 18.3%).

TABLE 6 PARTICIPANT'S VIEWS ON LONG TERM ANTIPSYCHOTIC MEDICATION

Survey question: **How do you feel about taking antipsychotic medication on a long-term basis?** (p=.26)	**Primary care %(N)**	**Secondary care%(N)**	**Total %(N)**

N	N=41	N=224	N=265
Happy to take long-term antipsychotic medication	43.9% (18)	30.8% (69)	32.8% (87)
Accept taking long-term antipsychotic medication reluctantly	22.0% (9)	18.8% (42)	19.2% (51)
Accept taking long-term antipsychotic medication for the present	12.2% (5)	26.3% (59)	24.2%
Do not want to take long-term antipsychotic medication/ Not sure	14.6% (6)	18.3% (41)	17.7% (47)
Other	7.3% (3)	5.8% (13)	6% (16)

4.4.2 Views on reducing medication between primary and secondary care sample

There was a statistically significant difference in views on reducing medication between groups (p= 0. 042, Table 7). Primary care participants were found to be more reluctant to reduce medication than their secondary care counterparts. These findings must be interpreted cautiously however, given the low number of participants in the primary care sample.

Table 7 Participant’s views on reducing antipsychotic medication

Survey question: **How would you feel about gradually trying to reduce your antipsychotic medication down to**	**Primary care %(N)**	**Secondary care%(N)**	**Total %(N)**

a lower dose, if you did this with the support of your doctor? (p= .042)			
N	N=40	N=222	N=262
Content to reduce antipsychotic medication	32.5% (13)	47.3% (105)	45.0% (118)
Willing to try to reduce antipsychotic medication	22.5% (9)	11.7% (26)	13.4% (35)
Not wanting to reduce antipsychotic medication	35.0% (14)	20.3% (45)	22.5% (59)
I might consider this in the future but not now	7.5% (3)	14.9% (33)	13.7% (36)
Other	2.5% (1)	5.9% (13)	5.3% (14)

4.4.3 Views on stopping medication

There were no statistically significant differences between the primary care and secondary sample on the topic of discontinuing antipsychotic medication (p=.21, Table 8). We found the primary care sample to be slightly more reluctant than the secondary care sample to stop their antipsychotic medication (17.1% vs 33.3%), but a similar percentage of participants wanted to try to stop their medication (19.5% vs 20.9%) and will consider it in the future (24.4% vs 20.9%).

TABLE 8 PARTICIPANTS' VIEWS ON DISCONTINUING ANTIPSYCHOTIC MEDICATION

Survey question: **How would you feel about gradually trying to stop your antipsychotic medication altogether, following a reduction, if you did this with the support of your doctor?** (p= .21)	**Primary care %(N)**	**Secondary care%(N)**	**Total %(N)**
N	N=41	N=225	N=266
Happy to stop taking antipsychotic medication	17.1% (7)	33.3% (75)	30.8% (82)
Willing to try stopping antipsychotic medication	19.5% (8)	20.9% (47)	20.7% (55)
Not wanting to stop taking antipsychotic medication	36.6% (15)	22.7% (51)	24.8% (65)
I might consider this in the future but not now	24.4% (10)	20.9% (47)	21.4% (57)
Other	2.4% (1)	2.2% (5)	2.3% (6)

4.4.1 Binary analysis

Given the similarity of answer options, it unclear where the differences lie for participants (difference between content to stay on medication, consider this in the future, content to try and reduce). In order to understand these differences more clearly, the data from each question was transformed into a binary variable, to allow for a better comparison. The findings of this must be interpreted cautiously, given the small number of primary care participants and the transformation of answer options into binary responses. Nonetheless, it may allow a clearer interpretation of the results listed above.

For Question 1 (Figure 25): How do you feel about taking antipsychotic medication on a long-term basis?

“Do not want to take antipsychotic medication” was compared with a newly computed variable including “content to take antipsychotic medication, accept medication reluctantly and accept taking antipsychotic medication for the present.”

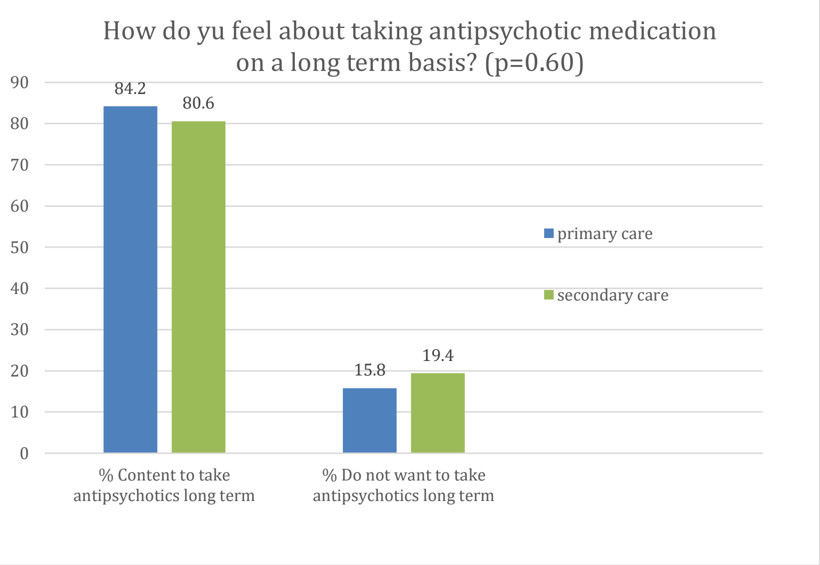


FIGURE 25 BINARY ANALYSIS LONG TERM ANTIPSYCHOTICS

In total, N=32/38 primary care participants and N=170/211 out of the secondary care participants were either happy or reluctantly accepted to take antipsychotic medication for the long term, whereas only N=6/38 in the primary care sample and N=41/211 out of the secondary sample did definitely not want to take antipsychotic medication long term. This difference is not statistically significant (X^2 (1, n=249) = .28, p=.60, phi=.033) and indicates that primary care and secondary participants have similar views on long term antipsychotic medication.

For Question 2 (Figure 26): How would you feel about gradually trying to reduce your antipsychotic medication down to a lower dose, if you did this with the support of your doctor?

“Not wanting to reduce antipsychotic medication” was compared with a newly computed variable including “content to reduce antipsychotic medication, willing to try to reduce and I might consider this in the future but not now”.

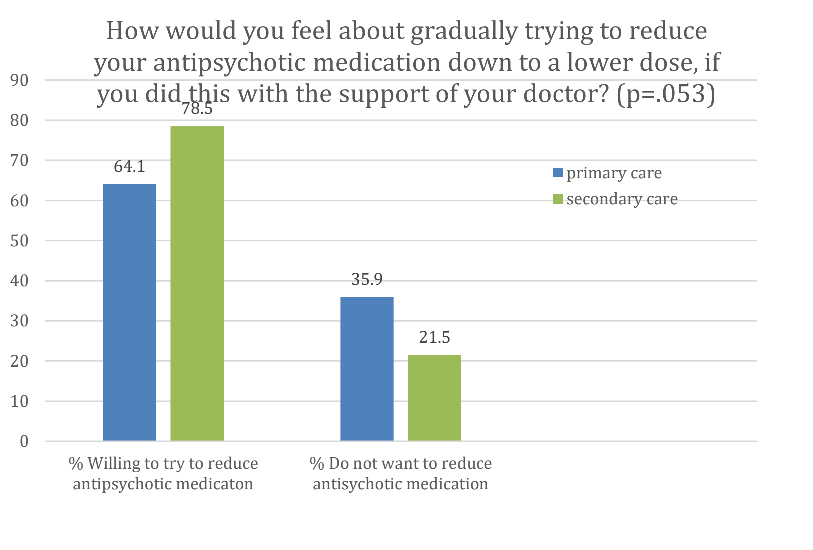


FIGURE 26 BINARY ANALYSIS - REDUCE ANTIPSYCHOTICS

In total, N=25/39 primary care participants and N=164/209 out of the secondary care participants were either content or willing to try to reduce antipsychotic medication. N=14/39 in the primary care sample and N=45/209 out of the secondary sample definitely did not want to reduce antipsychotic medication, even if they had the support of their doctor. This difference is close to being statistically significant (X^2 (1, n=248) = 3.74, p=.053, phi= -.123) and indicates that primary care participants may be more reluctant to reduce medication than their secondary care counterparts.

For Question 3 (Figure 27): “How would you feel about gradually trying to stop your antipsychotic medication altogether, following a reduction, if you did this with the support of your doctor?”

“Not wanting to stop antipsychotic medication” was compared with a newly computed variable including “content to stop antipsychotic medication, willing to try to stop and I might consider this in the future but not now” .

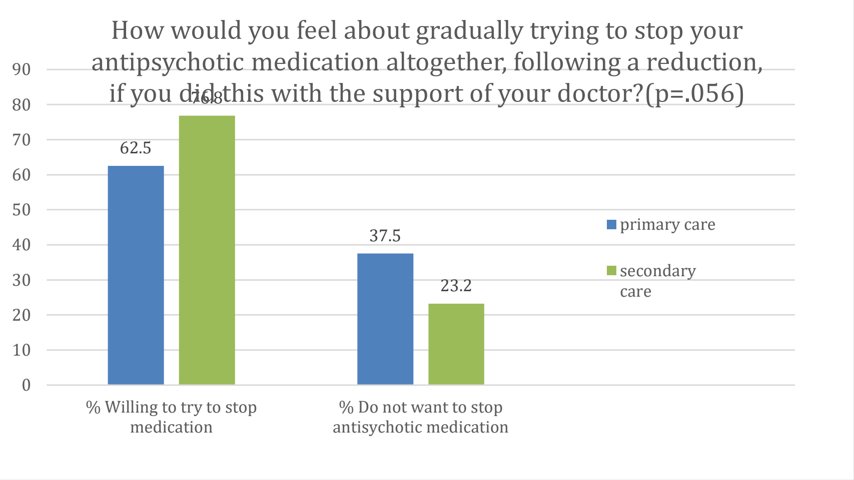


Figure 27 Binary Analysis - Discontinuation Antipsychotics

In total, N=25/40 primary care participants and N=169/220 out of the secondary care participants were either content or willing to try to stop antipsychotic medication. N=15/40 in the primary care sample and N=51/220 out of the secondary sample definitely did not want to stop antipsychotic medication, even if they had successfully reduced their medication already.

This difference is close to being statistically significant (X^2 (1, n=260) = 3.66, p=.056, phi= -.119) and indicates that primary care participants may be more reluctant to stop medication than their secondary care counterparts.

4.5 Reasons why participants who are under primary care only chose to reduce or stay on their medication – a thematic analysis of interviews

In total, N=22 participants out of the N=41 who were under primary care only, gave consent to audio recording. Despite thorough screening, one participant was in fact still under secondary care and was excluded from this analysis. This illustrates existing difficulties in identifying those patients who are no longer under secondary care.

Those consenting to audio recording did not differ in age, gender, ethnicity, marital status, employment, Drugs Attitude Inventory score, level of medication (CPZE), and fixed term responses on views on long term, reduction and discontinue of medication from those who did not consent (see Appendix 5).

Findings:

The majority of participants listed positives and negatives about their experience of taking antipsychotic medication. Although there was substantial overlap of experiences, participants appear to have weighed up their experiences and risks versus benefits of the medication differently. For example, most participants experience significant adverse effects (N=19 out of 21), which could be seen as a reason to stop medication, however most participants also reported a fear of relapse (N=19 out of 21), which could be seen as a reason to stay on medication. As reported above (see 4.4.2), 35% of primary care participants did not want to reduce their antipsychotic medication, 32.5% would be happy to reduce, 22.5% would be happy to try a reduction, and 7.5% might consider this in the future but not now. This illustrates that despite similar experiences, people make different choices regarding their antipsychotic medication.

The thematic analysis presented below aimed to explore what factors may contribute to people drawing different conclusions.

Using thematic analysis, considerations regarding antipsychotic medication fell into three broad themes (Figure 4):

1) key considerations for staying on medication,
2) key considerations for reducing medication
3) key considerations why changing medication is not applicable

Overall, the decision whether to reduce or stay on medication seemed to polarise participants. Only one participant reported feeling ambivalent: “*I’m not sure how I feel about this, this is the most truthful answer, there. I’m in two minds, aren’t I?” (P34).*

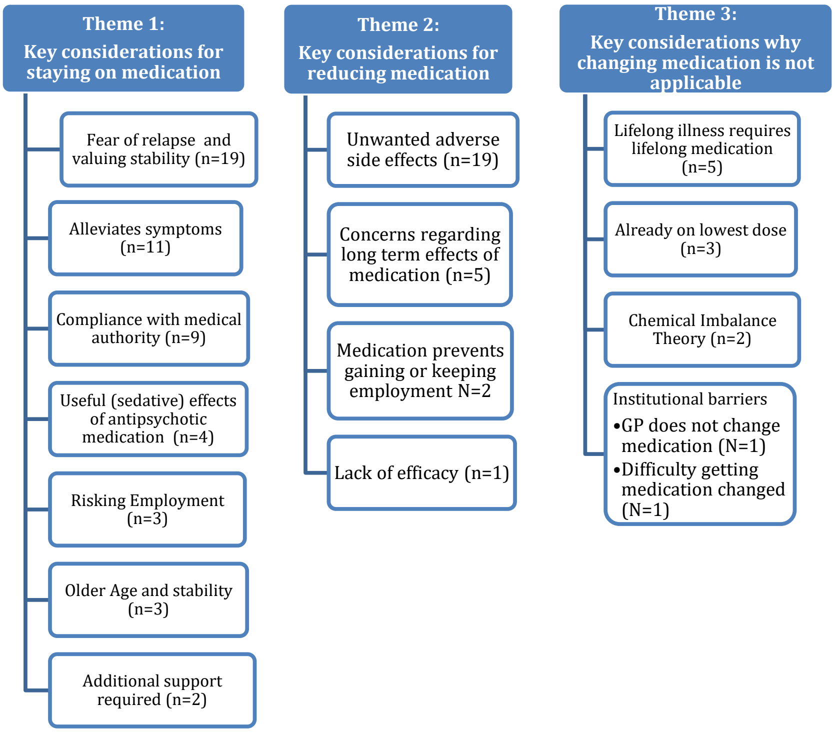


FIGURE 28- THEMATIC MAP: REASONS FOR AND AGAINST CHANGING MEDICATION

4.5.1 Theme 1 Key considerations for staying on antipsychotic medication

Several participants listed reasons to stay on medication, including 1) fear of relapse and valuing stability, 2) alleviating symptoms 3) compliance with medical authority 4) risking employment, 5) positive (sedative) effects of medication, 6) older age and stability and 7) additional support required.

1) Fear of relapse and valuing stability

By far the most cited reason for staying on medication is a fear of relapse and the importance of maintaining stable mental health:

"it may all go haywire" (P05). – "I don't want to make a change and I don't want to have a relapse again". – "Well, I feel it's kept me on an even keel for a long time and there's the old adage, if it ain't broke don't fix it sort of thing" (P34)

There are several ways in which a fear of relapses manifested. Most participants appeared to assume that reduction of medication would automatically lead to relapse. Two participants briefly referred to previous attempts at coming off medication (some abruptly) which actually resulted in relapses, indicating to them that any future attempt at reducing will result in relapse.

"*So, for me, it won't be wise for me to come off the medication completely, because I've had loads and loads and loads of experiences myself. So, I don't really need anybody to tell me to come off the medication, because I know what it will do to me "(P14).*

"Because I know what the problems are if I'm off medication, chances are symptoms reappear and I would have no control over it. I'll be back to square one and I've progressed quite well over the years". (P31).

Reductions can be associated with worsening symptoms and are therefore understandably not something service users may want to attempt: "*And that's why, why would I want to change that for" […] Coz the side effects to come off these drugs, it's horrific." (P05).* In those previous attempts however, some participants may have experienced withdrawal effects, which they interpret as having a relapse: *"I wake up after a couple of hours my mind feels like jelly, and [..] I get a lot of chest pain because I've been thinking and then I'll have to quickly take the medication, it rarely happens but that's what happens when I stop taking it or I forget to take it."* Confounding withdrawal with relapse can be a potential barrier to reducing medication.

Other participants referred to successful attempts of reducing medication, indicating that medication changes do not lead necessarily lead to relapses, again illustrating uncertainty and individual differences in antipsychotic medication usage. The uncertainty associated with changing antipsychotic medication and whether it will go well is a deterrent, as echoed by p31: *"I think I want to stay on the same dose. [..] I'm safe at the moment. I don't want to be restrained."* It appears that Service users value stability and reduction of uncertainty and believe that the safest way to prevent a relapse appears is to remain on the same dose of antipsychotics.

Fear of relapse is frequently cited in the interviews, potentially due to serious consequences participants feel this could have for them: *"without the medication I wouldn't be stable. I'll be verbally abusive" (*P14). Another participant stated *"I just feel like, if I don't take it, then I could hurt myself or someone else. And that's why I take it. Because I don't want to go to prison"* (p17) as does P30: "*When I wasn't well, I nearly went to prison, I smashed up a neighbours car thinking he was robbing me, burglaring me.".* Not all participants felt that they would pose a risk to themselves or others if they were to reduce, but that this is possibly a public perception: "*psychotics. Like Freddie Kruger on Halloween*. *I don't carry a knife; I don't try to fight anyone or do anything…I'm not a violent person. I've never been in trouble with the police over and arguing with anyone"* (P16).

Fear of relapse is thus a key consideration when thinking about changing antipsychotic medication.

2) Alleviating symptoms

Approximately half of the participants listed the beneficial effects of the medication as a reason to continue to stay on medication. The majority of service users who reported benefits, did not specifically mention that it reduces psychotic symptoms, some reported that it helps them “feel normal” and recover: “*I’m recovering, and it helps me you know, it helps me recovering” (P01).* Some reported it to be helpful to cope with specific psychotic symptoms, including hearing voices and distressing beliefs. *“But staying on the medication keeps me stable and they stop me from hearing voices”* (p14).

3) Compliance with medical authority

Another key consideration is the role of taking medication as a means to comply with the medical authority. Just under half of all participants discussed their role in taking antipsychotic medication. Some are encouraged by a lack of symptoms, which is seen as proof that the medication is working:

“*All the medication I’ve had, it seems to suit you, it don’t know what it is, it seems to suit me. I am falling in line with the people as well, I’m helping them as much as I can, by taking the medication, it’s in my favour to take it not in the doctors or the nurses. But if I’ve kept well for all these years, it must be working!” (P05)*

Nine other participants explain that “*well it’s up to my doctor*” (P20) and “*whatever my doctor says, is best*” (P23), illustrating that their doctor would need to support a reduction or discontinuation of medication. It appears that these participants see their role in treatment decisions as passive, and that it is their doctor’s view on treatment decisions takes priority.

4) Useful (sedative) effects of antipsychotic medication

Effects usually regarded as unwanted adverse effects are sometimes seen as positives, with some participants stating that the sedation associated with antipsychotic use helped them to sleep better at night. (p6,7,28). *“I feel okay.*

I feel it's safe, because sometimes I think I'm not using the … a sleeping pill, but I always in the evening when I take it, so I can, it looks like it helps me to go to sleep. But it's not sleeping pill. [laughs]" (P6). Some participants valued the sedative effects of the medication, and being able to sleep, despite the fact that antipsychotics are not prescribed for sedative purposes.

5) Risking Employment

Concerns about employment were prominent in this sample and included concerns that employment would be jeopardised by reducing or stopping antipsychotic medication, therefore likely being linked with a fear of relapse (as discussed above). When asked about the possibility of reducing or stopping medication, one participant said: *"I'd say I might consider this in the future but not now. It's just I don't want to have any variables when I'm starting a new job". (P09).* The survey data shows that the primary care sample was on average older and more likely to be in employment than the secondary care sample. This indicates that concerns regarding employment may be a key consideration and more important for the primary care sample. It again illustrates that stability is valued, and that reducing medication may introduce an uncertainty, or the possibility of relapse, which may impact employment. Therefore, participants were more reluctant to reduce their medication.

6) Older Age and stability

Out of the participants who consented to interviews, the two oldest participants considered age to be a particular difficulty when reducing medication and appeared to value stability over the negative side effects they were currently experiencing.

“Yeah, I’m just so worried, if I stop taking medication or reduce, might be my brains chemistry off balance or something and I shall be in trouble again or in the hospital again which I don’t want to. Because I am 71 now and it’s not too long, I can live so I don’t want to change, just live a peaceful life and then I go to heaven. [..] I cannot get this challenge again [..] I don’t want them to reduce my dose and risking my life again. I don’t want to do that risk. I am too old to take a challenge again. “ (P06)

“well, I think, is wrong what you said, I think erm, I’m 72, there’s a point in the changing. [..] You really want a younger patient to be able to change, not me at 72 years old. I’m … I’m stable as I’ll ever be. But it comes with all the ages, I’m 72, I’m not 16, so I think quite differently. [..] Plus I am older as well, so not like a young lad at 16 getting thrown into a lion’s den. “(P05)

It appears that concerns regarding relapse may increase with age. Participants describe that a relapse and subsequent admission to hospital would be devastating. It describes the challenging nature of changing medication, and how service users would need to be “young” in order to face this challenge. The possibility that a reduction may not automatically result in a hospital admission was not considered likely. The first quote goes beyond describing it as a challenge and equates reducing medication to “risking my life”. This is particularly important to consider, given that the survey showed that the primary care sample is on average older than the secondary sample. Age appears an important consideration when reducing medication, and it may be particularly pertinent for the primary care sample. In contrast to these statements, one participant, who was aged 52, has the opposite sentiment. Given increased age, the participant worries about long term consequences of taking medication, and continuously taking medication is like risking their life. In response to being asked about long-term medication use, the participant answered, "*I'm getting old now, I don't know if I'll even make it [due to side effects]" (P16)*

7) Require additional support

Additionally, participants were concerned about isolation and not having enough support to go through the process of reducing their antipsychotic medication.

"Because I'm living alone and if I am not very well then who will look after my life you know? Because I'm three or four times admitted into hospital." (p28).

"*You feel like nobody can help you, you're dealing with it on your own. This is where the medicine comes in because it gives you some respite"* (P27*).*

It appears that social support is crucial in facilitating medication reductions. The demographic data showed that only 22% of the primary care sample were in a relationship at the time of interview, and 70% of participants lived alone. Whereas other social contact can exist, this is an indication of the social support service users had available. Participants appear dependent on social support. Another participant who did have family support, was concerned about how a reduction would affect their relationships *"I am quite worried about messing with the medication that I'm on at the moment because when I do become unwell it does cause major problems for me with family, relationships and with friends and relationships because of my bizarre behaviour when I'm* *unwell."* (p30). Preventing isolation is a key consideration for service users and reducing medication may result in increased isolation. Participants highlight that appropriate support is required to maintain or build relationships.

4.5.2 Theme 2: Key considerations for reducing antipsychotic medication

1) Adverse effects of antipsychotic medication

Most participants (N=19/21) experienced unwanted side effects and were thus key considerations when discussing medication changes. Adverse effects were referred to as "horrific" and "terrible" and include weight gain ("It's probably gone up by a stone or a stone and a half", "fat", "pregnant bellies"), Gynaecomastia ("growing breasts"), extrapyramidal side effects (EPSE, "muscular movements affected", "makes me shake shake shake my head all the time", Sedation/ cognitive difficulties ("makes you slow"/ "slows you down", sedation , "numbs their brain" "I was more lively before"), "hip and breathing problems" […], "headaches". Participants appear to experience a range of adverse effects of varying severity.

There also appeared to be a lack of clarity around what potential adverse effects are, as can be seen by this participant: *"it says that it* [the antipsychotic medication] *has no sugar, but it does trigger a lot of cravings. And my problem, because I chose to take it at night, I wake up in the middle of the night and I crave sugar, sugary drinks or food […] it's very, very distressing because if the medication doesn't have sugar […] i don't know what is the ingredient that […] make you fat…maybe it's cravings, that make you eat. […] it took me a long time to understand why I had to get up in the middle of the night and then I* *realised that it is in fact the medication. “* (P27). Further communication and clarification is clearly required.

This illustrates quite clearly how impactful the adverse effects from medication can be. Understandably, adverse effects were therefore named frequently as impacting people’s Quality of Life and ability to complete their daily activities “*it’s making me lazier around the house, I used to do more” (p1*6).

Subsequently some wondered whether reducing medication would also decrease their adverse effects*: “I think that I’d be keen to see whether my side effects will reduce”*. However one participant has reduced medication and found that this did not reduce their side effects *“I was on 10mg initially and then it was gradually reduced to 2.5 […] but I still have the same side effects. as if I’ve taken the 10” (P14).*

2) Concerns regarding long term antipsychotic medication use

Reasons for participants wanting to reduce or discontinue their medication included concerns about long term antipsychotic use, and how the medication might affect their physical health in the long run. Current side effects such as weight gain signalled to people that the drugs might be physically harmful and lead to serious physical complications:

“I’m concerned about the long-term effects of taking antipsychotics and I think that they make you a bit, I think they’re putting weight on, and they make me a bit slow as well.” (P09)

“I am concerned about taking antipsychotic medication in the long-term as I had a scare of medication […], I am aware of the physical things that might happen taking it long-term, people don’t know do they?” (P30).

It appears that the uncertainty associated with long term medication use, and unknown effects on physical health, are a key consideration for SU.

3) Concerns regarding employment

Two participants considered effects of medication on employment; they felt that the use of antipsychotic medication was a barrier to employment due to sedative and cognitive side effects.

"*it's so hard for me to wake up in the morning because of the medication, so I haven't been able to work, so I just have to become self-employed*."

Equally, P16 would like work but feels unable to at the moment due, partially due to sedative effects *"Coz I've got all the hours. I get up early and then I've got the whole day in front of me, and I can't do anything, I can't work. Because I'd like to work until I'm retired. "*

As discussed in 4.5.1 – Key considerations for staying on medication, employment is a crucial consideration for Service Users. Rates of employment are higher in the primary care sample, thus potentially even more important to consider in this population. Whereas some participants felt that medication ensured stability, and thus continued employment, some service users also feel that medication is a barrier to employment, due to the sedative effects of medication. Participants reported that they would like to work but feel unable to.

4) Lack of efficacy

One participant described that the medication is not treating their psychotic symptoms:

“well, I want to change my medication; I’ve been on it for a long time and I don’t feel like it’s doing much for me. I just take it, coz I take it [...] it’s not really helping me with the voices, so yeah, I want to change it” (P17).

Given that only 35% of the primary care sample definitely did not want to reduce their medication, it appears that a lack of efficacy is not a key consideration for many of the participants, and other reasons must be more at the forefront. In fact, many stated positive effects of the medication as a reason to stay on (see 4.5.1). It is possible that medication may be more helpful to those in primary care, that they have adjusted to it more or are more accepting of adverse effects; this would explain their reluctance to change it and potentially explain why they are no longer under secondary care services.

4.5.3 Theme 3: Key considerations for change of medication is not an option

Theme 3 summarises reasons as to why participants do not consider changing their antipsychotic medication/dose an option. This includes 1) antipsychotics being seen as lifelong medication, 2) need for medication due to schizophrenia being caused by a chemical imbalance 2) participants feeling like they are on the lowest dose already and 3) institutional barriers which act as a barrier to medication changes. Institutional barriers include the perception that GPs do not change antipsychotic medication, and previous difficult experiences of changing antipsychotics.

1) Lifelong medication

Several participants stated that they have been told that they should stay on medication for the rest of their lives by their clinician and therefore did not consider themselves eligible to reduce medication: *“[…] even the doctor says*

I cannot stop my medication, it's a condition for the rest of my life" (P39). This suggests that participants might not consider it appropriate to discuss the subject with their GP.

3) Participants who were on the lowest dose already

Some participants reported that they were already on the lowest dose possible and therefore felt that further reductions were not possible for them. One participant stated that their doctor informed them that they were on the lowest dose, the other two participants did not elaborate on how they came to consider that this was the lowest dose. The lowest dose can be defined in multiple ways: different participants on the same medication but on different dosages considered themselves to be on the lowest dose, illustrating that it is difficult to determine a "lowest" dose. Those who considered themselves to be on the lowest dose, did not consider stopping the medication altogether.

2) Chemical Imbalance Theory

Two participants listed the need to balance brain chemistry as a reason to stay on medication: *"it helps me to balance my brain and I think I don't need to reduce the dose because it's the very mild dose. Balance the chemistry of my brain." (p06)*. This illustrates that service users may consider their diagnosis within the medical model, and thus do not feel that discontinuing antipsychotic medication is an option for them.

4) Institutional barriers

a) Participants who felt that the GP would not be able to reduce medication:

Since participants are under primary care only, one participant felt they had no option to reduce their medication as they believed their GP would not do this *"[..] I think it's the psychiatrist that has to change it. I don't know the* *psychiatrist" "[..] I want to change it. Keep saying this but no one wants to change it with me" (P17). Two other participants however reported changes to their medication in primary care (P38, P14).* This discrepancy in what GPs do in practice, or are perceived as being prepared to do, might reflect differences in GP practice characteristics, or between individual GPs. It also illustrated that the participant wanted to change their medication but was unable to in primary care.

b) Difficulties changing medication:

One participant stated that they would not want to reduce or even change medication to a different agent due to difficulties they experienced when changing medication previously. Services did not seem to communicate well to arrange a change of medication. Once it was changed, there were difficulties finding the right dose for the participant, adding further distress. When asked if they would consider reducing their medication, they answered: "*Not after it took 9 months to find this new one"*. (P05). This illustrates how past negative experiences and level of uncertainty influences people's decisions about medication.

Discussion

Main findings:

This was an exploratory analysis of differences and similarities in clinical and demographic variables, between primary and secondary care service users. The study also explored primary care only service users' view's on long term antipsychotic medication, reduction and discontinuation. Given the need to review (and potentially change) antipsychotic medication over time (as outlined in Chapter 1), it is crucial to explore service user views on the topic. Clinicians wishing to discuss long term antipsychotic treatment and potential reductions or discontinuations of dose, will also benefit from being aware of service user views on the topic.

To the author's knowledge, this chapter provides a first insight into primary care only service users views on long term antipsychotics, and outlines key similarities and differences between this population and their secondary care counterparts.

Overall, primary care only participants were on average older, more likely to be in employment and diagnosed later than their secondary care counterparts. There were no statistically significant differences in gender, age at diagnosis, time in contact with mental health services, marital status or living situation between groups.

In terms of clinical factors, the primary care population was more likely to be on oral medication and on a second-generation antipsychotic, than the primary care sample. There were no differences between groups on their Drug attitudes inventory (DAI) score, the amount of antipsychotics or antipsychotic dose (CPZE equivalent) between groups.

Primary care participants were overall content to be on antipsychotic medication. Given the responses to the questions regarding long term antipsychotics, reducing and stopping, it appears that this is not an easy decision to make. In comparison to the secondary care participants, the primary care group was more reluctant to reduce medication. There were no differences between groups on views regarding long term antipsychotics and discontinuing antipsychotics. Both primary and secondary care participants listed concerns regarding long term antipsychotics but were also overall reluctant to discontinue medication altogether. The clinical data showed that primary care only participants were on similar antipsychotic dosages than their secondary counterparts. Given that the primary care only sample should be on a maintenance dose and is on average older than their secondary care counterparts, lower antipsychotic dosages might be expected in this population. It may not be possible to achieve this if Service users are reluctant to reduce their medication.

The findings illustrate a range of considerations that primary care service users thought about when making a decision about their antipsychotic medication. Most service users describe experiencing adverse effects of the medication, and most of them report fears of relapse. This is in line with previous research (Morant et al., 2018; Thompson et al., 2020). Changing medication for them was associated with subsequent relapses and hospital admissions. Thus, many participants outlined their wishes for stability, and in order to not to endanger that stability, did not wish to reduce or discontinue medication. In particular, those participants who were oldest in the sample, felt that an admission to hospital was too difficult, or even “life-threatening”. It appears that fears of relapse do not diminish over time, despite the fact that many service users in primary care show low rates of psychotic symptoms (Kendrick et al., 2000).

Antipsychotics were seen as useful for improving symptoms; psychotic symptoms to a lesser degree, but in general seen as beneficial. Changing medication may also be a risk to their employment, thus some of those in employment were not in favour of changing their medication.

Some participants also saw following doctor’s orders as their role; some also felt that medication decisions were made by their doctors for them. This illustrates that some service users did not feel able to participate in treatment decisions, suggesting management of antipsychotics in primary care could be paternalistic as also suggested in other research (Morant, 2016; Gruenwald & Thompson, 2021). This is not compatible with the NHS guidance regarding Shared Decision Making (SDM). SDM is a key NHS objective, and service users should be empowered to participate in treatment decisions.

Those service users who wanted to reduce their medication, largely listed intolerable side effects as the reason. Some also listed concerns regarding long term antipsychotic use and its effect on physical health. Participants currently not in employment, also listed antipsychotic sedative side effects as a barrier to employment.

The last group of considerations revolved around potential reasons that meant that medication changes were not applicable (from a service user point of view). Some participants felt antipsychotics are to be taken for life or need to be taken due to a chemical imbalance, thus implying that medication reductions are not possible. Others felt they were on the lowest dose already; however it is not clear how the “lowest dose” is defined, or how the lowest dose was established

These are key considerations which should be discussed in any consultation regarding long term antipsychotic medication use. Service users must be made aware that discussing medication changes is an option, and that this can be discussed with their GP. It is also crucial to address the uncertainties associated with antipsychotic medication: it is possible that finding an acceptable dose of an antipsychotic takes time, relapses are possible and that it is not clear what the “lowest dose” would be. Fears regarding inpatient admissions and losing employment must be considered, and adequate support put in place, should a medication change, or reduction be indicated. It thus appears that a key, overarching priority, is to minimise uncertainty and maintain stability, which results in leaving medication as is it, despite experiencing adverse effects and potential physical health complications.

Implications

The primary care only sample likely represents a stable group of service users, as they are in primary care only and do not require specialist, secondary care support. It is thus possible that this group of participants has “more to lose” if changes to medication are made and they are not successful. On the other hand, primary care sample may also be more suitable for medication reductions as they have been discharged from secondary care and therefore likely represent a more stable segment of people with a diagnosis of psychosis, thus less likely to experience a devasting relapse, and may benefit from a reduction to reduce metabolic risk factors, for example. It is important to consider the risk – benefit ration on an ongoing basis for this population, and to tailor medication accordingly.

It may also be more important for some of this group of service users to reduce their medication. Given that this group of participants is older, on a similar dose of antipsychotics than their secondary care counterpart and has been on medication long term. It is therefore likely that many service users in this population could try to reduce their medication, as discussed in Chapter 1. Most participants also describe intolerable side effects. Guidance indicates that medication should be prescribed at the lowest possible dose, and only taken for as long as necessary (NICE, 2014). Given that primary care service users are potentially more reluctant to change medication, it is important to explore reasons for this. Taking the results together, there appears to be no good time to change medication however: reducing whilst in employment may put employment at risk, and not wanting to reduce in old age, out of increased fears of relapse. This is in line with previous research (Morant et al., 2018l).

Individual differences feature in their decision making as well. Given that most participants listed a fear of relapse, but also listed severe side effects, it is interesting that some participants still wanted to stay on medication, whereas others did not. This could be due to differences in severity of adverse effects, and severity of fear of relapse, as well as individual preferences and circumstances. Exploring these factors is crucial.

Reductions and relapses also warrant specific attention, as one of the most cited reasons for remaining on medication in the literature is the risk of relapse, preventing many from attempting to reduce (Moncrieff, Gupta & Horowitz, 2020). Some participants in this study report successful reductions without relapse, whereas other experienced distressing and disruptive relapses following stopping or reducing medication. Guidance around successful reduction of medication is still lacking, as outlined in the introduction. Based on the descriptions of relapse, it also appears that some participants are unsure between what is withdrawal from stopping medication and what is a “genuine” relapse of psychotic symptoms. This suggests that some of the fear of relapse is misplaced and may be helped by a gradual and supported discontinuation in which the possibly of withdrawal symptoms could be explored.

Although some of the reasoning listed in the thematic analysis may not be entirely unique to primary care participants, important differences when compared to secondary care were highlighted. For example, considerations surrounding employment will not be unique to the primary care sample, however rates of employment are higher in primary care and therefore considerations regarding employment are potentially applicable to more patients in primary care compared to secondary care. Reductions in medication (if needed) may need to be completed in secondary care before discharge to primary care, due to increased reluctance to do so (with increasing age) and barriers to implement reductions without GP liaison or secondary care support (as outlined in Chapter 1 and 2).

The primary care sample were also less likely to be on a depot than the secondary care sample. This may represent issues with depot administration in primary care; GPs may not offer depot administration; thus service users may be swapped to oral medication in order to be discharged. The primary care sample had a higher proportion of Asian participants. Increased levels of social support may mean that these communities either present to mental health services less or are better supported in the community by family or carers. This is in line with the findings of this study; the need for social support was highlighted as a key consideration when changing medication (4.5.7)

Shared Decision Making is also a key priority, which requires attention. Service users need to be empowered to take part in treatment decisions, and this should be facilitated in line with the NICE guidelines (2021). The current findings help to understand people’s viewpoints when making decisions regarding medication, and benefit clinicians in providing a list of key considerations to be used when discussing medication during medication reviews. It may allow them to discuss concerns that people on long term antipsychotics may have. This may in turn improve Shared Decision Making, a key NHS England recommendation.

Comparison with existing Literature

Previous research found that primary care sample is on average, older (Kendrick et al., 1994) and on more medication (Reilly et al., 2012) than their secondary care counterparts. This study replicates Kendrick's findings but not Reilly's, as there were no statistically significant difference in overall antipsychotic medication use between the primary and secondary sample. It is possible that the small sample size contributed to this, as well as reduction of dosages over time due to increased campaigns to reduce polypharmacy and prescribing above BNF limits. Previous research also indicates that medication reviews may not occur and if so, not in a structured way (Kendrick et al., 1994; Grünwald et al., 2021). This lack of communication became apparent in this study also. Participants in this study did not seem to be clear on what their medication options are, what is considered the lowest dose and what to expect from their GP, with some citing that GPs will not reduce medication and others reporting successful reductions in primary care. This may reflect some of the differences in what GPs consider within or beyond their remit, suggesting that medication reviews should be completed in secondary care. Differing views within the GP profession could have, at least in part, led to the described confusion in service users.

Our qualitative findings are in line with previous research (outlined in Chapter 1), stating that fear of relapse, serious adverse effects of medication and lack of efficacy are important considerations for service users. It appears that antipsychotics are the "least worst option" (Morant et al., 2018) for many service users. A recent systematic review of service user experiences of antipsychotic medication (Thompson et al., 2020) found themes similar to those identified in this review: the impact of medication on agency and subsequent compliance with medical authority, for example. Service users rarely feel involved in treatment decisions, and comply with their psychiatrist's treatment decisions, without complaint. The systematic review by Thompson et al. (2020) also identified positive and negative effects of the medication, in that some service users felt that medication helped their psychotic symptoms or insomnia, and others felt crippled by the adverse effects associated by the medication, much like participants describe in this study. In fact, an online survey of 650 people's views from 29 countries, only 14.3% reported that they had experienced nothing but positive effects from taking the medication, and 57.7% only reported negative ones (Read & Sacia, 2020). The study may have suffered from a sampling bias and may represent service users still under secondary care services. In our study, participants appeared largely content with medication, and reluctant to change it. Our sample may however represent a more conversative subgroup of people taking antipsychotics. Previous research for example has shown that older service users (>55 years) may prefer more paternalistic care (Lester et al., 2005), though as Pedley et al (2018) debated, whether this is a true choice or reflects the "doctor knows best notion", is unclear.

Some of the participants responses to the Read & Sacia (2020) survey however aligned with this study, with many participants discussing adverse effects, issues around reducing or stopping the medication, and "interactions with the prescriber" as difficult. The authors highlighted lack of information sharing, shared decision making in consultations and lack of support in reducing medication as key issues which need to be addressed (Read & Sacia, 2020). Previous qualitative research has largely ignored the service setting (primary care or secondary care). As outlined above, the findings are in line with primary care only service user perspectives in this study, indicating that experiences of the medication are similar for both primary and secondary care groups. The main difference in this study was that the primary care group was less likely to want to reduce the medication, which could either represent a more positive experience of the medication or may suggest that primary care service users have “more to lose” or that they are older and more accepting of the medical view of their problems and the role of treatment.

In the sample of this study as a whole, Crellin et al (2022) found that attitudes towards antipsychotic medication (as measured by the Drug Attitudes Inventory) was the main predictor when asked whether SUs would consider stopping their antipsychotic medication. We did not find any differences here between primary and secondary care patients; therefore it is likely that attitudes towards antipsychotics play a significant role for primary care SUs deciding whether they would consider stopping their medication.

To our knowledge, there is little other research on the topic of primary care only patients diagnosed with schizophrenia or psychosis and their unique characteristics and requirements. This study outlines key considerations, which require further exploration. Future research should address this.

Strengths and limitations

Although the study benefits from an overall large sample, recruited across several secondary and primary care services, the sub-analysis included only a small primary care only sample (N=40). Therefore it is likely that the sample is not representative and findings may not be generalizable. It is also possible, that the study did not find any significant differences between groups due to a lack of power.

Given that the study also only included service users currently on antipsychotic medication, it likely missed those primary care only service users, with an SMI diagnosis, who had successfully discontinued their medication. It may also have excluded any service users who had covertly reduced their medication and did not want to participate to avoid their GP becoming aware of their medication change. The participants who did take part, may also represent a more engaged group of service users, who are potentially more adherent with their antipsychotic medication. This may have affected their responses may have introduced a sampling bias. Future guidance needs to cater for all service users, therefore future research should ensure that potentially under-represented groups of service users are included in research. It is also important that a range of service users are consulted to ensure that guidance documents and service designs are relevant and useful to those who use it.

The univariate analyses highlighted important differences but could have benefited from a larger sample to allow further analyses of result and increase generalizability of the results. The survey is also not standardized or validated (other than the Drug Attitudes Inventory) but was piloted before implementation. Due to the lack of literature on the subject, this was an exploratory analysis, which included a range of analyses. The likelihood of chance findings is increased with multiple comparisons, which must be considered. Larger sample sizes, clearer a priori hypotheses and purposive sampling is required to explore this further.

The qualitative data was derived from a structured interview and only from a subsample of participants (N=21). Where consent was given, researchers audio recorded the interview with the participant. This allowed a better insight as to why participants chose their answer options and facilitated a short discussion for most questions. However, the data derived from these structured interviews is not as in depth as data from unstructured interviews could have been. Nevertheless, the qualitative data confirms findings from existing literature and highlight a range of novel issues and considerations when reducing antipsychotic medication, lending it credibility. It also allows triangulation of the data, which helps to clarify the quantitative findings. Further research is still required needed to replicate the results and explore service users view in further detail.

The analysis did not consider current psychotic symptoms, which could have been a confounding factor. The primary care sample may be more “stable” and therefore likely be in employment, or experience fewer symptoms due to older age and reduced symptoms in the schizophrenia illness trajectory (as seen in Kendrick et al., 2000). Lastly, SUs who are more ambivalent regarding their medication, may be less motivated to take part in research or expand on their thoughts with medication, which could have skewed the data we have collected.

Adverse effects of the medication and fear of relapse were not objectively measured; therefore, severity of experiences of adverse effects or relapse may contribute to this finding. There were a few participants who did not want to reduce despite “horrific” adverse effects however, showing that the decision-making process is difficult, and may not be related to severity of adverse effects alone.

Conclusion

To the authors knowledge, this is the first research study to specifically explore primary care only service users’ demographics, clinical variables, and views on long antipsychotics, reduction and discontinuation of medication. It illustrated many similarities to those of secondary care service users, but also highlighted important differences. It is crucial that conversations regarding antipsychotic medication are facilitated, as primary care participants may be older and are on similar antipsychotic doses as secondary care, and thus likely to suffer from increased physical health issues. This suggests that medication changes or reductions may be appropriate to consider, but more difficult to execute, given the increased reluctance to change medication.

This study provides key considerations for service users and clinicians to discuss during consultations. It is important to understand and support service users to manage adverse effects of the medication, to discuss their concerns regarding employment, and empower Service users to participate in treatment decisions. Many service users are understandably worried about relapse, and value stability. It is important to address these concerns. Given that primary care population may now represent 50% of all Service users with an SMI diagnosis (Kings Fund, 2020), it is crucial to adapt consultations to their needs, and clarify what GPs can and cannot do with regards to medication changes and what secondary care support can be accessed and how.

There is a paucity of evidence available on this topic to guide treating GPs in navigating discussions around long term antipsychotic use, and if indicated, antipsychotic reduction and discontinuation. This study is an exploratory analysis; further research is urgently needed, to improve outcomes for those stable, primary care only service users on long term antipsychotic medication.

Chapter 4 Antipsychotic Medication Reviews in Primary Care – A survey of UK General Practitioners.

1. Introduction

As discussed in the previous chapters, increasing numbers of service users are discharged from secondary care services in the UK and therefore rely on their GP to provide antipsychotic medication reviews. As reported in the realist review (Chapter 1), there are no studies exploring GPs' views of reviewing, reducing and stopping antipsychotic medication for people with a diagnosis of schizophrenia and/or psychosis, who are under primary care only. People who continue to experience psychotic symptoms and relapses, may end up getting referred to secondary care, where their medication is reviewed. However stable patients are at risk of not being adequately reviewed or considered for medication reductions (as discussed in Chapter 1 & 2).

As highlighted in Chapter 1, it is crucial that medication is reviewed regularly, especially since Chapter 3 (the Service User interviews) indicate that primary care service users are on average older. It also suggests that they are on a similar dose of antipsychotics than their secondary care counterparts. Together, this indicates that there are service users who may benefit from a thorough medication review and potential reduction in antipsychotic medication. This is supported by research: A study Mortimer et al (2005) audited primary care antipsychotic prescribing based on nine criteria, including prescription without diagnosis, polypharmacy, and doses above BNF limits and not being reviewed by a health care professional in the last 12months. Fifty-two percent of records screened failed at least one of the criteria.

Following a pharmacist review of the drug charts, 80% of people audited required a medication review and changes to medication. This is in line with Reilly et al's (2012) findings, illustrating that medication is likely not reviewed and/or adjusted in this sample. It is important to review medication and address issues with medication reviews and changes in primary care.

The realist review (Chapter 1) suggested that antipsychotic medication reviews may not occur in primary care and identified several barriers to medication reviews. The realist review identified 5 CMOCS and an initial programme theory which may explain why antipsychotic medication review do not occur and/or are not conducted thoroughly.

This includes:

Barrier 1: Low expectations regarding recovery from mental illness

Barrier 2: Perceived lack of patients' capabilities to participate in medication reviews

Barrier 3: Lack of information sharing between GPs and patients

Barrier 4: Perceived risk of service users

Barrier 5: Uncertainty regarding medication and illness trajectory

Facilitators to antipsychotic medications reviews.

The Realist Review highlights a lack of research especially on the topic of risk associated with a diagnosis of schizophrenia and psychosis, and whether this influences medication reviews for primary care only patients. It also illustrated that patients may potentially be stuck on medication for years if not reviewed, and that reviews are possibly superficial or may not occur at all. The realist review also highlighted issues as a result of a lack of guidance. As outlined in

Chapter 1, a yearly physical health check for service users on the SMI register has been mandatory since 2014 as part of the Quality Outcomes Framework. Service Users receive additional reviews by a psychiatrist and potentially a care coordinator whilst under secondary care. Despite being on long term antipsychotic medication, there is no additional guidance for those service users no longer under secondary care. It is unclear if GP surgeries have developed specific guidance to support those patients who are no longer under secondary care, as suggested by Byng (2004). As outlined in Chapter 1, the annual QOF review requirements are vague (other than the mandatory weight and blood tests). It is thus not clear how comprehensive the medication review is whether side effects are discussed and if medication is reviewed and reduced when indicated.

Little research has been found on the effects of uncertainty on medication reviews. Given that service users had concerns regarding long term antipsychotic treatment (Chapter 3), it is important to understand if GPs have similar views. There are many types of antipsychotic medications available, and it is unclear what dosages should be used for maintenance treatment, what a “lowest” dose is (as it differs for each person; Marland & Sharkey, 1999) and how medication is reduced and stopped safely. It is also difficult to predict relapses, adding further uncertainty. These factors could be of concern to patients and their GPs, potentially leading to mutual reluctance to review and/or change medication. The realist review also identified the role of hope and trust in overcoming these barriers to the completion of medication reviews.

To the authors knowledge, this is the first survey that has a specific focus on GPs views on their care of service users with an SMI diagnosis, on long term antipsychotics, who are under primary care only. It is crucial to explore GPs views on this topic to gain an understanding of their experiences with antipsychotic medication reviews, and to explore how to better support GPs and service users, subsequently.

This Chapter aims to further test and refine the CMOCs, and overall programme theory identified in Chapter 1 by surveying GPs in the UK on this topic.

Aim

The aim of the study is to answer the following research questions:

1. 3. 2.4
2. To determine if GPs are able to identify service users who are solely under primary care and whether there are any specific practice specific guidelines for this population?
3. 3.2.5
4. To determine GPs' views on long term antipsychotic medication for service users with an SMI diagnosis.
5. 3.2.6
6. To determine if primary care only antipsychotic medication reviews are occurring, and if so, how comfortable GPs are in reviewing, reducing and stopping (where appropriate) antipsychotic medication.
7. 3.2.7
8. To collect data, specifically for those areas that lack literature in the Realist Review, to further refine the programme theory.

2. Methods

2.1 Survey Design process

The survey is based on CMOCs, and the initial programme theory identified in Chapter 2 - Realist Review. The survey aims to test and refine the programme theory and address any evidence gaps. This meant the survey had a clear, pre-defined focus.

The decision to complete a survey rather than interviews was based on the fact that GPs may not be available for interviews, as they require a greater time commitment from participants. Especially during Covid, the aim was to keep GPs time commitment to a minimum. It was also important to recruit a larger and more diverse sample size, so that the results were more generalizable. Additionally, as some of the questions pertain to stigma and stereotyping, GPs may not feel comfortable to share their views and experiences openly in an interview. Surveys offer anonymity and help to prevent social desirability biases. In summary, a survey appeared to be the most suitable way to explore the research question.

The survey questions were drafted based on Chapter 2's programme theory and were refined within the supervisory team, consisting of a policy researcher, a psychiatrist, and an academic GP. In the development stages, the survey was discussed with a range of academic GPs and experienced NHS researchers. Following discussions, the aim was to design a survey that would take no longer than 10-15minutes to complete and to include a case study as part of the survey. GPs may find it easier to complete the survey with a specific case in mind, rather than answer more generally phrased questions. Questionnaire design was an interactive process; questions had undergone several rounds of review before they were piloted.

The questions were added to the Opinio platform (UCL Opinio version 7.12) and sent to two independent clinicians (one GP liaison psychiatrist and one GP) for review. Once piloted, a follow up conversation was arranged to discuss their experience of completing the survey, whether they had feedback and to see how long it had taken them. Following their feedback, only a couple of questions were amended, mainly changing the order of questions and answer options. Both were able to complete the survey within the target of 15 minutes.

The final questionnaire consists of 36 items and includes a demographic section, a case study, multiple choice questions with free text options, and some standalone free text questions. The survey consisted of questions regarding primary care only guidelines, secondary care support and views on reviewing, reducing and stopping antipsychotics. It included questions on the Realist Review's CMOCs, including risk and uncertainty regarding care and treatment of people with an SMI diagnosis (for full survey, please see Appendix 6).

2.2 Ethical Approval

The study was reviewed, and ethical approval was given via UCL University Ethics, application number 19059/001 (Appendix 7).

2.3 Sample size calculation

The sample size was calculated by using the surveys sample size calculator (see Appendix 8). Based on 50,000 GPs in the UK, an error margin of 5% and confidence interval of 95, the required number of participants is 382.

2.4 Recruitment pathways:

The survey went live in November 2020 and was open for recruitment until October 2021. No incentives were provided for taking part. The recruitment strategy included several different channels (Figure 29).

1) Social Media & personal contacts

- Posted and re-tweeted between Nov 2020 and August 2021
- circulated via personal networks
- circulated in North Thames CRN

2) Journal

- Article published in BJGP Life on 10th February 2021 - "Antipsychotic medication reviews in primary care - searching for best practice".

3) NHS Digital List

- 6000 Practices screened
- Excluded: 2139 surgeries did not have an email address on the website , 1647 specialist clinics, 999 could not be located on the website, 4 practices had closed
- 903 Practices had an email address available & were contacted

FIGURE 29 RECRUITMENT PATHWAY

Firstly, the survey was distributed across the authors social media (Twitter) accounts, circulated via personal networks and the North Thames CRN.

It was also advertised via an article written by the authors for BJGP Life (Appendix 9). Lastly, using the NHS Digital List of all registered GP practices in the UK, 6000 GP surgery records were screened (entered on “find my GP”, link: https://www.nhs.uk/service-search/find-a-gp, which lists GPs surgeries email addresses) and those surgeries with email addresses were contacted, using the studies recruitment email template (reviewed and approved by UCL, Appendix 10).

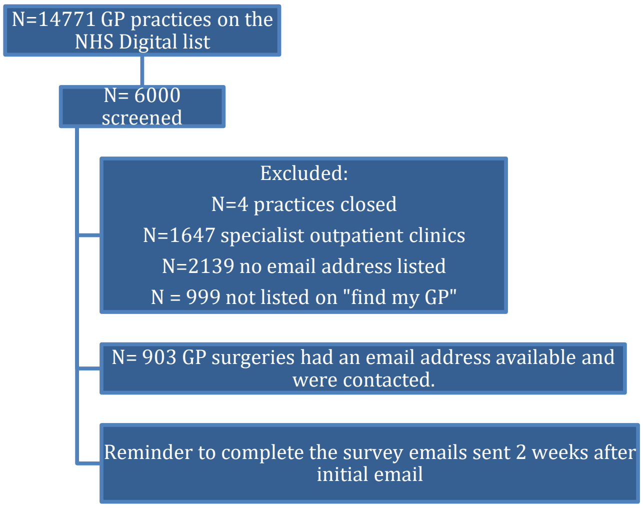


FIGURE 30 GPS CONTACTED

The list of GPs was downloaded on the 25th May 2021 and included 14,771 GP and specialist clinics (including dermatology for example) in England and Wales (Figure 30, https://digital.nhs.uk/services/organisation-data-service/data-downloads/gp-and-gp-practice-related-data). Within the recruitment period, 6000 of those records were screened. Due to time constraints, it was not possible to screen all 14,771 practices for email addresses. The screened records were randomised by postcode, to avoid bias by only screening certain postcodes (and therefore biasing the sample by location in the UK).

Four practices had since closed, N= 1,647 were specialist outpatient clinics (including dermatology and cardiology for example), N= 999 could not be located through the “Find a GP system”, N= 2,139 were listed but did not have an email address listed on the “Find a GP” section the NHS website, N= 903 had an email address listed, to which the recruitment email (Appendix 10) was sent between July and August 2021. Reminders were sent 2 weeks after the initial email.

2.5 Consent & Ethical Considerations

Participants were informed about the nature of the survey in the recruitment email and via the survey's landing page, which provided information about the aim of the survey, the type of questions being asked, data protection links, and corresponding author contact details, information regarding consent, how the data will be used and the ethical approval reference number.

The survey was designed to be anonymous due to potentially delicate questions regarding stigma against people with a diagnosis of schizophrenia or psychosis. Therefore, participants were advised that it may not be possible to withdraw their responses after completion of the survey, as it may not be possible to identify their response.

GPs consented to taking part by clicking "I consent to taking part in the survey" at the bottom of the landing page. GPs could only participate if this box was ticked.

2.6 Analysis

The quantitative analysis was completed using the Statistical Package for Social Sciences (SPSS, Version 25.0). The quantitative analysis included analysis of frequencies and descriptive statistics, and Pearson's Chi square tests were used to assess the relationship between categorical variables, such as demographic and clinical variables. The survey was analysed on a per question basis, and missing responses were excluded from the analysis.

Qualitative data, derived from the free test responses, were analysed using content analysis, as outlined in Erlingsson & Brysiewicz (2017): the free text responses were re-read multiple times to gain an understanding of the responses. Due to the short nature of free-text responses, categories, rather than themes, were formulated. Once categories were formed, LG compared those to the original text to ensure that the core meaning is retained, and that no information was missed. Categories were reviewed within the supervisory team.

3. Results

3.1 Sample size

In total, N=103 GPs consented to taking part in the survey, and N= 72 completed the minimum data set, comprising of demographic data and contact with secondary care services. N= 51 completed every applicable question in the survey. The sample size goal of N=382 was not achieved in the timeframe. The recruitment phase for the survey was disrupted by the COVID pandemic. The pandemic placed considerable burden on primary care services (due to redeployment of staff, staff illness and isolation, and the instrumental role of primary care in the vaccine roll out). This will have likely affected the sample size.

Due to the nature of recruitment (see 2.4), it is impossible to calculate a definitive response rate, as the survey was distributed online (social media and advertised in the BJGP Life) and through snow balling through professional contacts. Additionally, 903 emails were sent to GPs directly. Based on the timing of responses, approx. half of all responses were collected before the emails were sent out to GPs directly. Given that 903 emails were sent out and the total number of responses is 103 (half of which were collected before emails were sent), we can estimate that the response rate to emails is approx. 5.7% (N=51.5 responses gained from emails/N= 903 emails sent).

Data on the time taken to complete the survey was available for 34 participants (out of 51 GPs who completed the entire survey), captured automatically by the Opinio software. Apart from one outlier of 81 minutes, the remaining 33 GPs took on average 8 minutes to complete the survey (range 3-15 minutes). The aim to keep the survey to a maximum of 15 minutes was therefore met met. Please see Appendix 11 for the Opinio summary output report.

3.2 Demographics

The following section illustrates the demographics of the N=71 GPs who took part in the survey:

TABLE 9 PARTICIPANT DEMOGRAPHICS

Age	M =47.31 years (St.D. 9.86) Range 29-80 years
Gender	
Male	43.7% (N=31)
Female	54.9% (N=39)
Prefer not to say	1.4% (N=1)
Particular Interest in Mental Health (but not necessarily specialised?)	52.9% (N=37)
Yes	44.3% (N=31)
No	2.9% (N=2)
Other	
Urban or Rural GP practice?	
Urban	70.0% (N=49)
Rural	27.1% (N=19)
Other	2.9% (N=2)
How many patients registered at your practice?	1.4% (N=1)
0-3k patients	22.9% (N=16)
4-7k patients	31.4% (N=22)
8-11k patients	41.4% (N=29)
>11k patients	2.9% (N=2)
Other	
Length of time registered as a GP N=69	M= 14.33 years (St.D. 8.48) Range = 2-33years

* Total N=71* (unless specified otherwise)

Demographic data show a wide age range; GPs were 29-80 years old, with an average age of 47 years old. The sample is nearly evenly split between male and female participants (44% vs 55%). Out of all survey respondents, 44% reported having no special interest and the remaining 53% reported a special interest in mental health, and 3% selected "other".

Most practices were located in urban settings (70%). No formal definition of urban or rural was given, GPs were able to select which option they think applied to them most. The sample included practices of a range of sizes (defined by number of patients registered), with the majority of responding GPs working in practices with more than 11,000 registered patients (41%).

Urban practices were associated with higher numbers of patients registered to them (Table 10). Three practices reported being located in Rural settings but having more than 11000 patients registered.

TABLE 10 NO OF PATIENTS BY GP PRACTICE LOCATION

No of patients registered	Rural N	Urban N
0-3000	1	0
4000-7000	6	10
8000-11000	9	13
Over 11000	3	25

3.3 Research Question 1: Are GPs able to identify service users who are solely under primary care and are there practice specific guidelines for this population in place?

As the survey specifically concerns treatment and care of those patients no longer under secondary care, GPs were asked how easy it is for them to identify patients who are solely under their care. Out of 51 GPs, only one GP stated that it is clearly visible from patients notes if they are currently under secondary care or not. 42 GPs (82.3%) responded stating that they can only identify these patients if they check through their individual notes (e.g. checking discharge letters, checking ongoing notes, recent contact with secondary care team). Seven GPs (13.7%) stated that it was not even possible to identify primary care-only patients through those means.

Primary care only specific practice guidelines

Eighty-four percent of GPs (N= 42/51) reported that their practice did not have any specific guidance or agreement in place on how to conduct medication reviews with patients who are no longer under secondary care. Out of the GPs who stated that they have specific guidance in place (N= 7, 13.7%), they stated that guidance includes an agreement to review regularly (N=4), attendance of short courses on the topic (N=1), conducting basic checks (including bloods, blood pressure, height weight, N=4), ECG if appropriate (N=1), and assessing risk factors for cardiovascular disease (N=2). One GP noted that a yearly “Severe Illness Review” covers reviews for primary care only patients. This is however not specific to this group of patients.

However, one GP reported issues with yearly reviews and the patient record system: To enable GPs to complete the “severe illness review”, patients with schizophrenia and/or psychosis have to be added to an “SMI register” which triggers yearly review reminders. The GP highlighted that their system was not accurate and therefore impeded review: *“Many patients in my practice were on long term antipsychotics without a Read (Snomed) code for psychosis or* *schizophrenia. So, they were being missed from the severe mental illness register. I conducted an extensive audit and managed to code them all correctly. However, this shows how easily patients can be discharged and fail to be followed up properly."*

3.4. Research Question 2: What are GPs views on long term antipsychotic medication?

Thirty- eight GPs (74.5%) out of N=51 stated that they had concerns with long-term antipsychotic treatment, 12 GPs (23.5%) said they had no concerns. When asked about concerns, 37 GP respondents provided reasons in free text responses. Content analysis of these responses found:

Most GPs described concerns regarding adverse effects, including metabolic and cardiovascular side effects (N=22, 59.5%), as well as obesity and diabetes, atherosclerosis, dyskinesia, blunting of affect, reducing motivation, sedation, decreased quality of life and dementia. Some GPs felt they were not sure how long to continue medication for: "*May not be required long term. May be better to use to stabilise as an adjunct to other treatment. May need long term, but at a reduced dose than when in crisis."* This is important, as one GP wrote "*Often medication gets escalated in a crisis by psychiatrist and then patients are discharged without any advice about deprescribing"*, meaning that "*patients get stuck on medication that they might no longer need, or could take at a lower dose*" as another GP stated. Another GP responded with *"[it] feels very unclear in many cases if antipsychotics should be continued indefinitely. Often seem to be started in patients without schizophrenia or psychosis but more depression/personality disorder diagnoses and rationale/plan seems v* *vague."* In addition, GPs also cited a lack of secondary care support (n=6, 16.2%) required to manage long term antipsychotics: "*[…] secondary care start it then leave it up to primary care expecting that we can cope with crisis, side effects and long-term risks but won't be available to help the patient if needed."*

Using the free text options, GPs responded saying that deprescribing plans would be beneficial to help manage long term antipsychotic use: *"I think any antipsychotic prescription should come with a deprescribing/exit plan, and GP timely access to psychiatric advice/secondary care input when needed. Unfortunately, that is almost never in place!".* Another GP suggested a similar approach: "*[…] CMHTs [Community Mental Health Teams] should try and give a plan about stopping the meds if they see fit. I've never seen a letter from a CMHT where they have stopped any meds or advised when or how to.*" GPs were also worried about dependence on antipsychotic medication (N=2, 5.4%) and the stigma and institutionalization (N=2, 5.4%) associated with long term antipsychotic medication use.

3.5 Research Question 3 : Are primary care antipsychotic medication reviews happening, and if so, how comfortable are GPs in reviewing, reducing, and stopping antipsychotic medication (if this is indicated)?

Number and frequency of medication reviews in primary care (N=51)

GPs were asked how often they reviewed antipsychotic medication in primary care only. Several answer options were given, GPs could choose as many as were applicable. Most GPs reported that they review antipsychotic medication during the yearly physical health review (N=35, 68.6%). Five GPs (9.8%)

stated that they never review, as this is beyond their remit (despite the patient being under primary care only). Eleven GPs (21.6%) review only when this is requested by the patient. Twelve GPs (23.5%) would review only when patients present with significant side effects or contraindications, 10 GPs (19.6%) report that they review medication at every consultation, 6 GPs (11.76%) report that they rarely review, and 1 GP (1.96%) said “other”.

One GP highlighted: “*Annual SMI reviews are now part of QOF from April 21 onwards. This involves a comprehensive mental and physical health review, blood test and medication review using a template. Mostly medication is left unchanged if no side effects. Referral back to secondary care if side effects.”*

When asked if any of the reviews in the last 12 months resulted in antipsychotic medication changes, on average, 11.7% (St.d. = 20.29) of appointments for people diagnosed with schizophrenia or psychosis reportedly resulted in a change. Participants’ responses indicated that between 0% to 100% of consultations resulted in a change (Figure 31).

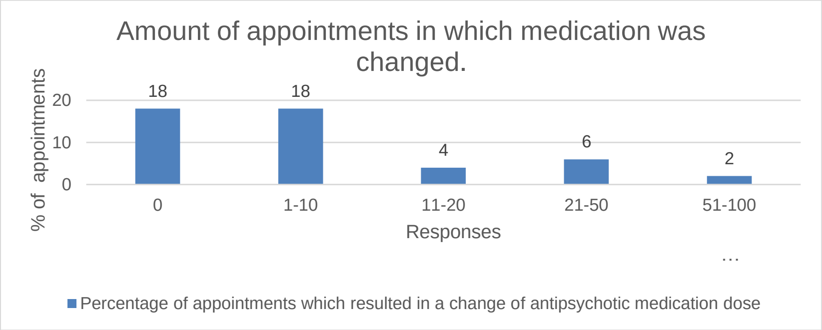


Figure 31 Percentage of appointments which resulted in a change of antipsychotic medication

Out of the 48 GPs who answered this question, a large proportion of GPs (N=18, 37.5%) stated that they had not changed antipsychotic medication dose in any appointments with people diagnosed with schizophrenia or psychosis the last 12months.

Secondary care support for medication reviews

Secondary care support may help GPs to review medications. When asked how much support GPs had available, 47.5% (N=32) out of 70 GPs stated that they had no access to secondary care support (unless they referred the patient back). 22.9% (N=16) stated that they had support of a primary care mental health team (PCMH) team and/or psychiatrist located at their practice, 21.4% (N=15) stated that they had access to an advice line or email address, 10.0% (N=7) reported that they had easy access to the patient's named psychiatrist and 8.6% (N=6) said other. Other included GP liaison meetings, referrals, and ad hoc responses from psychiatrists. 2.9% (N=2) said they did not know if they had any access available to them.

GPs were then asked if they had asked for advice with changing antipsychotics as part of a proactive review (rather than acute relapse) in the last year, 57.1% (N=40/70) said yes, 29 GPs (41.4%) said "no" and 1 GP said, "cannot recall".

Out of those who said yes, GPs stated that they contacted psychiatrists on average 5.6 times (St.D. 8.29, Range 1-45 times) in the last year.

Reviewing antipsychotic medication (N=51)

GPs were presented with a case study scenario; they were asked how they would feel about reviewing medication for a patient who is stable, on long term antipsychotic medication, with no recent risk history, and no longer seen by a secondary care psychiatrist. 47.1% (N =24) of GPs said that they did not feel comfortable reviewing the patient's antipsychotic medication. 45.1% (N=23) said they felt comfortable, and 7.84% (N=4) said they were very comfortable.

GPs who selected "not comfortable" to review antipsychotics were asked to list their reasons why. GPs could select as many options as were appropriate (see Figure 32).

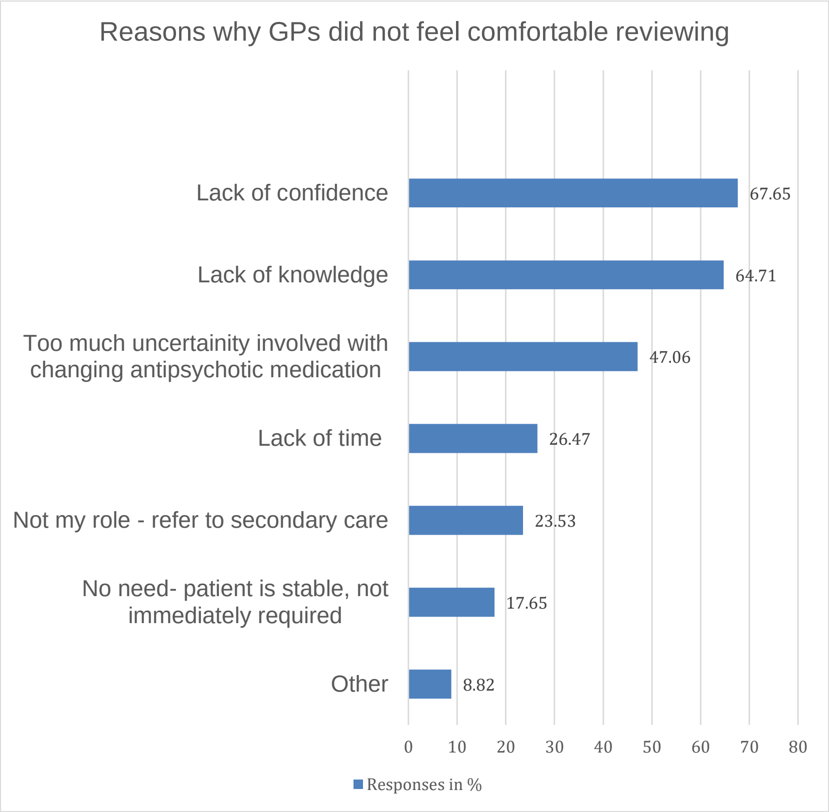


FIGURE 32 REASONS WHY GPS DID NOT FEEL COMFORTABLE REVIEWING ANTIPSYCHOTIC MEDICATION

Based on the survey responses, it appears that a lack of knowledge and confidence were the main barriers to reviewing medication (67.7% and 64.7%

or N=23 and N=22). Interestingly, 47.1% (N=16) reported that they were not comfortable to review as changing medication is associated with a lot of uncertainty. Some listed that reviews are not required as the patient is stable (17.7%, N=6) and that it is beyond their remit (23.5%, N=8). One GP wrote that it is "*difficult in 10 min time frame to explore with a mentally ill patient who cannot see the wood for the trees and may refuse all medications anyway*."

Reducing antipsychotic medication in primary care (N=51)

In the case study scenario, GPs were then asked if they felt comfortable reducing antipsychotic medication (imagining that they had reviewed the medication and felt that a reduction was appropriate). 49.0% (N=25) stated that they did not feel comfortable reducing medication, 43.1% (N=22) felt comfortable, and 5.9% (N=3) felt very comfortable and one GP said that this was not applicable. One GP commented, stating *"This is very interesting. I have been a GP a very long time. I don't think I have considered that it is my role to reduce/stop anti-psychotics. I usually discuss it if the patient brings it up. I would only reduce if the patient and carers agree good idea and monitor carefully. unfortunately, I have had a few relapsed patients but maybe that is a price worth paying."*

Stopping antipsychotics in primary care (N=51)

In the case study scenario, GPs were then asked how comfortable they felt stopping the antipsychotic medication, assuming the reduction went well (e.g. no recurrence of psychotic symptoms). 64.7% (N=33) of GPs did not feel comfortable stopping the medication and 31.4% (N=16) felt comfortable. One GP felt very comfortable, and one GP stated not applicable.

3.6 Research Question 4: Refine the CMOCS identified in the realist review relating to barriers and facilitators to reviewing medication.

The Realist Review (Chapter 1) identified five barriers and a range of facilitators to antipsychotic medication reviews in primary care (for a summary see 1. Introduction, this Chapter). The survey was designed to test and refine the CMOCS identified in the review.

Barrier 1: Low expectations regarding recovery from mental illness

In the survey, 44% (N=22) of 50 GPs either agreed or strongly agreed with the statement that "GPs have low expectations regarding the recovery of patients diagnosed with schizophrenia/psychosis". 30% (N=15) ticked "neither agree nor disagree", and 20% (N=10) stated they disagreed, and 6% (N=3) that they strongly disagreed.

However, GPs were also asked whether they themselves felt hopeless (meaning they felt that there was nothing else they can do) regarding the treatment and recovery for patients diagnosed with schizophrenia/psychosis. 20% (N=10) either agreed strongly or agreed with this statement, and 16% (N=8) stated that they neither agreed nor disagreed. 64% stated that they either disagreed or strongly disagreed with the statement, meaning they did not feel hopeless.

The hopelessness question was followed up by the question of whether those GPs, who felt hopeless, would communicate this with their patients. Out of those GPs who reported feeling hopeless (N=20), 8 GPs stated that they would communicate this with service users, 10 GPs stated that they would not communicate this and one GP stated that they would contact secondary care if they felt hopeless.

Barrier 2: Perceived lack of patients' capabilities to participate in medication reviews

Lack of capacity (N=51)

GPs were asked whether they agreed or disagreed with the statement "most patients diagnosed with psychosis or schizophrenia lack capacity or insight regarding their treatment."

60% (n=30) of GPs stated that they either disagreed or strongly disagreed with the statement that patients in primary care have capacity or insight regarding their treatment. 32% (N=16) selected "neither agree nor disagree", and only 8% (N=4) stated that they agreed or strongly agreed with the statement, meaning that service users lacked capacity and insight.

Communication difficulties (N=51)

49.0% (N=25) reported that they experienced communication difficulties with people with schizophrenia and/or psychosis. 47.1% (N=24) reported that they had no communication difficulties, and 3.9% (N=2) reported "Other": one participant wrote, *"a minority [of patients]"* and another stated *"sometimes when acutely unwell, not at other times"*

GPs were also asked if they experienced communication difficulties when discussing antipsychotic medication. 34% (N=17) selected either "agree" or “agree strongly”, 26% (N=13) selected neither agree nor disagree, and 40% (N=20) selected “disagree” or “disagree strongly”.

Reasons for communication difficulties (N=23)

GPs were asked in an open text question to describe any communication difficulties experienced. A content analysis of responses found the following:

GPs reported communication difficulties especially when service users were unwell (N=9) and fewer when the service user was well and stable.

Communication difficulties increased where there was also a language barrier (N=3), a learning difficulties diagnosis (N=2) and increased psychotic symptoms (N=2). GPs reported that they felt that some service users struggled to express themselves (N=4), and one of them felt that they had to repeat what they had said across consultations (N=1).

Additional barriers were described; these include lack of insight (N=4) and poor compliance (N=1). Three GPs felt that service users sometimes don’t engage with services (N=3) and/or are difficult to contact (N=2); *“they can ignore phone calls and letters, sometimes they sofa surf.”,* as one GP described. A lack of therapeutic relationship can also affect communication, one GP reports *“trust issues”*, another “*a lack of rapport*” as barriers. Two GPs report “*aggressive, abusive and violent”* consultations as a barrier, a lack of time (N=1; “*Also there is very little we can do in a 10-minute appointment with other patients waiting”*), and difficulties getting hold of secondary as barriers to effective communication. One GP felt that supported accommodation staff and carers were very good at supporting communication, another GP felt that family wasn’t always able to fulfil that role; family difficulties can be a barrier to good communication.

Pressure on GPs (N=50)

A potential confounding factor is the pressure GPs may feel to ensure adherence of antipsychotic treatment. GPs were asked whether they agreed or disagreed with the following statement: “There is pressure on GPs to ensure adherence of antipsychotics in order to prevent relapse.” 68% (N=34) either agreed or strongly agreed with the statement that there is pressure on GPs to ensure medication adherence to prevent relapse, 26% (N=13) stated that they neither agreed nor disagreed, and only 6% (N=3) disagreed. None of the GPs strongly disagreed.

GPs also report an overall pressure on services: “*There has been a continual increase in mental health services discharging patients with all diagnoses and increasing expectation that GPs can, somehow, provide the same input as mental health services. For example, urgent telephone appointments for patients who are expressing suicidal thoughts/deterioration of psychotic symptoms - there is nothing I can do as GP in a 10 minute appointment other than signpost to crisis line/call 999 - which would have been better done at the point the patient/relative(it is usually relatives that make this type of call) makes contact ie at reception/triage stage, rather than wait for a call back in 4-6 hours. We do not have the capacity in GP to deal with complex mental health issues/crises.”*

Barrier 3: Lack of information sharing between GPs and patients

Lack of engagement with yearly physical health reviews due to a lack of information sharing (N=50)

One GP reported “*Patients who suffers psychoses do present a challenge. As they have high DNA rates, are less engaging, may have periods of non-*

compliance. Very often carers, relatives, support workers, medication management teams and local pharmacies are recruited to repeat messages about blood tests, medication monitoring and reviews as well as physical health checks."

When asked whether GPs agreed with the statement "A lack of information about the nature of antipsychotic medication, meant that patients do not see the importance of physical health checks and potentially do not attend yearly physical health reviews", 82% (N=41 out of N=50) of GPs either strongly agreed or agreed. 12% (N=6) neither agreed nor disagreed, 6% (N=3) disagreed, none of the GPs strongly disagreed.

Additionally, 70% of GPs (N=35) agreed or strongly agreed with the statement that patients would discontinue their medication if they experienced side effects that they had not been made of aware before. 24% (N=12) neither agreed nor disagreed, 6% (N=3) disagreed, and none of the GPs strongly disagreed.

Side effect information sharing

GPs were then asked how often they discussed side effects in consultations. Out of 51 GPs, 49.0% (N=25) reported that they discuss side effects "sometimes", 23.5% (N=12) stated that they discussed them often, 19.6% (N=10) stated that they discussed them rarely and 7.8% (N=4) said they never discuss them.

GPs were then asked to indicate why they do not discuss side effects with services users. GPs could select as many options as they felt applicable (see Figure 33).

FIGURE 33 REASONS WHY SIDE EFFECTS ARE NOT REGULARLY DISCUSSED

The most cited reason was a lack of time (50.0% of responders, N=16). 31.3% (N=10) reported that they are worried that the patient will stop their medication if they list all side effects, and 9.4% (N=3) worried about the effect on the therapeutic relationship should they discuss side effects. 31.3% (N=10) stated that they do not know all side effects of antipsychotic medication.

18.8% (N=6) of GPs felt that it was beyond their remit to discuss side effects, and 15.6% (N=5) felt that since they did not initiate the initial prescription, it is not their role to discuss side effects. One GP added *“I rarely review antipsychotics – side effects normally discussed at initiation. I would normally ask about them generally rather than specifically”.* Only 6.25% (N=2) report that other health care professionals, including pharmacists and nurses discuss side effects: *“pharmacists would do it”* as one GP commented. 9.4% (N=3) felt that the leaflet would provide information, meaning that a discussion is only required if the patient has questions. However, one GP stated, “*will discuss side effects if patient mentions it and also if I see them (e.g., TD)”.*

One GP added *“If a patient has been stable on a medication for a long time WITHOUT side effects, then I would probably only discuss the possibility of long-term side effects and ask them to contact us if they feel a symptom they have could be related to their long term”.*

Barrier 4: Perceived risk of service users

Risk in consultations (N=51)

GPs were asked whether they ever felt at risk or apprehensive in consultations with people who had a diagnosis of schizophrenia and/or psychosis. N=29 (57%) of GPs stated that they did not feel at risk and N=22 (43%) said they felt at risk or apprehensive.

This was followed up by a question asking those GPs who felt at risk, whether they felt that this has changed their practice: N=20 (57.1%) said it had not changed their practice, N=8 (22.9%) said maybe, and N= 4 (11.4%) said it had changed their practice. N=3 (8.6%) said “other”.

GPs were then asked how their practice had changed (GPs could tick all that applied to them):

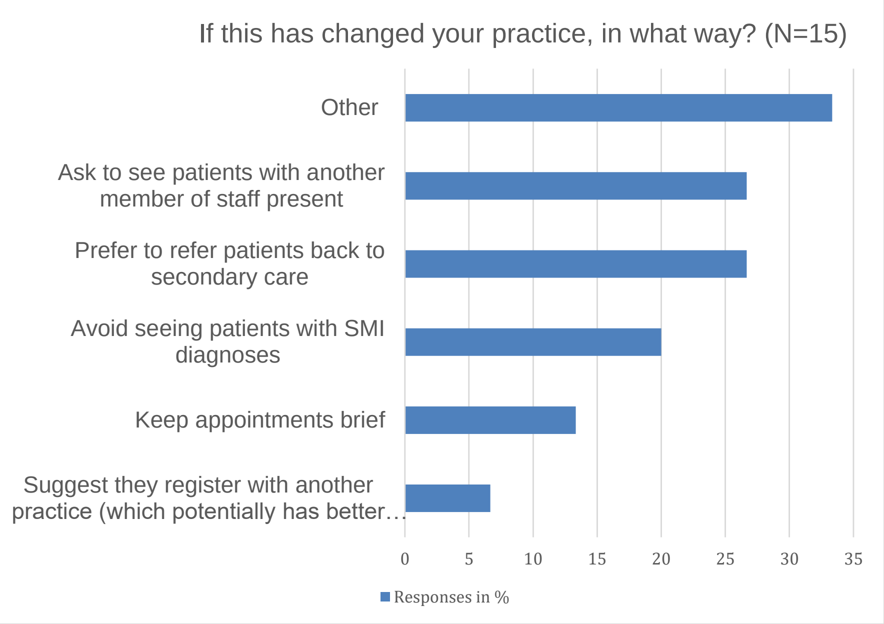


FIGURE 34 WAYS IN WHICH RISK CHANGED PRACTICE

Most GPs ticked “other” and added their own text responses. Two GPs stated that they use panic buttons, ensure the patient/GP had an escape route and making other staff aware that they are in a potentially risky consultation. Another GP stated that they would prepare by ensuring that the patients risk assessment was up to date.

Four GPs (26.7%) stated that they would ask another staff member to join if they felt apprehensive as illustrated by this answer in the text box: *“[..] get another (second) clinical to attend if situation gets out of hand”.* Four GPs

(26.7%) would prefer to refer the patient back to secondary care, N=3 (20.0%) stated that they avoid seeing people with SMI diagnoses and two GPs (13.3%) keep appointments brief. One GP stated that they would suggest for the patient to register with another practice (one that potentially has better links with secondary care and/or offers more specialist help).

Barrier 5: Uncertainty regarding medication and illness trajectory

The literature in the realist review (Chapter 1) identified that stable patients, who have been on long term antipsychotic medication, with little risk and potentially concerning metabolic side effects may be most at risk of staying on antipsychotic medication unnecessarily. To adequately illustrate and enquire about this, GPs were presented with a case study (Figure 35) to focus on medication reviews in primary care, for those patients no longer under secondary care services:

CASE STUDY

Please answer the following questions based on this case example:

A 50-year-old married patient attends your practice for her yearly physical health check. She was diagnosed with schizophrenia at

19, and remains on 15mg Olanzapine. She has 2 inpatient admissions in 1989 and 1991 but has remained stable since and shows no residual symptoms. She was discharged from the local mental health team (secondary care) 7 years ago. She rarely attends the

practice. She presents with high BMI, pre-diabetic. No risk events since her last admission in 1991.

FIGURE 35 CASE STUDY

When asked if GPs would review and consider changing the dose of Olanzapine (antipsychotic medication), 44.2% (N=23) responded with “Yes” and 48.1% (N=25) with “No”. 7.7% (N=4) responded with “other” – two GPs stated that they would be happy to reduce but contact secondary care first to discuss, and one GP stated that they would review, but be reluctant to reduce if the patient was stable.

GPs, who stated that they would not want to reduce the above listed antipsychotic medication gave the following reasons for their decision (GPs could select as many answer options as applied; see Figure 36):

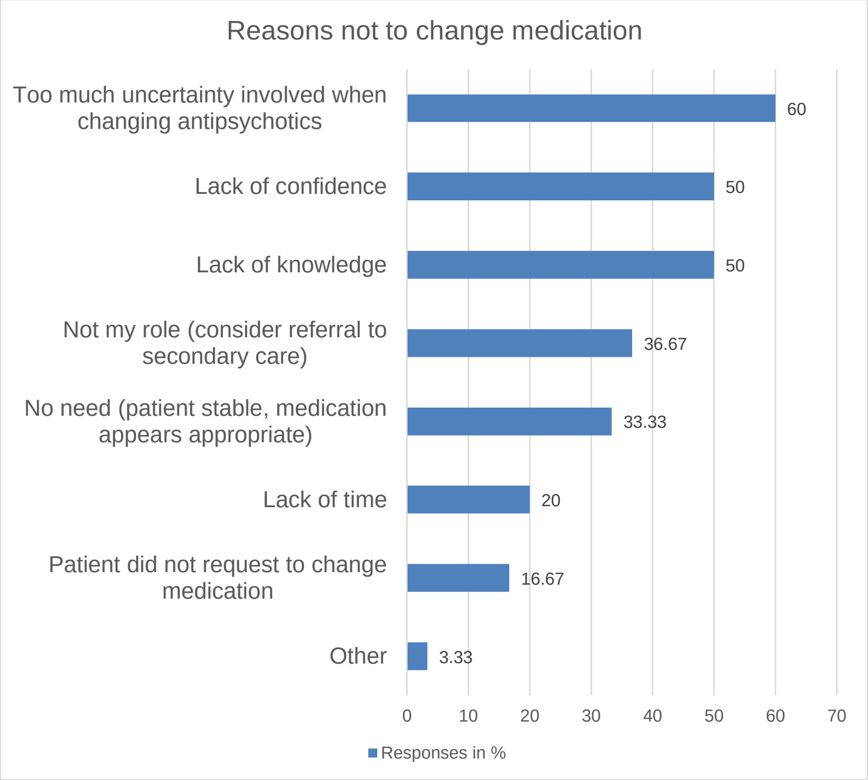


FIGURE 36 REASONS NOT TO CHANGE MEDICATION

The most endorsed reason for not changing medication in the survey was the uncertainty involved in changing antipsychotics (60.0%, N=18), followed closely by a lack of confidence and lack of knowledge (50.0% or N=15 respectively) on how to change antipsychotic medication, as illustrated by this quote: *"GP is left to it, but I have minimal training in this. My senior colleagues in primary care have more knowledge and provide some support."*

36.7% (N=11) felt that changing antipsychotic medication was not part of their remit. 20.0% (N=6) felt that there was not enough time in appointments to reduce medication. 16.7% (N=5) highlight that the patient did not ask for a medication change and would therefore not change it.

In the free text boxes, GPs reported concerns due to the uncertainty associated with relapses and lack of guidance on prescribing. One GP said: "*Dose changing is very risky and the blame the clinician system that is in place if a medical error happens is a strong deterrent to change antipsychotics especially if the patient is not known to you",* another GP wrote *"If, after a long time stable on a certain medication, changes occur and a patient becomes unstable, it is worrying to know what could be the trigger and what the medication should then be changed to, particularly because when they occur the change is often sudden and can be dramatic. So, it is a rush to try and find a solution and help for a patient who may be unstable in the community, and we do not have the ability to get them under the care of a specialist quickly."*
When considering medication changes, GPs also described difficulties with deprescribing (n=3), as there is a lack of guidance and secondary care support available:

"[…] lack of guidance/support from secondary care to appropriately risk assess and reduce. Often medication gets escalated in a crisis by psychiatrist and

then patients are discharged without any advice about deprescribing." This is paired with a concern that *"patients get stuck on medication that they might no longer need, or could take at a lower dose",* with others highlighting that less medication may be needed outside of crisis, or only used as a stabilizer in crisis and that alternatives should be made available, including therapeutic support.

Reasons why GPs felt uncomfortable reviewing antipsychotics in general

Aside from the case study, GPs who reported feeling uncomfortable reviewing antipsychotic medications for primary care only patients were asked why they felt uncomfortable. Lack of knowledge and confidence (64.7%/N=22 and 67.7%/N=23 respectively) were the most listed reason, followed by 47.1% (N=16) of GP respondents who felt that there was too much uncertainty associated with changing medication. 26.5% (N=9) of GP respondents felt that there was a lack of time to review, 23.5% (N=8) felt it was beyond their remit to review (and should refer to secondary care), and 17.7% (N=6) felt that there was no immediate need to review patients who are stable. 8.8% (N=3) GPs selected "other".

Reasons why GPs felt uncomfortable reducing antipsychotics in general

In addition, GPs were asked why they felt uncomfortable reducing antipsychotics. GPs reported a variety of reasons which made them uncomfortable to reduce antipsychotics (Figure 37). GPs could select as many options as were deemed appropriate. The most cited reasons were a fear of relapse (86.1%, N=31), closely followed by a lack of secondary care support in case any issues arise (61.1%, N=22) and concerns over risk of patient to self or others should medication be reduced (52.8%, N=19).

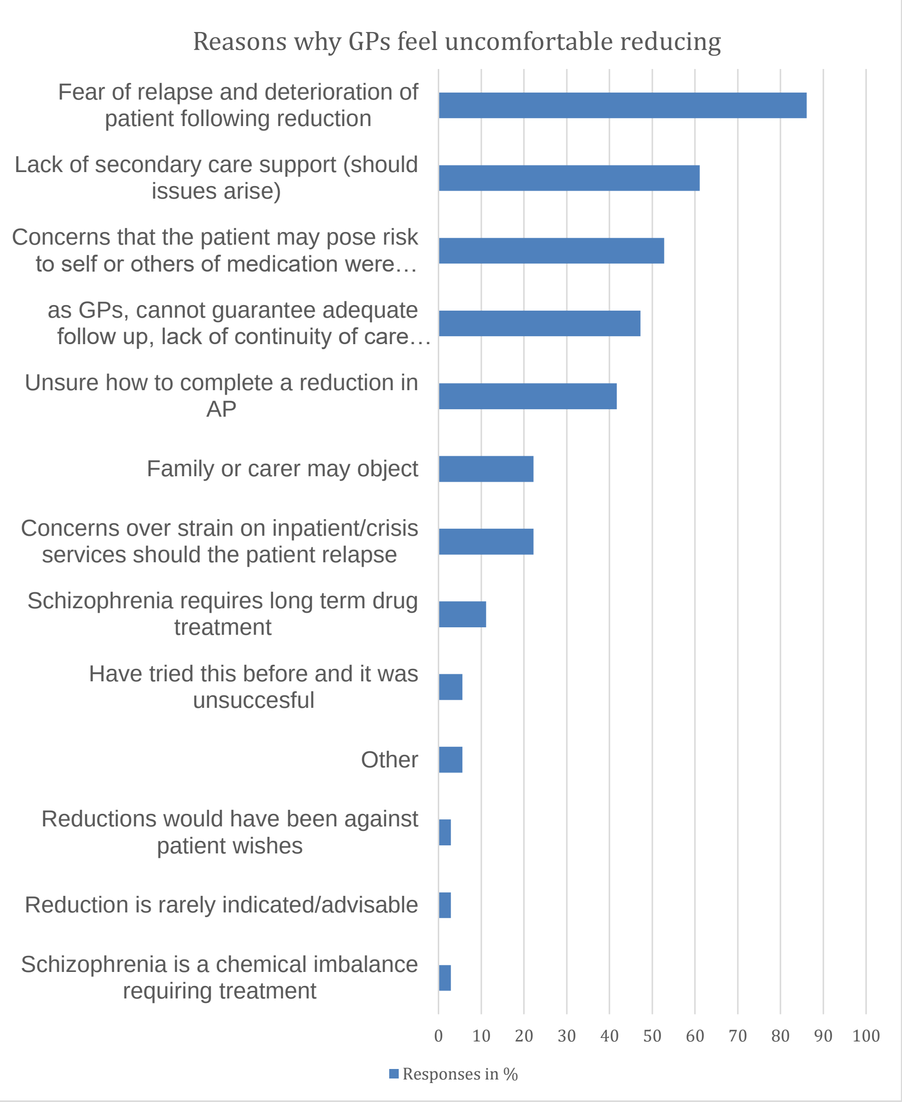


FIGURE 37 REASONS WHY GPS FEEL UNCOMFORTABLE REDUCING ANTIPSYCHOTIC MEDICATION

One GP felt that schizophrenia was a chemical imbalance and required treatment and one felt that reductions are rarely indicated, and 11.1% (N=4) of GPs felt schizophrenia needed long term drug treatment and should therefore not be reduced.

Forty-two percent (N=15) also felt that they did not know how to reduce medication and 22.2% (N=8) felt that the patient's family or carer may object to a reduction. Only one GP felt that reduction would be against patient wishes, indicating that most patients would be interested in reviewing or reducing their medication. One GP stated that "*I would feel comfortable doing this if advised by psychiatry with guidance."* One GP stated that issues arising from changing medication is a barrier to reducing medication, as clinicians are blamed for errors. GPs who did not feel comfortable stopping antipsychotics were asked to indicate their reasons for why (Figure 38). GPs could select as many of the answer options as they felt were appropriate.

Reasons why GPs felt uncomfortable stopping antipsychotic medication

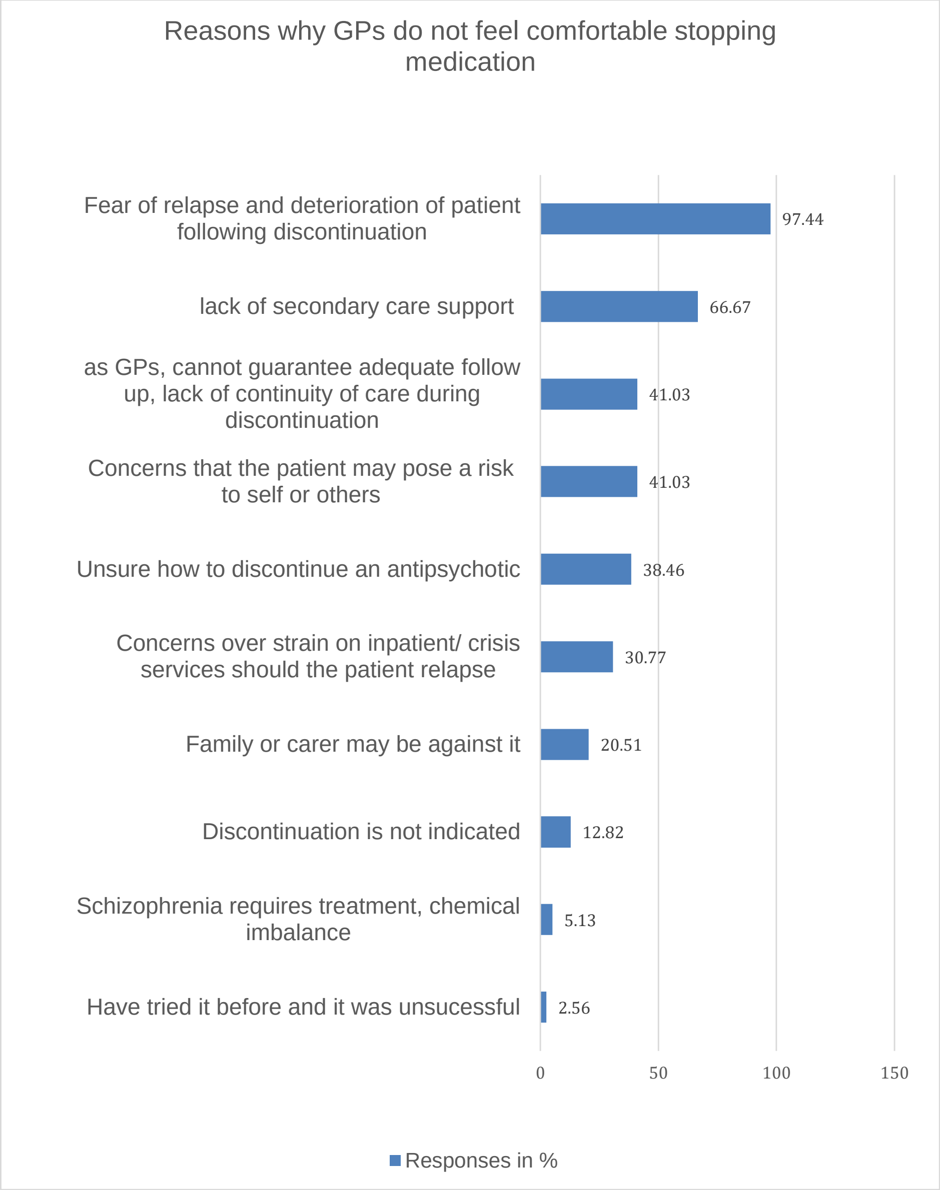


FIGURE 38 REASONS WHY GPS FELT UNCOMFORTABLE STOPPING ANTIPSYCHOTIC MEDICATION

97.4% (N=38) of GPs listed a fear of relapse as the reason why they would not discontinue antipsychotic medication, despite a successful reduction of medication, without re-occurrence of psychotic symptoms.

Lack of secondary care support and lack of continuity of care in primary care were also cited by many (66.7%/N=26 and 41.0%/N=16 respectively). 41.0% (N=16) of GPs also felt that, should medication be discontinued, service users may pose a risk to themselves or others.

38.5% (N=15) reported that they did not know how to discontinue an antipsychotic. 20.5% (N= 8) felt that the service user’s family or carers might be against a discontinuation.

One GP wrote “*Secondary care are very slow to respond when we ask for help. I have only tried to admit 2 patients to hospital acutely in the past 20years or so (and have asked for lots of urgent OP reviews) but with the 2 patients it took about 3 hours of negotiating with the secondary care team and they seemed reluctant to admit but on both occasions the patient was an inpatient for 6-7 months so clearly my requests were justified*”, another said that “*Difficult when CMHT says they have nothing to offer but the patient is not coping and all concerns from neighbours etc come to GP.”* Another GP highlights “*appropriate support from secondary care and appropriate training. That there is a severe lack of follow up in secondary care”.*

Relationship between access to secondary care support and level of comfort in reviewing and reducing medication

Further analysis to understand whether access to secondary care was related to GPs views found that access to secondary care support (whether it be via a PCMH team, an advice line or access to the patients named psychiatrist), was not associated with level of comfort at reviewing (p=0.16, OR= .429, 0.13-1.41 95% CI) and reducing antipsychotic medication (X^2 =1.47, p=0.23, OR= 0.484, 0.148-1.578 95% CI).

Having a special interest was also not related to how comfortable GPs felt reducing antipsychotic medication (X^2=2.833, p=.243).

Out of those GPs who did not feel comfortable to review, N= 14/24 (58%) said that they had contacted a psychiatrist in the previous three years to ask for advice on medication changes, and N= 10/24 (42%) did not contact a psychiatrist.

This illustrates that some of the GPs who were uncomfortable, did not seek additional advice from secondary care, and there was no difference in level of comfort between those GPs who had secondary care contact available and those who did not.

Facilitators to antipsychotic medications reviews.

Lastly, GPs were asked to endorse a list of potential facilitators in medication reviews.

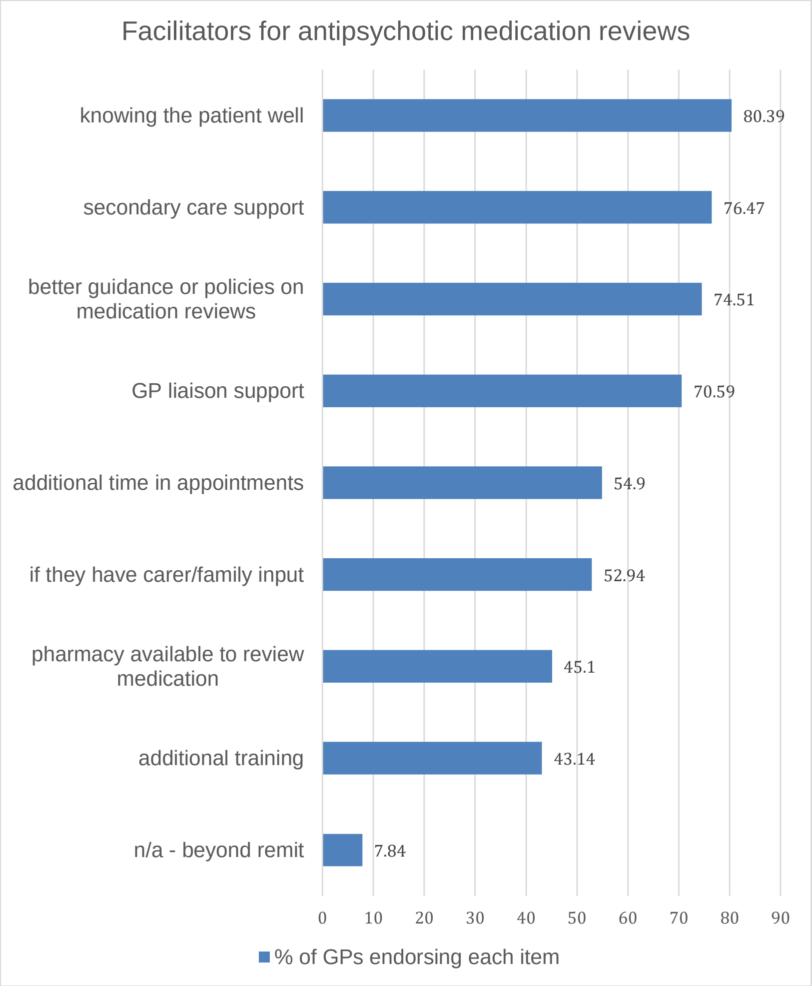


FIGURE 39 FACILITATORS FOR MEDICATION REVIEWS

The most cited reason was knowing the patient well (N=41, 80.4%). This was closely followed by having secondary care support (N=39, 74.47%), GP liaison support (N= 36, 70.59%) and having better guidance or policies for medication reviews (N=38, 74.51%). Twenty-seven GPs (52.9%) would like family or carer input to support, 43% (N=22) said that they would find additional training helpful. Twenty-eight GPs (54.9%) would find more time for appointments beneficial, and 23 GPs (45%) would consider pharmacy support helpful. 7.84% (n=4) GPs felt that this question did not apply to them as antipsychotic medication reviews were beyond their remit as GPs.

One GP mentioned the health improvement workers' scheme: "*Health improvement workers (HIWs) were recently appointed by the local NHS. Their role was supposed to be to engage patients in primary care with severe mental illness in their physical and mental health checks. However, they have been working mostly in secondary care outpatient clinics. This is an example of how the NHS cynically creates posts and takes funding but spends it in secondary care. The money was supposed to re-engage SMI patients in primary care and prevent their non-engagement with their physical and mental health."*

Discussion

Main results

The survey aimed to answer four research questions:

1) Are GPs able to identify participants who are solely under primary care and are there practice specific guidelines in place?
2) What are GPs views on long term antipsychotic medication?
3) Are primary care antipsychotic medication reviews happening, and if so, how comfortable are GPs in reviewing, reducing, and stopping antipsychotic medication (if this is indicated?).
4) Further test and refine the hypotheses identified in the realist review in Chapter 1 relating to barriers and facilitators to reviewing medication.

Identifying primary care only patients and practice guidelines

There are no national guidelines in place specifically for people who have been discharged from primary care, leaving it to individual GP practices to develop guidelines. It is crucial that guidelines are developed, given the need to review medication regularly (as outlined in Chapter 1). There is a risk that primary care service users are not reviewed adequately without appropriate guidelines, as they will no longer be reviewed by secondary care. The community mental health framework does not offer further guidance and is vague in regard to care of those who are no longer under secondary care (NHSE, 2019). Most GPs in the survey reported that their practice did not have any specific guidance or agreement in place on how to conduct medication reviews with patients who are no longer under secondary care. It is also very difficult for GPs to identify them in their caseload: the survey showed that only one out of 51 GPs could readily identify who had been discharged from secondary. This has clear treatment implications; people may not receive adequate support and reviews if there are not identifiable.

Views on long term antipsychotics, reviewing, reducing, and stopping

The majority of GPs stated that they had concerns about long-term antipsychotic treatment, and most GPs review medication at the yearly health check, which is not defined in detail and therefore likely varies in depth of the review. Five GPs stated that they do not review antipsychotic medication at all. The survey showed that nearly half of all surveyed GPs did not feel comfortable to review antipsychotic medication, half of the GPs stated that they did not feel comfortable reducing it and over two thirds of GPs did not feel comfortable stopping the medication (even if the reduction had gone well).

The reasons appear to be a lack of secondary support, uncertainty regarding the possible consequences of reducing medication for the person, and a lack of knowledge and confidence. GPs state that secondary care support would help, as well as better guidance and knowing the patient. Knowing the patient may reduce the uncertainty and shares the responsibility associated with medication reviews and reductions. Less than half of surveyed GPs think that more training would help, despite lack of knowledge and confidence being frequently endorsed as a reason why GPs feel uncomfortable (see above). Secondary care support in the form of GP liaison and guidance on reviewing and reducing might be a viable solution.

Although GPs report access to secondary care services in the form of Primary care mental health teams or advice lines, the sense of abandonment from secondary care comes through throughout the responses: GPs report increasing numbers of secondary care discharges, and a lack of exit plans on what to do with antipsychotic medication long term. This is paired with many concerns regarding long-term prescribing and subsequent effects on people's health. This survey did not find an association between access to secondary care and how comfortable the GPs felt reviewing or reducing antipsychotic medication. It is therefore important to look at the quality of secondary care support, and ease of access, rather than the quantity of contacts. Many also feel that they do not have any access at all. There is variability in the capacity of secondary care mental health teams, and some may not accept a referral from a GP for a stable patient, who has been on long term antipsychotics, "just" to review the medication and change it, if appropriate. Reducing the rigid referral process to secondary care and increasing supported shared learning between GPs and primary care embedded mental health professionals may also be a way forward (as discussed in the Kings Fund, 2020).

Although there are understandable concerns that a reduction or discontinuation of antipsychotic medication may lead to a relapse; there is also a risk that many stable patients, who are on long term antipsychotic medication, may get stuck on their current dose indefinitely. Service users who want to reduce and/or may need to reduce due to health concerns, must be able to try a reduction. The issue is clearly not just on reducing medication, even reviewing medication appears to be something that some GPs feel is not part of their remit, and/or they may not be comfortable to do so. Given the health concerns associated with long term antipsychotic medication use, this issue warrants urgent attention.

Refinement of CMOCs

The survey also added further data to the CMOCs identified as part of the realist review. This allows further refinement of the proposed theories.

Regarding the low expectations regarding recovery, the survey added that nearly half of all surveyed GPs reported that they had low expectations regarding recovery; one third of GPs neither agreed nor disagreed. Schizophrenia used to be seen as a progressive brain disease (Zipursky, Reilly & Murray, 2013), which may explain this finding. This is in line with Magliano et al (2019) discussion that "viewing schizophrenia as mainly due to a biological cause is associated with greater confidence in drugs, higher conviction of needing lifelong pharmacological treatment and prognostic pessimism" (p.7).

The third of GPs who neither agreed nor disagreed may represent GPs who feel that there are some of their patients who they feel this for, but not all. Just under a third of surveyed GPs disagreed with having low expectations. GPs did not report that they felt hopeless often, and out of those who did, only very small proportion would communicate their hopelessness to patients.

Regarding the lack of capabilities CMOC, only 4 GPs felt that their patients lacked capacity. One third of GPs also reported communication difficulties, and a further 25% reported that they neither agreed nor disagreed with having communication difficulties. This may again show that GPs feel that it does not apply to all patients, but potentially some of them. Fewer communication difficulties were reported for those patients who were stable and well at time of consultation.

Sixty-eight percent of GPs also either agreed that there is pressure on GPs to ensure medication adherence to prevent relapse, only 6% (n=3) disagreed.

This will clearly influence GPs priorities in consultations and may reduce Shared Decision Making.

With regards to the information sharing CMOC, 82% of GPs agreed that patients may not attend yearly physical health checks due to a lack of information given about antipsychotics and the need for regular monitoring. Some GPs report that many health care workers and carers may remind patients, but that they are still difficult to engage. Increased information sharing about the rationale of regular checks may increase engagement.

Increased information sharing may also be needed in the area of side effects. 27.4% of GPs report that they either rarely or never discuss side effects with patients, largely due to a lack of time, but also due to concerns that this may impact the therapeutic relationship or that service users may stop the medication if they knew all of them. This is understandable, given the pressure GPs feel that they are under to ensure medication adherence. Informing service users should still remain a priority however, and as the realist review illustrates, not informing service users of side effects can actually have the opposite effect and lead to medication discontinuation (once service users experience side effects, they were not aware of). The survey confirmed this hypothesis, most GPs agreed that service users would stop medication if they were not adequately informed about side effects ahead of experiencing them.

The two theories in the realist review with the fewest amount of evidence were: 1) perceived risk and 2) uncertainty regarding medication and illness trajectory following medication discontinuation.

The survey found that about half of GPs felt apprehensive or at risk in consultations. Most GPs felt that this did not change their practice, 22.9% said maybe, and 11.4% said it had changed their practice. For those, whose practice has changed, this has included adding panic alarms, letting other staff members know when they felt at risk, 26.7% would prefer to refer the patient back to secondary care, 20.0% stated that they avoid seeing people with SMI diagnoses and 13.3% keep appointments brief. To the authors knowledge, this topic is rarely discussed in the literature but evidently has important considerations for consultations.

Lastly, the survey has confirmed a lack of knowledge and confidence is the biggest barrier to reviewing medication, and that the feeling of uncertainty associated with changing antipsychotic medications and the fear of relapse is a barrier to reducing and stopping medication for nearly all GPs. Most GPs ticked more than 1 option in the multiple-choice questions, this shows that this is not a straightforward issue, and that many factors play a role. This includes lack of secondary care support, family and carer influence, availability of inpatient beds, worries about risk of the patient to themselves and others and a lack of guidelines.

GPs were therefore also asked about facilitators or ways to overcome the barriers listed. Overall, it appears that GPs feel a sense of abandonment and uncertainty. Facilitators need to be put in place to overcome these barriers. Knowing the patient well was the most endorsed facilitator by GPs, closely followed by secondary care support and appropriate guidance on reviewing and reducing antipsychotic medication. Additional training was endorsed by 43% of GPs, and 45% felt that pharmacists could help with medication reviews. GPs also highlighted the need for “exit” or deprescribing plans, to help them reduce or stop antipsychotics, which were initially prescribed in crisis.

As described above, GPs also sometimes experience communication difficulties and may feel apprehensive or at risk in consultations. Addressing these difficulties may also result in higher rates of in-depth medication reviews.

Comparison with the literature

There are many surveys on GPs' knowledge of antipsychotic prescribing (Magliano et al., 2017; Toews et al., 1996; Verdoux et al., 2006). To the authors knowledge, this is the first survey which specifically focuses on stable, primary care only patients and the first to focus on GPs views of reviewing and reducing antipsychotic medication. Previous surveys focus on the awareness of guidelines, including recommended length of antipsychotic prescribing and the avoidance of polypharmacy, but rarely discuss the execution of these guidelines, including finding the "lowest dose" and reducing medication, where appropriate.

Previous literature has also highlighted the communication difficulties between primary and secondary care (Hampson, 1996). Given that GPs are largely relying on discharge letters and communication with the secondary care team to identify which of their patients have been discharged, this raises concerns. Clearer ways of identifying primary care only caseloads are urgently needed, potentially through better data infrastructure and data linkage of electronic health records.

Recent research has identified safer ways to reduce antipsychotics(Horowitz et al., 2021). Given that GPs report that they do not know how to reduce, or feel uncomfortable when doing so, it is important that guidelines on the topic of reducing and stopping antipsychotics, withdrawal effects, decision tools outlining risks and benefits of medication, and effective communication between primary and secondary care are developed and implemented in in primary care also. This may increase confidence and levels of comfort and ease some concerns regarding relapses associated with reducing mediation.

Another important implication is the lack of information sharing identified in the survey. Research has shown that people with a diagnosis of psychosis have a reduced life expectancy, and that many do not have regular blood tests, or their BMI recorded (Crawford et al., 2014). GPs in this survey reported that they consider a lack of information sharing regarding the possible adverse effects of antipsychotics to be the reason why service users may not see the need for physical health reviews. A lack of information sharing regarding side effects, reason for antipsychotic prescription and need for regular monitoring is well documented (as discussed in Chapters 1 and 2). GPs responses in this survey appear to mirror this, including discussion of side effects. Some GPs will only discuss them when the patient asks for it. Shared Decision Making and genuine informed consent are key NHS constitution recommendations, and only possible if all information is shared. Service users may not feel able to enquire about side effects or rationale for their prescriptions, out of fears of being seen as “non-compliant” or sectioned as a result (Maidment et al., 2011, Morant, 2016). It is therefore important that GPs proactively share information with service users to ensure that service users trust their clinicians and feel able to discuss their concerns openly. Most GPs in this survey (70%) agreed that service users may discontinue their medication if they are not adequately informed about side effects, leading to the opposite effect as intended.

Strengths and weaknesses

The survey failed to reach its target recruitment sample and therefore should be interpreted with caution. Despite recruitment in the middle of a pandemic, a total of 103 GPs consented to taking part, 72 GPs completed the minimum data set, and 51 GPs completed all questions. However, demographic data collected show the recruited sample is relatively diverse, including age, practices size, gender and specialist interest. GPs with a special interest in mental health could bias the results due to potentially increased knowledge or awareness of the issue, therefore it is important to assess this percentage in the sample. Given that the survey recruited a similar number of GPs with and without special interest, it is likely that the findings are more generalisable. It is not possible to determine how responders differed from non-responders in the survey, which is a possible bias and must be considered when interpreting the results.

The survey benefits from involvement of a range of stakeholders in the iterative design process and is based on an extensive literature review (Chapter 2). It was also piloted and found to be acceptable. For multiple choice questions, all answer options were at least selected once, illustrating that the proposed answer options were relevant to GPs.

To the authors knowledge, this is also one of the first realist-based surveys (introduced by Schoonenboom, 2017). It is now common practice to interview stakeholders to refine CMOCs (Manzano, 2016), but fewer chose to complete a realist survey. Rather than conducting time intensive interviews, the survey enhances generalisability. The extensive literature review (Chapter 2 – Realist Review) and feedback informed survey development process also gives further strength to the questions asked as part of the survey. The survey questions are embedded within the literature and illustrate theorised statements. Much like realist interviews, putting these hypotheses to GPs allows researchers to infer a stronger sense of causality (Manzano,2016), than potentially other surveys are able to. The survey data will be used to triangulate the CMOCs identified in the realist review and contribute to the final programme theory (outlined in Chapter 5). It has been a useful method to explore this under-researched area. Further research, potentially in the form of interviews, could enhance this even further.

The use of “strongly agree – strongly disagree” response format could have been improved on. A large proportion of GPs reported “neither agree nor disagree”; this could mean that GPs are not sure, or it could mean that they either agree or disagree with statements in different contexts. Clearer phrased questions may have been able to elicit better answers.

Responders also opened up about feeling at risk in consultations, and feeling uncomfortable in reviewing, which may not have been possible in in person interviews. Completing an anonymous survey appears to have been an appropriate methodology. It is still possible that some questions were affected by social desirability bias, including questions on passing on feelings of hopelessness to service users.

Despite the survey only taking 8 minutes on average to complete, a large volume of data was collected, helping to further test and refine the theories identified in the realist review. Due to the low sample size, future research is still required to replicate the findings identified here.

Due to the lack of definition of what constitutes an adequate medication review, it is also possible that survey participants had different understandings of medication reviews and thus responded differently. Levels of comfort may depend on levels of knowledge of medication reviews and how each GP defines a medication review. It is possible that a Dunning – Kruger effect can be observed; more competent “medication reviewers” may report higher levels of discomfort due to knowing more about medication reviews. More in-depth studies on medication reviews are required to fully understand the amount and content of medication reviews. Future research should address this.

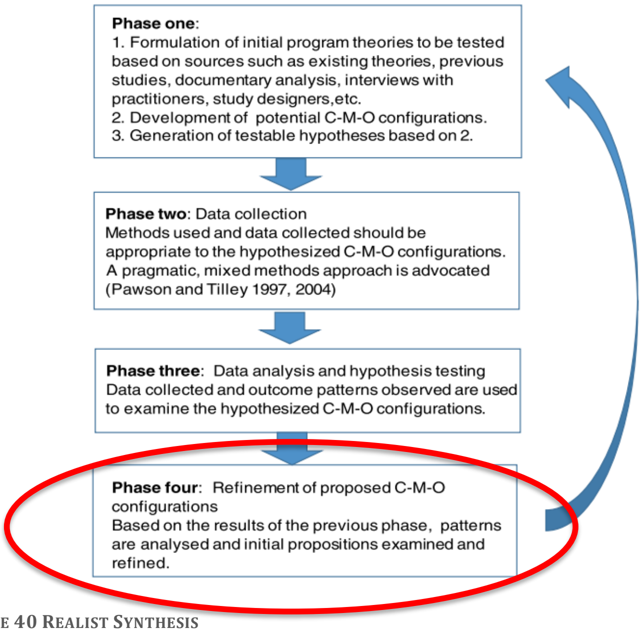
Conclusion

The survey highlights key points of consideration when discussing antipsychotic medication reviews in primary care. GPs clearly outline their concerns with long term antipsychotic medication, but approx. half of them report not feeling comfortable to review or reduce medication. Only a third of GPs report that they would be willing to support the discontinuation of antipsychotics, even if the reduction had gone successfully. The consequences of long-term antipsychotics on people’s health and lack of guidance around reducing and stopping medication where appropriate, risking service users potentially being left on unnecessary antipsychotic medication indefinitely, requires urgent attention.

GPs require further support from secondary care and better guidance to increase their knowledge and confidence, which may result in increased medication reviews in primary care. Future research should address this.

Chapter 5: Data synthesis

The following chapter describes the results of the data synthesis of the realist review, the SU interviews, and the GP survey. The process followed the principles outlined in detail in Chapter 1 and 2, which were informed by Pawson & Tilley (2006) and the RAMESES guidelines (Wong et al., 2013). AS introduced in Chapter 1,the process can be summarised as describe in Figure 40 (taken from Slater & Kothari, 2014). Phase one was completed in Chapter 2, Chapter 3 and 4 outline the data collection aspect of this realist informed synthesis. Phase 3, hypothesis testing, was completely iteratively and throughout. The red circle highlights the purpose of this Chapter: Phase four, refinement of the proposed CMOCs.



Phase one:
1. Formulation of initial program theories to be tested based on sources such as existing theories, previous studies, documentary analysis, interviews with practitioners, study designers,etc.
2. Development of potential C-M-O configurations.
3. Generation of testable hypotheses based on 2.

Phase two: Data collection
Methods used and data collected should be appropriate to the hypothesized C-M-O configurations. A pragmatic, mixed methods approach is advocated (Pawson and Tilley 1997, 2004)

Phase three: Data analysis and hypothesis testing
Data collected and outcome patterns observed are used to examine the hypothesized C-M-O configurations.

Phase four: Refinement of proposed C-M-O configurations
Based on the results of the previous phase, patterns are analysed and initial propositions examined and refined.

FIGURE 40 REALIST SYNTHESIS

CMOCs and the programme theory were tested and refined iteratively throughout the PhD, as described in the chapters throughout. It included juxtaposing, reconciling, adjudicating and consolidating the data. The results of the iterative refinement process are outlined in this chapter.

This chapter will also discuss the influence of substantive theory and how this supports the final programme theory. To illustrate how the CMOCs have changed since the Realist review (Chapter 2), the following section will list each of the five CMOCs and outline how these were refined. Where the collected data (SU interviews and GP survey) strengthened the findings from the realist review, these are highlighted in green, where they showed mixed evidence, this is highlighted in orange, where it found contradictory evidence or refuted a theory, this is highlighted in red. Where new information was added to the CMOC based on the additional primary data collected, this is highlighted in purple (see Table 11).

TABLE 11 COLOUR CODES FOR REFINED CMOCS

New Data supports C, M or Os identified in the realist review
New Data shows mixed evidence for C,M, or O identified in the realist review
New Data contradicts evidence found in the realist review
New C, M or O added to existing CMOC
No new data collected or added

Alternative theories, or rival theories, are also outlined. As outlined in Pawson (2006), even if a pattern, or demi-regularity, is only observed once, this still indicates that there is value in the CMOC and can be seen as a “nugget” to further guide theorising. Therefore, if additional evidence was mixed, the C, M or O were not automatically dismissed, but both possibilities outlined.

1.1. CMOC1 Low expectations regarding recovery from mental illness

1.1.1. GP view

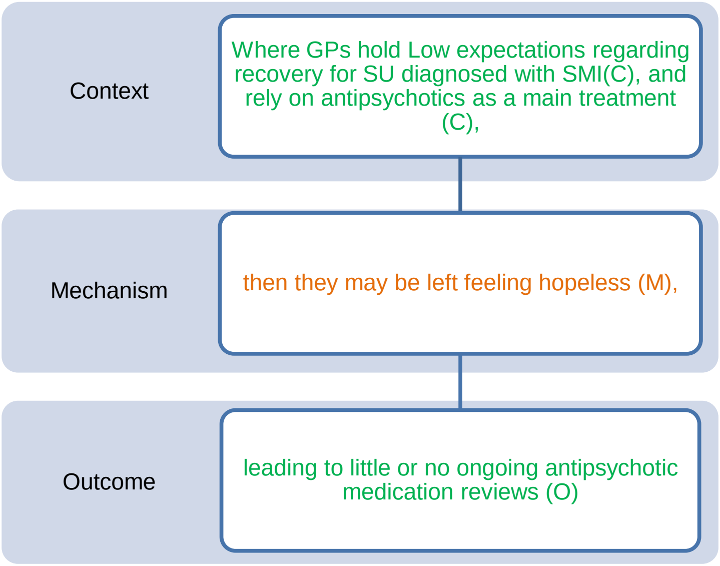


FIGURE 41 CMOC1 - GP VIEW

The GP survey confirmed that 44% of the sample have low expectations regarding the recovery of SMI patients. Whereas the literature identified in the realist review strongly suggests feelings of hopelessness (in parts described as “therapeutic nihilism”), the majority of GPs (64%) in the survey disagreed with feeling hopeless (defined as “meaning there was nothing else left to do for SU”). Hopelessness is a possible demi-regularity, in that some GPs feel hopeless, and others do not. Implications of this have to be explored further.

The GP survey also indicated that many do not review medication regularly. Thus, if GPs did not feel hopeless, and felt there was more they could do, it is unclear what drives the lack of medication reviews instead. It is of course possible that the question was not phrased or understood properly. Due to methodological constraints of using an online survey, it was not possible to ask GPs what they felt instead of hopelessness. The question may also have been impacted by social desirability bias (as discussed in Chapter 4). Overall, the GP survey supports the Context and Outcome in this CMOC, however the mechanism in this CMOC requires further testing.

1.1.2. Service User View

Out of those GPs who did feel hopeless, 40% stated that they would communicate their feelings of hopelessness with Service Users, supporting the to the Service User View below:

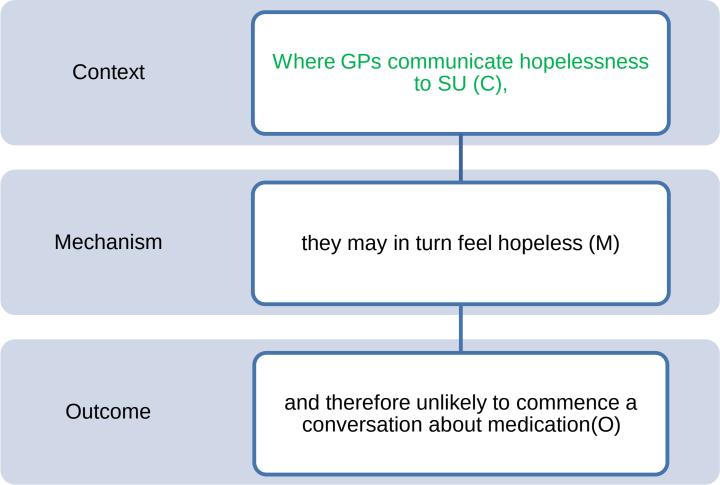


FIGURE 42 CMOC1 - SERVICE USER VIEW

As the SU interviews are a secondary analysis of already existing data, Service users were not questioned regarding hopelessness in the interviews. It was thus not possible to refine this CMOC further.

2. CMOC2 Perceived lack of capability to participate in medication reviews

The additional data collection for CMOC2 now offers two possible mechanisms from the GP view, which may affect medication reviews in the context of a perceived lack of capability. They are presented here:

2.1. GP view

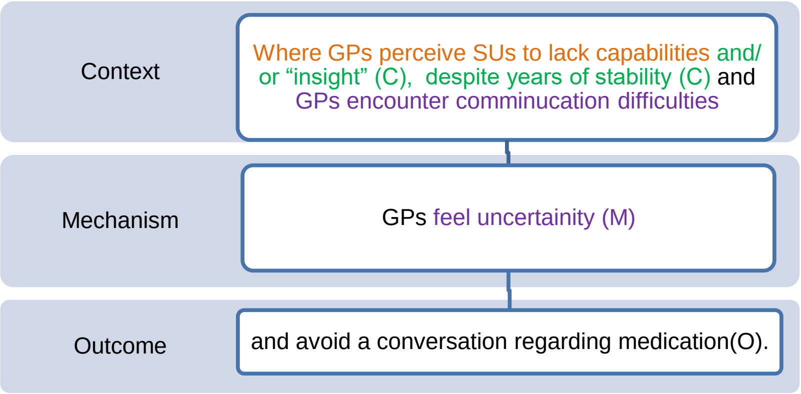


FIGURE 43 CMOC2.1 –GP VIEW- UNCERTAINTY LEADING TO AVOIDANCE

CMOC 2.1b – Paternalism leading to lack of discussion around medication.

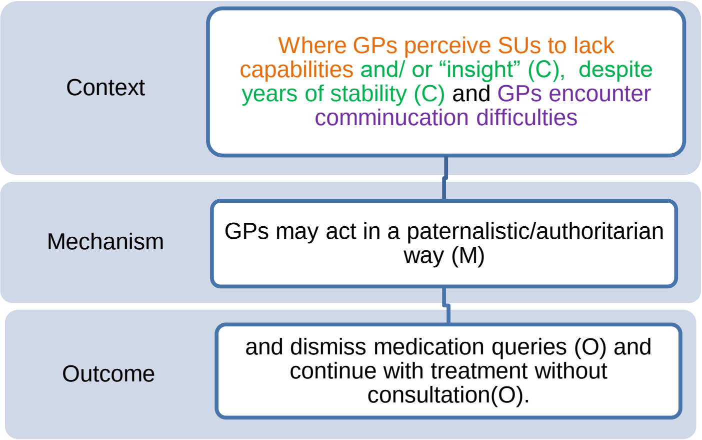


FIGURE 44 CMOC 2.1B – PATERNALISM LEADING TO LACK OF DISCUSSION AROUND MEDICATION.

The realist review and GP survey also highlighted other relevant contexts (Figure 45) *:

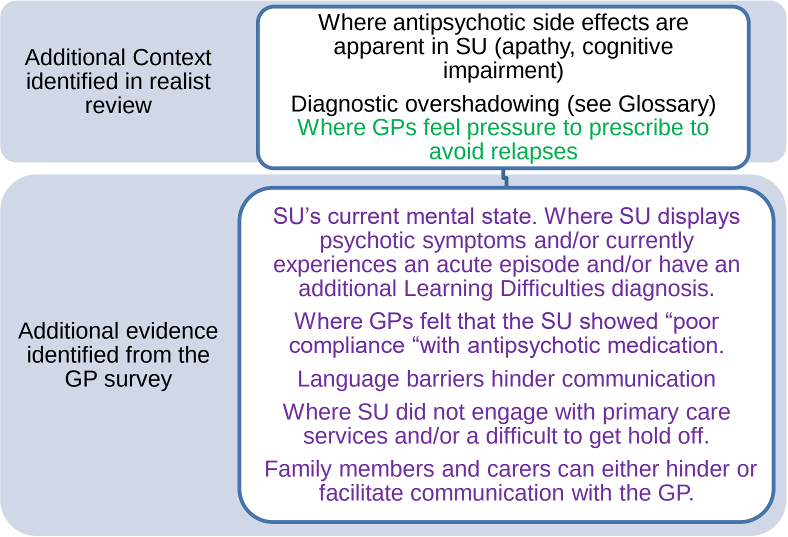


FIGURE 45 CMOC2 ADDITIONAL CONTEXT

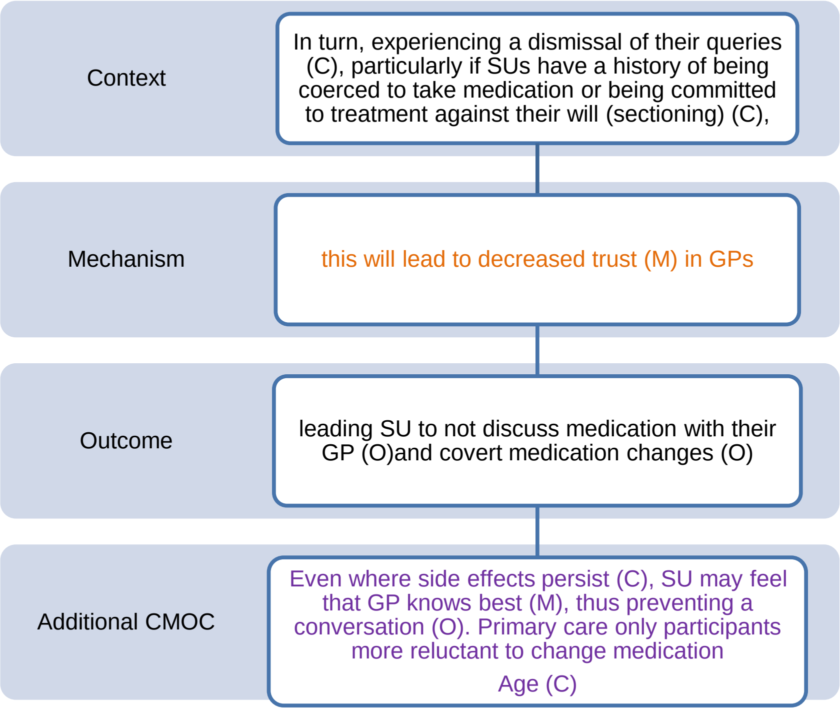
* (black= from realist review with no new data, green = realist review data supported by GP survey, purple = data identified as part of the GP survey.)

The GP survey identified mixed evidence with regards to Service Users lacking insight, with 60%(N=30) GPs stating that they disagreed with the statement that *“most patients diagnosed with psychosis or schizophrenia lack capacity or insight regarding their treatment”.* Half of the GPs however reported communication difficulties with service users, although largely during acute episodes. Some report communication difficulties, specifically with rationale and dosage for antipsychotic medication. This may play a role in this CMOC; therefore this has been added (in purple). When discussing communication difficulties, GPs also listed psychotic symptoms, language barriers and a learning difficulty diagnosis as additional barriers. GPs also felt that a lack of insight, poor compliance with antipsychotic medication, and/or lack of SU engagement added to their communication difficulties. Some GPs felt that a lack of secondary care support and lack of time were additional barriers. Family members and carers were described as either helpful in facilitating communication or were an additional barrier to effective communication. These factors have been added to the CMOC (in purple).

These additional factors may thus make GPs feel more out of control (lack of engagement, difficult communication, increased symptoms, and lack of secondary care support), which may give GPs the feeling that it is their responsibility to manage care. Especially where lack of engagement and possible factors around mental state give the impression that the SU themselves cannot participate meaningfully in conversations. This may lead to increased paternalism and a more one-way conversation, led by GPs, in consultations. A lack of time may mean that GPs cannot spend time to establish to which degree SU can participate meaningfully in conversations. This addition to the CMOC is theorised based on the additional evidence from the GP survey but was not formally tested as part of the PhD.

The GP survey highlighted that GPs felt pressure to prescribe to avoid relapses (68% of GPs endorsed this statement in the survey), thus adding further information to the CMOC. GPs were not specifically asked regarding the levels of paternalism displayed in consultations and dismissal of queries in the survey.

2.2 CMOC 2 – Lack of capabilities - Service User view



In turn, experiencing a dismissal of their queries (C), particularly if SUs have a history of being coerced to take medication or being committed to treatment against their will (sectioning) (C),

this will lead to decreased trust (M) in GPs

leading SU to not discuss medication with their GP (O)and covert medication changes (O)

Even where side effects persist (C), SU may feel that GP knows best (M), thus preventing a conversation (O). Primary care only participants more reluctant to change medication

Age (C)

Figure 46 4.2 **CMOC 2 – Lack of capabilities - Service User view**

A second CMOC has been identified based on the Service user interviews. SU reported being content with their antipsychotics, despite most reporting severe side effects. A fear of relapse was also reported by most; 19 out of 21 (90%) service users of the sample felt that there were some positive effects from the medication (not necessarily with psychotic symptoms, but general wellbeing) and about half of the participants reported that it was their role to take medication and that “the doctor knows best”. A study identified in the Realist Review highlighted that service users above the age of fifty-five tended to prefer that their doctor made treatment decisions (Lester et al., 2005). Whether this is a true choice is unclear (as discussed in Ponyer, 2008).

Following the “doctor knows best” may however demonstrate a level of trust in their clinician. People in primary care are likely older and more likely to be in employment than people with the same diagnosis in secondary care; the interviews highlighted that primary care SU may therefore have more at stake, should they relapse, particularly if they have been stable for a long time. The original CMOC, based on literature, found more dissatisfaction with medication than the SU interviews did, and outlined lack of trust leading to covert medication changes. It is possible that both CMOCs in this area are of merit, but show different mechanisms and outcomes depending on context:

Context 1 could represent the original CMOC, with SU who are more dissatisfied with their medication, and potentially younger and a second Context could represent SU who are more satisfied and potentially older, as seen in the service user interviews.

The original CMOC is also based on literature, which was largely taken from secondary care literature and literature on the experience of taking antipsychotic medication, which may also have attracted service users who are dissatisfied with their medication more and is thus open to a level of bias.

An alternative explanation is that the SU in our interviews did not wish to disclose their dissatisfaction with the medication or were not aware of the risks associated with medication or the increased literature on the importance of regular reviewing and reducing, to facilitate better health outcomes. SU were not specifically asked about their experience of previous coercion, their levels of trust or covert dissatisfaction. Thus, this section is inferred based on the data available. The simplest explanation may be that compared to those in secondary care, primary care SU either

A) experience better outcomes from the medication (many positive factors of medication listed),
B) and/or represent a population which is more "stable" or at lower risk of relapse (derived from the fact that they are in primary care)
C) have more at stake (older age meaning SU are more fearful of relapsing, and higher rates of employment).

It is thus likely that SU are more reluctant to change their medication, and may thus not avoid conversations with their clinician, but rather just not seek them out/ feel like they are required. Further research is required to refine this CMOC.

3. CMOC3 Lack of information sharing between GPs and Service Users

The next section illustrates how CMOC 3 has been refined; firstly, from a GP (Figure 47) and then from a service user perspective (Figure 48).

3.1 CMOC 3 Information regarding antipsychotic side effects – GP view

Context	Where GPs are aware of side effects (C),
Mechanism	they may fear or worry (M)
Outcome	that SU will discontinue their medication (O) and feel it is in the SUs interest (M) to not share more information regarding side effects (O) or worry that this may impact their therapeutic relationship (M).
Additional Information	1) Effects may be increased where the GP has a lack of time 2) This CMOC may not be applicable to those GPs who do not feel that discussing side effects is part of their remit.

FIGURE 47 CMOC 3 – INFORMATION REGARDING ANTIPSYCHOTIC SIDE EFFECTS – GP VIEW

In the GP survey, 70% (N=35) of GPs agreed with the statement that patients would discontinue their medication if they experienced side effects that they had not been made aware of previously. Forty-nine (N=25) percent of GPs reported discussing side effects “sometimes” and 8% (N=4) stated that they never discussed them. The most endorsed reason for not discussing side effects were a lack of time (50% of GPs), 31.3% were worried that the SU would stop their medication if they discussed side effects, and 9.4% felt that discussing side effects would strain their relationship. 31% stated that they did not know all the side effects, and 20% of responders felt that discussing side effects was beyond their remit. The CMOC was thus updated to reflect these findings:

The GP survey highlighted that some GPs felt that it was not within their remit to discuss it, others felt that since the prescription was not initiated by them (but by another GP or even secondary care), they would not discuss side effects. Some GPs felt that the information leaflet or pharmacists would provide sufficient information. Regardless of why GPs did not discuss side effects, it is thus likely that Service Users are not sufficiently informed. This is supported by findings of the realist review.

3.2. CMOC 3 - Service user view regarding information about side effects

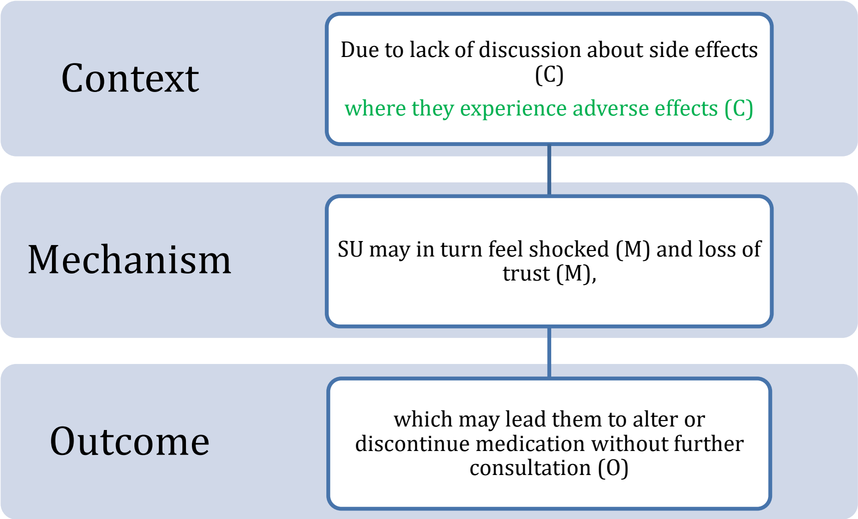


Figure 48 CMOC 3 - Service user view regarding information about side effects

Further context:

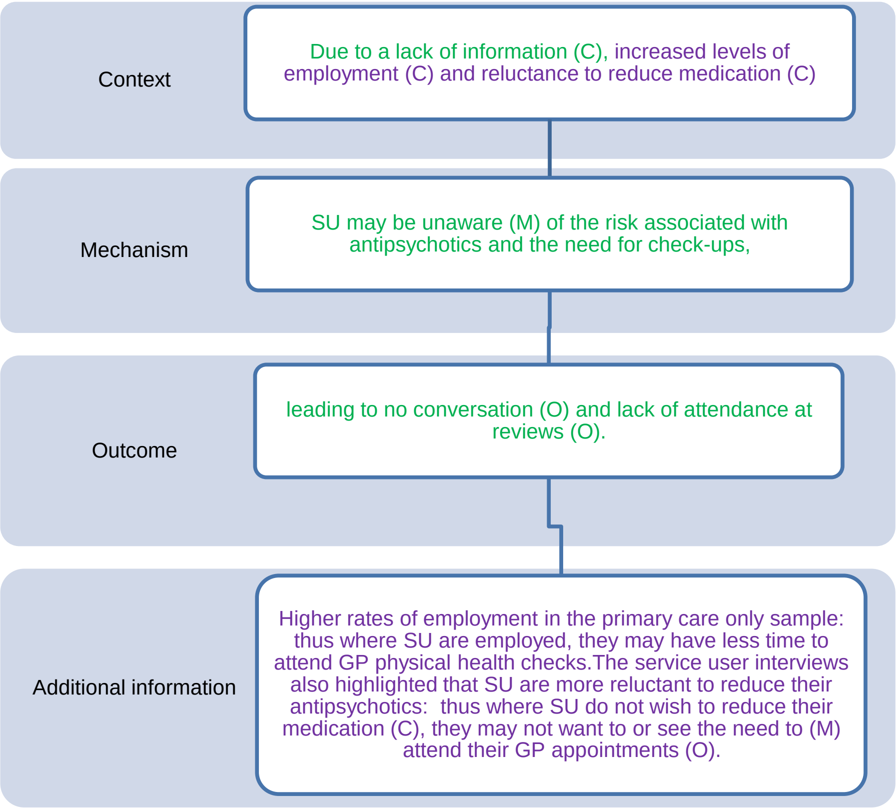
Distrust (M) is potentially amplified when SU access information elsewhere (C), like the internet, and realise that those are potentially common adverse effects.

Although most service users who were interviewed reported experiencing adverse effects, they were not further questioned on their experience of having adverse effects, thus it was not possible to refine this part of the CMOC further.

3.3 GP and Service User View regarding information about antipsychotic medication in general

Whereas this is an important question to ask service users, this was equally important to ask GPs to allow for increased empathy and understanding how their behaviour may affect service users, to potentially create a change in working practices. One GP reported that people with an SMI diagnosis usually present with high DNA rates, periods of "noncompliance" and having to repeat messages about physical health appointments. Eighty-two percent of GPs felt that "*A lack of information about the nature of antipsychotic medication, meant that patients do not see the importance of physical health checks and potentially do not attend yearly physical health reviews*". Whereas this question was only asked of GPs and not of service users, the available evidence supports this CMOC. In addition to the original CMOC, further C, M and Os were identified:

Chapter 3 showed higher rates of employment in the primary care only sample: thus, where SU are employed, they may have less time to attend GP physical health checks. The service user interviews also highlighted that SU are more reluctant to reduce their antipsychotics. Thus, where SU do not wish to reduce their medication (C), they may not want to or see the need to (M) attend their GP appointments (O).



Context

Due to a lack of information (C), increased levels of employment (C) and reluctance to reduce medication (C)

Mechanism

SU may be unaware (M) of the risk associated with antipsychotics and the need for check-ups,

Outcome

leading to no conversation (O) and lack of attendance at reviews (O).

Additional information

Higher rates of employment in the primary care only sample: thus where SU are employed, they may have less time to attend GP physical health checks.The service user interviews also highlighted that SU are more reluctant to reduce their antipsychotics: thus where SU do not wish to reduce their medication (C), they may not want to or see the need to (M) attend their GP appointments (O).

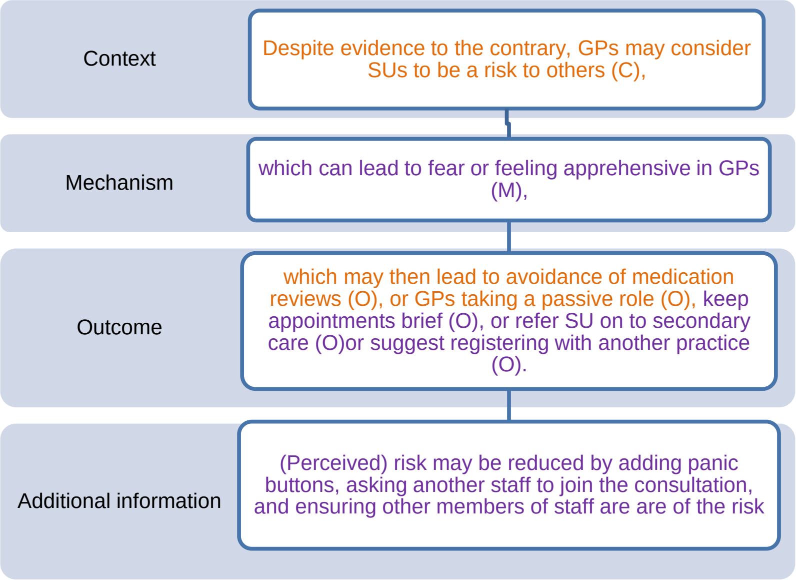
Figure 49 CMOC3B SU and GP view

4. CMOC4 Perceived risk of Service Users

4.1 GP view

The realist review did not identify much evidence on this topic; therefore, this CMOC was heavily featured in the GP survey. Forty-three percent of GPs reported feeling apprehensive or at risk in consultations. Out of those who felt at risk, 57% stated that they had not changed their practice as a result, while 23% stated that they may have changed their practice, and 9% said ‘other’.

For those who changed their practice (N=15) they either did so by asking another member of staff to be present (N=4), to refer the SU back to secondary care (N=4), avoid seeing SU with a SMI diagnosis (N=3), keeping appointments brief (N=2) or suggest to register with another practice (N=1), which may have better links with secondary care. GPs reported adding panic buttons (N=2), updating the person's risk assessment (N=1) and making other members of staff aware of the potential level of risk in their consultation (N=2).



Despite evidence to the contrary, GPs may consider SUs to be a risk to others (C),

which can lead to fear or feeling apprehensive in GPs (M),

which may then lead to avoidance of medication reviews (O), or GPs taking a passive role (O), keep appointments brief (O), or refer SU on to secondary care (O)or suggest registering with another practice (O).

(Perceived) risk may be reduced by adding panic buttons, asking another staff to join the consultation, and ensuring other members of staff are are of the risk

FIGURE 50 CMOC4 GP VIEW

4.2. Service user view

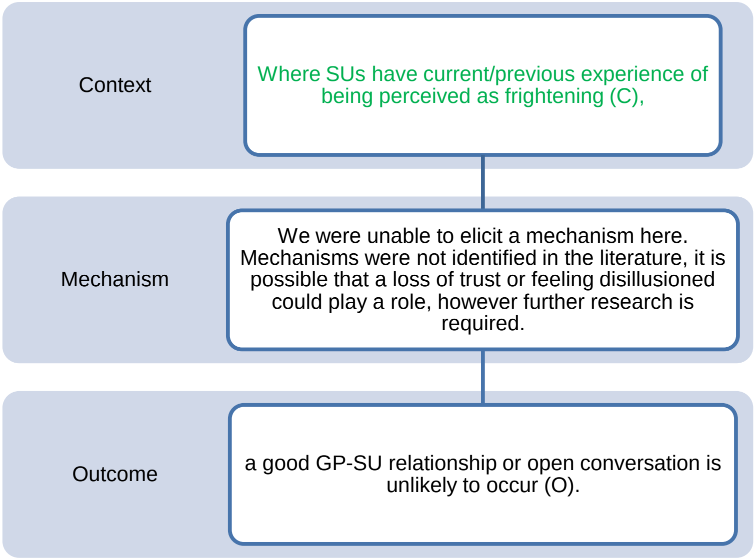


FIGURE 51 CMOC4 SU VIEW

In the SU interviews, three reported being verbally and physically abusive previously, despite this not being a question that was specifically asked as part of the survey. One felt that without their medication, they may hurt themselves or others, and feared going to prison. None of them reported any risk events whilst they felt well within themselves. It is unclear whether previous experiences of risk affect GPs in consultations, or how SU feel about themselves after a period of stability, as this was not directly queried in the interviews. One service user did feel that the public perception of people with schizophrenia was that they are violent, and that this view persisted, despite the person never being violent before. This indicates a level of stigma and/or stereotyping, based on the diagnosis. No further data on this topic was collected as part of the interviews, this the CMOC remains unchanged.

5. CMOC5 Uncertainty regarding Medication and illness trajectory

This CMOC had the least amount of data available in the realist reviews. This CMOC was thus also a focus of the GP survey.

5.1 GP view

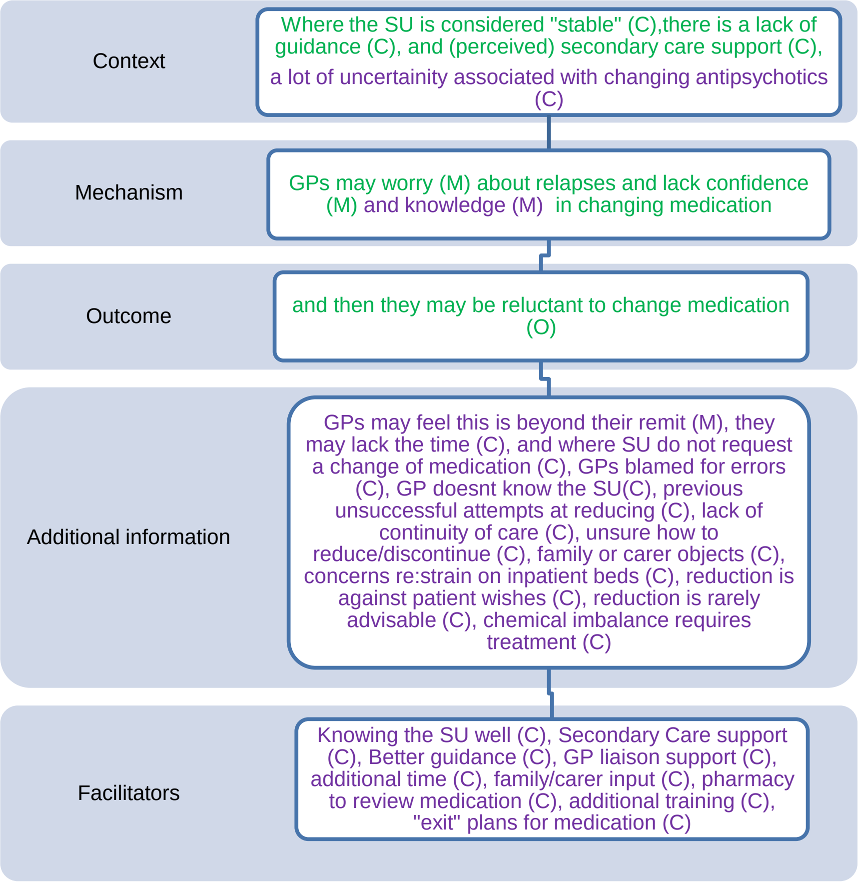
The findings of the GP survey support this CMOC. Forty-eight percent of GPs reported that they would not change the medication of a stable, primary care only service user, who is on long term antipsychotic medication, has no recent risk history, but is developing signs of diabetes. GPs listed a lack of secondary care support as a reason not to review or reduce medication, and two GPs stated that they would only consider it, following a discussion with secondary care services. This suggests that secondary care support is an important context.

When asked why GPs would not change the medication, the most common reason reported was fear of relapse (N=31), lack of secondary care support (N=22) and concerns over risk of SU to themselves or others if the medication was changed (N=19). This was closely followed by uncertainty (N=18), lack of confidence and knowledge (N=15 respectively), “not my role” (N=11), no need to change medication (N=10), lack of time (N=6), patient did not request medication change (N=5). As the CMOCs above highlight, SU may not feel able to request a change of medication, due to fears of sectioning. Thus, the lack of request may not reflect a wish to stay on medication, but merely that SU do not feel they can request this information. One GP felt that they would be blamed for errors if any issues occurred whilst changing medication, especially if they did not know the SU. Given the interaction between GP and

SU outlined above, it is unlikely that stable SU are well known to GPs or that strong therapeutic alliances can be built that would reduce the level of uncertainty the GP feels.

One GP felt that reductions are against SU wishes. This is further confirmed by the SU interviews, where primary care only SU were largely content to stay on medication, and more reluctant than their secondary care counterparts to reduce antipsychotics. GPs were also asked about facilitators, or factors that would make them feel more comfortable reviewing and reducing medication. This has been added under “Facilitators” below. It may be reasonable to assume, that the facilitators are likely reducing the uncertainty associated with medication changes, thus making GPs more comfortable and more likely to review and reduce (where appropriate). This theory is based on the information gathered from the GP survey but was not formally tested as part of the GP survey.

The other information from the survey was added to the CMOC also:



Where the SU is considered "stable" (C),there is a lack of guidance (C), and (perceived) secondary care support (C), a lot of uncertainity associated with changing antipsychotics (C)

GPs may worry (M) about relapses and lack confidence (M) and knowledge (M) in changing medication

and then they may be reluctant to change medication (O)

GPs may feel this is beyond their remit (M), they may lack the time (C), and where SU do not request a change of medication (C), GPs blamed for errors (C), GP doesnt know the SU(C), previous unsuccessful attempts at reducing (C), lack of continuity of care (C), unsure how to reduce/discontinue (C), family or carer objects (C), concerns re:strain on inpatient beds (C), reduction is against patient wishes (C), reduction is rarely advisable (C), chemical imbalance requires treatment (C)

Knowing the SU well (C), Secondary Care support (C), Better guidance (C), GP liaison support (C), additional time (C), family/carer input (C), pharmacy to review medication (C), additional training (C), "exit" plans for medication (C)

FIGURE 52 CMOC5 GP VIEW

GPs reported concerns regarding long term antipsychotics and the effect this has on Service Users. One GP felt that “*patients get stuck on medication that they may no longer need or could take at a lower dose”* (GP survey). This indicates that GPs might see the need to reduce, but in the current framework might not feel able to. This confirms concerns outlined in the introduction, that many service users may be stuck on medication indefinitely and unnecessarily.

5.2 Service user view

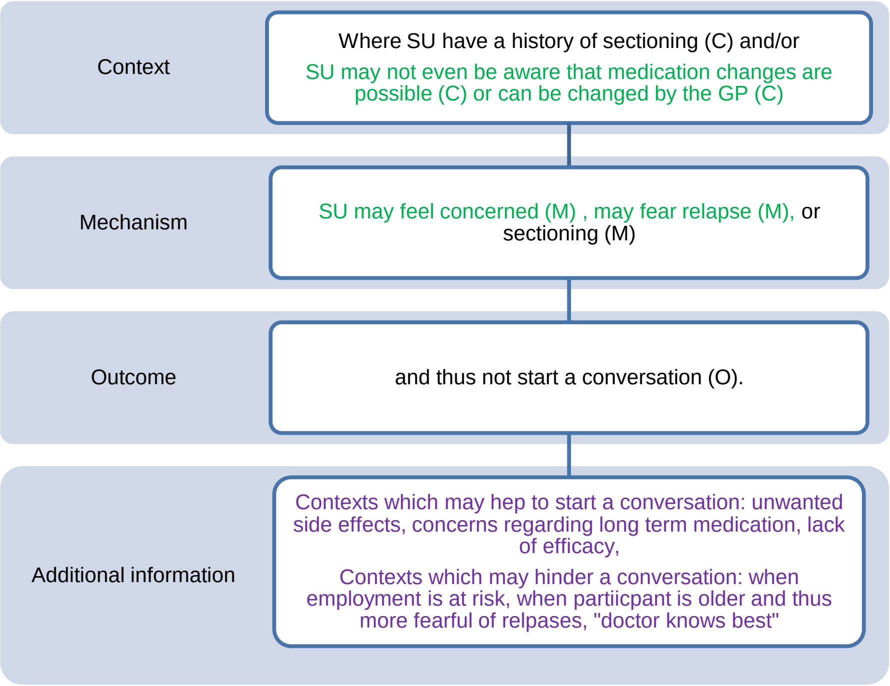


FIGURE 53 CMOC5 SERVICE USER VIEW

The service user interviews supported most of this CMOC. SU reported not being aware that medication changes are possible, as they had previously been told that medication is lifelong, or to treat a chemical imbalance. One SU was also not aware that the GP was able to change medication. SU reported concerns regarding the long-term effects of antipsychotics, and most SU reported a fear of relapse. Overall, the primary care sample was more reluctant to change their medication, indicating that they may not seek a conversation with their GP.

The interviews also provided additional data to this CMOC. SU may be more likely to approach their GP if their experience unwanted side effects, paired with a lack of efficacy and concerns regarding long term medication. Factors that may stop the SU from discussing medication when the SU feels that their employment may be at risk if they were to change mediation (due to a potential relapse), when the SU is older (as they are more fearful of inpatient hospitalisations) and when the SU feels that their doctor acts in their best interest and rely on the doctor to approach the topic of changing antipsychotics. Severe side effects by themselves did not necessarily result in SU wanting to change their medication, just like a fear of relapse did not always result in the SU wanting to stay on the medication. Other factors are influencing this decision.

Summary

In summary, the interview and survey data largely support the initial CMOCs. The data collection largely focused on CMOC 4 and 5, for which the least amount of data was available in the initial realist review. Due to data collection restraints and limited scope of the PhD, data was not collected on all CMOCs and could not be refined further. Only limited evidence was available for some CMOCs. The data available to each CMOC and any subsequent refinement was outlined for each CMOC, ensuring transparency.

The next section will focus on substantive theory, followed by the final programme theory.

6. Drawing on substantive theory

The PhD draws on two substantive theories, which underpin and support the CMOCs. The theories cover different aspects of the programme theory and were selected based on continued review over the course of the PhD. The two theories are: Corrigan’s Attribution Theory (2000), as outlined in the realist review, and trust theory as outlined in Misztal (1992) and Alaszewski & Brown (2007).

7.1 Attribution Theory

The realist review highlighted the impact of stereotypes and stigma in GP – SU interactions. For example, the CMOC 2 highlighted issues around perceived levels of capabilities, which impact SUs ability to participant in treatment decisions, and the perceived levels of risk, which may also impact treatment decisions. The GP survey added evidence in this regard and thus warrants attention. The realist review also highlights paternalism in information giving and side effect discussions. Attribution theory (Corrigan, 2000) offers a useful lens to better understand these findings (as outlined in Chapter 2). Corrigan proposes that “signals” like visible side effects of medication, or an SMI diagnosis suggest perceived skill deficits in SUs, which can lead to stereotypes and more authoritarian or paternalistic behaviour.

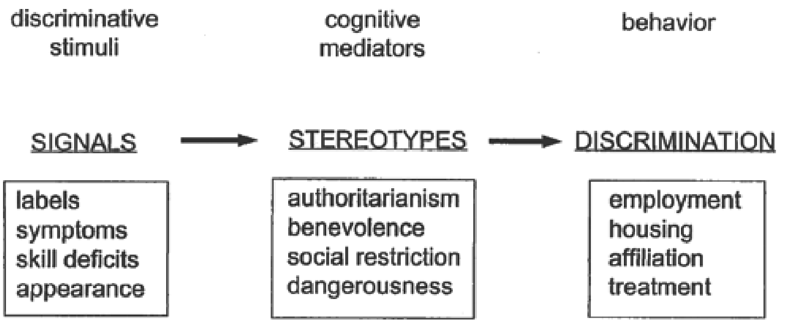


FIGURE 54 THE RELATIONSHIP BETWEEN STIGMA SIGNALS (CUES), STEREOTYPES (ATTITUDES) AND BEHAVIOURS (DISCRIMINATION). TAKEN FROM CORRIGAN (2000), P49.

Attribution theory thus adds further strength to the identified programme theory: in order to overcome authoritarian, paternalistic or benevolent actions, “signals” need to be addressed. Despite the Severe mental illness label, symptoms of schizophrenia or perceived skill deficits, Service Users must be seen as capable participants in treatment discussions and decisions.

7.2 Trust theory

“Trust has traditionally been considered a cornerstone of effective doctor – patient relationships. The need for interpersonal trust related to the vulnerability associated with being ill, the information asymmetries arising from the specialist nature of medical knowledge and the uncertainty and element of risk regarding the competence and intentions of the practitioner on whom the patient is dependent. Without trust, patients may well not access services at all, let alone disclose medically relevant information.” (Rowe and Calnan, 2006, p. 4).

Trust is a crucial aspect of the clinician - SU relationship (Fugelli, 2001). The following section is not an all-encompassing theory of trust, but highlights relevant literature, which underpins the programme theory. Trust impacts patient satisfaction, adherence, and continued enrolment (Anderson & Dederick, 1990; Hall, 2006, Hall et al 2001, Safran et al 1998, Thom, Hall & Pawson et al, 2004). There is no one encompassing theory, however summarising existing research illustrates the theory behind trust and how it is connected to uncertainty (See Figure 55).

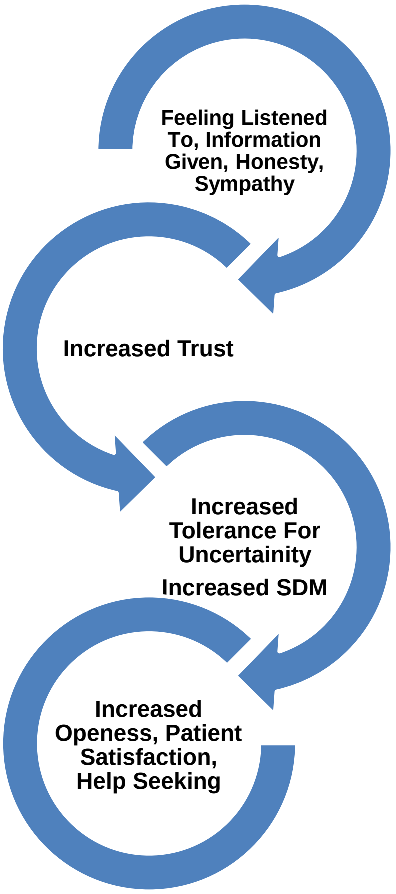


FIGURE 55 SYNTHESISED DATA ON TRUST THEORY

Misztal (1992) highlights that trust was previously an under-researched area in social theory. Luhmann (1988) highlighted that trust never received much attention in sociology but may have gained more attention due to a need to explain “irrational behaviour” or behaviour that does not “serve our own interests, but the common interests of society” (Jencks, 1979). Hobbes suggested that trust is to “*act as if the uncertain future actions of others were indeed certain in circumstances wherein the violation of those expectations results in negative consequences for those involved”* (Lewis & Weigert, 1985, in Misztal, 1992). Trust, from a sociological point of view, is required for “*the stability of the moral order by forming trusting relations*” (p.9, Misztal, 1992). The theory of trust can be taken back to Durkheim (1964), who never used the concept of trust per se, but spoke of the importance of collective order and emphasis on consensus within society. According to Luhman (1979), trust is required to increase the “*tolerance of uncertainty*” (p. 150). This interplay supports the CMOCs identified above:

Despite advances in medical understanding, uncertainty will remain in medical consultations (Rowe and Calnan, 2006). Potentially even more so in primary care mental health consultations, which are less clearly defined than physical illnesses. Uncertainty regarding SMI illness trajectories and antipsychotic medication requirements remain and are unlikely to change. Increased trust is required to overcome this (Maidment et al, 2011). Trust is a cornerstone of the clinician – SU relationship. As it is never discussed specifically in consultations, it is difficult to describe and empirically assess (Skirbekk et al, 2011).

The lack of trust and increased uncertainty does not just affect the SU- GP relationship, but also the wider institutional context. CMOC 5 and the GP survey highlight the lack of trust and uncertainty in the interaction between primary and secondary care. As discussed in the GP survey chapter, GPs do not feel adequately supported by secondary care and do not appear to consult secondary care frequently. GPs are concerned about relapses, effects on inpatient bed availability, and comment on the lack of “exit plans” with regards to antipsychotic prescribing.

Equally, the CMOCs consistently highlight lack of trust between GPs and Service users. Both sides appear to experience a lot of uncertainty, regarding illness trajectories and medication requirements, fear of relapse and concerns about long effects of medication. GPs at times, do not appear to trust service users to participate in treatment decisions and make “good” treatment decisions (as seen in CMOC2). GPs may not trust that SU will agree with their treatment decisions if they share all the information regarding the need for yearly physical health screening and adverse effects from the medication, as seen in CMOC 3. As Maidment et al (2011) highlighted, increased trust is required in SMI, due to the increased level of uncertainty.

Service users on the other hand, may (have) experience(d) coercion with regards to their treatment and may thus not trust their GP enough to share their current symptoms (if any), whether they have adjusted the dose of their antipsychotic or may not even attend the GP appointment entirely (CMOC3 and Rowe & Calnan, 2006). Research has shown that SU trust their clinician more if they felt able to speak openly, were treated as equals and with respect (Skirbekk et al, 2011). SU showed increased openness in consultations when they felt trust (Skirbekk et al, 2011). If queries are dismissed, and information not shared openly (as seen in CMOC 2 and 3), trust is difficult to build (Skirbekk et al, 2011)

As highlighted in the CMOCs above, it can be argued that GPs experience increased uncertainty due to an aforementioned lack of SU engagement, difficulties in communication, and lack of secondary care support to name a few. As discussed above, this may result in GPs feeling that it is their responsibilities to manage care in a more paternalistic way. Especially where lack of engagement and possible factors around mental state give the impression that SU themselves cannot participate meaningfully in conversations.

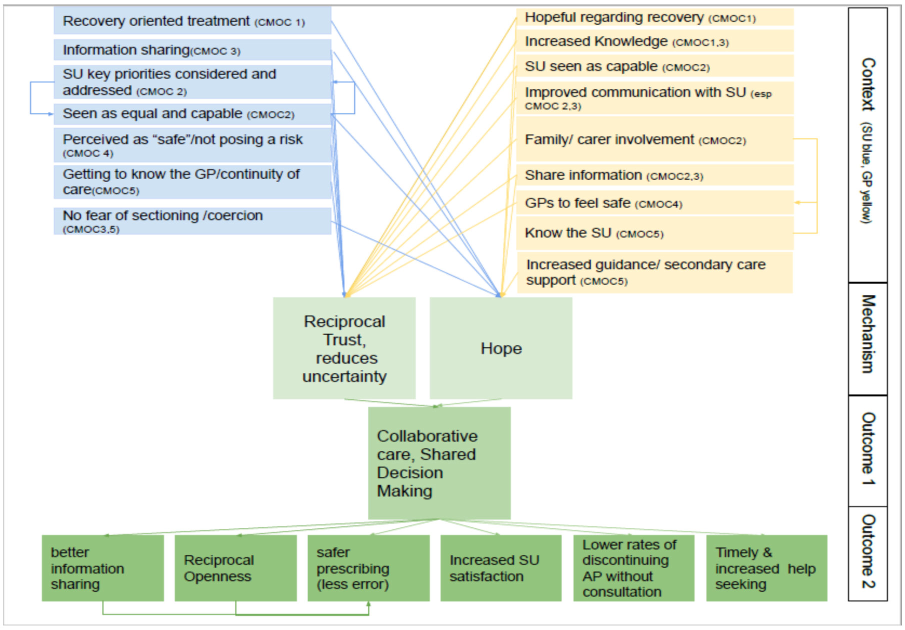
A system of trust must be built between GP and SUs, as well as between primary and secondary care services, to facilitate better health care. As Misztal (p.12, 1992) outlines "*trust on a personal level becomes a project, to be worked at by the parties involves, and demands the opening out of the individual to the other. Where it cannot be controlled by fixed normative codes, trust must be won, and the means of doing this in demonstrable warmth and openness*" (Misztal, 1990). This supports the findings of the GP survey, in which GPs highlight that knowing the person and family/carer involvement would be a facilitator to medication reviews. This may be related to increased feelings of trust and reduced uncertainty. Trust can be increased by displaying or increasing competence, respecting service users' views, having confidence in service users to manage their own wellbeing and increased information sharing (Dibben et al.,2003).

In summary, the association between Attribution Theory and Trust Theory is evident. Both theories offer a useful lens to understand the Context, Mechanism and Outcome Configuration better and adds further strength to the final programme theory, as outlined in the next section.

7. Final programme theory

Based on the refined CMOCs above, the programme theory outlined in the Realist Review was also tested and refined iteratively. The final programme theory is outlined visually in Figure 56 below. The CMOCs above largely theorise barriers to meaningful GP – Service User interactions, whereas the programme theory theorises ways to overcome these, based on the synthesised evidence. Each C, M and O in the final programme theory stems from the CMOCs identified above. As the evidence collected largely supports the initial CMOCs and programme theory, the refined programme theory is not significantly different to the initial one. Some of the initial CMOCs, especially CMOC 4 and 5, were not supported by much of literature, and this is where most of the evidence within this PhD has been collected, allowing further testing and refinement. Attribution theory and the addition of trust theory further strengthen and support the findings below.

The overarching programme theory focuses less on those SU who do not want to discuss or change their medication, as highlighted in CMOC 3 and 5, but instead focuses on facilitating a conversation between SU and GP, and explains how and under what circumstances trust can be built (M), leading to increased collaborative working and Shared Decision Making (O2), which in turn leads to safer prescribing, increased openness, increased SU satisfaction and improved help seeking (O2).



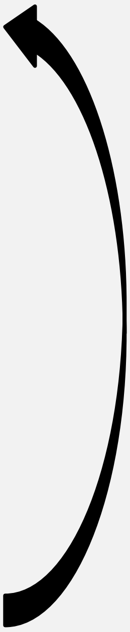


FIGURE 56 FINAL PROGRAMME THEORY

The most common Mechanism in all CMOCs is trust and/or reducing uncertainty, which is an obstacle to collaborative working and shared decision making.

The SU interviews and GP survey both highlighted how crucial trust and managing uncertainty is in the SU- GP interaction. Primary care only service users appear to have more "at stake" and fear relapse, meaning they are more reluctant to change their medication. Equally, GPs fear relapse, and may not wish to change medication, unless this is explicitly requested by the SU, and even then, they may not wish to do so. Since uncertainty is inherent in the course and outcome of mental health problems, increasing the tolerance for uncertainty and trust in general appear to be key mechanisms to overcome this lack of meaningful communication between GPs and SU. Uncertainty can be decreased by knowing each other better, e.g. improved continuity of care and family/carer involvement, operating in a safe environment (safe from coercion and safe from abuse), seeing the SU as equals and remaining hopeful regarding recovery. Where information is shared reciprocally, using good communication and this information is listened to and considered, uncertainty can be further reduced, and trust can be built.

This leads to better collaborative working increased shared decision making (O1). This, in turn increased openness and help seeking, leading to safer prescribing, fewer instances of medication discontinuation or modification without consultation and improved physical health. Information sharing appears to be a critical component, and has been listed as a Context, as well as an Outcome. The programme theory can be seen reinforcing cycle, as described in Jagosh et al (2015) in the context of building a partnership in community based participatory research (Figure 57 below).

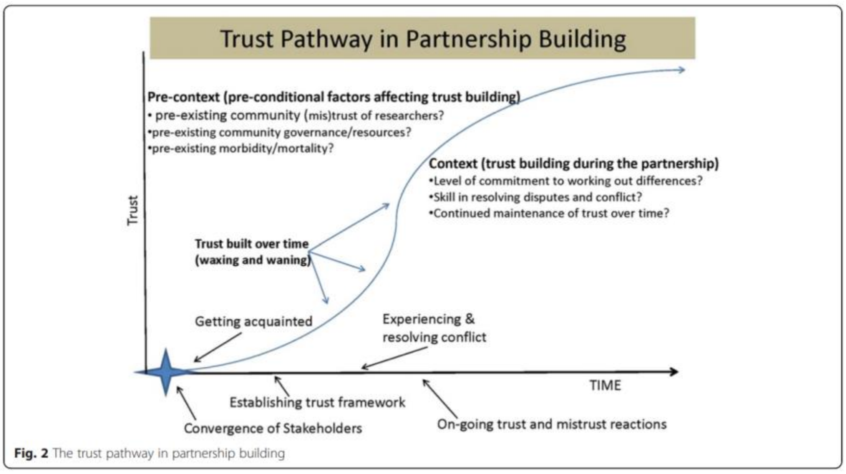


Figure 57 taken from Jagosh et al (2015, p.4) “The trust pathway in partnership building”.

In this programme theory, increased information sharing (C), in combination with the other contexts (including a safe environment for example), can lead to increased trust (M), increased SDM (O1) which reinforces openness and information sharing (O2) further. The increased SDM and information sharing can then be seen as the context for the next consultation, starting the process outlined in the PT again. With every consultation, this programme theory should reinforce information sharing, reducing the difficulties caused by (unavoidable) uncertainty, and increasing trust. Trust needs to be built up over time, thus the CMOC sequence would need to occur over several consultations to continue to build up trust, leading to better outcomes. It is possible that these can then impact trust on other levels, starting with trust building between SU and GP, and then impacting relationships on an institutional level, e.g. between GPs and secondary care services. This can be considered a "ripple effect "(Jagosh et al., 2015). A strengthening bond is also able to overcome future events of (potential) conflict and mistrust (Figure 57). It is thus crucial that trust is built and maintained over time.

8. Summary

This chapter outlined the CMOC refinement, leading to the final programme theory. It integrates the findings from the GP survey and the SU interviews, with the initial CMOCs identified in the realist review. It also discussed substantive theory, and how attribution and trust theory add further strength to the final programme theories. The next chapter will discuss the findings of the PhD as a whole, strengths and limitations of the research, and end with a list of recommendations for policy, practice, and research.

Chapter 6 - Discussion

The aim of this PhD was to explore antipsychotic medication reviews for people with a diagnosis of SMI, who are under primary care only.

The PhD aimed to develop an initial programme theory of antipsychotic medication reviews in primary care, therefore a realist review (Chapter 2) was conducted with the aim to explore "what works, for whom, how, in what respects, to what extent and in which contexts". Specifically, potential barriers and facilitators to conducting comprehensive medication reviews from a GP and service user perspective were explored, for those service users who have been discharged from secondary care services. An initial programme theory was derived from the data, supported by substantive theory (Attribution Theory, Corrigan, 2000). Two empirical studies were conducted to expand on the original realist review and to refine the programme theory. The first data study, service user interviews (Chapter 3), aimed to understand particular characteristics of service users who were under primary care only, in comparison to service users who were still under secondary care, and compared their views on long term antipsychotic medication, reducing and stopping antipsychotics.

Additionally, a GP survey (Chapter 4) was designed, based on the initial programme theory. It aimed to determine if GPs are able to identify those service users who were solely under their care, and to refine the CMOCs identified in Chapter 2, Data collection mirrored the service user interviews, in that it also explored GP views on long term antipsychotics, views on reducing and stopping antipsychotics. It also aimed to collect data on perception of risk and uncertainty in treating this group, as little literature was identified on these CMOCs in the realist review.

Chapter 5, the data synthesis chapter, describes how the data collected in Chapters 3 and 4 was used to refine the final programme theory.

The realist informed data synthesis highlights the need to integrate service user and GP perspectives to find a meaningful way forward and to re-start conversations. It highlights potential areas for change, including the need for service users and GPs to feel safe and know each other better to reduce some of the uncertainties associated around antipsychotic treatment and mental health trajectories, and to build trust and to facilitate Shared Decision Making. Trust is an ongoing process, as suggested by the substantive theory, and needs to be worked on at every consultation. Continuity of care may be crucial in in facilitating that. Possible outcomes are improved information sharing, openness, and attendance at appointments. It may improve GP prescribing and physical health reviews. This, in turn may improve Service User engagement, help seeking and reduce the prevalence of service users discontinuing antipsychotic medication without clinician input. This may increase service user participation in treatment decisions, enable genuine choice and informed consent. At a service level, fewer discontinuations without consultation may lead to safer reduction of medication, potentially fewer relapses and thus a potential reduction in service users requiring inpatient care, a key objective of the latest Mental Health Act review (Department of Health and Social Care, 2021). Improved physical health (due to a reduction of unnecessary antipsychotic medications) may also reduce the adverse effect burden and reduce physical health complications. A reduction in medication may, for example, lead to a reduction in weight (Speyer et al., 2021), and thus reduce the risk of diabetes or CVD. It may also reduce the need for physical health hospital appointments and reduce the occurrence of more serious physical health complications in the long run. This would also make a positive impact for the person's wellbeing and quality of life.

As discussed here, the implications of improved medication reviews are wide reaching, and do not just include the GP and service user interaction, but affect the person's mental health, physical health, and the wider NHS context, including secondary care and inpatient services.

Recommendations

The overall recommendation is to re-start conversations with the aim of building trust and hope in GPs and people who are under primary care only, on long term antipsychotics, presenting as stable in the community. The following section outlines how this might be achieved. We have divided the recommendations into those for clinical practice, policy and research.

1. Clinical recommendations

Six key recommendations for clinical practice are outlined below (Table 12).

TABLE 12 CLINICAL RECOMMENDATIONS

Create safe environment for Service Users

- Assurances that they won't be sectioned for questioning their medication (or if they disclose that they have reduced/stopped them).
- Conversation should be free from coercion
- Queries should be heard, and SU should be given time to engage in consultations, and empowered to participate (i.e. double appointment if possible).
- As outlined in the SDM guidelines, opting to not receive treatment should be an option (that is communicated to service users)
- These conditions may enable trust, Shared Decision Making and openness

Create safe environment for GPs • Discuss what safety means at practice level and how this can be achieved • Suggestions from the GP survey included: panic alarms, or asking an extra member of staff to be present • Pressure must be removed from GPs to feel the need to prescribe. • Access to advice and support from secondary care and reviews for complex cases or if GPs have concerns
Recovery orientated treatment: • Ensure GPs are aware of non-pharmacological treatment options (such as therapy, IAPT – SMI) • GPs should offer ways to overcome side effects • Increased pharmacist involvement • This can help to ensure hope is maintained and avoid “therapeutic nihilism”
Increased, reciprocal information sharing: • Where there are uncertainties regarding medication and illness trajectory, this needs to be shared and discussed. • Side effects should be discussed openly. • Options for reduction or discontinuation should be discussed where appropriate (e.g. significant side effects; stability, ageing). • A safe environment may allow SU to disclose any self-adjustments to prescribed doses or regimens they may have made to tailor medication to suit their needs. • Whereas clinicians may fear that sharing side effects leads to discontinuation, actually sharing them may increase SUs trust, and in turn their attendance for physical health checks and may make SU more likely to re-approach their clinician and discuss medication, rather than lose trust and disengage. • Key considerations, should be discussed, including fear of relapse, benefits of medication, and adverse effects of the medication, employment, age, role of patient, institutional barriers and concerns regarding long term antipsychotic treatment.
Continuity of care • Uncertainty is reduced and trust can increase over time when GP and SU know each other better, building a therapeutic relationship. Current staffing issues may be a barrier, efforts should be made to ensure continuity of care where possible.
Increased family and carer involvement • Isolation and the need for additional support when reducing medication are a potential barrier to reducing medication. GPs and Service users value carer/ family involvement, and it may reduce some of the uncertainties when reviewing and reducing medication, by supporting the service user. Carers and/or family members should be involved in all decisions, where this is appropriate.

These clinical recommendations should lead to increased trust between GPs and Service Users. Trust is a process and needs time (as outlined in Chapter 5). Improving trust over time can have many advantages, including:

a. May lead to higher rates of physical health screening, increased help seeking
b. improvement of physical health overall
c. Increased action from GPs if service users are engaging
d. Information sharing will lead to safer prescribing, as exact doses and regimens taken are known
e. Fewer abrupt discontinuation, as GP – Service User relationship is strengthened, and Service Users may be more likely to seek advice
f. Avoid unnecessary prescriptions

2. Policy recommendations

Six key recommendations for policy are outlined in Table 13. Whereas a key NHSE policy includes improved shared care and easier referrals between secondary and primary care, to allow service users to access secondary care services more easily and move between services as needed, it is also important to ensure that resources are distributed to those who are in need of it, as outlined in the Community Mental Health Framework for Adults (NHSE, 2019) For some service users, this may mean putting policies in place for easier and quicker referrals to secondary services when needed, and for improved working relationships of secondary and primary care services, but also for policies to include specific guidance for those services users who have been discharged from secondary services, who cannot be referred, or are unable to be referred due to constraints and high referral thresholds in secondary care teams. Funding and workforce should be allocated appropriately. The placement of mental health nurses in primary care practices can be a helpful way to execute policy and guidance as issued by NHSE.

TABLE 13 POLICY RECOMMENDATIONS

Data linkage between primary and secondary care Combining or more closely linking primary and secondary care records to improve communication and allow GPs to easily identify who is under their care only – this may prevent stable primary care only services from falling between the cracks.

Clearer pathways for primary care only SU. The pathway outlined by NICE (2019) and the community mental health framework for adults (NHSE, 2019) only provide a vague pathway, without specific considerations for primary care only service users. They may not experience severe enough difficulties for secondary care but are too complex for primary care. Their mental health care may suffer as a consequence. Integrated Care Boards (ICBs) should be included to consider issues relating to workforce, funding and training needs of existing secondary and primary care services.
“Exit plans” to be recommended when SU are discharged to primary care, outlining long term antipsychotic management plans. This may include a recommendation on length of treatment and a suggested reduction schedule or re-referral to secondary services for review of their options including planned reduction or discontinuation of antipsychotics.
Increased communication between secondary and primary care services. The effect of GP liaison on this could be explored and periodic secondary care medication reviews or joint reviews.
Increased co-production in pathway and service design, integrating the clinician and Service user point of view literature, to improve implementation. It is crucial to involve service users who are under primary care only in this.
Clearer guidance for people with SMI who are under primary care only: need to differentiate and clearly outline what a review might entail. Pay close attention to factors that are different for primary care SU based on clinical and demographic variables. If GPs feel thorough reviewing and adjusting antipsychotic medication is not their remit, alternatives must be sought

3. Research recommendations

Table 14 outlines three areas of recommendations where further research is needed.

Table 14 Research Recommendations

Research is needed focusing on service User views of: • Discharge process from secondary care, • GP only appointments and effects on their mental health care • SU experience on being seen as “frightening” or “at risk” in consultations, and the impact this has on their relationship with their GP • How to build trust in the GP-SU relationship
Research is needed to focus on GP views of: • Antipsychotic medication reduction/discontinuation education and training • Increasing knowledge around side effects • Whether and how primary care reviews should happen • Relationships with secondary care and mutual roles • How to build trust in the SU-GP relationship
Interventions focused on improving the delivery or management of care for people taking antipsychotics in primary care should be designed and implemented and evaluated with consideration of the recommendations above:

- Interventions are required to find out best way of having a medication review in primary care, in a way that is judgement free, coercion free, and both parties can speak freely
- Interventions to increase secondary care support
- Design and assess the efficacy of “exit plans”
- Assess interventions aimed at increasing trust and whether these lead to better mental and physical health outcomes
- Explore how Shared Decision Making can be facilitated in the context of antipsychotic medication reviews for people with an SMI diagnosis.

These are the key recommendations, derived from the data collected and synthesised as part of this PhD.

Comparison with the literature

To the author’s knowledge, this is the first study to assess antipsychotic medication reviews in primary care, for those service users with a diagnosis of schizophrenia or psychosis disorders who are no longer under secondary care. As outlined in previous chapters, previous research has assessed GP involvement in SU care, but not specifically differentiated between the care of those who are still in secondary care and those who are not (Kendrick & Burns, 1997; Nazareth, King & Haines, 1991). Lester et al. (2005) questioned service users on their satisfaction levels with GP care, but no data was collected on whether service users were just under primary care or not. It was thus not possible to estimate if any primary care only SU were recruited in this study, and whether the findings of the study apply to the primary care only population.

Reilly et al (2012;2021) have tried to estimate the proportion of service users currently under secondary care, and Mortimer et al (2004) have assessed primary care antipsychotic prescribing. Again, due to data linkage issues, it was not possible to compare antipsychotic prescribing for those still under secondary care, with those only in primary care. Previous research has thus assessed factors around primary care medication reviews, but not specifically assessed the impact on long term, stable, service users, who no longer have access to regular reviews by their psychiatrist.

The PhD has highlighted the importance of trust in medication reviews. Increased levels of trust are required due to higher levels of uncertainty in this area (Maidment, 2011). The diagnoses of schizophrenia and other psychotic disorders are based on subjective factors, such as patterns of behaviour and speech, and not on the basis of objective biological findings. There is considerable variation between individuals with these diagnoses, adding to the sense of uncertainty. Therefore, understanding each individual's difficulties and finding the correct antipsychotic medication and dose can be long-winded, as there is uncertainty and variability in how people respond to antipsychotics.

As discussed in the introduction, ethnicity and culture can also impact medication reviews. Trust in health care services may be especially low for certain ethnicities as Maura et al (2017) highlight. Interestingly, a retrospective study interviewing people who had been admitted to inpatient wards by Cole et al (1995), found that the pathway to psychiatric care did not differ between ethnicities. Instead, they found that family and GP support played a crucial role in determining whether people were admitted via health services or via the police. The authors suggest that ethnicity may play a greater role following initial diagnosis and admission. This study illustrates the importance of GP support in getting access to health services, and that ethnicity may play a more important role once people have first accessed health services. As seen in Chapter 3, participants were rarely in relationships and largely lived alone, which may pose an additional barrier. It is key that people are engaged with primary care services to ensure better access to primary care services. As also seen in Chapter 3, Asians were more likely to be in primary care services than secondary services, which may indicate that they are better supported in primary care, and may not need specialised secondary care services, potentially as they may be better supported by their families and community.

Many uncertainties also remain regarding safe reductions and discontinuation of antipsychotic medication, in those who have been prescribed it for years (Morant et al., 2018, Pinfold et al., 2019).

It is thus important that trust is built to facilitate this relationship, as outlined in the substantive theory section in the data synthesis (Chapter 5). Increased information sharing, creating a safe environment for Service Users, free from coercion or fears of sectioning (Morant, 2016), as well as a safe environment for GPs, is crucial. Trust may also facilitate shared decision making. SDM is a key NHS recommendation in consultations (NICE, 2021), but has been neglected in this area (Morant, 2016). It is not clear how SDM can be achieved, given that the tenets of shared decision making, as defined by NICE (2021), including reciprocal information sharing and the option to decline treatment, are not met. Enabling trust and thus shared decision making has significant implications, as discussed in Chapter 5 and the final programme theory.

The recent SDM guidelines have also been criticised for exploring SDM from a clinician point of view, and not enough from a SU point of view (Zisman-Ilani et al., 2021). Coproduced studies are required to explore how shared decision making can be facilitated and to ensure that guidelines are implemented in a meaningful way. The programme theory has shed light on how this might be facilitated.

Further Implications

Significant barriers are yet to be overcome for primary care only medication reviews. These include pessimism regarding treatment and gaps in the service provision for primary care only service users:

Although the GP survey found little evidence for the “therapeutic nihilism” identified in the realist review, research continues to highlight this as an issue: a recent survey by Magliano et al. (2020) also found that “*prognostic pessimism among doctors negatively influence[s] clinical decisions, the information doctors provide to their clients, and the clients’ own beliefs about chances of recovery”* (p.683), which is in line with the initial findings from the realist review. It is possible that GPs were unwilling to discuss this in this PhD survey, or that the sampling resulted in GPs who had a special interest in antipsychotic prescribing, and may thus feel more hopeful regarding recovery, than the findings by Magliano et al (2020) and the realist review suggest.

The King’s fund (2020) also highlighted issues in current service provision for people diagnosed with SMI, especially given increasing numbers of people discharged from primary care. The systematic search conducted as part of the realist review did not identify any research on the topic of primary care only medication reviews. It appears that little research has been conducted previously to assess the current pathway and medication reviews in primary care. As the King’s fund (2020) highlights, many “stable” primary care service users are not “severe” enough to be seen in secondary care yet are considered “too complex” for the primary care therapy service, IAPT. IAPT SMI services have been trialled, with good results (Johns et al., 2019), but have not been rolled out nationally. Ensuring adequate mental health care provision for this population is crucial. The current The Community Framework for Adults and

Older Adults (NHS,2019) aims to improve service provision. The PhD illustrates that stable, primary care only service users may fall between cracks and are not adequately reviewed, some may not even be reviewed at all.

Service users are therefore also at risk of staying on unnecessary antipsychotic medication or unnecessarily high doses of antipsychotic medication indefinitely. Adverse effects associated with antipsychotic medication can impact the person's quality of life, their mental health and their physical health. As described in Chapter 1, reduced life expectancy has been attributed in part to antipsychotic medication, and must thus only be prescribed if necessary, and reduced or discontinued where appropriate. Ensuring that medication is reviewed and reduced regularly is thus crucial. The PhD has highlighted how a trusting relationship between GPs and service users has the potential to improve medication reviews and thus improve service user's health holistically. It also shed light on how these changes can be achieved and implemented, to ensure adequate service provision for those who are under primary care services.

The realist informed synthesis has been a useful methodology to theorise the findings identified in this literature, and enabled the development of actionable recommendations, despite the initial lack of evidence in the area. The realist review was expanded by the GP survey and the SU interviews, which largely supported the initial programme theory, lending further credibility to the findings and the use of realist methodologies to explore complex systems.

Strengths

Individual strengths of the methodology of each chapter are outlined in the discussion section of each chapter. In summary, the realist review benefits from stakeholder input throughout and an extensive, systematic literature review and iterative searches. Realist methodology allowed the development of an initial programme theory, embedded in the available literature. It was further strengthened by the inclusion of a substantive theory. The service user structured interviews benefit from a large overall sample size (N=269). As with the realist review and the GP survey, the Service User interviews are the first research studies on the topic of primary care only service users and offer valuable insights. The GP survey benefits from being embedded in the literature and based on the programme theory identified in the realist review. The GP survey design benefited from being an online survey, and thus an easily accessible way to participate, whilst also ensuring anonymity. Participants were able to select multiple choice answers, as well as use free text boxes to submit their responses. The overall PhD benefits from being mixed methods, and the use of realist methodologies throughout. The initial programme theory was tested and refined in subsequent chapters, lending further credibility to the results. It allowed the development of a final programme theory, which is further supported by a second substantive theory. The area of antipsychotic medication reviews in primary care for primary care only service users lacked research, and the PhD identified a range of implementable, context relevant, recommendations for clinical practice, policy and research.

The PhD also benefits from continuous stakeholder input. The Realist Review was completed with the help of a lived experience panel including people with experience of taking antipsychotic medication, their carers, peer researchers and policy makers, and was supervised by an academic GP, Psychiatrist, and policy researcher. Sections of the PhD were also advised on by other GPs, a GP liaison psychiatrist, and a member of the local CCG. The multidisciplinary team ensured that the research continued to stay relevant to those who use and provide services, as well as academics and policy makers.

Limitations

Limitations are outlined in each chapter in depth. In summary, both the sub study of 21 structured interviews and GP survey did not include questions to all CMCOs identified in the realist review, due to time limitations as part of the PhD, and pragmatic data collection methods associated with the wider RADAR programme. The qualitative analysis was a secondary analysis of pre-existing data, and the interviews were not specifically conducted with the CMOCs in mind. Data relevant to the issues identified in the realist review were therefore not as detailed or in-depth as might be obtained from formal qualitative interviews, had the study been done specifically for the purposes of the current project. Conducting interviews with the CMOCs identified in the realist review would have allowed more in depth data collection and allowed further refinement of the CMOCs. Given that the realist review did not identify any data on medication reviews for those discharged from secondary care services, this PhD and any future study looking to interview SUs on this topic will however still benefit from this exploratory analysis. Analysing the data using framework analysis allowed further insight into service user perspectives, and highlighted areas the realist review did not uncover, such as the importance of (older) age and differences in employment as key considerations for medication changes. Future interviews can include these findings in their topic guides. It may also be considered unethical to not analyse this data with primary care only service users in mind, despite the data being superficial and not as in depth. Service Users gave their time to respond to questions, and interesting findings were highlighted. These can serve as a starting point to any future research. However it is important to acknowledge that this was a structured interview, and therefore conclusions have to be drawn with caution. Future research is needed to gain a better and more in depth understanding of the service user experience.

Although the GP survey had 103 respondents, it still needed further participants to ensure that its findings are generalisable. As outlined in Chapter 4, however only 72 completed the minimum data set, and 51 completed the full data set. In combination with the realist review, both still added to our understanding and helped refine the programme theory. Due to the number and complexities of the CMOCS identified in the realist review, the survey had to be balanced between asking enough questions to cover a lot of the CMOCS or choosing to cover one or two in depth. Interviews are considered superior for exploring patterns in depth; thus, the chosen approach was to assess many topics, rather than focusing on one CMOC in particular. This helped generate a lot of relevant data but meant that certain aspects are not covered in depth. For example, it included a question on hopelessness. A significant number of participants answered that they did not feel hopeless, but the survey design did not allow for follow up questions, such as," what did you feel instead?". In person interviews may have allowed for more in-depth answers. Additionally, whereas some questions in the survey were able to capture the interaction between Context, Mechanisms and Outcome (e.g. "*A lack of information about the nature of antipsychotic medication* (Context), *meant that patients do not see the importance of physical health checks* (Mechanism) *and potentially do not attend yearly reviews*" (Outcome)), others did not fully (e.g "Patients diagnosed with schizophrenia/psychosis (C) understand the need for antipsychotic medication (O)").. It is crucial that research establishes whether certain contexts trigger certain mechanisms, which lead to specific outcomes. For those questions where the interaction between C,M and O were not assessed, further questions should have been included to elicit the remaining C,M or O (in the above example, the mechanisms was missing).

With both the service user interviews and the GP survey, sampling issues and fears of social desirability have to be taken into account, which may impact to what degree the results of the data can be generalised. The GP survey was anonymous, so may have addressed some of the social desirability.

The programme theory may benefit from further refining, to include topics that were not discussed in the interviews and GP survey. CMOCs were theorised based on literature identified in the realist review and refined based on service user interviews and a GP survey. They represent patterns or demi regularities, but are likely not complete, and other factors may be at play. Not all CMOCs were presented to GPs and SU in this way, therefore further research is required to refine them. CMOCs are theorised based on available data and may not be representative of all GP and SU views.

Realist Synthesis Quality Standards

The PhD is a realist informed synthesis on the topic of antipsychotic medication reviews. Realist Synthesis Quality standards were developed by RAMESES (2014). The following section outlines to what extent quality standards were met; for an in-depth description of quality standards please see Appendix 14.

1. The Research problem

The first criteria concerns the research question, and assesses to which degree it is phrased in a realist way. The PhD has a clear research question, which includes elements of “what works, how, why, for whom, to what extent and in what circumstances, in what respect and over what duration”. The realist philosophy is outlined throughout, but in depth in Chapters 1 and 2, and includes discussion of generative causation (C, M, O). It compares the realist approach to more traditional systematic reviews in Chapter 1, and outlines why a realist approach is considered superior for the PhD’s research question. The exclusion of elements of the “research question” is outlined in Chapter 2 and was informed by relevant data and stakeholder input.

2. Understanding and applying the underpinning principles of realist reviews

The realist principles were outlined and discussed throughout, but most specifically in Chapters 1,2,5 and 6. Strengths and limitations were discussed throughout, and problems were resolved with realist principles in mind.

3. Focussing the review

This quality standard refers to the need to focus the review, and assesses whether this has been adequately described throughout. The review was significantly narrowed down and focused throughout, based on available evidence, time and resource constraints of the PhD, and based on stakeholder advice: The realist review was presented to the LEAG – a lived experience advisory group consisting of people with lived experience and carers three times throughout the realist review. The supervisory team consists of a psychiatrist, a GP and a policy research fellow, who had oversight over the PhD to ensure that the findings remained relevant. For relevant sections of the

PhD, other stakeholders were consulted, including a GP, a GP-liaison psychiatrist and a member of the local CCG. It was also presented at two conferences, prompting further discussions and refinement. Ensuring that the PhD's results are relevant to those using it was a key priority throughout.

Chapter 2 outlines the focussing process in section 5, 6 and 11.3. The review was focussed down in several stages, including at the data extraction and data synthesis stage. The GP survey was also designed with the programme theory in mind, and specifically focused on collecting data on those CMOCs, for which the least amount of literature was identified (CMOC 4 Risk and CMOC5 Uncertainty).

4. Constructing and refining a realist programme theory

An initial programme theory was developed and refined throughout the PhD. It comprises several Context, Mechanisms, Outcome configurations. Substantive theory (attribution theory, trust theory) was applied to further refine and develop the programme theory. Implications of the programme theory are outlined in Chapter 6 – recommendations.

5. Developing a search strategy

This quality standard assesses whether the search strategy is in line with realist philosophy. The search strategy was developed with the support of a librarian. It was piloted and refined before the first, systematic search was completed. It followed the principles outlined by Booth ("the realist search", 2020). Data were sought from a variety of sources, including grey literature. There were no restrictions on the type of documentation type or study. Two further searches were conducted, alongside the main systematic search, to help refine the programme theory. The searches did include literature from antipsychotic medication reviews in dementia care, and from secondary care services, but did not specifically seek out data from situations further outside the programme theory, where it can be reasonable inferred that the same mechanism may be in operation.

6. Selection and appraisal of documents

Realist synthesis is not quality assessed in the same way as systematic reviews are, therefore this quality standard assesses if the realist equivalent of assessing quality ("relevance and rigour") was completely adequately. An extensive relevance and rigour appraisal process was developed (as outlined in Chapter 2). The process was informed by Jagosh et al (2011) and Francis Graham et al (2019) and refined further. Relevance and rigour were first assessed for all included papers. As not all papers contributed to the individual CMOCs in the same way, the quality appraisal process was repeated for each CMOC individually. The quality appraisal process can thus be considered sophisticated and suitable for the purposes of this PhD.

7. Data extraction

A second rater rated 10% of each data extraction step, to ensure that the data extraction standards were adhered to (as outlined in Chapter 2). In discussion with the second rater, the data extraction was piloted and refined. For example, documents regarding people with a diagnosis of bipolar or evidence regarding clozapine medication reviews were later excluded, as a result of the refinement process. All documents were screened based on their contribution to either C, M or O and main CMO patterns were identified. Further data was collected as part of Chapters 3 and 4. Evidence from this was extracted using the same principles, and the programme theory was refined accordingly, in Chapter 5.

8. Reporting

The method is outlined throughout the PhD: Chapter 1 introduced realist methodology and philosophy and outlines the methodology for the PhD. Each chapter of the PhD includes a detailed method section. Quotations and references are also included throughout, to ensure transparency. Added to this are appendices, which include the literature search strategy, the quality appraisal outcomes, the raw data and SPSS outputs. This further enhances transparency.

In summary, realist quality standards were largely adhered to throughout the PhD, and the PhD is thus considered realist informed. Improvements the methodology could have been made, as outlined in the limitations section. The main limitation is that the service user interviews were not conducted with the programme theory in mind, which future research should address.

Reflexivity

The Social GGRRRAAACCEEESSS model was used to assess how my personal biases may have affected the results of the PhD (Partridge, 2019). Biases are assessed according to my Gender, Geography, Race, Religion, Age, Ability, Appearance, Culture, Class, Education, Employment, Ethnicity, Spirituality, Sexuality and Sexual Orientation.

As a white, female, social scientist, I do not have experience of working as a GP, nor do I have a diagnosis of Severe Mental Illness. Having worked in clinical and research settings in the NHS for the past 10 years, I have observed some of the care described here, and have formed my own opinions based on these experiences. These can be seen as valuable first-person experience, but can also cloud my analysis, as it may be difficult to imagine alternative ways to the processes described here. I was also a researcher on the RADAR study, which is a study designed to reduce antipsychotic medication, on the premise that reducing medication may be beneficial for some service users. This may have also biased my views. Throughout the PhD I was supported by a psychiatrist, a GP and a policy researcher, as well as ongoing contact with another GP and GP-liaison psychiatrist. The realist review was supported by a librarian and NIHR research fellow, with no prior mental health research experience. A second rater also supported the thematic analysis, to avoid potential biases.

Future research

In realist terms, any intervention, in this case medication reviews, is a ‘theory incarnate’ – it has a theoretical underpinning, whether it is made explicit or not (RAMESES Guidelines II – Developing Realist Programme Theories, 2017). The PhD has outlined why medication reviews are currently not completed thoroughly, in what contexts, and what factors may help to improve medication reviews in primary care for those stable SUs on long term antipsychotic medication.

Future research should include qualitative interviews with service users and their carers, on the CMOCs identified in the realist review. This could allow further refinement of the programme theory and ensure that service user and carer views are adequately considered. Ethnographic studies observing medication reviews in a select number of GP practices could also give valuable insights.

The PhD’s recommendations also need to be evaluated. Further research should explore how the recommendations can be implemented and evaluate the implementation, to see if the outlined barriers can be overcome. A process evaluation and ethnographic approaches may be a suitable methodologies, as they align with realist methodology. Such studies would allow further data collection on how the recommendations identified in this PhD, if implemented, affect service provision and the GP – service user interaction and can lead to further refinement of the programme theory, with the goal of improving trust, shared decision-making, and overall physical health, as outlined above.

Any future research should include meaningful stakeholder input throughout and is best co-produced with people who are under primary care only. As outlined in Chapter 3 (Service user interviews), future research should also aim to include less engaged service users, who may have reduced or come off their medication covertly, or do not attend for regular reviews. It is important to include these sub-groups, to ensure that any guidance developed from this work is useful to all service users who are under primary care only. Particular attention should also be paid to the needs of ethnic minorities accessing services. Further refinement in this area is required to ensure that services are acceptable to all.

Research in this area is made more difficult by the lack of data linkage between primary and secondary care. It is not possible to easily identify who is under secondary care and who is not, and equally whether yearly physical health checks were completed or not. If GPs and psychiatrists were able to see each other’s notes on the patient records system, better communication may be possible, potentially improving patient care. It would also ensure that GPs have a more accessible and accurate record of which service users are still under secondary care, and who is not. This would allow them to tailor their reviews and focus their efforts on those service users, who are not regularly reviewed in secondary care. Service user satisfaction may also increase, as information would not need to be repeated between primary and secondary care appointments. This is an issue service users highlight throughout. The likelihood of key information not being shared with either primary or secondary is also reduced, if both services can access the same notes. It is unclear if there are any disadvantages to data sharing; it is possible that service users may not wish to share certain information with their psychiatrist or their GP, and some information should potentially not be shared with the other service. Future research should explore this.

As highlighted in the introduction, a study by Garcia et al (2019), in which specifically Chinese and Latino communities were interviewed in primary care about their mental health needs, they found that people with limited English proficiency, regardless of ethnicity, had higher unmet mental health needs than those with English proficiency, illustrating that language proficiency, in addition to ethnicity, must be considered by health services. Services must ensure that they are able to cater to people of all levels of understanding of English, in addition to ensuring that they are culturally appropriate. Future research should explore this in more depth.

Future research should also evaluate the recommendations outlined above, for example test out whether the suggested exit plans are beneficial. Exit plans must be meaningful and should not include superficial notes on the service user and antipsychotic medication in general. Whereas it is not possible to predict when and how each person should reduce their medication, psychiatrists could include information on risk factors, such as risk to self and others, as well as metabolic risk factors. It could also include an indication of when a reduction could be considered, and in which context. Ideally, the letter is co-produced with the service user who is about to be discharged. The effect of co-producing an exit letter should be examined; it may improve trust, shared decision making, and may ensure that service users continue to engage with their GP and/or attend yearly health reviews.

Conclusion

The PhD explores a previously neglected area of research, antipsychotic medication review in primary care, for Service Users diagnosed with SMI, who are no longer under secondary care. The final programme theory outlines barriers to effective communication between GPs and Service Users, with a lack of trust and increased uncertainty at its core. The PhD outlines how a trusting relationship has the potential to not only improve antipsychotic medication reviews, but to improve the person's mental and physical health overall. It can result in improved shared decision making, a key NHSE recommendation. This may allow service users to engage in treatment decisions more meaningfully, and offer real choice and empowerment. This has far reaching implications, including safer prescribing, increased service user engagement and help seeking. Increased information sharing may improve treatment decisions and lead to fewer discontinuations without clinician support. In turn, this can improve the use of NHS resources, reduce the number of inpatient admissions, for both physical and mental health issues.

Research estimates that the number of service users under primary care only is on the increase; therefore this issue requires urgent attention. The PhD highlights that these service users may be a neglected group who fall between the remits of different services. Therefore, it is important that the recommendations listed here implemented (as outlined above) to ensure evidence-based treatment.

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Appendix

Appendix 1 Search Terms

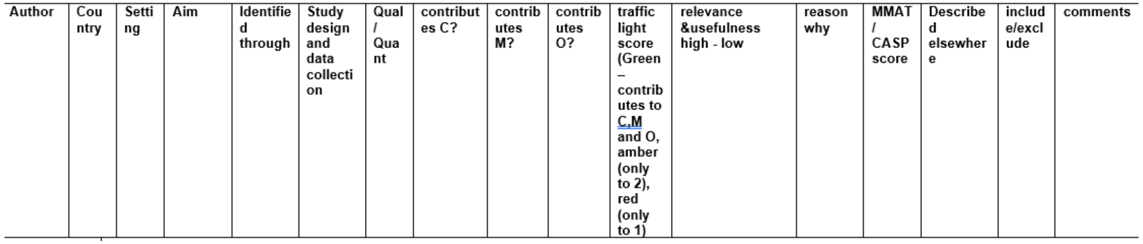
1.2 Main Search Strategy

: ~"(((antipsychotic*).ti,ab OR (exp "TRANQUILIZING AGENTS"/ OR exp "ANTIPSYCHOTIC AGENTS"/) OR (anti-psychotic*).ti,ab OR (neuroleptic*).ti,ab OR ("major tranquiliser*").ti,ab OR ("major tranquilizer*").ti,ab OR (atypical*).ti,ab) AND (("general practice*").ti,ab OR ("general practitioner*").ti,ab OR exp PHYSICIANS/ OR exp "GENERAL PRACTITIONERS"/ OR exp "GENERAL PRACTICE"/ OR exp "GENERAL PRACTICE"/ OR exp "GENERAL PRACTITIONERS"/ OR (GP*).ti,ab OR ("family practice*").ti,ab OR exp "GENERAL PRACTICE"/ OR exp "FAMILY PRACTICE"/ OR (physician*).ti,ab OR *PHYSICIANS/ OR *"GENERAL PRACTITIONERS"/ OR *PHYSIATRISTS/ OR *"PHYSICIANS, FAMILY"/ OR *"PHYSICIANS, PRIMARY CARE"/ OR ("primary care").ti,ab OR exp "PRIMARY HEALTH CARE"/ OR ("primary health care").ti,ab OR (pharmacy).ti,ab OR *PHARMACY/ OR *"PHARMACY RESEARCH"/ OR exp *"COMMUNITY PHARMACY SERVICES"/ OR (pharmacist*).ti,ab OR exp PHARMACISTS/ OR ("nurse prescriber").ti,ab)) [DT 1954-2018] [Human age groups Young adult OR Adult OR Middle Aged OR Aged OR Aged,80 and over] [Languages English] [Humans]**"**

1.2 Iterative Search Strategy – conducted in google scholar

(GP OR General practitioner OR Primary care) AND (stigma OR stereotype) AND (severe mental illness OR SMI OR schizophrenia OR psychosis)

3. Additional File : Data extraction tool template (adjusted from Seth Graham et al & Jagosh et al).



Author	Country	Setting	Aim	Identified through	Study design and data collection	Qual / Quant	contributes C?	contributes M?	contributes O?	traffic light score (Green – contributes to C,M and O, amber (only to 2), red (only to 1)	relevance &usefulness high - low	reason why	MMAT / CASP score	Described elsewhere	include/exclude	comments

Appendix 2 Overall Quality Appraisal

Overall quality appraisal – sorted by quality appraisal tool.

TABLE 2 PAPERS ASSESSED USING CASP

First author	country	setting	Aim	Study Design and data collection	Traffic light score	Relevance & Usefulness	S1	S2	1	2	3	4	5	6	7	8
Britten, 2010	UK	SC	Describe lay perspectives on prescribed psychotropic medicines.	Systematic review of qualitative studies	Green (C,M,O)	High	y	y	y	n	y	y	y	y	n	n/a

TABLE 3 PAPERS ASSESSED USING MMAT

First author	country	setting	Aim	Study Design and data collection	Traffic light score	Relevance & Usefulness	Qual Appraisal	S1	S2	1	2	3	4	5
Adams, 2007	USA	SC	Perceived roles and preferences were explored for shared decision making among persons with severe mental illnesses.	Questionnaire	Amber (C,O)	Low	MMAT	y	y	y	y	y	n	y
Aref-Adib, 2016	UK	SC	To explores the nature, extent and consequences of online mental health information seeking behaviour by people with psychosis and to investigate the acceptability of a	Qualitative interviews	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	y	y

			mobile mental health application (app).											
Boardman, 2008	Australia	SC + GP	To describe SUs' access to and satisfaction with health care professionals, including nurses, as related to users' antipsychotic medication concerns.	Questionnaire	Green (C,M,O)	High	MMAT	y	y	y	m	y	m	y
Carr, 2004	Australia	PC	To examines the attitudes and roles of Australian GPs in the treatment of schizophrenia and their relationships with specialist services.	Questionnaires (completed by GPs, mental health staff and service users)	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	m	?
Carrick, 2004	UK	SC	To outline the experience of taking antipsychotic medication	Qualitative interviews + focus group	Amber (C,M)	Moderate	MMAT	y	y	y	y	y	m	y
Crawford, 2014	UK	SC + GP	To examine the quality of assessment and treatment of physical health problems in people with schizophrenia.	Audit of routine data + questionnaire	Amber (C,O)	Low	MMAT	Y	y	y	y	y	n	y

Delman, 2015	USA	SC	To explore factors influencing active participation of young SU in psychotropic medication decision making	Qualitative interviews	Green (C,M,O)	High	MMAT	y	y	y	y	y	y	y
Dixon, 2008	UK	PC	We describe a study of the attitudes and predicted behaviours of medical students towards patients with mental illness in primary care. To investigate the effects that level of undergraduate medical training and personal characteristics might have on responses.	Vignettes (either schizophrenia, depression, diabetes or no illness) and questionnaire	Amber (C,O)	Moderate	MMAT	y	y	y	y	y	y	y
Feeney, 2006	Ireland	SC	To examine the knowledge and experiences of side-effects and their monitoring in patients prescribed atypical antipsychotic medications.	Questionnaire	Green (C,M,O)	Moderate	MMAT	Y	Y	Y	Y	Y	Y	y
Galon, 2012	USA	PC	To describe the social process of engagement in primary care	Qualitative interviews	Green	Moderate	MMAT	y	y	y	y	y	y	y

			treatment from the perspective of persons with SPMI.		(C,M,O)									
Happell, 2004	Australia	SC	To examine the experiences of consumers, specifically in relation to education and decision making with regards to medication.	Focus group	Green (C,M,O)	High	MMAT	y	y	y	y	y	y	Y
Johnson, 1997	UK	mixed	To assess length of time considered suitable for treatment of schizophrenia	Teleconference between consultant psychiatrists, GPs, pharmacists and CPNs + Questionnaire + commentary	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	Y	n
Kendrick, 1995	UK	PC	To assess the impact of teaching general practitioners to carry out structured assessments of their long term mentally ill patients.	RCT of structured assessments vs TAU	Green (C,M,O)	Moderate	MMAT	y	y	n	y	y	n	Y

Lawrie, 1998	UK	PC	To examine the attitudes of general practitioners to patients with different psychiatric and medical illnesses.	Vignettes	Green (C,M,O)	High	MMAT	y	y	y	y	n	y	y
LeGeyt, 2016	UK	SC	To explore personal accounts of making choices about taking medication prescribed for the treatment of psychosis (neuroleptics).	Qualitative Interviews	Green (C,M,O)	High	MMAT	y	y	y	y	y	y	Y
Lester, 2005	UK	PC	To explore the experience of providing and receiving primary care from the perspectives of primary care health professionals and patients with SMI respectively	Focus group	Green (C,M,O)	High	MMAT	y	y	y	y	y	y	Y
Lester, 2003	UK	PC	This study aimed to explore the elements of satisfaction with primary care for people with schizophrenia.	Qualitative interviews	Green (C,M,O)	High	MMAT	y	y	y	y	y	y	y

Magliano, 2017	Italy	PC	To investigate GPs' views of schizophrenia and whether they were influenced by a 'schizophrenia' label, passively accepted or actively used.	Vignette + Questionnaire		High	MMAT	y	y	y	y	y	y	y
Maidment, 2011	UK		To develop understandings of the nature and influence of trust in the safe management of medication within mental health services	Focus groups	Green (C,M,O)	High	MMAT	y	y	y	y	y	y	y
McDonnell, 2011	USA	PC	This study assessed barriers to metabolic care for persons with serious mental illness (SMI) by surveying experienced healthcare providers.	Questionnaire	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	y	y
Mortimer, 2005	UK	PC	To audit and intervene in the suboptimal prescribing of antipsychotic drugs to primary care patients.	Audit + intervention study	Amber (C,O)	Moderate	MMAT	y	y	y	?	y	n	Y

Morrison, 2015	Australia	SC	The present study explores people's experience of living with antipsychotic medication side-effects	Qualitative interview	Green (C,M,O)	High	MMAT	y	y	y	y	y	n	y
Oud, 2009	UK	PC	Responsibility and nature of care for people with SMI was explored from a GP perspective	Questionnaire	Amber (C,O)	Moderate	MMAT	y	y	y	y	y	n	y
Pereira, 1997	UK	SC	To assess the acceptability of depot among those patients receiving medication via this route and, finally, to assess the views of subjects receiving oral medication about depot.	Questionnaire	Amber (C,O)	Moderate	MMAT	y	y	y	y	y	y	y
Pilgrim, 1993	UK	PC	positive and negative views about general practitioners (GPs) and psychiatrists are examined.	Questionnaire (with open ended Q)	Green (C,M,O)	High	MMAT	y	y	y	y	y	y	ct*
Roe, 2009	Israel	SC	The purpose of the present study was to explore why and how people with a serious mental illness (SMI) choose to	Qualitative interviews	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	y	y

			stop taking prescribed medication											
Rogers, 1998	UK	SC	To describe the meaning and management of neuroleptic medication by people who have received a diagnosis of schizophrenia.	Qualitative interviews	Green (C,M,O)	High	MMAT	y	y	y	y	y	?	n
Salomon, 2013	Australia	SC	The purpose of the survey was to better understand the experiences of people who attempt antipsychotic discontinuation.	Questionnaire	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	y	y
Schachter, 1999	Canada	PC	To educate about informed consent	Survey	Amber (C,M)	Moderate	MMAT	y	y	y	y	y	y	y
Seale,2007	UK	SC	To explore how discussions about side effects are managed in practice	Observational study + Conversation Analysis	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	y	y
Toews,	Canada	PC	To assess family physician learning needs related to the	Questionnaire	Green	Moderate	MMAT	y	y	y	?	y	n	y

1996			care of patients with schizophrenia.		(C,M,O)									
Tranulis, 2011	Canada	SC	To explore views on illness and medication use and emphasized key turning points, such as periods of nonadherence and illness relapses.	Qualitative interviews	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	y	Y
Usher, 2001	Australia	SC	To explore the experience of taking neuroleptic medications from the individual's perspective	Qualitative interviews	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	y	y
Younas, 2016	UK	PC	To explore the views and experiences of UK mental health pharmacists regarding the use of SDM in antipsychotic prescribing in people diagnosed with SMI.	Qualitative Interviews	Green (C,M,O)	Moderate	MMAT	y	y	y	y	y	y	y

- ct = can't tell

TABLE -0 NON QUALITY ASSESSED PAPERS

First author	country	setting	Aim	Study Design and data collection	Traffic light score	Relevance & Usefulness
BMJ News, 1995	UK	SC	news report	News report	Green (C,M,O)	Moderate
Burns, 1997	UK	PC	To develop practice for establishing a register and organizing regular reviews; comprehensive assessments; information and advice for patients and carers; indications for involving specialist services; and crisis management.	Consensus group developed good practice guidelines based on current literature	Green (C,M,O)	High
Corrigan, 2000	USA	G	To illustrate how attribution model advances research questions related to mental health stigma	Non-systematic literature review	Green (C,M,O)	High
Corrigan, 2013	USA	G	Review of existing research regarding public stigma reduction, looking at approaches within mental health and other stigmatised communities.	Non-systematic literature review	Green (C,M,O)	High
Donlon,1987	USA	PC	Overview of care of schizophrenia in primary care	Non – systematic literature review	Amber (C,O)	Moderate

Hustig, 1998	Australia	PC	Overview of care of schizophrenia in primary care	MJA Practice Essentials (non systematic literature review)	Amber (C,M)	low
Jones, 1987	USA	PC	overview of care of schizophrenia in primary care	Non – systematic literature review	Amber (C,M)	Moderate
Jones, 2015	UK (but studies from all over)	PC	overview of care of schizophrenia in primary care	Non – systematic literature review	Green (C,M,O)	High
Katschnig, 2018	Austria	SC	To discuss the origins of the idea of a chronic brain disease, of the split personality concept derived from the term "schizophrenia" , and the craziness idea reflected in the "first rank symptoms", which are all hallucinations and delusions .	Non – systematic literature review	Amber (C – "split personality", Lack of expectations, M fear)	Moderate
Lambert, 2009	USA mostly	PC	barriers of physical health testing in primary care	Non systematic literature review	Green (C,M,O)	Moderate
Royal College of	UK	SC	Report to combat and reduce stigmatisation of people with mental disorders.	Non – systematic literature review	Amber (C,M)	Moderate

Psychiatrists						
Mitchel & Selmes, 2007	UK	SC	To discuss patients' reasons for failure to concord with medical advice, and predictors of and solutions to the problem of nonadherence.	Non – systematic literature review	Green (C,M,O)	Moderate
Morant, 2016	UK	SC	This conceptual review argues that several aspects of mental health care that differ from other health-care contexts may impact on processes and possibilities for SDM.	Conceptual review	Green (C,M,O)	High
Mortimer, 2004	UK	PC	Review on antipsychotic prescribing	Non – systematic literature review	Green (C,M,O)	Low
NICE, 2014	UK	SC	Guidelines on treatment and management	Evidence based guideline	Amber (C,O)	Low
Rasmussen 2006	UK	PC	Overview of care of people with SMI for GPs	Non – systematic literature review	Green (C,M,O)	High
Schizophrenia Commission, 2012	UK	G	To examine the provision of care for people living with psychotic illness.	Non-systematic literature review + survey + visits to services	Amber (C,M)	Low

Schulze, 2017	Switzerland	SC	To explore ways in which mental health professionals are 'entangled' in anti-stigma activities. It will outline the complex relationships between stigma and the psychiatric profession, presenting evidence on how its members can stigmatizers, stigma recipients and powerful agents of de-stigmatization.	Non – systematic literature review	Green (C,M,O)	Moderate
Viron,2012	USA	PC	This review provides primary care providers with a general understanding of the psychiatric and medical issues specific to patients with schizophrenia and a clinically practical framework for engaging and assessing this vulnerable patient population	Non- systematic literature review	Green (C,M,O)	Moderate

Appendix 3 Individual Quality Appraisal

Following the development of specific Context, Mechanism and Outcome Configurations (CMOCs, see Glossary), each was quality assessed. The overall quality of the data included in the development of each CMOC was considered in relation to several criteria. For each CMOC, included data was first assessed in relation to its contribution of information relating to C, M or O (as above). Scores were given accordingly: A - papers providing evidence on C, M and O relevant to this CMOC, B - papers providing evidence on only two of the three (C, M, O) criteria or C - providing information only on one of C, M or O). Secondly, relevance was further assessed on a 3 point scale of A to C: A - papers of high relevance to the CMOC, B- papers of moderate relevance to the CMOC and C- low relevance. The closer the data was to discussing C,M or O in primary care, for people diagnosed with SMI and treated with antipsychotics, the higher the relevance. Reasons for each scoring was recorded for transparency. Thirdly, the quality of the evidence was assessed, again on a A-C scale: A - evidence was derived directly through the studies' findings B -evidence was taken from the discussion, based on the study's findings (this allows for the inclusion of the authors suggestions on the nature of their findings) and C - taken from the introduction or from a non-systematic literature review, opinion or editorial. LG completed this assessment for each individual CMOC, any queries were discussed with CD and resolved by discussion.

TABLE 5 CMOC1 LOW EXPECTATIONS

First author, year	**Country**	**Setting**	**Aim**	**Study design and data collection**	**Dimensions of relevance**	**Strength of relevance**	**Methodological quality**
Burns, 1997	UK	PC	To develop practice for establishing a register and organizing regular reviews; comprehensive assessments; information and advice for patients and carers; indications for involving specialist services; and crisis management.	Consensus group developed good practice guidelines based on current literature	B (C- aware of risks, medication indefinitely, O - do not intervene often)	B relevant, no M though	B vague methodology but regardless finding from study
Carrick, 2004	UK	SC	To outline the experience of taking antipsychotic medication	Qualitative interviews + focus group	C - lack of hope, uncertainty of treatment and trajectory, M fear of	C little relevance	A from findings

First author, year	Country	Setting	Aim	Study design and data collection	Dimensions of relevance	Strength of relevance	Methodological quality
					relapse, low expectations		
Dixon, 2008	UK	PC	We describe a study of the attitudes and predicted behaviours of medical students towards patients with mental illness in primary care. To investigate the effects that level of undergraduate medical training and personal characteristics might have on responses.	Vignettes (either schizophrenia, depression, diabetes or no illness) and questionnaire	A (C - diagnosis, M - stigma, negative views O - GP less likely to take action	B - not GPs but trainees	A (taken from results section, empirical finding)
Donlon,1987	USA	PC	Overview of care of schizophrenia in primary care	Non – systematic literature review	B (C - low expectations, medication required indefinitely O - no action taken)	B thin on M	C (non systematic lit review)

First author, year	Country	Setting	Aim	Study design and data collection	Dimensions of relevance	Strength of relevance	Methodological quality
Galon, 2012	USA	PC	To describe the social process of engagement in primary care treatment from the perspective of persons with SPMI.	Qualitative interviews	C- stereotype, don't value treatment despite evidence otherwise	B relevant but thin	C from intro
Happell, 2004	Australia	SC	To examine the experiences of consumers, specifically in relation to education and decision making with regards to medication.	Focus group	B (C - medication required indefinitely M - patients feel hopeless	B not GP	A (taken from study findings)
Hustig, 1998	Australia	PC	Overview of care of schizophrenia in primary care	MJA Practice Essentials (non systematic literature review)	B (C- low expectations, M - feel hopeless "not much you can do")	B (plenty of low expectations, but little on what action results)	C (non systematic lit review)
Johnson, 1997	UK	mixed	To assess length of time considered suitable for treatment of schizophrenia	Teleconference between consultant psychiatrists, GPs, pharmacists and CPNs	**C** (C - medication required indefinitely)	C low relevance, but shows that medication is required	A - finding from results

First author, year	**Country**	**Setting**	**Aim**	**Study design and data collection**	**Dimensions of relevance**	**Strength of relevance**	**Methodological quality**
				+ Questionnaire + commentary		indefinitely for most	
Jones, 1987	USA	PC	overview of care of schizophrenia in primary care	Non – systematic literature review	A (C low expectations, M - hopeless, burnout O don't see too many with SMI, refusal to provide treatment)	A high relevance, SMI in primary care	C (non systematic lit review)
Jones, 2015	UK (but studies from all over)	PC	overview of care of schizophrenia in primary care	Non – systematic literature review	A (low expectations, feeling hopeless, not confident, O -don't see)	A high relevance, setting specific	C (non systematic lit review)

First author, year	Country	Setting	Aim	Study design and data collection	Dimensions of relevance	Strength of relevance	Methodological quality
Katschnig, 2018	Austria	SC	To discuss the origins of the idea of a chronic brain disease, of the split personality concept derived from the term “schizophrenia” , and the craziness idea reflected in the “first rank symptoms”, which are all hallucinations and delusions .	Non – systematic literature review	C(C - "death sentence", no recovery, split personality)	B (relevant, little on M or O though)	C (non systematic lit review)
Kendrick, 1995	UK	PC	To assess the impact of teaching general practitioners to carry out structured assessments of their long term mentally ill patients.	RCT of structured assessments vs TAU	C (lack of time for assessments, reviews don’t result in changes)	B (probably won't do assessments if changes aren’t obvious)	A (RCT)
Lambert, 2009	USA mostly	PC	barriers of physical health testing in primary care	Non systematic literature review	**A** (C - barriers M - therapeutic nihilism O - tests not performed)	B (in physical health mainly rather than MH)	C (non systematic lit review)

First author, year	Country	Setting	Aim	Study design and data collection	Dimensions of relevance	Strength of relevance	Methodological quality
Lawrie, 1998	UK	PC	To examine the attitudes of general practitioners to patients with different psychiatric and medical illnesses.	Vignettes	A (C neg views of schizophrenia - M - low expectations/ scared/ avoid O - unclear what outcomes of these negatives stereotypes are , to what degree do they interfere)	A (primary care, SMI	A study finding
LeGeyt, 2016	UK	SC	To explore personal accounts of making choices about taking medication prescribed for the treatment of psychosis (neuroleptics).	Qualitative Interviews	C (medication main option M - risk aversion O - little to do in terms of recovery)	B not GP	C from intro
Lester, 2005	UK	PC	To explore the experience of providing and receiving primary care from the perspectives of	Focus group	A (C - chronic long term condition, meds for life,	A - highly relevant	A (findings from study)

First author, year	Country	Setting	Aim	Study design and data collection	Dimensions of relevance	Strength of relevance	Methodological quality
			primary care health professionals and patients with SMI respectively		unrealistic expectations M no hope given, low expectations O "write him off"		
Lester, 2003	UK	PC	This study aimed to explore the elements of satisfaction with primary care for people with schizophrenia.	Qualitative interviews	A (low expectations, feeling hopeless, not confident O - don't have goals)	A high relevance, setting specific	A (study finding)
Magliano, 2017	Italy	PC	To investigate GPs' views of schizophrenia and whether they were influenced by a 'schizophrenia' label, passively accepted or actively used.	Vignette + Questionnaire	A (negative views of schizophrenia, diagnostic label specific, worse outcomes, prefer others to deal, risk)	A v relevant	A (study findings)

First author, year	**Country**	**Setting**	**Aim**	**Study design and data collection**	**Dimensions of relevance**	**Strength of relevance**	**Methodological quality**
Morant, 2016	UK	SC	This conceptual review argues that several aspects of mental health care that differ from other health-care contexts may impact on processes and possibilities for SDM.	Conceptual review	C (professional pessimism)	B (relevant, but little detail and no M or O)	C (non systematic lit review)
Morrison, 2015	Australia	SC	The present study explores people's experience of living with antipsychotic medication side-effects	Qualitative interview	**B** (M=hopelessness, O = give up)	**B** (relevant but in secondary care, not GP)	**A** (taken from results section, empirical finding of interview study)
Mortimer 2005	UK	PC	To audit and intervene in the suboptimal prescribing of antipsychotic drugs to primary care patients.	Audit + intervention study	**A** (C - lack of GP interest, lack of diagnosis, sec advising against changes , institutional barriers, M - fear of making change	**B (**relevant, but not 100% on stereotypes)	**A (**largely taken from findings, only last comment from discussion).

First author, year	**Country**	**Setting**	**Aim**	**Study design and data collection**	**Dimensions of relevance**	**Strength of relevance**	**Methodological quality**
					against advice, M - unawareness (institutional barrier, oversight, O - no changes made)		
Pereira, 1997	UK	SC	To assess the acceptability of depot among those patients receiving medication via this route and, finally, to assess the views of subjects receiving oral medication about depot.	Questionnaire	C (C -indefinite medication)	C (low relevance)	A from findings
Pilgrim, 1993	UK	PC	positive and negative views about general practitioners (GPs) and psychiatrists are examined.	Questionnaire (with open ended Q)	A(C- (perceived?) lack of empathy, stigma? M- indifference, O- lack of engagement)	A high relevance,	A from findings

First author, year	**Country**	**Setting**	**Aim**	**Study design and data collection**	**Dimensions of relevance**	**Strength of relevance**	**Methodological quality**
Toews, 1996	Canada	PC	To assess family physician learning needs related to the care of patients with schizophrenia.	Questionnaire	**B** (C see very few patients -M - SMI is problematic/ negative views O - prefer not to see	**A** high relevance, SMI in primary care	**A** taken from findings of study
Tranulis, 2011	Canada	SC	To explore views on illness and medication use and emphasized key turning points, such as periods of nonadherence and illness relapses.	Qualitative interviews	B (C -chemical imbalance, M - medication considered helpful O - taking medication indefinitely)	B relevant, impact of chemical imbalance theory rather than acutely unwell vs stable	A taken from findings of study
Viron, 2012	USA	PC	This review provides primary care providers with a general understanding of the psychiatric and medical issues specific to patients with schizophrenia and a clinically practical framework for	Non- systematic literature review	**A** (C- limited experience, complex regimen M - feel SU cannot manage, therapeutic nihilism O - effective	**A** v relevant, PC, SMI	**C** (non systematic lit review)

First author, year	**Country**	**Setting**	**Aim**	**Study design and data collection**	**Dimensions of relevance**	**Strength of relevance**	**Methodological quality**
			engaging and assessing this vulnerable patient population		measures not offered to patient		

TABLE 06 CMOC2 LACK OF CAPABILITY

First author, year	Country	Setting	Aim	Study design and data collection	Dimensions of relevance	Strength of relevance	Methodological quality
Adams, 2007	USA	SC	Perceived roles and preferences were explored for shared decision making among persons with severe mental illnesses.	Questionnaire	**C** (M - wishing for more active role)	**C (active role - but why/how etc).**	**A** (taken from findings)
Boardman, 2008	Australia	SC + GP	To describe SUs' access to and satisfaction with health care professionals, including	Questionnaire	**B** (C - not satisfied with GP, stigma, M trust in relationships, SDM)	**B** (trust is important facilitator,	**C** (largely taken from intro and discussion)

			nurses, as related to users' antipsychotic medication concerns.			largely not in PC though)	
Britten, 2010	UK	SC	Describe lay perspectives on prescribed psychotropic medicines.	Systematic review of qualitative studies	C - focus on adherence, coercion M -non adherence = lack of insight or lack of comprehension/ irrational, doctor knows best , C- nonadherence O - no access to future care, M fear of coercion/social sanctions O - covert medication use	A v relevant, good model of medication	A (largely taken from findings)
Carrick, 2004	UK	SC	To outline the experience of taking antipsychotic medication	Qualitative interviews + focus group	A (C - power imbalance, doctors priorities different to SU, lack of adherence	B (relevant but not specific enough)	B came from findings but potentially biased sample - all authors and

					O sectioning, M fear of sectioning O people might not take what they are prescribed, C issues of control		then convenience sample,
Delman, 2015	USA	SC	To explore factors influencing active participation of young SU in psychotropic medication decision making	Qualitative interviews	A(C-barriers to communication is a lack of M- trust, C cognitive issues, psychiatrist paternalism, M - youth cannot make good decisions, O - do not ask youth about choices, C- issues around capacity, M not treated equally)	A v relevant	B mixture of intro findings and discussion
Donlon,1987	USA	PC	Overview of care of schizophrenia in primary care	Non – systematic	C (C - need for doctors guidance)	C – vague	C (non systematic lit review)

				literature review			
Galon, 2012	USA	PC	To describe the social process of engagement in primary care treatment from the perspective of persons with SPMI.	Qualitative interviews	B (C- diagnosis of SMI, O - more likely to go to A&E than GP; fear of sectioning prevents them from going to seek help	B - relevant, no M though	B from discussion
Happell, 2004	Australia	SC	To examine the experiences of consumers, specifically in relation to education and decision making with regards to medication.	Focus group	C (C - diagnosis -M - undermines SU credibility O - queries dismissed, requests "questionable" M - feel like have no voice, M - SU fear of repercussions O - did not discuss medication with doctors, O - alter medications without	A - v relevant	A taken from findings

					consultation to deal with side effects		
Schachter, 1999	Canada	PC	To educate about informed consent	Survey	C - doctors know patients, many are not symptomatic	C- low relevance, GPs not likely to know patients now maybe?	A (taken from findings)
Johnson, 1997	UK	mixed	To assess length of time considered suitable for treatment of schizophrenia	Teleconference between consultant psychiatrists, GPs, pharmacists and CPNs + Questionnaire + commentary	C- medication prescribed long term, any relapse to be seen as evidence of non compliance, doctors seen as non compliant if they don't prescribe	B - high relevance, illustrates pressure, fear of consequences, tension between GP and patient, tension between GP and GP as want to be	B - discussion section

						seen as doing a good job	
Kendrick, 1995	UK	PC	To assess the impact of teaching general practitioners to carry out structured assessments of their long term mentally ill patients.	RCT of structured assessments vs TAU	C (C-proactive care)	B (not the most relevant as its just about proactive care, but its SMI and GP)	B (taken intro, authors are GPs)
LeGeyt, 2017	UK	SC	To explore personal accounts of making choices about taking medication prescribed for the treatment of psychosis (neuroleptics).	Qualitative Interviews	C- in primary care, GP not confident and O - do not act, in C of MH services, M - fear of sectioning, uncertainty over help from GP O - go rouge	B v relevant, but largely secondary care, then again they didn't even consider GP as person to discuss this with/said GP	A largely taken from findings

						would get involved	
Lester, 2005	UK	PC	To explore the experience of providing and receiving primary care from the perspectives of primary care health professionals and patients with SMI respectively	Focus group	A (C- diagnosis O - difficulties in talking, M lack of knowledge and confidence, C - historical pessimism, lifelong illness)	B primary care, SMI, thin on mechanism though	B - largely taken from findings/ discussions, some anecdotal/interpretation in discussion
Lester, 2003	UK	PC	This study aimed to explore the elements of satisfaction with primary care for people with schizophrenia.	Qualitative interviews	A (C- diagnosis O - not participating in discussions, M fear of coercion, stereotyped view, not included in conversations, do not influence outcome	B v relevant, GP, SMI, primary care	A - study findings
Maidment, 2011	UK		To develop understandings of the	Focus groups	A (C coercion, uncertainty, M – trust,	B not PC	A - largely findings

			nature and influence of trust in the safe management of medication within mental health services		O – adherence, better relationship)		
McDonnell, 2011	USA	PC	This study assessed barriers to metabolic care for persons with serious mental illness (SMI) by surveying experienced healthcare providers.	Questionnaire	B - C patient psychosis/depression, o - no review/barrier to review	B important context, mainly given by GPs, but no M	B - taken from study findings, but study methodologically not the best
Royal College of Psychiatrists	UK	SC	Report to combat and reduce stigmatisation of people with mental disorders.	Non – systematic literature review	B (M- stigmatisation, O- do not talk, o- devalue views, C - SU seen as not having capacity, M - paternalistic behaviour)	A v relevant	C (non systematic lit review)

Katschnig, 2018	Austria	SC	To discuss the origins of the idea of a chronic brain disease, of the split personality concept derived from the term “schizophrenia” , and the craziness idea reflected in the “first rank symptoms”, which are all hallucinations and delusions .	Non – systematic literature review	C(C - "death sentence", no recovery, split personality)	B (relevant, little on M or O though)	C (non systematic lit review)
Mitchel & Selmes, 2007	UK	SC	To discuss patients’ reasons for failure to concord with medical advice, and predictors of and solutions to the problem of nonadherence.	Non – systematic literature review	B (O stop medication without consultation, M side effects, fear of rejection or being disbelieved)	B - relevant, but not GP specific, (would they tell their GP?)	C (non systematic lit review)

Morant, 2016	UK	SC	This conceptual review argues that several aspects of mental health care that differ from other health-care contexts may impact on processes and possibilities for SDM.	Conceptual review	A (C history of coercion, M not taken seriously, O – changes to medication without prior consultation)	B not GP	C (non systematic lit review)
Mortimer, 2005	UK	PC	To audit and intervene in the suboptimal prescribing of antipsychotic drugs to primary care patients.	Audit + intervention study	C (C- people who were identified in an audit as needing medication changes were all mildly symptomatic (maybe that's why changes in medication were needed)	C (GP and SMI, but little relevance)	A (finding of empirical study)
NICE, 2014	UK	SC	Guidelines on treatment and management	Evidence based guideline			

Oud, 2009	UK	PC	Responsibility and nature of care for people with SMI was explored from a GP perspective	Questionnaire	C (C - call for more practice care, C SU with SMI seen as having disturbances and retardation (paper is from 2009!!?)	B - SMI and GP, but not as relevant)	B - taken from intro and discussion of paper
Pereira, 1997	UK	SC	To assess the acceptability of depot among those patients receiving medication via this route and, finally, to assess the views of subjects receiving oral medication about depot.	Questionnaire	C (C doctors chose medication, medication helpful, no perceived benefit from medication	C – no M or O, low relevance	A - findings
Pilgrim, 1993	UK	PC	positive and negative views about general practitioners (GPs) and	Questionnaire (with open ended Q)	A (C - experience of not being taken seriously, O - told to go	A v relevant	A – taken from findings

			psychiatrists are examined.		away, M- diagnostic overshadowing.		
Roe, 2009	Israel	SC	The purpose of the present study was to explore why and how people with a serious mental illness (SMI) choose to stop taking prescribed medication	Qualitative interviews	A (C- coercion, M fearful, O - do not discuss/ hide decision, C - stigma, M - doctors frustrations at not taking medication, O- SU not part of decision making process, questioning medication means getting their sanity questioned	B v relevant but not GP	A largely taken from findings
Rogers, 1998	UK	SC	To describe the meaning and management of neuroleptic medication by people who have	Qualitative interviews	A (history of coercion, fearful of sectioning, do not discuss medication, reduce in secret) not taken seriously	B relevant but not GP	A taken from findings

			received a diagnosis of schizophrenia.				
Salomon, 2013	Australia	SC	The purpose of the survey was to better understand the experiences of people who attempt antipsychotic discontinuation.	Questionnaire	A (C - side effects M indifference/zombie O - do not want to talk / come across as high?)	B thin on M	A taken from findings
Seale,2007	UK	SC	To explore how discussions about side effects are managed in practice	Observational study + Conversation Analysis	A M fear of sectioning, O - not discuss with doctors, M fear that not taking medication would mean no more specialist services, fear of repercussions, C coercion	B relevant but not GP	A taken from findings & discussion
Seale,2007	UK	SC	To explore how discussions about side	Observational study +	A (C- side effects, M- side effects prevent you from coming	B not GP specific	A from findings

			effects are managed in practice	Conversation Analysis	across as "competent"? and O stop conversations. some of the cognitive impairment could come from side effects		
Seale,2007	UK	SC	To explore how discussions about side effects are managed in practice	Observational study + Conversation Analysis	B (C - side effects, patient visit, M denial or avoidance of complaints)	B – not GP specific	A from findings

Table 7 CMOC 4 Perceived Risk

First author, year	Country	Setting	Aim	Study design and data collection	Dimensions of relevance	Strength of relevance	Methodological quality
BMJ News, 1995	UK	SC	news report	News report	C person with schizophrenia committed homicide, risk continues, need detaining, at the same time attack described as random and unpredictable, medication would have prevented risk behaviour	C - low	C news report
Corrigan, 2000	USA	G	To illustrate how attribution model advances research questions related to mental health stigma	Corrigan, 2000	B (C- symptoms of schizophrenia, M – frightened)	B relevant but not GP specific	C non systematic literature review

Corrigan, 2013	USA	G	Review of existing research regarding public stigma reduction, looking at approaches within mental health and other stigmatised communities.	Non-systematic literature review	B (C – reports of violence, M – seen as more violent than they actually are)	B relevant but not GP specific	C non-systematic literature review
Dixon, 2008	UK	PC	We describe a study of the attitudes and predicted behaviours of medical students towards patients with mental illness in primary care. To investigate the effects that level of undergraduate medical training and personal characteristics might have on responses.	Vignettes (either schizophrenia, depression, diabetes or no illness) and questionnaire	B (C - concerns of violence, affects of media M - more concerned through media dramatization)	B (relevant, but not GP specific)	B - taken from discussion
Hustig, 1998	Australia	PC	Overview of care of schizophrenia in primary care	MJA Practice Essentials (non systematic	C (C- medication reduces suicide attempts, C medication controls	C low - but connotation that aggressive	C - non systematic lit review

				literature review)	aggressive behaviour)	behaviour needs to be remedied with medication warrants inclusion)	
Johnson, 1997	UK	mixed	To assess length of time considered suitable for treatment of schizophrenia	Teleconference between consultant psychiatrists, GPs, pharmacists and CPNs + Questionnaire + commentary	C (C - prophylactic treatment based on inquiry of homicides - M - scared?)	B (relevant, but not GP specific)	B - taken from discussion
Katschnig, 2018	Austria	SC	To discuss the origins of the idea of a chronic brain disease, of the split personality concept derived from the term	Non – systematic literature review	B (C- stereotypes, M - people seen as crazy, insanity)	B (relevant, but nothing on outcomes,	C- non systematic lit review

			"schizophrenia" , and the craziness idea reflected in the "first rank symptoms", which are all hallucinations and delusions .			nothing on GPs)	
Lawrie, 1998	UK	PC	To examine the attitudes of general practitioners to patients with different psychiatric and medical illnesses.	Vignettes	A (C diagnosis, M fear, O prefer psychiatrist to treat)	A (v relevant)	A - results and discussion
LeGeyt, 2017	UK	SC	To explore personal accounts of making choices about taking medication prescribed for the treatment of psychosis (neuroleptics).	Qualitative Interviews	C - concerns about medication, lack of choice, doctors risk aversion, M limits recovery approaches	B – not GP specific, thin on what M would look like in practice	B - taken from discussion
Lester, 2003	UK	PC	This study aimed to explore the elements of satisfaction with primary care for people with schizophrenia.	Qualitative interviews	A(stereotype, M - scared O - refuse to see)	A (v relevant)	A - results and discussion

Magliano, 2017	Italy	PC	To investigate GPs' views of schizophrenia and whether they were influenced by a 'schizophrenia' label, passively accepted or actively used.	Vignette + Questionnaire	A (M - lack of hope for complete recovery, C medication taken indefinitely, M fear, C SMI are risky, C notion that reduction will result in relapse	A (v relevant)	A - taken from findings
McDonnell, 2011	USA	PC	This study assessed barriers to metabolic care for persons with serious mental illness (SMI) by surveying experienced healthcare providers.	Questionnaire	B (C - not my responsibility, M - scared)	B (v relevant but not O)	A - taken from findings
Oud, 2009	UK	PC	Responsibility and nature of care for people with SMI was explored from a GP perspective	Questionnaire	B (scared, threatening, O- prefer psychiatrist input)	B (v relevant, but no C,)	C- taken from intro

Schulze, 2017	Switzerland	SC	To explore ways in which mental health professionals are ‘entangled’ in anti-stigma activities. It will outline the complex relationships between stigma and the psychiatric profession, presenting evidence on how its members can stigmatizers, stigma recipients and powerful agents of de-stigmatization.	Non – systematic literature review	A (C -media fuels perception of danger, M – threatening, scared, O – stigma prevents help seeking)	B (relevant, but not GP specific)	C – taken from non systematic lit review
Rasmussen 2006	UK	PC	Overview of care of people with SMI for GPs	Non – systematic literature review	B (diagnosis, stereotype, scared, view that more dangerous, O - prefer not to get involved)	B (v relevant, but no C,)	C - non systematic lit review

The Schizophrenia Commission	UK	SC	Report	Report	B (C -role of the media, focus on MH difficulty, M - fear, frightening O - stereotypes	B (relevant, but not GP specific, more popular view of SMI)	C - non systematic lit review
Royal College of Psychiatrists	UK	SC	Report to combat and reduce stigmatisation of people with mental disorders.	Non – systematic literature review	A (C- stereotyped views, M- maybe fear? but nothing in text O - isolation, "cannot communicate")	B (relevant, but no GP and no M)	C - non systematic lit review

Table 8 CMOC 3 Lack of information sharing

First auth	**Country**	**Setting**	**Aim**	**Study design and data collection**	**Dimensions of relevance**	**Strength of relevance**	**Methodological quality**

or, year							
Aref-Adib, 2016	UK	SC	To explores the nature, extent and consequences of online mental health information seeking behaviour by people with psychosis and to investigate the acceptability of a mobile mental health application (app).	Qualitative interviews	A (lack of info - M break trust - O discontinue alone, Facilitator: collaborative care	A highly relevant	A study findings
Boardman, 2008	Australia	SC + GP	To describe SUs' access to and satisfaction with health care professionals, including nurses, as related to users' antipsychotic medication concerns.	Questionnaire	B (C GP lack knowledge, C SU feel that GP lack knowledge and are not satisfied with GP management of queries, M SU feel uncomfortable O - may not discuss medication with GP, lack of info given	B low relevance	B - taken from intro and from findings
Britten, 2010	UK	SC	Describe lay perspectives on prescribed psychotropic medicines.	Systematic review of qualitative studies	A (C- lack of info given, M - worries about medication, assess pros and cons but with incomplete info O- stopping	A - v relevant, little on GPs action though	B - taken from intro and from findings

					abruptly (as they have incomplete knowledge)		
Burns, 1997	UK	PC	To develop practice for establishing a register and organizing regular reviews; comprehensive assessments; information and advice for patients and carers; indications for involving specialist services; and crisis management.	Consensus group developed good practice guidelines based on current literature	C (C acceptable to have honest discussion)	C low relevance	C non systematic lit review
Carrick, 2004	UK	SC	To outline the experience of taking antipsychotic medication	Qualitative interviews + focus group	C (C - move towards more info, less paternalistic treatment, increasing emphasis)	C low relevance	C from intro
Crawford, 2014	UK	SC + GP	To examine the quality of assessment and treatment of physical health problems in people with schizophrenia.	Audit of routine data + questionnaire	B (C-lack of info, no action taken for patients with SMI and physical health issues, M - not taken seriously, O necessary treatment not given)	B moderate relevance	B - taken from findings and summarised in discussion

Delman, 2015	USA	SC	To explore factors influencing active participation of young SU in psychotropic medication decision making	Qualitative interviews	B (C- seek info online, M - reassure about effects of medication, double check info given	B - relevant but unclear of outcome, says they would not speak to doctors about info online, but not stated why. Also all psychotropics, not just AP	A from findings
Feeney, 2006	Ireland	SC	To examine the knowledge and experiences of side-effects and their monitoring in patients prescribed atypical antipsychotic medications.	Questionnaire	B (unaware of side effects, do not tell doctor as perception is that doctor is too busy, or embarrassing to tell them, did not know blood tests were recommended, did not	C (relevant, but little on M)	B-taken from intro and study findings

					have them, cognitive impairment not a reason		
Happell, 2004	Australia	SC	To examine the experiences of consumers, specifically in relation to education and decision making with regards to medication.	Focus group	A (C- some people lack of info given at start of taking AP, others not , C - some health professionals trivialise effects of medication C - full info -> O - deal with it better as know what to expect, C - more info about reasons for medication given than side effects, C - MH professionals don't give end date for medication, M - SU feel less in control. C- doctors evasive - O - SU see doctors until they feel comfortable -> so M is feeling uncomfortable??, C- pharmacists provide great info, either verbally or via	A- v relevant	A - taken from findings

					leaflets, O- informed consent cannot exist if too little info is given. C- lack of knowledge of medication? M- too worried about potential bad outcome?		
Schachter, 1999	Canada	PC	To educate about informed consent	Editorial	A (C - responsibility to inform SU of risks, SU need capacity and voluntary decision to take it. O- 83% explained reasons for prescribing, less than half explained serious side effects. M - fear of issues with GP doctor relationship, C - consent for medication not documented (but does it need to be?) M - fear of decreased compliance?, C- sign lack in GPs in discussing negative side effects, C- variability in info given, C pharmacists and	A - highly relevant, barriers to care, facilitators, GP and SMI and AP	A – taken from findings

					nurses stepping in C - few SU actively psychotic in primary care, C - software can help give info about medication, C - in PC, GPs have opportunity to revisit consent when SU is well		
Jones, 2015	UK (but studies from all over)	PC	overview of care of schizophrenia in primary care	Non – systematic literature review	A(C SU think physical health well catered for, when this is not the case, C high risk of other illness when diagnosed with SMI, O- physical health checks fall below standards, M - GP lack confidence, do not know how to talk to people with schizophrenia)	B relevant, thin on mechanisms though	C non systematic lit review
LeGeyt, 2017	UK	SC	To explore personal accounts of making choices about taking medication prescribed for the treatment of psychosis (neuroleptics).	Qualitative Interviews	C - lack of info given, need to learn by yourself through experience, lack of info on side effects, surprised when experienced side effects, not given options with regards of	B relevant, thin on mechanisms though	A taken from findings

					medication, don't allow to question it M, C- wrong information given (chemical imbalance which is cured with medication), M wish to regain control, O explore other options, O lack of discussion, lack of trust		
Maidment, 2011	UK		To develop understandings of the nature and influence of trust in the safe management of medication within mental health services	Focus groups	A(C mental health care, more uncertainty, M trust is harder to achieve, C lack of info given M doctors worried about compliance , O - if SU then does not trust clinician, they won't seek help or give accurate history, C lack of info & SU experiences side effect they weren't warned about -> M trust is broken O- increased risk for SU taking this medication , C education O decreases vulnerability, C GP not providing info, O do not get involved	A v relevant	B taken from intro, findings and discussion

Mitchel & Selmes, 2007	UK	SC	To discuss patients' reasons for failure to concord with medical advice, and predictors of and solutions to the problem of nonadherence.	Non – systematic literature review	C - lack of info given, lack of acknowledgement that medication has bad side effects and that prescribing isn't always great, being told how long to take meds for O improved taking it for longer , C- Su cannot recall info sometimes, C - SU not involved in process M- rationale is that they do things because they are being told to, M - importance of good therapeutic alliance, C SU misunderstand medical terms. C people not told their diagnosis, C lack of info given about meds and side effects	B - v relevant, little on GP though and M are not evidenced but presumptions	C non systematic lit review

Morant, 2016	UK	SC	This conceptual review argues that several aspects of mental health care that differ from other health-care contexts may impact on processes and possibilities for SDM.	Conceptual review	A(C Lack of information, psychiatrist dominated, little known about GP views, less info given out of fear M that knowing about side effects could O - result in nonadherence)	B relevant but not GP specific	C non systematic lit review
Pereira, 1997	UK	SC	To assess the acceptability of depot among those patients receiving medication via this route and, finally, to assess the views of subjects receiving oral medication about depot.	Questionnaire	C (C - medication from GP or nurse, prefer to have this from them. C would like more info about medication and illness in written form and would read it)	C low relevance	A findings
Pilgrim, 1993	UK	PC	positive and negative views about general practitioners (GPs) and psychiatrists are examined.	Questionnaire (with open ended Q)	C - SU not satisfied with info given, lack of info, GPs do not consider alternatives, M lack of empathy, C seen as over reliant on medication O - no convo about medication, just repeat prescription, some more flexible and sensitive	A v relevant	A taken from findings

Salomon, 2013	Australia	SC	The purpose of the survey was to better understand the experiences of people who attempt antipsychotic discontinuation.	Questionnaire	C - lack of info given, m - fear of side effects occurring o- discontinue medication. C - side effects, M - worried O - go to doctor, O2 - doctor doesn't do anything, M - breakdown in communication, O - isolation of this population	A (v relevant)	A - from findings
Seale,2007	UK	SC	To explore how discussions about side effects are managed in practice	Observational study + Conversation Analysis	B -(C- lack of info given, variance in info given, M doctors optimistic , C recall bias in studies, C SU might forget, M reluctance and discomfort in engaging with psychotic symptoms, M not taken seriously)	A (v relevant)	C from intro
Tranulis, 2011	Canada	SC	To explore views on illness and medication use and emphasized key turning points, such as periods of nonadherence and illness relapses.	Qualitative interviews	C - medication first given when in crisis without much explanation M - trusting doctors, coercion, pressure O - medication was taken	B relevant but not GP specific	A from findings

TABLE 9 CMOC5 UNCERTAINTY ABOUT MEDICATION AND ILLNESS TRAJECTORY

First author, year	**Country**	**Setting**	**Aim**	**Study design and data collection**	**Dimensions of relevance**	**Strength of relevance**	**Methodological quality**
Britten, 2010	UK	SC	Describe lay perspectives on prescribed psychotropic medicines.	Systematic review of qualitative studies	B (C lack of info M uncertainty)	B moderately relevant, not AP specific	A taken from findings
Britten, 2010	UK	SC	Describe lay perspectives on prescribed psychotropic medicines.	Systematic review of qualitative studies	A (C- lack of info given, M - worries about medication, assess pros and cons but with incomplete info O- stopping abruptly (as they have incomplete knowledge)	A - v relevant, little on GPs action though	B - taken from intro and from findings
Burns, 1997	UK	PC	To develop practice for establishing a register and organizing regular reviews; comprehensive assessments; information and advice for patients and carers; indications for involving specialist services; and crisis management.	Consensus group developed good practice guidelines based on current literature	(C need for individual treatment, stable after a few years, lack of guidance, M - GPs feel uncomfortable O - no med change without secondary care, C uncertainty as to how long to continue meds for, need for continuous reviews of medication	B relevant, shows some of the uncertainty, thin on mechanisms	C non systematic literature review

Carr, 2004	Australia	PC	To examines the attitudes and roles of Australian GPs in the treatment of schizophrenia and their relationships with specialist services.	Questionnaires (completed by GPs, mental health staff and service users)	A(M - uncomfortable, lacking confidence, O - reluctant to treat, C not my responsibility, MH medication is more specialist work)	C low relevance	B - take from mixture of intro, findings and discussion
Carrick, 2004	UK	SC	To outline the experience of taking antipsychotic medication	Qualitative interviews + focus group	B (C - unpredictable illness, side effects, SU and doctors in same uncertainty, M - lucky to be well, M mistrust in medical institution)	B relevant but not GP specific	A - taken from findings
Donlon,1987	USA	PC	Overview of care of schizophrenia in primary care	Non – systematic literature review	C - close monitoring, reduce dose after a while, rough guidance, need to know relapse symptoms to reinstate medication, chronic illness and limitations, need empathy	C low	C non systematic literature review
Happell, 2004	Australia	SC	To examine the experiences of consumers, specifically in relation to	Focus group	C misconception about being unwell, blame SU, GP have different priorities to SU, O -SU	B relevant but not GP specific	A taken from findings

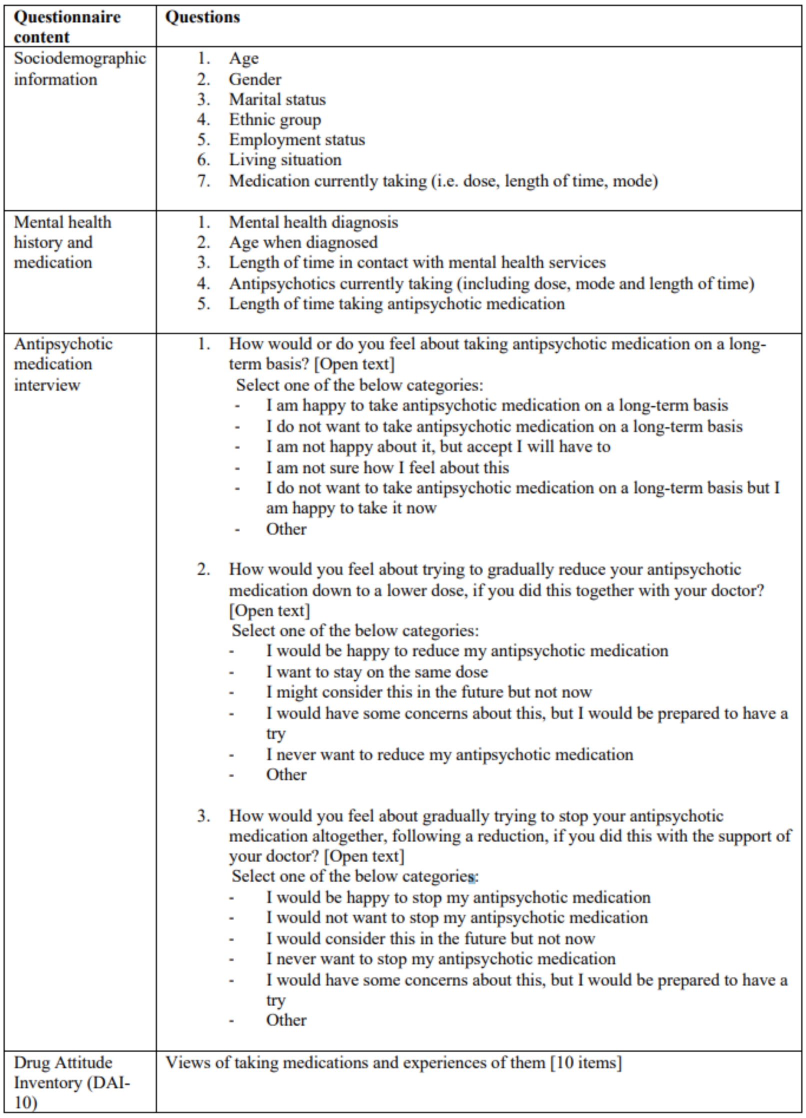
			education and decision making with regards to medication.		manage own medication without consultation, M - not listened to/blamed, M fear of repercussions		
Johnson, 1997	UK	mixed	To assess length of time considered suitable for treatment of schizophrenia	Teleconference between consultant psychiatrists, GPs, pharmacists and CPNs + Questionnaire + commentary	C (unable to say who can come off meds)	B relevant, illustrates uncertainty	C - taken from discussion
Jones, 2015	UK (but studies from	PC	overview of care of schizophrenia in primary care	Non – systematic literature review	C (lack of confidence managing SMI)	C- low relevance, unclear what O and M is	C non systematic lit review

	all over)						
LeGeyt, 2017	UK	SC	To explore personal accounts of making choices about taking medication prescribed for the treatment of psychosis (neuroleptics).	Qualitative Interviews	C(C - GP does not feel comfortable, no option but doing it on your own, discontinuation not an option, wishing for alternatives, lack of communication)	B - relevant, but little on O and M	A finding from study
Maidment, 2011	UK	SC	To develop understandings of the nature and influence of trust in the safe management of medication within mental health services	Focus groups	A (C uncertainty, M - affects trust O doctors do not consider reduction possible, relapse is possible with reduction of dose)	B - relevant, but little on M	A finding from study
Morant, 2016	UK	SC	This conceptual review argues that several aspects of mental health care that differ from other health-care contexts may impact on processes and possibilities for SDM.	Conceptual review	B (C - risk adverse culture, favouring relapse avoidance over issues with long term medication, M lack of confidence in stopping or reducing)	B relevant, but little on GP	C non systematic lit review
Mortimer, 2004	UK	PC	Review on antipsychotic prescribing	Non – systematic literature review	B (no gain in changing things? scared of what might happen/rocking the boat esp. in this group of people)	A – valuable M	C non specific lit review

Morrison, 2015	Australia	SC	The present study explores people's experience of living with antipsychotic medication side-effects	Qualitative interview	A (C requests to change medication as way to deal with side effects, doctors dissuade, M Su just resigned to taking meds, O - nothing changes C coercion? F- nurses could help rebalance)	B relevant, different to papers from uk	A largely taken from study findings
Mortimer, 2005	UK	PC	To audit and intervene in the suboptimal prescribing of antipsychotic drugs to primary care patients.	Audit + intervention study	A(C - CPN as other agent, M -fear of relapse in staff despite evidence that medication was inappropriate O - medication wasn't taken)	B moderate relevance	A taken from findings
Roe, 2009	Israel	SC	The purpose of the present study was to explore why and how people with a serious mental illness (SMI) choose to stop taking prescribed medication	Qualitative interviews	A (M - fear that there will be repercussions, question sanity, O - changes made alone C stigma)	C low	A taken from findings
Seale, 2007	UK	SC	To explore how discussions about side effects are managed in practice	Observational study + Conversation Analysis	C- power imbalance, O concern not taken seriously, M question ability to say that reduction in medication might be appropriate	B - not GP	A from findings
Seale, 2007	UK	SC	To explore how discussions about side effects are managed in practice	Observational study +	C -reductions are happening, but it's secondary care	C low	A - taken from findings

				Conversation Analysis				
Usher	Australia	SC	To explore the experience of taking neuroleptic medications from the individual’s perspective	Qualitative interviews	A (C struggle to stay well, frequent relapses M - fear of relapse, O continue to take medication)	B moderate relevance	A taken from findings	
Younas, 2016	UK	PC	To explore the views and experiences of UK mental health pharmacists regarding the use of SDM in antipsychotic prescribing in people diagnosed with SMI.	Qualitative Interviews	C medication working M reluctance to make changes, scary	B relevant but not GP specific	A taken from findings	

Appendix 4 Overview of Service User interview



Questionnaire content	**Questions**
Sociodemographic information	1. Age 2. Gender 3. Marital status 4. Ethnic group 5. Employment status 6. Living situation 7. Medication currently taking (i.e. dose, length of time, mode)
Mental health history and medication	1. Mental health diagnosis 2. Age when diagnosed 3. Length of time in contact with mental health services 4. Antipsychotics currently taking (including dose, mode and length of time) 5. Length of time taking antipsychotic medication
Antipsychotic medication interview	1. How would or do you feel about taking antipsychotic medication on a long-term basis? [Open text] Select one of the below categories: - I am happy to take antipsychotic medication on a long-term basis - I do not want to take antipsychotic medication on a long-term basis - I am not happy about it, but accept I will have to - I am not sure how I feel about this - I do not want to take antipsychotic medication on a long-term basis but I am happy to take it now - Other 2. How would you feel about trying to gradually reduce your antipsychotic medication down to a lower dose, if you did this together with your doctor? [Open text] Select one of the below categories: - I would be happy to reduce my antipsychotic medication - I want to stay on the same dose - I might consider this in the future but not now - I would have some concerns about this, but I would be prepared to have a try - I never want to reduce my antipsychotic medication - Other 3. How would you feel about gradually trying to stop your antipsychotic medication altogether, following a reduction, if you did this with the support of your doctor? [Open text] Select one of the below categories: - I would be happy to stop my antipsychotic medication - I would not want to stop my antipsychotic medication - I would consider this in the future but not now - I never want to stop my antipsychotic medication - I would have some concerns about this, but I would be prepared to have a try - Other
Drug Attitude Inventory (DAI-10)	Views of taking medications and experiences of them [10 items]

Appendix 5 SPSS output Consent to audio recording vs those who did not consent

SPSS outputs

```
GET
  FILE='\\ad.ucl.ac.uk\homeg\uctvlmg\Documents\PhD\recruitment study\Interview study
08.09_new.sav'
    PASSWORD='=P/(#K/(!l'.
DATASET NAME DataSet1 WINDOW=FRONT.
SORT CASES BY MEDS_LONGTERM_NOOTHER (A).
RECODE MEDS_LONGTERM_NOOTHER (1=1) (2=1) (3=1) (4=2) INTO meds_binary_longterm.
EXECUTE.
SORT CASES BY MEDS_REDUCE_NOOTHER (A).
SORT CASES BY MEDS_STOP_FINAL (A).
RECODE MEDS_REDUCE_NOOTHER (1=1) (2=1) (3=1) (4=2) INTO meds_binary_reduce.
EXECUTE.
RECODE MEDS_STOP_FINAL (1=1) (2=1) (4=1) (3=2) INTO meds_binary_stop.
EXECUTE.
CROSSTABS
  /TABLES=meds_binary_longterm meds_binary_reduce meds_binary_stop BY PRIM_SECON_CARE
  /FORMAT=AVALUE TABLES
  /STATISTICS=CHISQ PHI
  /CELLS=COUNT ROW COLUMN TOTAL
  /COUNT ROUND CELL.
```

Crosstabs

Notes

Output Created	01-MAY-2022 09:43:31

Comments		
Input	Data	\\ad.ucl.ac.uk\homeg\uctvlmg\Documents\PhD\recruitment study\Interview study 08.09_new.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	269
Missing Value Handling	Definition of Missing	User-defined missing values are treated as missing.
	Cases Used	Statistics for each table are based on all the cases with valid data in the specified range(s) for all variables in each table.

Syntax

```
CROSSTABS

/TABLES=meds_binary_longterm meds_binary_reduce meds_binary_stop BY PRIM_SECON_CARE
  /FORMAT=AVALUE TABLES
  /STATISTICS=CHISQ PHI
  /CELLS=COUNT ROW COLUMN TOTAL
  /COUNT ROUND CELL.
```

Resources	Processor Time	00:00:00.03
	Elapsed Time	00:00:00.03
	Dimensions Requested	2
	Cells Available	524245

[DataSet1] \\ad.ucl.ac.uk\homeg\uctvlmg\Documents\PhD\recruitment study\Interview study 08.09_new.sav

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
meds_binary_longterm * PRIM_SECON_CARE	249	92.6%	20	7.4%	269	100.0%
meds_binary_reduce * PRIM_SECON_CARE	248	92.2%	21	7.8%	269	100.0%
meds_binary_stop * PRIM_SECON_CARE	260	96.7%	9	3.3%	269	100.0%

meds_binary_longterm * PRIM_SECON_CARE

Crosstab

			PRIM_SECON_CARE		
			primary care	secondary care	
meds_binary_longterm	1.00	Count	32	170	
		% within meds_binary_longterm	15.8%	84.2%	
		% within PRIM_SECON_CARE	84.2%	80.6%	

		% of Total	12.9%	68.3%	
	2.00	Count	6	41	
		% within meds_binary_longterm	12.8%	87.2%	
		% within PRIM_SECON_CARE	15.8%	19.4%	
		% of Total	2.4%	16.5%	
Total		Count	38	211	
		% within meds_binary_longterm	15.3%	84.7%	
		% within PRIM_SECON_CARE	100.0%	100.0%	
		% of Total	15.3%	84.7%	

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.279[a]	1	.597		
Continuity Correction[b]	.092	1	.762		
Likelihood Ratio	.289	1	.591		
Fisher's Exact Test				.822	.393
Linear-by-Linear Association	.278	1	.598		
N of Valid Cases	249				

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 7.17.

b. Computed only for a 2x2 table

Symmetric Measures

		Value	Approximate Significance
Nominal by Nominal	Phi	.033	.597
	Cramer's V	.033	.597
N of Valid Cases		249	

meds_binary_reduce * PRIM_SECON_CARE

Crosstab

			PRIM_SECON_CARE		
			primary care	secondary care	Total
meds_binary_reduce	1.00	Count	25	164	189
		% within meds_binary_reduce	13.2%	86.8%	100.0%
		% within PRIM_SECON_CARE	64.1%	78.5%	76.2%
		% of Total	10.1%	66.1%	76.2%
	2.00	Count	14	45	59
		% within meds_binary_reduce	23.7%	76.3%	100.0%
		% within PRIM_SECON_CARE	35.9%	21.5%	23.8%
		% of Total	5.6%	18.1%	23.8%
Total		Count	39	209	248
		% within meds_binary_reduce	15.7%	84.3%	100.0%
		% within PRIM_SECON_CARE	100.0%	100.0%	100.0%

% of Total	15.7%	84.3%	100.0%

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	3.741[a]	1	.053		
Continuity Correction[b]	2.991	1	.084		
Likelihood Ratio	3.471	1	.062		
Fisher's Exact Test				.065	.045
Linear-by-Linear Association	3.726	1	.054		
N of Valid Cases	248				

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 9.28.

b. Computed only for a 2x2 table

Symmetric Measures

		Value	Approximate Significance
Nominal by Nominal	Phi	-.123	.053
	Cramer's V	.123	.053
N of Valid Cases		248	

meds_binary_stop * PRIM_SECON_CARE

Crosstab

			PRIM_SECON_CARE		
			primary care	secondary care	Total
meds_binary_stop	1.00	Count	25	169	194
		% within meds_binary_stop	12.9%	87.1%	100.0%
		% within PRIM_SECON_CARE	62.5%	76.8%	74.6%
		% of Total	9.6%	65.0%	74.6%
	2.00	Count	15	51	66
		% within meds_binary_stop	22.7%	77.3%	100.0%
		% within PRIM_SECON_CARE	37.5%	23.2%	25.4%
		% of Total	5.8%	19.6%	25.4%
Total		Count	40	220	260
		% within meds_binary_stop	15.4%	84.6%	100.0%
		% within PRIM_SECON_CARE	100.0%	100.0%	100.0%
		% of Total	15.4%	84.6%	100.0%

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	3.663[a]	1	.056		
Continuity Correction[b]	2.946	1	.086		
Likelihood Ratio	3.422	1	.064		
Fisher's Exact Test				.074	.046
Linear-by-Linear Association	3.649	1	.056		
N of Valid Cases	260				

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 10.15.

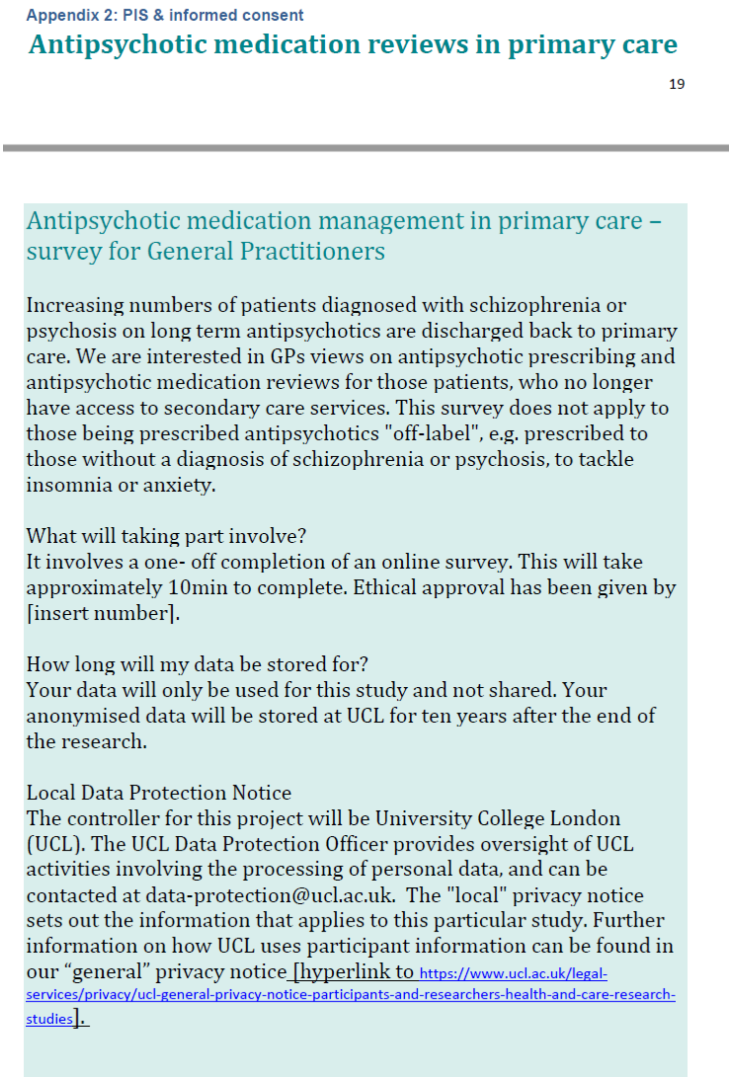
b. Computed only for a 2x2 table

Symmetric Measures

		Value	Approximate Significance
Nominal by Nominal	Phi	-.119	.056
	Cramer's V	.119	.056
N of Valid Cases		260	

```
SORT CASES BY MEDS_REDUCE_NOOTHER (A).
```

Appendix 6 GP survey



Appendix 2: PIS & informed consent

Antipsychotic medication reviews in primary care

Antipsychotic medication management in primary care – survey for General Practitioners

Increasing numbers of patients diagnosed with schizophrenia or psychosis on long term antipsychotics are discharged back to primary care. We are interested in GPs views on antipsychotic prescribing and antipsychotic medication reviews for those patients, who no longer have access to secondary care services. This survey does not apply to those being prescribed antipsychotics "off-label", e.g. prescribed to those without a diagnosis of schizophrenia or psychosis, to tackle insomnia or anxiety.

What will taking part involve?
It involves a one- off completion of an online survey. This will take approximately 10min to complete. Ethical approval has been given by [insert number].

How long will my data be stored for?
Your data will only be used for this study and not shared. Your anonymised data will be stored at UCL for ten years after the end of the research.

Local Data Protection Notice
The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. The "local" privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our “general” privacy notice [hyperlink to https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies].

Concerns
Any queries or concerns please contact Lisa Gruenwald, lisa.gruenwald.17@ucl.ac.uk or alternatively Maria Long, maria.long@nelft.nhs.uk, who is independent of this study, but can still answer any queries you might have.

Consent:
I understand that

- My participation is completely voluntary
- My responses are anonymised. The data gathered in this study will be stored securely and it will not be possible to identify me in any outputs from this research. Answers given in text boxes may be used as anonymous quotes in publications.
- Due to this anonymisation it will not be possible to withdraw any answers after they have been submitted

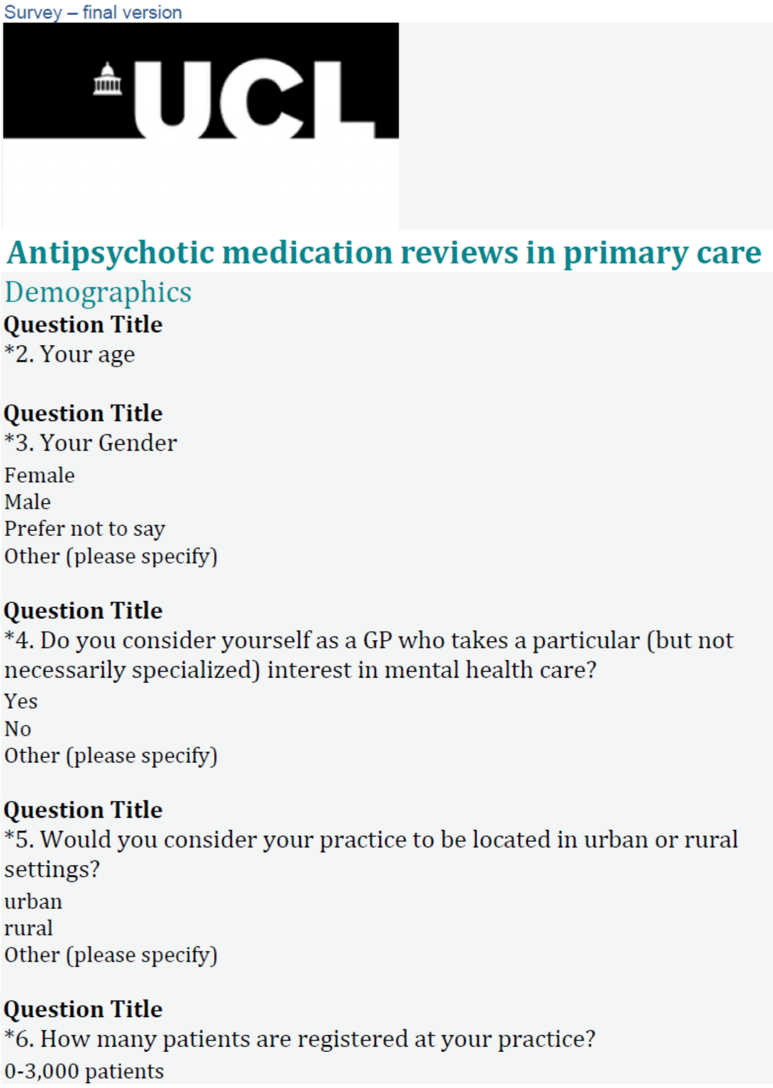
IRAS ID: 282215

Consent

By ticking the box below, you are agreeing that you have read the information about the study, and that you voluntarily agree to part in this study:

☐ I am a GP practising in the UK and I agree to take part in the above study

Survey – final version



Antipsychotic medication reviews in primary care

Demographics

Question Title

*2. Your age

Question Title

*3. Your Gender

Female
Male
Prefer not to say
Other (please specify)

Question Title

*4. Do you consider yourself as a GP who takes a particular (but not necessarily specialized) interest in mental health care?

Yes
No
Other (please specify)

Question Title

*5. Would you consider your practice to be located in urban or rural settings?

urban
rural
Other (please specify)

Question Title

*6. How many patients are registered at your practice?

0-3,000 patients

4,000 - 7,000 patients
8,000 - 11,000 patients
more than 11,000 patients

Question Title

*7. How long have you been a GP? (In years)

Question Title

*8. Do you have access to a GP liaison/ GP plus team (e.g. a dedicated psychiatrist who may visit your practice or be available to primary care specifically to support you with cases that are not under secondary care?). Please tick all that apply.

Yes, my practice has the support of a primary care mental health (PCMH) team and/or there is a psychiatrist located at my practice that I can speak to.
Yes, I have easy access to patients' named psychiatrist
I have access to an advice line/email address for one-off advice regarding patients presenting with mental health difficulties.
No
Don't know
Other (please specify)

Question Title

*9. Have you, in the last 3 years asked for advice about changing antipsychotics in relation to a proactive review (rather than during acute relapse)?

Yes
No
Other (please specify)

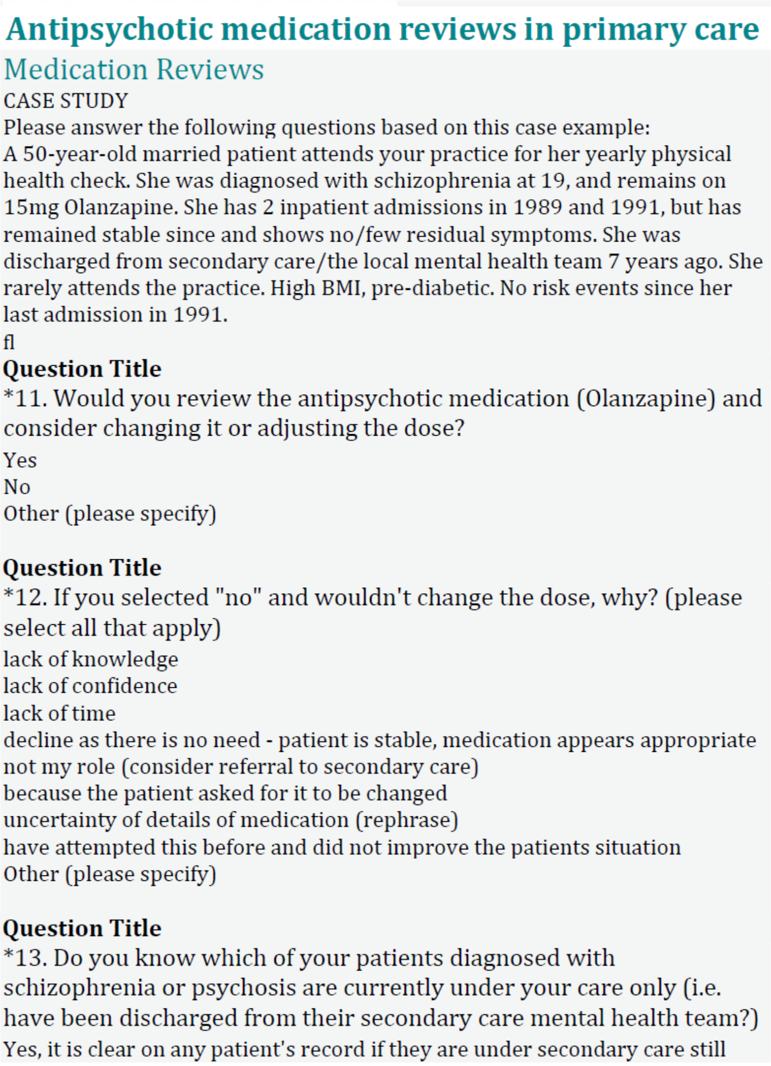
Question Title

*10. If you have asked for advice, approximately on how many occasions have you done so? Please enter the number of occasions using numbers only

—

or Copy and paste questions

PREV NEXT



Antipsychotic medication reviews in primary care

Medication Reviews

CASE STUDY

Please answer the following questions based on this case example:

A 50-year-old married patient attends your practice for her yearly physical health check. She was diagnosed with schizophrenia at 19, and remains on 15mg Olanzapine. She has 2 inpatient admissions in 1989 and 1991, but has remained stable since and shows no/few residual symptoms. She was discharged from secondary care/the local mental health team 7 years ago. She rarely attends the practice. High BMI, pre-diabetic. No risk events since her last admission in 1991.

fl

Question Title

*11. Would you review the antipsychotic medication (Olanzapine) and consider changing it or adjusting the dose?

Yes
No
Other (please specify)

Question Title

*12. If you selected "no" and wouldn't change the dose, why? (please select all that apply)

lack of knowledge
lack of confidence
lack of time
decline as there is no need - patient is stable, medication appears appropriate
not my role (consider referral to secondary care)
because the patient asked for it to be changed
uncertainty of details of medication (rephrase)
have attempted this before and did not improve the patients situation
Other (please specify)

Question Title

*13. Do you know which of your patients diagnosed with schizophrenia or psychosis are currently under your care only (i.e. have been discharged from their secondary care mental health team?)

Yes, it is clear on any patient's record if they are under secondary care still

Only if I check through the individuals notes (e.g. by checking for discharge letters, checking ongoing notes, recent contact with secondary care team)
No
Other (please specify)

Question Title
*14. How often do you review the appropriateness of antipsychotic medication in primary care only patients in general? (please select all that apply)

never - secondary care responsibility
rarely
at their yearly physical health review
only when the patient requests a review
only when they present with significant side effects/contraindications
every time I am in an appointment with someone prescribed antipsychotics
Other (please specify)

fl

Question Title
*15. Does your practice have a separate guidance or agreement on how to conduct a medication review with someone who is only seen in primary care?

Yes
No
Other (please specify)

Question Title
*16. If yes, what does this guidance/agreement include?

Question Title
*17. How comfortable are you REVIEWING the case study patient's antipsychotic medication?

ıfortable comfortable very comfortable

Question Title
*18. If you are in any way uncomfortable, why? (tick all that apply)

lack of knowledge
lack of confidence
lack of time
no - need, stable patient, not immediately required
not my role - refer to secondary care
Other (please specify)

*19. If you decided to review the medication, and felt a reduction may be appropriate, how comfortable do you feel REDUCING the patient's antipsychotic medication?

not comfortable comfortable very comfortable

Question Title

*20. If you do not feel comfortable to reduce, why? Please select all that apply

fear of relapse & deterioration of patient following that
lack of support from secondary care (should any issues arise)
unsure how to complete a reduction
reductions would have been against patient wishes
reduction is rarely indicated/advisable
concerns over strain on inpatient/crisis services should the patient relapse
concerns that patient may pose risk to self or others if medication were reduced
family or carer may object
schizophrenia requires long term drug treatment
as GPs,cannot guarantee adequate follow up, lack of continuity of care during reduction
have tried this before and it was unsuccessful
schizophrenia is a chemical imbalance requiring treatment
Other (please specify)

Question Title

*21. How comfortable would you feel to DISCONTINUE the patients antipsychotic medication, should the reduction go well? (e.g no recurrence of psychotic symptoms)

not comfortable comfortable very comfortable

Question Title

*22. If you do not feel comfortable to discontinue, why? Please tick all that apply

fear of relapse & deterioration of patient following that
lack of support from secondary care (should any issues arise)
unsure how to complete a discontinuation of an antipsychotic
discontinuation would have been against patient wishes
discontinuation is not indicated
concerns over strain on inpatient/crisis services should the patient relapse
concerns that patient may pose risk to self or others if medication were reduced
family or carer may be against it
schizophrenia requires treatment, chemical imbalance

as GPs, cannot guarantee adequate follow up, lack of continuity of care during reduction
have tried this before and it was unsuccessful
Other (please specify)

Question Title
*23. Please tick what you would find helpful for medication reviews (please tick all that apply)
knowing the patient well
if they have carer/family input
secondary care support
GP liaison support
additional time in appointments
better guidance/policies on medication reviews
pharmacy available to help review medication
additional training
n/a - not primary care role to review or reduce
Other (please specify)

Question Title
*24. During an appointment, how often do you usually discuss common side effects or unwanted effects from antipsychotic medication and need for regular monitoring?
Never
Rarely
Sometimes
Often
Other (please specify)

Question Title
*25. If you do not usually discuss common side effects, please list reasons why (please tick all that apply)
worries that patients may stop their medication if I list too many side effects
it is not necessary to list all
worries about the effect this will have on my relationship with the patient
I do not know all side effects
Not my role to discuss side effects (secondary care should discuss this)
I did not initiate the prescription - therefore not my role to discuss it
No time to discuss this
Other people discuss side effects already (pharmacist, nurses)
Information is in the leaflet- i only discuss it if there are questions
Only discuss side effects if patient mentions them
Other (please specify)

fl
Question Title

*26. Do you have concerns regarding long term antipsychotic prescribing?
Yes
No
Other (please specify)

Question Title
*27. If yes, what are your concerns?

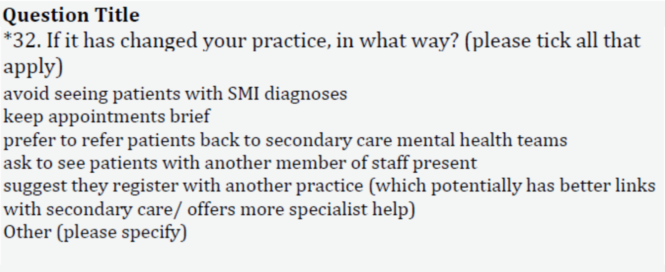
Question Title
28. If you felt hopeless regarding the treatment of people with schizophrenia or psychosis (i.e. felt like there was not anything more you could do treatment wise), do you communicate this with patients in any way?
Yes
No
n/a - I do not feel hopeless
Other (please specify)

Question Title
*29. Out of all appointments you had with patients diagnosed with schizophrenia or psychosis in the last 12 months, roughly which PERCENTAGE (give an estimate) of appointments resulted in a change of antipsychotic medication? (including increase, decrease, or change of type of antipsychotic medication?)

0 50% of all appointments resulted in an antipsychotic medication change

fl
Question Title
*30. Have you ever felt at risk or apprehensive when completing a consultation with someone with a diagnosis of schizophrenia or psychosis?
Yes
No
Other (please specify)

Question Title
*31. if you selected have felt at risk, has this subsequently changed your practice?
Yes
No
Maybe
Other (please specify)



Question Title

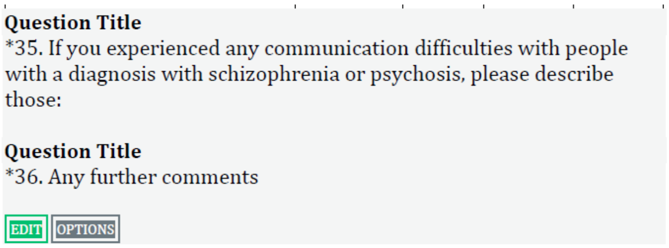
*32. If it has changed your practice, in what way? (please tick all that apply)

avoid seeing patients with SMI diagnoses
keep appointments brief
prefer to refer patients back to secondary care mental health teams
ask to see patients with another member of staff present
suggest they register with another practice (which potentially has better links with secondary care/ offers more specialist help)
Other (please specify)

Question Title
*33. Please state to which extent you agree or disagree with the following statements:

	Strongly Agree	Agree	Disagree	Strongly Disagree
GPs have low expectations regarding the recovery of patients diagnosed with schizophrenia/psychosis				
I feel hopeless (meaning you felt there was nothing else you can do) regarding treatment and recovery for patients diagnosed with schizophrenia/psychosis.				
I experience difficulties when discussing antipsychotic medication with patients diagnosed with schizophrenia or psychosis				
Patients diagnosed with schizophrenia/psychosis understand the need for antipsychotic medication.				
There is pressure on GPs to ensure adherence of antipsychotics in order to prevent relapse.				
A lack of information about the nature of antipsychotic medication, meant that patients do not see the importance of physical health checks and potentially do not attend yearly reviews.				
Patients will discontinue their medication if they experience side effects that they were not advised of before.				
Most patients diagnosed with psychosis or schizophrenia lack capacity or insight regarding their treatment				

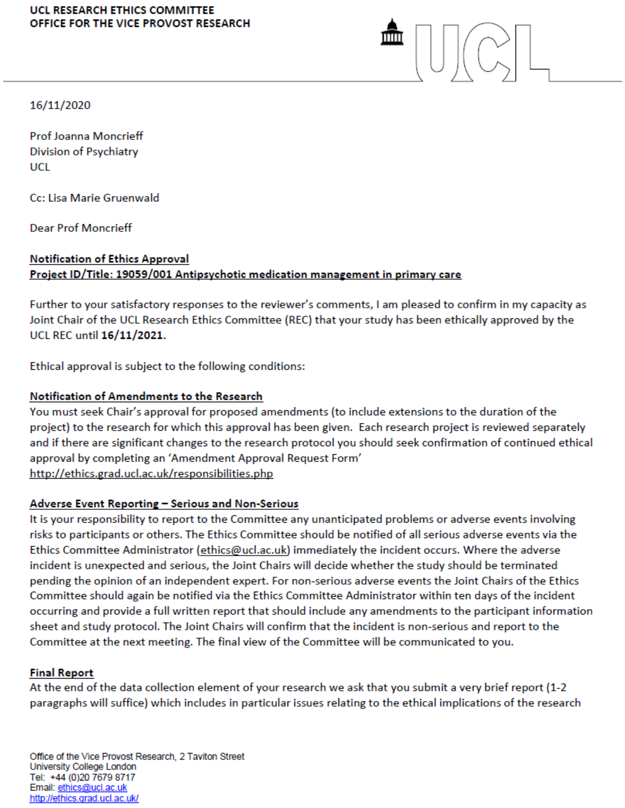
Question Title



Question Title
*35. If you experienced any communication difficulties with people with a diagnosis with schizophrenia or psychosis, please describe those:

Question Title
*36. Any further comments

Appendix 7 UCL Ethics Approval



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

16/11/2020

Prof Joanna Moncrieff
Division of Psychiatry
UCL

Cc: Lisa Marie Gruenwald

Dear Prof Moncrieff

Notification of Ethics Approval
Project ID/Title: 19059/001 Antipsychotic medication management in primary care

Further to your satisfactory responses to the reviewer's comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **16/11/2021.**

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. 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 an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
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 Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs 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.

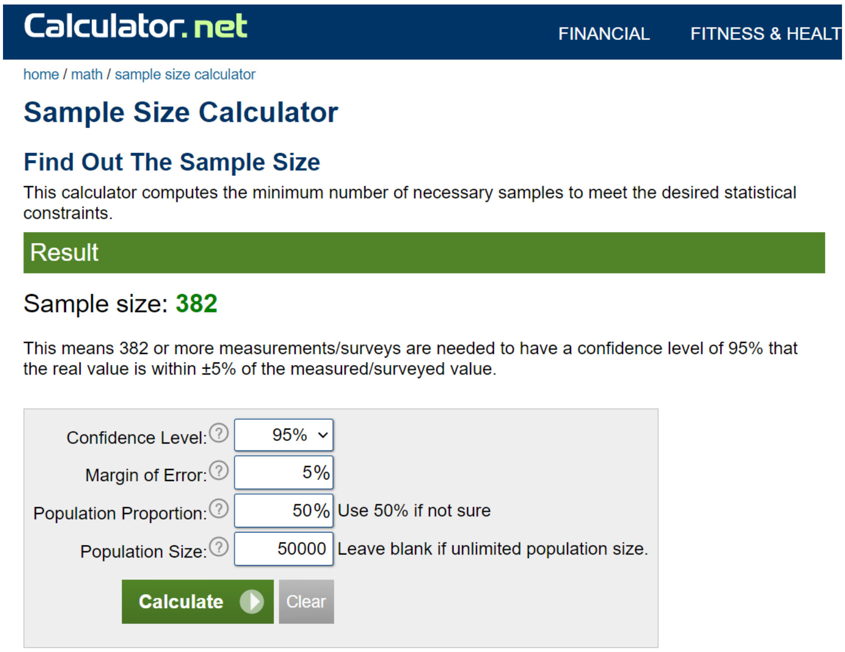
Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

Appendix 8 Sample size calculator

Last accessed on 19May2022: https://www.calculator.net/sample-size-calculator.html?type=1&cl=95&ci=5&pp=50&ps=50000&x=57&y=13

Based on 50,000 GPs in the UK, Confidence Interval of 95% 5% Margin of error



Sample Size Calculator

Find Out The Sample Size

This calculator computes the minimum number of necessary samples to meet the desired statistical constraints.

Result

Sample size: **382**

This means 382 or more measurements/surveys are needed to have a confidence level of 95% that the real value is within ±5% of the measured/surveyed value.

Confidence Level: 95%
Margin of Error: 5%
Population Proportion: 50% Use 50% if not sure
Population Size: 50000 Leave blank if unlimited population size.

Appendix 9 BGJP Publication

Antipsychotic Medication Reviews in Primary Care – Searching for best practice.

by BJGP Life

10 February 2021

Lisa Grünwald is a PhD Student at the Division of Psychiatry, UCL, interested in antipsychotic medication management in primary care for people diagnosed with Severe Mental Illness. She previously worked on the RADAR study (Research into Antipsychotic Discontinuation and Reduction) – to find out more see https://www.ucl.ac.uk/psychiatry/research/epidemiology-and-applied-clinical-research-department/research-antipsychotic

Dr Nadia Crellin is a fellow at the Nuffield Trust and was previously programme manager for the RADAR study.

Prof Joanna Moncrieff is the RADAR Chief Investigator and a Professor in Critical and Social Psychiatry at UCL, as well as a community psychiatrist at North East London NHS Foundation Trust.

In the UK, little guidance is available on how mental health and the use of antipsychotic medication should be reviewed when patients no longer have access to a psychiatrist. Whereas the Quality Outcomes Framework mandates a yearly review, it is unclear what the review needs to cover exactly. Additionally, research is lacking as to whether GPs feel able to complete reviews in a comprehensive way, and about how patients feel about the treatment they receive. Increasing numbers of service users diagnosed with schizophrenia and/or psychosis are being discharged back to Primary care. Research found that currently up to 31% are under primary care only.[1] This number is likely to have increased due to the Covid-19 pandemic, as secondary care trusts have been asked to discharge up to 20% of their caseload.

Increasing numbers of service users diagnosed with schizophrenia and/or psychosis are being discharged back to Primary care.

What are the issues with antipsychotic medication?

Whereas a review might not seem a priority for those who are stable and on long term medication, increasing evidence of the severe and debilitating adverse effects associated with antipsychotics suggest that continuing medication indefinitely may not be the best option for some people.[2] Recognised adverse effects include drowsiness, weight gain, diabetes, tardive dyskinesia and sudden cardiac death, and potentially decreased brain volume and possible cognitive impairment.[3,4] People diagnosed with schizophrenia and/or psychosis also have a reduced life expectancy of, on average, 20 years in comparison to the general public, which may be partially attributable to antipsychotics.[5] These adverse effects, combined with the fact that some people do not benefit from antipsychotics, mean that medication will need to be reviewed regularly and adapted as required.

Adverse effects ....[and] that some people do not benefit from antipsychotics, mean that medication will need to be reviewed regularly.

Why is a review necessary?

The need for thorough review of antipsychotic medication in primary care is underlined by the finding that patients under primary care only are prescribed significantly more medication overall than people who are also seen in secondary care[1]. Moreover, levels of polypharmacy are high and antipsychotics are frequently prescribed to people without a diagnosis of psychosis or severe mental disorder. Additionally, as the need for medication also changes across the lifetime, medication should to be reviewed on an ongoing basis. Guidance advises that older adults should be on lower doses. Which is particularly pertinent to primary care only patients, who are on average older, and have been diagnosed with schizophrenia/ psychosis for longer than people still under secondary care[1]. Barriers to completing thorough reviews exist, however: GPs report a lack of support from secondary care and a lack knowledge and confidence – not to mention the pressures of completing reviews in 10 minute appointments.

Barriers to completing thorough reviews exist, however…..

In summary, once people are discharged, GPs have increased responsibilities in the monitoring and prescribing of antipsychotic medication, yet may not feel fully equipped to manage these. Given that 1) an increasing proportion of people diagnosed with schizophrenia and/or psychosis are being discharged from secondary care 2) most people with this diagnosis are prescribed antipsychotic medication and 3) there are significant concerns regarding associated adverse effects of medication, it is important that medication is reviewed regularly and adapted as necessary.

A search for best practice – we need your help

Given the lack of guidance, GP practices are likely to have developed working practices of their own. In the search for best practice for those primary care only patients, research is urgently required on how this can best be achieved for patients who are only under primary care. We have therefore set up a short online survey for GPs practicing in the UK to gain further insights on their views and working practices on the topic. Please complete this anonymous, 10 minute online survey on your views on medication reviews in primary care. The study has ethical approval (*University College London* [19059/001]) and can be accessed through https://opinio.ucl.ac.uk/s?s=70230

References

1. Reilly, S., Planner, C., Hann, M., Reeves, D., Nazareth, I., & Lester, H. (2012). The role of primary care in service provision for people with severe mental illness in the United Kingdom. PloS one, 7(5), e36468.
2. Murray RM, Quattrone D, Natesan S, van Os J, Nordentoft M, Howes O, Di Forti M, Taylor D. Should psychiatrists be more cautious about the long-term prophylactic use of antipsychotics? Br J Psychiatry. 2016 Nov;209(5):361-365. doi: 10.1192/bjp.bp.116.182683. PMID: 27802977.
3. Moncrieff, J., & Leo, J. (2010). A systematic review of the effects of antipsychotic drugs on brain volume. *Psychological Medicine*, *40*(9), 1409–1422. https://doi.org/10.1017/S0033291709992297
4. Husa, A. P., Moilanen, J., Murray, G. K., Marttila, R., Haapea, M., Rannikko, I., Barnett, J. H., Jones, P. B., Isohanni, M., Remes, A. M., Koponen, H., Miettunen, J., & Jääskeläinen, E. (2017). Lifetime antipsychotic medication and cognitive performance in schizophrenia at age 43 years in a general population birth cohort. *Psychiatry research*, 247, 130–138. https://doi.org/10.1016/j.psychres.2016.10.085
5. Ralph, S. J., & Espinet, A. J. (2018). Increased All-Cause Mortality by Antipsychotic Drugs: Updated Review and Meta-Analysis in Dementia and General Mental Health Care. *Journal of Alzheimer's disease reports*, 2(1), 1–26. https://doi.org/10.3233/ADR-170042

Appendix 10 GP recruitment email

UCL Research Enquiry

– Have your say!

Dear [insert GP name],

More and more service users diagnosed with schizophrenia and/or psychosis are being discharged back to primary care, many on long – term antipsychotic medication. Little guidance exists on how GPs should manage the care and treatment of this population. We are therefore keen to hear GPs views and experiences of this situation. We would be grateful if you could complete this one-off, anonymous questionnaire on the topic. This should take no longer than 10 minutes to complete.
The link is https://opinio.ucl.ac.uk/s?s=70230
This questionnaire has ethical approval from University College London [19059/001]. For any queries, please contact lisa.gruenwald.17@ucl.ac.uk.

Many thanks,

Lisa

Appendix 11 Opinio GP survey output summary report

Comment report

Lists all the questions in the survey and displays all the free text responses to these questions, if applicable.

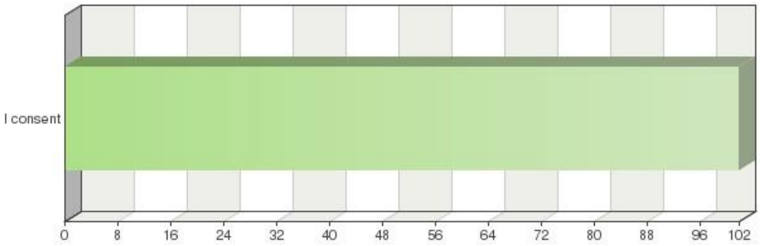
Table of contents

Report info

Report date:	Wednesday, September 1, 2021 9:43:57 AM BST
Start date:	Tuesday, November 10, 2020 8:13:00 AM GMT
Stop date:	Wednesday, November 17, 2021 8:13:00 AM GMT
Stored responses:	103
Number of completed responses:	50

Question 1

By ticking the box below, you are agreeing that you have read the information about the study, and that you voluntarily agree to part in this study:

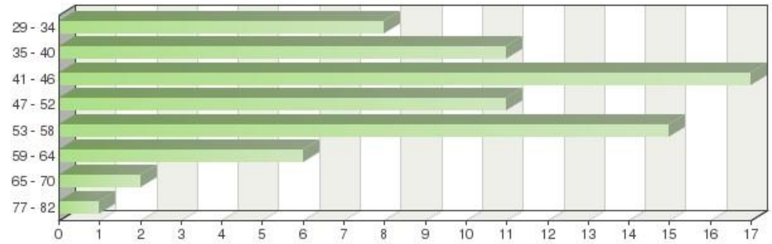


Frequency table

Choices		Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
I consent		102	102	99.03%	99.03%	100%	100%
Sum:		102	-	99.03%	-	100%	-
Not answered:		1	-	0.97%	-	-	-
Average:	1	Minimum:	1		Variance:	0	
Median:	1	Maximum:	1		Std. deviation:	0	

Total answered: 102

Question 2 What is your age?

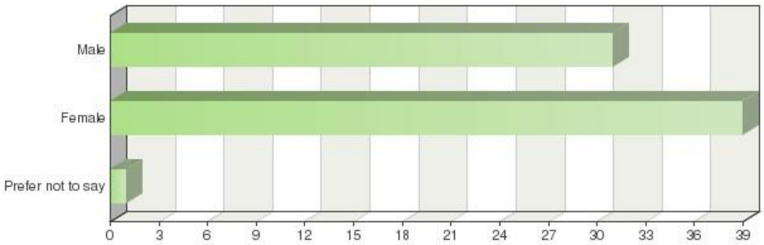


Frequency table

Intervals	**Absolute frequency**	**Cum. absolute frequency**	**Relative frequency**	**Cum. relative frequency**	**Adjusted relative frequency**	**Cum. adjusted relative frequency**
29 - 34	8	8	7.77%	7.77%	11.27%	11.27%
35 - 40	11	19	10.68%	18.45%	15.49%	26.76%
41 - 46	17	36	16.5%	34.95%	23.94%	50.7%
47 - 52	11	47	10.68%	45.63%	15.49%	66.2%
53 - 58	15	62	14.56%	60.19%	21.13%	87.32%
59 - 64	6	68	5.83%	66.02%	8.45%	95.77%
65 - 70	2	70	1.94%	67.96%	2.82%	98.59%
77 - 82	1	71	0.97%	68.93%	1.41%	100%
Sum:	71	-	68.93%	-	100%	-
Not answered:	32	-	31.07%	-	-	-
Average: 47.31	Minimum:	29	Variance:		97.22	
Median: 46	Maximum:	80	Std. deviation:		9.86	

Total answered: 71

Question 3 Your gender?



Frequency table

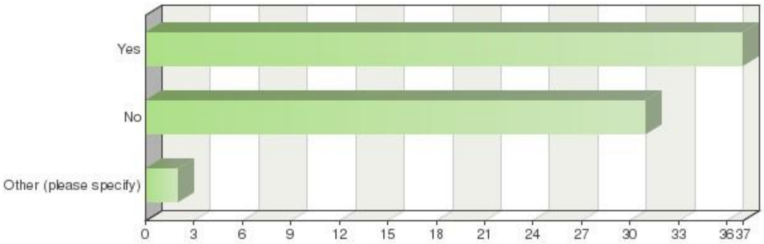
Choices	**Absolute frequency**	**Cum. absolute frequency**	**Relative frequency**	**Cum. relative frequency**	**Adjusted relative frequency**	**Cum. adjusted relative frequency**
Male	31	31	30.1%	30.1%	43.66%	43.66%
Female	39	70	37.86%	67.96%	54.93%	98.59%
Prefer not to say	1	71	0.97%	68.93%	1.41%	100%
Sum:	71	-	68.93%	-	100%	-

Not answered:	32	-	31.07%	-	-	-
Average: 1.58	Minimum:	1	Variance:		0.28	
Median: 2	Maximum:	3	Std. deviation:		0.53	

Total answered: 71

Question 4

Do you consider yourself as a GP who takes a particular (but not necessarily specialized) interest in mental health care?



Frequency table

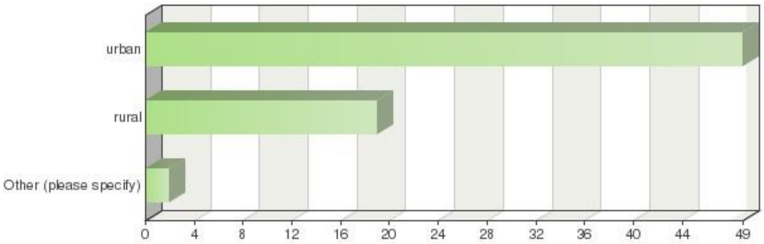
Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes	37	37	35.92%	35.92%	52.86%	52.86%
No	31	68	30.1%	66.02%	44.29%	97.14%
Other (please specify)	2	70	1.94%	67.96%	2.86%	100%
Sum:	70	-	67.96%	-	100%	-
Not answered:	33	-	32.04%	-	-	-
Average: 1.5	Minimum:	1	Variance:		0.31	
Median: 1	Maximum:	3	Std. deviation:		0.56	

Total answered: 70

Last choice text input

It is part of the job but not special interest

Question 5 Would you consider your practice to be located in urban or rural settings?



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
urban	49	49	47.57%	47.57%	70%	70%
rural	19	68	18.45%	66.02%	27.14%	97.14%
Other (please specify)	2	70	1.94%	67.96%	2.86%	100%
Sum:	70	-	67.96%	-	100%	-
Not answered:	33	-	32.04%	-	-	-
Average: 1.33	Minimum:	1	Variance:		0.28	
Median: 1	Maximum:	3	Std. deviation:		0.53	

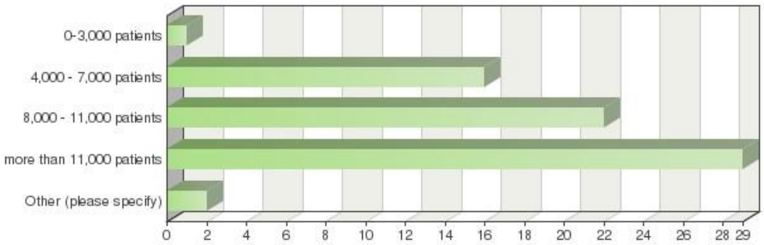
Total answered: 70

Last choice text input

Out of hours GP

semi-rural

Question 6 How many patients are registered at your practice?



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
0-3,000 patients	1	1	0.97%	0.97%	1.43%	1.43%
4,000 - 7,000 patients	16	17	15.53%	16.5%	22.86%	24.29%
8,000 - 11,000 patients	22	39	21.36%	37.86%	31.43%	55.71%
more than 11,000 patients	29	68	28.16%	66.02%	41.43%	97.14%
Other (please specify)	2	70	1.94%	67.96%	2.86%	100%
Sum:	70	-	67.96%	-	100%	-
Not answered:	33	-	32.04%	-	-	-
Average: 3.21	Minimum:	1	Variance:		0.78	
Median: 3	Maximum:	5	Std. deviation:		0.88	

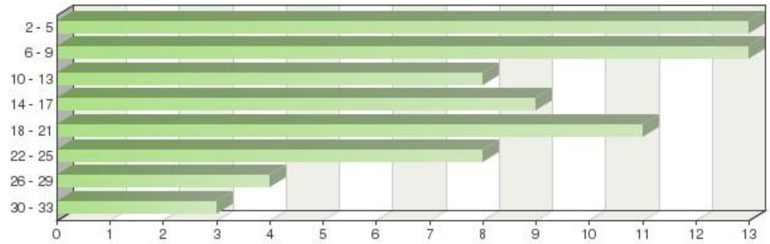
Total answered: 70

Last choice text input

I work OOHs

N/a

Question 7 How long have you been a GP? (In years)



Frequency table

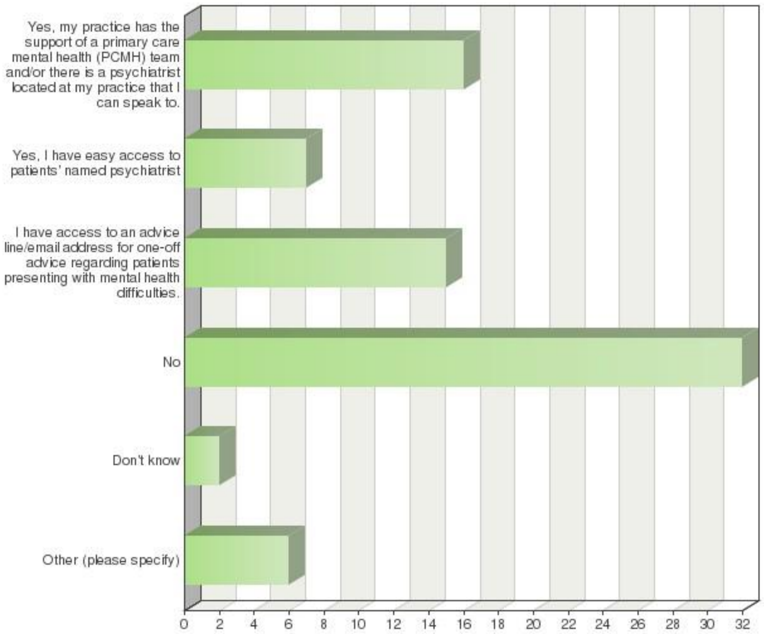
Intervals		Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
2 - 5		13	13	12.62%	12.62%	18.84%	18.84%
6 - 9		13	26	12.62%	25.24%	18.84%	37.68%
10 - 13		8	34	7.77%	33.01%	11.59%	49.28%
14 - 17		9	43	8.74%	41.75%	13.04%	62.32%
18 - 21		11	54	10.68%	52.43%	15.94%	78.26%
22 - 25		8	62	7.77%	60.19%	11.59%	89.86%
26 - 29		4	66	3.88%	64.08%	5.8%	95.65%
30 - 33		3	69	2.91%	66.99%	4.35%	100%
Sum:		69	-	66.99%	-	100%	-
Not answered:		34	-	33.01%	-	-	-
Average:	14.33	Minimum:	2	Variance:		71.9	
Median:	14	Maximum:	33	Std. deviation:		8.48	

Total answered: 69

Question 8

Do you have access to a GP liaison/ GP plus team (e.g. a dedicated psychiatrist who may visit your practice or be available to primary care specifically to support you with cases that are not under secondary care?).

Please tick all that apply.



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes, my practice has the support of a primary care mental health (PCMH) team and/or there is a psychiatrist located at my practice that I can speak to.	16	16	20.51%	15.53%	15.53%	22.86%	22.86%
Yes, I have easy access to patients' named psychiatrist	7	23	8.97%	6.8%	22.33%	10%	32.86%
I have access to an advice line/email address for one-off advice regarding patients presenting with mental health difficulties.	15	38	19.23%	14.56%	36.89%	21.43%	54.29%
No	32	70	41.03%	31.07%	67.96%	45.71%	100%
Don't know	2	72	2.56%	1.94%	69.9%	2.86%	102.86%
Other (please specify)	6	78	7.69%	5.83%	75.73%	8.57%	111.43%
Sum:	78	-	100%	-	-	-	-
Not answered:	33	-	-	32.04%	-	-	-

Average:	3.19	Minimum:	1	Variance:	2.11
Median:	4	Maximum:	6	Std. deviation:	1.45

Total answered: 70

Last choice text input

I am a Psychiatrist too (dual trained)

did but not now

Ad hoc response from psychiatrist by email; no official email advice service

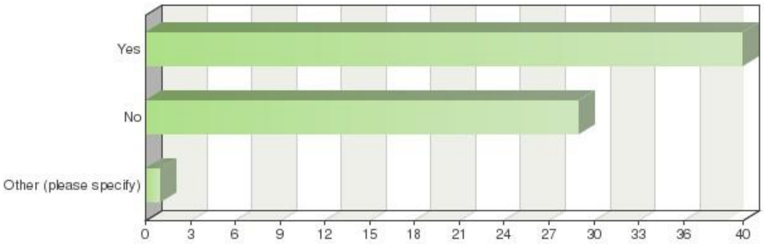
A quarterly meeting

There are avenues for referral but not easy access for advice for patients not under he care of psychiatrist. The avenues that do exist often incur lengthy waits unless it is urgent or crisis situation

GP liaison meetings occur

Question 9

Have you, in the last 3 years asked for advice about changing antipsychotics in relation to a proactive review (rather than during acute relapse)?



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes	40	40	57.14%	38.83%	38.83%	57.14%	57.14%
No	29	69	41.43%	28.16%	66.99%	41.43%	98.57%
Other (please specify)	1	70	1.43%	0.97%	67.96%	1.43%	100%
Sum:	70	-	100%	-	-	-	-
Not answered:	33	-	-	32.04%	-	-	-
Average: 1.44	Minimum:	1		Variance:		0.28	
Median: 1	Maximum:	3		Std. deviation:		0.53	

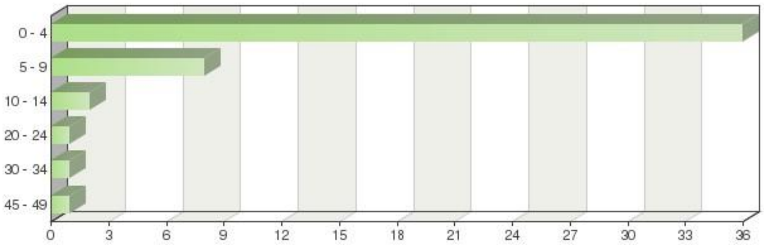
Total answered: 70

Last choice text input

I can't recall

Question 10

If you have asked for advice, approximately on how many occasions have you done so? Please enter the number of occasions using numbers only



Frequency table

Intervals	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum.

						adjusted relative frequency
0 - 4	36	36	34.95%	34.95%	73.47%	73.47%
5 - 9	8	44	7.77%	42.72%	16.33%	89.8%
10 - 14	2	46	1.94%	44.66%	4.08%	93.88%
20 - 24	1	47	0.97%	45.63%	2.04%	95.92%
30 - 34	1	48	0.97%	46.6%	2.04%	97.96%
45 - 49	1	49	0.97%	47.57%	2.04%	100%
Sum:	49	-	47.57%	-	100%	-
Not answered:	54	-	52.43%	-	-	-
Average: 4.8	Minimum:	0	Variance:		62.54	
Median: 3	Maximum:	45	Std. deviation:		7.91	

Total answered: 49

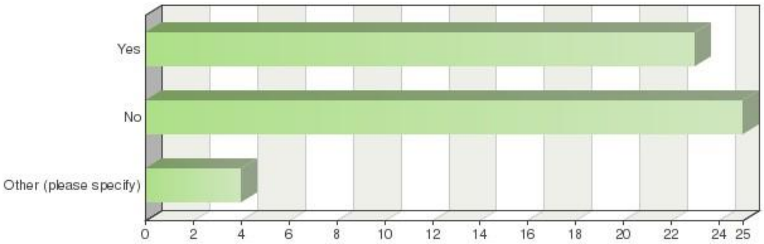
Question 11

CASE STUDY

Please answer the following questions based on this case example:

A 50-year-old married patient attends your practice for her yearly physical health check. She was diagnosed with schizophrenia at 19, and remains on 15mg Olanzapine. She has 2 inpatient admissions in 1989 and 1991, but has remained stable since and shows no residual symptoms. She was discharged from the local mental health team (secondary care) 7 years ago. She rarely attends the practice. She presents with high BMI, pre-diabetic. No risk events since her last admission in 1991.

Would you review the antipsychotic medication (Olanzapine) and consider changing it or adjusting the dose?



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes	23	23	22.33%	22.33%	44.23%	44.23%
No	25	48	24.27%	46.6%	48.08%	92.31%
Other (please specify)	4	52	3.88%	50.49%	7.69%	100%
Sum:	52	-	50.49%	-	100%	-
Not answered:	51	-	49.51%	-	-	-
Average: 1.63	Minimum:	1	Variance:		0.39	
Median: 2	Maximum:	3	Std. deviation:		0.63	

Total answered: 52

Last choice text input

I would wish to reduce but would discuss with the psychiatry team

Might write to AMHT for advice if wishing to reduce

Would review patient but if stable would be hesitant to change regime

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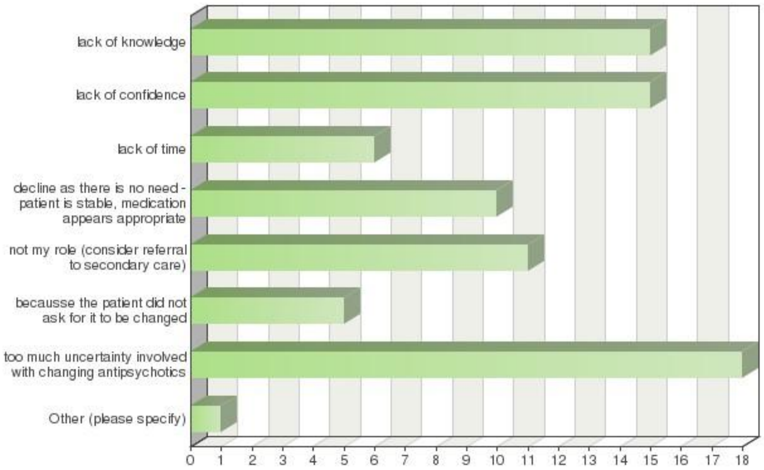
Question 12 If you selected "no" and wouldn't change the dose, why? (please select all that apply)



Frequency table

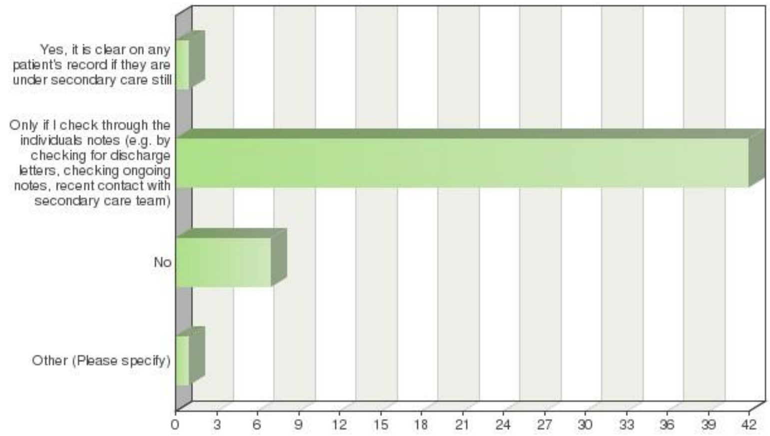
Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
lack of knowledge	15	15	18.52%	14.56%	14.56%	50%	50%
lack of confidence	15	30	18.52%	14.56%	29.13%	50%	100%
lack of time	6	36	7.41%	5.83%	34.95%	20%	120%
decline as there is no need - patient is stable, medication appears appropriate	10	46	12.35%	9.71%	44.66%	33.33%	153.33%
not my role (consider referral to secondary care)	11	57	13.58%	10.68%	55.34%	36.67%	190%
becausse the patient did not ask for it to be changed	5	62	6.17%	4.85%	60.19%	16.67%	206.67%
too much uncertainty involved with changing antipsychotics	18	80	22.22%	17.48%	77.67%	60%	266.67%
Other (please specify)	1 81		1.23%	0.97%	78.64%	3.33%	270%
Sum:	81	-	100%	-	-	-	-
Not answered:	73	-	-	70.87%	-	-	-

Average:	3.99	Minimum:	1	Variance:	5.24
Median:	4	Maximum:	9	Std. deviation:	2.29

Total answered: 30

Question 13

Do you know which of your patients diagnosed with schizophrenia or psychosis are currently under your care only (i.e. have been discharged from their secondary care mental health team?)



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes, it is clear on any patient's record if they are under secondary care still	1	1	0.97%	0.97%	1.96%	1.96%
Only if I check through the individuals notes (e.g. by checking for discharge letters, checking ongoing notes, recent contact with secondary care team)	42	43	40.78%	41.75%	82.35%	84.31%
No	7	50	6.8%	48.54%	13.73%	98.04%
Other (Please specify)	1	51	0.97%	49.51%	1.96%	100%
Sum:	51	-	49.51%	-	100%	-
Not answered:	52	-	50.49%	-	-	-

Average:	2.16	Minimum:	1	Variance:	0.21
Median:	2	Maximum:	4	Std. deviation:	0.46

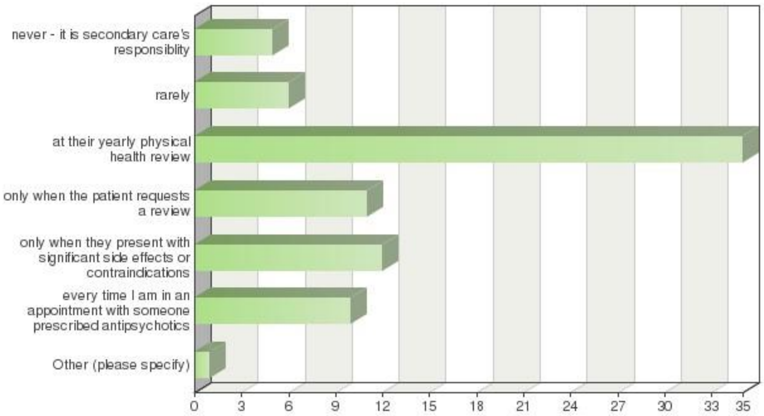
Total answered: 51

Last choice text input

I do not have full access to the notes OOHs

Question 14

How often do you review the appropriateness of antipsychotic medication in primary care only patients in general? (please select all that apply)



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Relative frequency by choice	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
never - it is secondary care's responsiblity	5	5	6.25%	4.85%	4.85%	9.8%	9.8%
rarely	6	11	7.5%	5.83%	10.68%	11.76%	21.57%
at their yearly physical health review	35	46	43.75%	33.98%	44.66%	68.63%	90.2%
only when the patient requests a review	11	57	13.75%	10.68%	55.34%	21.57%	111.76%
only when they present with significant side effects or contraindications	12	69	15%	11.65%	66.99%	23.53%	135.29%
every time I am in an appointment with someone prescribed antipsychotics	10	79	12.5%	9.71%	76.7%	19.61%	154.9%
Other (please specify)	1	80	1.25%	0.97%	77.67%	1.96%	156.86%
Sum:	80	-	100%	-	-	-	-
Not answered:	52	-	-	50.49%	-	-	-
Average: 3.66	Minimum:	1		Variance:		1.97	
Median: 3	Maximum:	7		Std. deviation:		1.4	

Total answered: 51

Last choice text input

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when signing off repeat meds and if they present with physical symptoms but also show some MH issues

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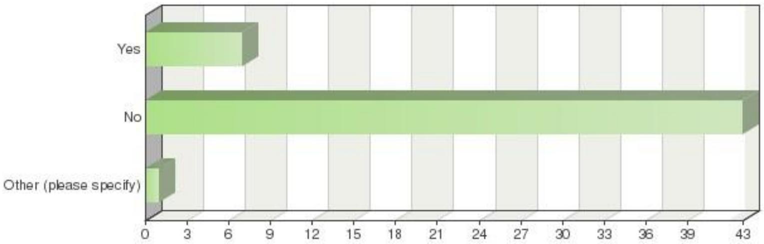
Question 15

Does your practice have a separate guidance or agreement on how to conduct a medication review with someone who is only seen in primary care?



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes	7	7	6.8%	6.8%	13.73%	13.73%
No	43	50	41.75%	48.54%	84.31%	98.04%
Other (please specify)	1	51	0.97%	49.51%	1.96%	100%
Sum:	51	-	49.51%	-	100%	-
Not answered:	52	-	50.49%	-	-	-
Average: 1.88	Minimum:	1	Variance:		0.15	
Median: 2	Maximum:	3	Std. deviation:		0.38	

Total answered: 51

Last choice text input

Not sure

Question 16 If yes, what does this guidance/agreement include?

Text input

I don't do it

basic review principles but not specific to MH

n/a

Regular review of anti paychotics/ anti depressants/ controlled drugs and acute prescriptions, short courses

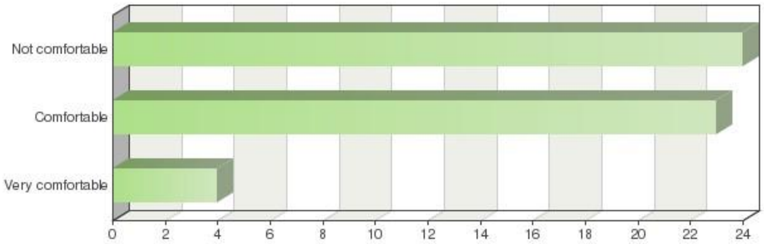
Bloods, ECG if appropriate, assessing risk factors for cardiovascular disease

Basic checks for bp, weight, height. Lifestyle choices and bloods to be done

Severe Mental Illness reviews cover this

n/a

Question 17 How comfortable are you REVIEWING the case study patient's antipsychotic medication?

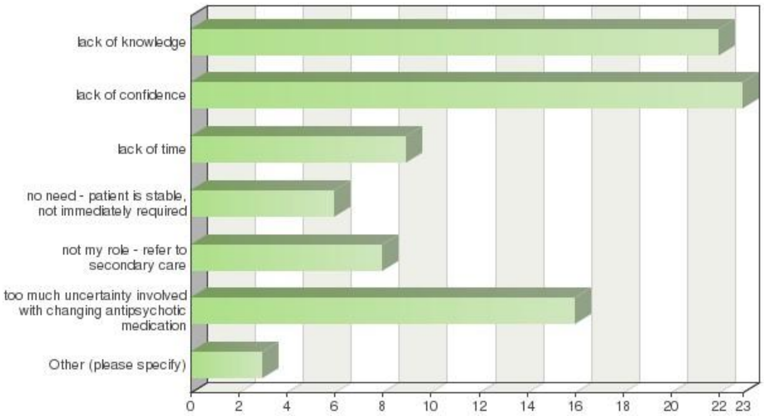


Frequency table

Levels		Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Not comfortable		24	24	23.3%	23.3%	47.06%	47.06%
Comfortable		23	47	22.33%	45.63%	45.1%	92.16%
Very comfortable		4	51	3.88%	49.51%	7.84%	100%
Sum:		51	-	49.51%	-	100%	-
Not answered:		52	-	50.49%	-	-	-
Average:	1.61	Minimum:	1	Variance:		0.4	
Median:	2	Maximum:	3	Std. deviation:		0.63	

Total answered: 51

Question 18 If you are in any way uncomfortable, why? (tick all that apply)



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
lack of knowledge	22	22	25.29%	21.36%	21.36%	64.71%	64.71%

lack of confidence	23	45	26.44%	22.33%	43.69%	67.65%	132.35%
lack of time	9	54	10.34%	8.74%	52.43%	26.47%	158.82%
no need - patient is stable, not immediately required	6	60	6.9%	5.83%	58.25%	17.65%	176.47%
not my role - refer to secondary care	8	68	9.2%	7.77%	66.02%	23.53%	200%
too much uncertainty involved with changing antipsychotic medication	16	84	18.39%	15.53%	81.55%	47.06%	247.06%
Other (please specify)	3 87		3.45%	2.91%	84.47%	8.82%	255.88%
Sum:	87	-	100%	-	-	-	-
Not answered:	69	-	-	66.99%	-	-	-
Average: 3.17	Minimum:	1		Variance:		3.94	
Median: 2	Maximum:	7		Std. deviation:		1.98	

Total answered: 34

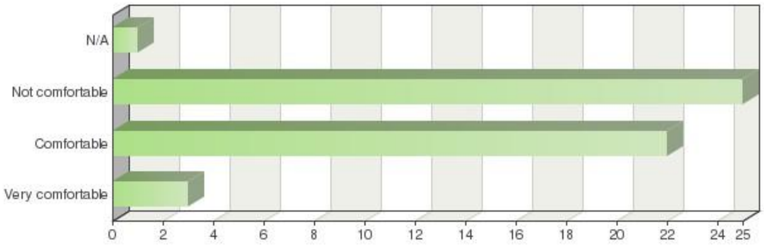
Last choice text input

difficult in 10 min time frame to explore with a mentally ill patient who cannot see the wood for the trees and may refuse all medications anyway.

Not uncomfortable

Question 19

If you decided to review the medication, and felt a reduction may be appropriate, how comfortable do you feel REDUCING the patient's antipsychotic medication?



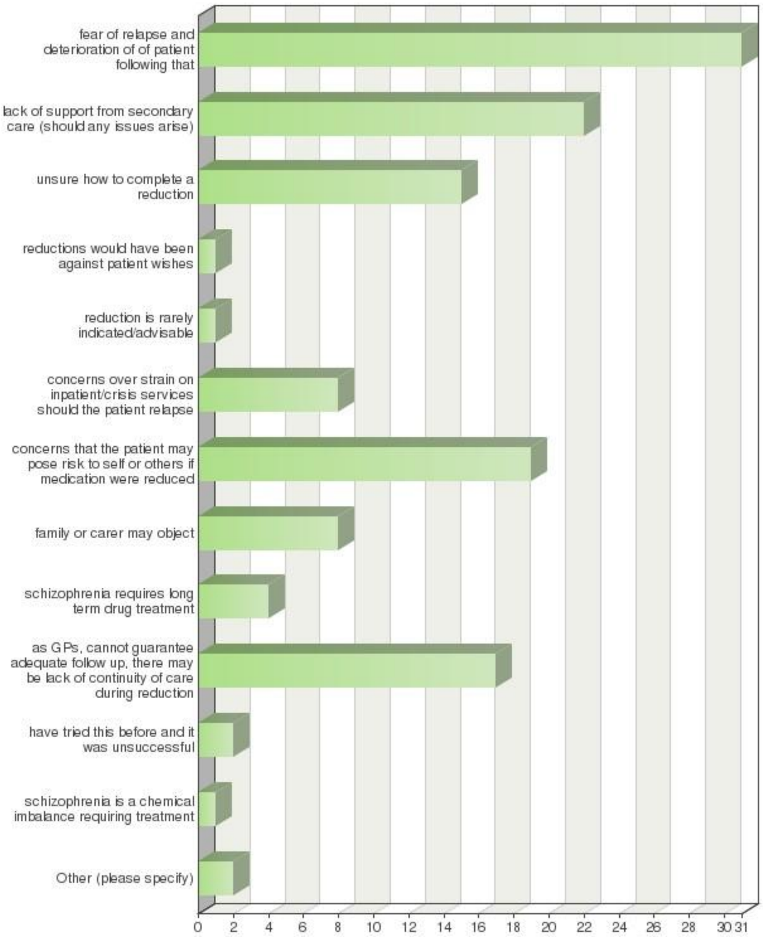
Frequency table

Levels	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
N/A	1	1	0.97%	0.97%	1.96%	1.96%
Not comfortable	25	26	24.27%	25.24%	49.02%	50.98%
Comfortable	22	48	21.36%	46.6%	43.14%	94.12%
Very comfortable	3	51	2.91%	49.51%	5.88%	100%
Sum:	51	-	49.51%	-	100%	-
Not answered:	52	-	50.49%	-	-	-
Average: 1.56	Minimum:	1	Variance:		0.37	

Median:	1.5	Maximum:	3	Std. deviation:	0.61

Total answered: 51

Question 20 If you do not feel comfortable to reduce, why? Please select all that apply



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
fear of relapse and deterioration of of patient following that	31	31	23.66%	30.1%	30.1%	86.11%	86.11%
lack of support from secondary care (should any issues arise)	22	53	16.79%	21.36%	51.46%	61.11%	147.22%
unsure how to complete a reduction	15	68	11.45%	14.56%	66.02%	41.67%	188.89%

reductions would have been against patient wishes	1	69	0.76%	0.97%	66.99%	2.78%	191.67%
reduction is rarely indicated/advisable	1	70	0.76%	0.97%	67.96%	2.78%	194.44%
concerns over strain on inpatient/crisis services should the patient relapse	8	78	6.11%	7.77%	75.73%	22.22%	216.67%
concerns that the patient may pose risk to self or others if medication were reduced	19	97	14.5%	18.45%	94.17%	52.78%	269.44%
family or carer may object	8	105	6.11%	7.77%	101.94%	22.22%	291.67%
schizophrenia requires long term drug treatment	4	109	3.05%	3.88%	105.83%	11.11%	302.78%
as GPs, cannot guarantee adequate follow up, there may be lack of continuity of care during reduction	17	126	12.98%	16.5%	122.33%	47.22%	350%
have tried this before and it was unsuccessful	2	128	1.53%	1.94%	124.27%	5.56%	355.56%
schizophrenia is a chemical imbalance requiring treatment	1	129	0.76%	0.97%	125.24%	2.78%	358.33%
Other (please specify)	2	131	1.53%	1.94%	127.18%	5.56%	363.89%
Sum:	131	-	100%	-	-	-	-
Not answered:	67	-	-	65.05%	-	-	-

Average:	4.89	Minimum:	1	Variance:	12.67
Median:	3	Maximum:	13	Std. deviation:	3.56

Total answered: 36

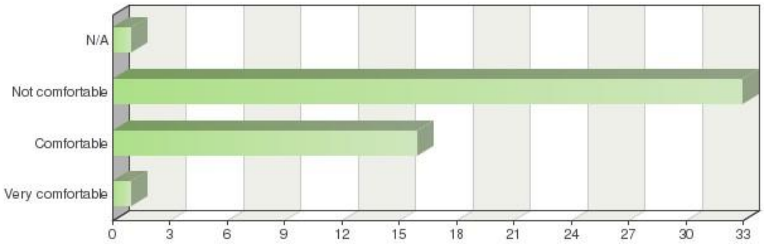
Last choice text input

I would feel comfortable doing this if advised by psychiatry with guidance.

N/A not uncomfortable

Question 21

How comfortable would you feel to DISCONTINUE the patients antipsychotic medication, should the reduction go well? (e.g no recurrence of psychotic symptoms)



Frequency table

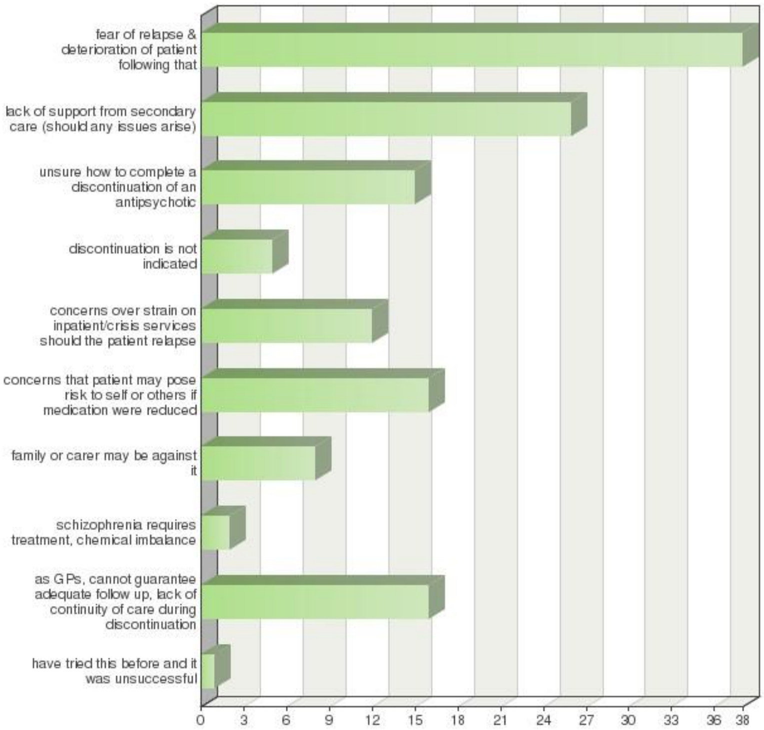
Levels	**Absolute frequency**	**Cum. absolute frequency**	**Relative frequency**	**Cum. relative frequency**	**Adjusted relative frequency**	**Cum. adjusted relative frequency**
N/A	1	1	0.97%	0.97%	1.96%	1.96%
Not comfortable	33	34	32.04%	33.01%	64.71%	66.67%

Comfortable	16	50	15.53%	48.54%	31.37%	98.04%
Very comfortable	1	51	0.97%	49.51%	1.96%	100%
Sum:	51	-	49.51%	-	100%	-
Not answered:	52	-	50.49%	-	-	-

Average:	1.36	Minimum:	1	Variance:	0.28
Median:	1	Maximum:	3	Std. deviation:	0.53

Total answered: 51

Question 22 If you do not feel comfortable to discontinue, why? Please tick all that apply



Frequency table

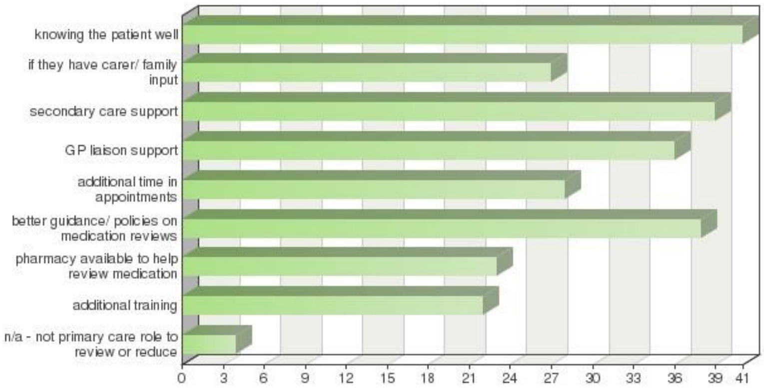
Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
fear of relapse & deterioration of patient following that	38	38	27.34%	36.89%	36.89%	97.44%	97.44%
lack of support from secondary care (should any issues arise)	26	64	18.71%	25.24%	62.14%	66.67%	164.1%
unsure how to complete a discontinuation of an antipsychotic	15	79	10.79%	14.56%	76.7%	38.46%	202.56%
discontinuation is not indicated	5	84	3.6%	4.85%	81.55%	12.82%	215.38%
concerns over strain on inpatient/crisis services should the patient relapse	12	96	8.63%	11.65%	93.2%	30.77%	246.15%

concerns that patient may pose risk to self or others if medication were reduced	16	112	11.51%	15.53%	108.74%	41.03%	287.18%
family or carer may be against it	8	120	5.76%	7.77%	116.5%	20.51%	307.69%
schizophrenia requires treatment, chemical imbalance	2	122	1.44%	1.94%	118.45%	5.13%	312.82%
as GPs, cannot guarantee adequate follow up, lack of continuity of care during discontinuation	16	138	11.51%	15.53%	133.98%	41.03%	353.85%
have tried this before and it was unsuccessful	1	139	0.72%	0.97%	134.95%	2.56%	356.41%
Sum:	139	-	100%	-	-	-	-
Not answered:	64	-	-	62.14%	-	-	-
Average: 3.86 Minimum:		1		Variance:		7.79	
Median: 3 Maximum:		10		Std. deviation:		2.79	

Total answered: 39

Question 23

Please tick what you would find helpful for medication reviews (please tick all that apply)



Frequency table

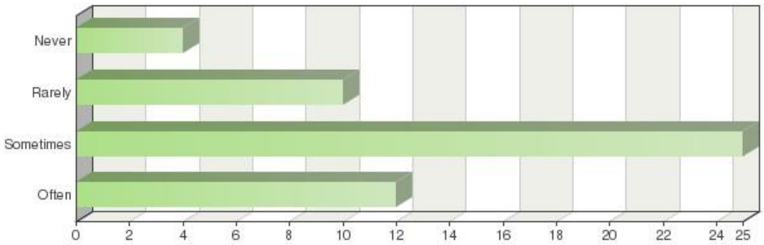
Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
knowing the patient well	41	41	15.89%	39.81%	39.81%	80.39%	80.39%
if they have carer/ family input	27	68	10.47%	26.21%	66.02%	52.94%	133.33%
secondary care support	39	107	15.12%	37.86%	103.88%	76.47%	209.8%
GP liaison support	36	143	13.95%	34.95%	138.83%	70.59%	280.39%
additional time in appointments	28	171	10.85%	27.18%	166.02%	54.9%	335.29%
better guidance/ policies on medication reviews	38	209	14.73%	36.89%	202.91%	74.51%	409.8%
pharmacy available to help review medication	23	232	8.91%	22.33%	225.24%	45.1%	454.9%
additional training	22	254	8.53%	21.36%	246.6%	43.14%	498.04%
n/a - not primary care role to review or reduce	4	258	1.55%	3.88%	250.49%	7.84%	505.88%
Sum:	258	-	100%	-	-	-	-
Not answered:	52	-	-	50.49%	-	-	-

Average:	4.25	Minimum:	1	Variance:	5.21
Median:	4	Maximum:	9	Std. deviation:	2.28

Total answered: 51

Question 24

During an appointment, how often do you usually discuss common side effects or unwanted effects from antipsychotic medication and need for regular monitoring?



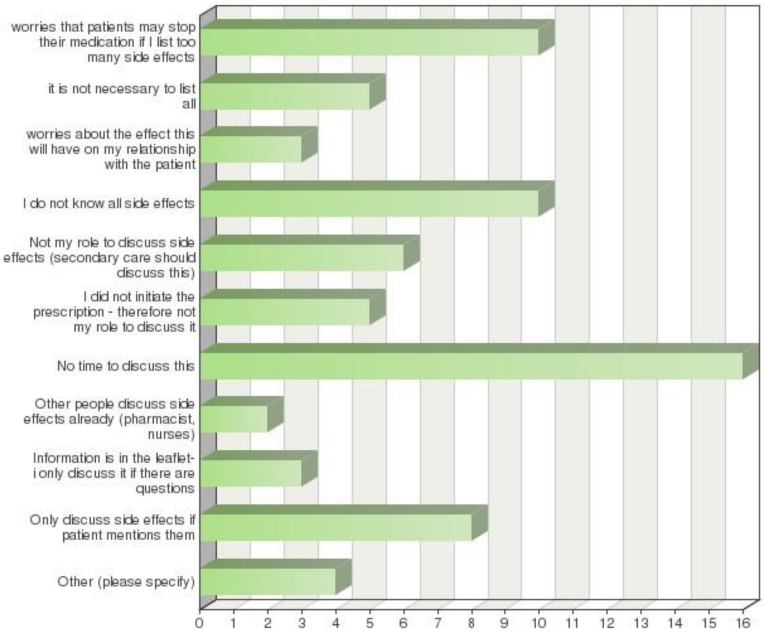
Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Never	4	4	7.84%	3.88%	3.88%	7.84%	7.84%
Rarely	10	14	19.61%	9.71%	13.59%	19.61%	27.45%
Sometimes	25	39	49.02%	24.27%	37.86%	49.02%	76.47%
Often	12	51	23.53%	11.65%	49.51%	23.53%	100%
Sum:	51	-	100%	-	-	-	-
Not answered:	52	-	-	50.49%	-	-	-
Average: 2.88	Minimum:	1		Variance:		0.75	
Median: 3	Maximum:	4		Std. deviation:		0.86	

Total answered: 51

Question 25

If you do not usually discuss common side effects, please list reasons why (please tick all that apply)



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
worries that patients may stop their medication if I list too many side effects	10	10	13.89%	9.71%	9.71%	31.25%	31.25%
it is not necessary to list all	5	15	6.94%	4.85%	14.56%	15.62%	46.88%
worries about the effect this will have on my relationship with the patient	3	18	4.17%	2.91%	17.48%	9.38%	56.25%
I do not know all side effects	10	28	13.89%	9.71%	27.18%	31.25%	87.5%
Not my role to discuss side effects (secondary care should discuss this)	6	34	8.33%	5.83%	33.01%	18.75%	106.25%
I did not initiate the prescription - therefore not my role to discuss it	5	39	6.94%	4.85%	37.86%	15.62%	121.88%
No time to discuss this	16	55	22.22%	15.53%	53.4%	50%	171.88%
Other people discuss side effects already (pharmacist, nurses)	2	57	2.78%	1.94%	55.34%	6.25%	178.12%
Information is in the leaflet- i only discuss it if there are questions	3	60	4.17%	2.91%	58.25%	9.38%	187.5%
Only discuss side effects if patient mentions them	8	68	11.11%	7.77%	66.02%	25%	212.5%
Other (please specify)	4 72		5.56%	3.88%	69.9%	12.5%	225%
Sum:	72	-	100%	-	-	-	-
Not answered:	71	-	-	68.93%	-	-	-

Average:	5.67	Minimum:	1	Variance:	9.49
Median:	6	Maximum:	11	Std. deviation:	3.08

Total answered: 32

Last choice text input

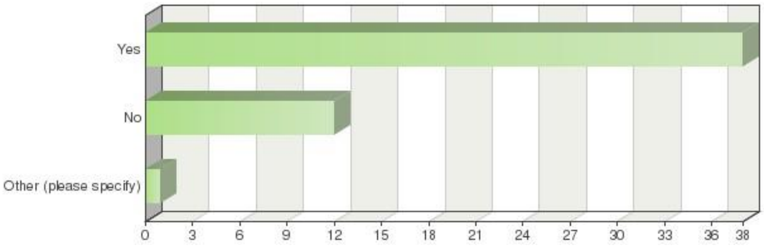
re box above - i will discuss SEs if pt mentions them but alos if I see some (eg TD)

I rarely review anti-psychotics. S.E normally discussed at initiation. I would normally ask generally about s.e rather than specifically

pharmacists would do

If a patient has been stable on a medication for a long time WITHOUT side effects then I would probably only discuss the possibility of long term side effects and ask them to contact us if they feel a symptom they have could be related to their long term

Question 26 Do you have concerns regarding long term antipsychotic prescribing?



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes	38	38	36.89%	36.89%	74.51%	74.51%
No	12	50	11.65%	48.54%	23.53%	98.04%
Other (please specify)	1	51	0.97%	49.51%	1.96%	100%
Sum:	51	-	49.51%	-	100%	-
Not answered:	52	-	50.49%	-	-	-
Average: 1.27	Minimum:	1	Variance:		0.24	
Median: 1	Maximum:	3	Std. deviation:		0.49	

Total answered: 51

Last choice text input

Some - so high yes and no

Question 27 If yes, what are your concerns?

Text input

Effect on cardiovascular system and increased BMI

long term risk of atherosclerosis

Lack of reviews, metabolic and cardiovascular side effects

Side effects physical and mental, tolerance, dependence, stigma, institutionalisation

Increased risk of metabolic and cardiovascular effects Deprescribing can be difficult to initiate

Weight gain, metabolic syndrome and higher risk of cardiovascular events, cognitive impairment........

toxicity/long-term harms, use as substitute for meaningful therapeutic treatment and support, reinforces idea of secondary care as 'prescription providers only' service

Sedation weight gain cardiac risks

Dyskinesia and other symptoms

obesity and diabetes

Metabolic effects Blunting of affect and reducing motivation Cardiac SEs

side effect concerns, quality of life, dependency etc

that patients get stuck on medication that they might no longer need, or could take at a lower dose

Movement disorder, weight gain, diabetes

I am not confident enough

Feels very unclear in many cases if antipsychotics should be continued indefinitely. Often seem to be started in patients without schizophrenia or psychosis but more depression/personality disorder diagnoses and rationale/plan seems v vague.

Not knowing when it is appropriate to reduce or stop.

uncertainty re risks of long term effects

motor symptoms

Cardiovascular risk due to weight gain and diabetes

appropriate support from secondary care and appropriate training.

That there is a severe lack of follow up in secondary care

Numerous side effects

Physical health risks

impact of drugs in physical health and the lack of guidance/support from secondary care to appropriately risk assess and reduce. Often medication gets escalated in a crisis by psychiatrist and then patients are discharged without any advice about deprescribing

Dose changing is very risky and the blame the clinician system that is in place if a medical error happens is a strong deterrent to change antipsychotics especially if the patient is not known to you

May not be required long term. May be better to use to stabilise as an adjunct to other treatment. May need long term, but at a reduced dose than when in crisis.

Many patients in my practice were on long term antipsychotics without a Read (Snomed) code for psychosis or schizophrenia. So they were being missed from the severe mental illness register. I conducted an extensive audit and managed to code them all correctly. However, this shows how easily patients can be discharged and fail to be followed up properly.

Side effects

Side effects. Support abs monitoring from secondary care.

There is not the time/expertise in GP to monitor and manage antipsychotic prescribing.

GP is left to it but I have minimal training in this. My senior colleagues in primary care have more knowledge and provide some support.

that secondary care start it then leave it up to primary care expecting that we can cope with crisis, side effects and longterm risks but wont be available to help the patient if needed. Risk to patients of weight increase, diabetes and dementia if on longterm drugs.

Associated with physical ill health eg cardiac events, obesity, diabetes

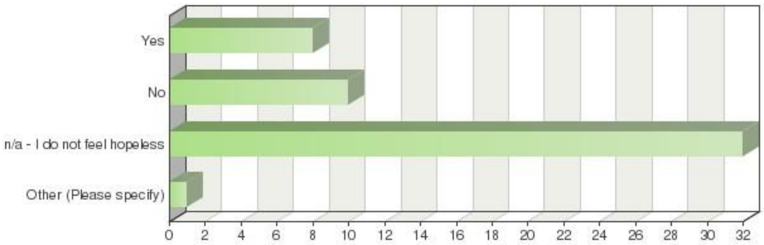
If, after a long time stable on a certain medication, changes occur and a patient becomes unstable, it is worrying to know what could be the trigger and what the medication should then be changed to, particularly because when they occur the change is often sudden and can be dramatic. So it is a rush to try and find a solution and help for a patient who may be unstable in the community and we do not have the ability to get them under the care of a specialist quickly.

Long-term side-effects, including metabolic, and movement disorders

side effects

Question 28

If you felt hopeless regarding the treatment of people with schizophrenia or psychosis (i.e. felt like there was not anything more you could do treatment wise), do you communicate this with patients in any way?



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes	8	8	7.77%	7.77%	15.69%	15.69%
No	10	18	9.71%	17.48%	19.61%	35.29%
n/a - I do not feel hopeless	32	50	31.07%	48.54%	62.75%	98.04%
Other (Please specify)	1	51	0.97%	49.51%	1.96%	100%
Sum:	51	-	49.51%	-	100%	-
Not answered:	52	-	50.49%	-	-	-
Average: 2.51	Minimum:	1	Variance:		0.61	
Median: 3	Maximum:	4	Std. deviation:		0.78	

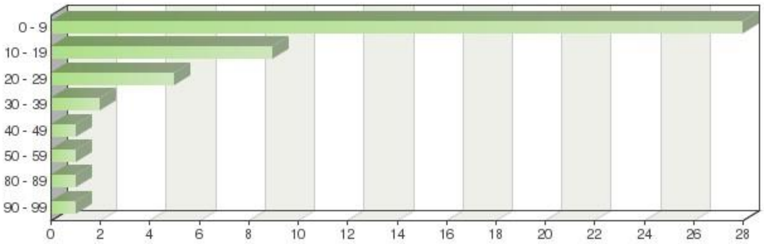
Total answered: 51

Last choice text input

I would consult secondary care

Question 29

Out of all appointments you had with patients diagnosed with schizophrenia or psychosis in the last 12 months, roughly which PERCENTAGE (give an estimate) of appointments resulted in a change of antipsychotic medication? (including increase, decrease, or change of type of antipsychotic medication?)



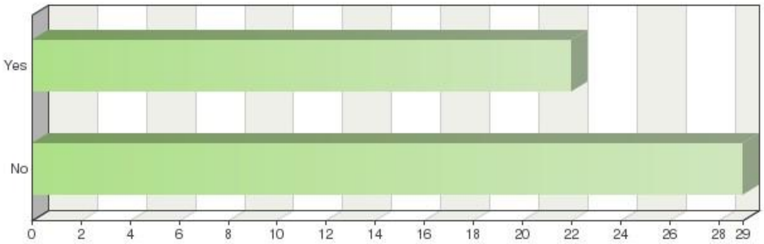
Frequency table

Intervals		Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
0 - 9		28	28	27.18%	27.18%	58.33%	58.33%
10 - 19		9	37	8.74%	35.92%	18.75%	77.08%
20 - 29		5	42	4.85%	40.78%	10.42%	87.5%
30 - 39		2	44	1.94%	42.72%	4.17%	91.67%
40 - 49		1	45	0.97%	43.69%	2.08%	93.75%
50 - 59		1	46	0.97%	44.66%	2.08%	95.83%
80 - 89		1	47	0.97%	45.63%	2.08%	97.92%
90 - 99		1	48	0.97%	46.6%	2.08%	100%
Sum:		48	-	46.6%	-	100%	-
Not answered:		55	-	53.4%	-	-	-
Average:	11.65	Minimum:	0		Variance:	411.55	
Median:	2	Maximum:	100		Std. deviation:	20.29	

Total answered: 48

Question 30

Have you ever felt at risk or apprehensive when completing a consultation with someone with a diagnosis of schizophrenia or psychosis?

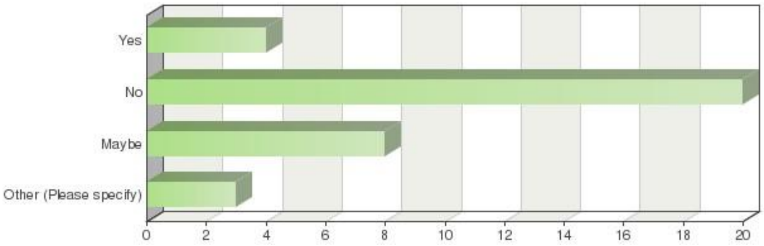


Frequency table

Choices		Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes		22	22	21.36%	21.36%	43.14%	43.14%
No		29	51	28.16%	49.51%	56.86%	100%
Sum:		51	-	49.51%	-	100%	-
Not answered:		52	-	50.49%	-	-	-
Average:	1.57	Minimum:	1	Variance:		0.25	
Median:	2	Maximum:	2	Std. deviation:		0.5	

Total answered: 51

Question 31 If you selected have felt at risk, has this subsequently changed your practice?



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes	4	4	3.88%	3.88%	11.43%	11.43%
No	20	24	19.42%	23.3%	57.14%	68.57%
Maybe	8	32	7.77%	31.07%	22.86%	91.43%
Other (Please specify)	3	35	2.91%	33.98%	8.57%	100%
Sum:	35	-	33.98%	-	100%	-
Not answered:	68	-	66.02%	-	-	-
Average: 2.29	Minimum:	1	Variance:		0.62	
Median: 2	Maximum:	4	Std. deviation:		0.79	

Total answered: 35

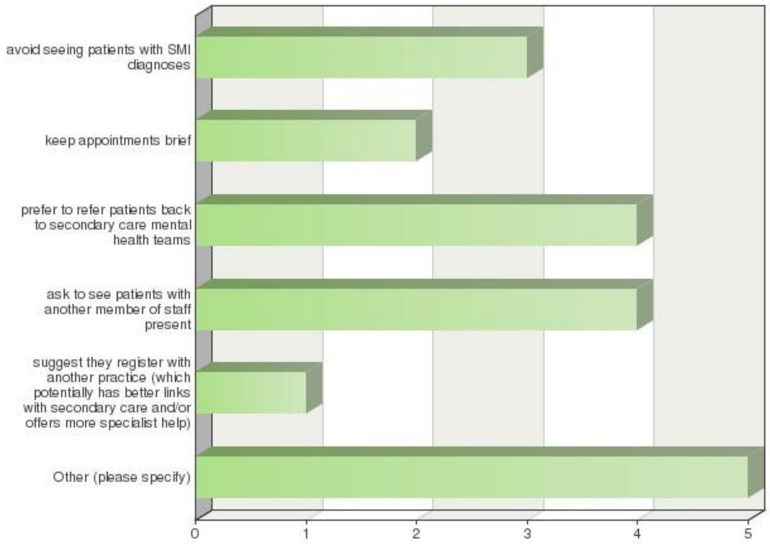
Last choice text input

n/a

n/a

n/a

Question 32 If it has changed your practice, in what way? (please tick all that apply)



Frequency table

Choices	Absolute frequency	Cum. absolute frequency	Relative frequency by choice	Relative frequency	Cum. Relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
avoid seeing patients with SMI diagnoses	3	3	15.79%	2.91%	2.91%	20%	20%
keep appointments brief	2	5	10.53%	1.94%	4.85%	13.33%	33.33%
prefer to refer patients back to secondary care mental health teams	4	9	21.05%	3.88%	8.74%	26.67%	60%
ask to see patients with another member of staff present	4	13	21.05%	3.88%	12.62%	26.67%	86.67%
suggest they register with another practice (which potentially has better links with secondary care and/or offers more specialist help)	1	14	5.26%	0.97%	13.59%	6.67%	93.33%
Other (please specify)	5	19	26.32%	4.85%	18.45%	33.33%	126.67%
Sum:	19	-	100%	-	-	-	-
Not answered:	88	-	-	85.44%	-	-	-

Average:	3.68	Minimum:	1	Variance:	3.23
Median:	4	Maximum:	6	Std. deviation:	1.8

Total answered: 15

Last choice text input

try to ensure full risk assessment/preparation in advance

panic button and can make reception / other staff aware you are in a riskier consultation so they keep a watch

n/a

I have not changed my practice

make sure patient has an escape route,make sure doctor has a panic button,make sure staff know I am with someone who is high risk for attacking ,get another (second) clinician to attend if situation gets out of hand

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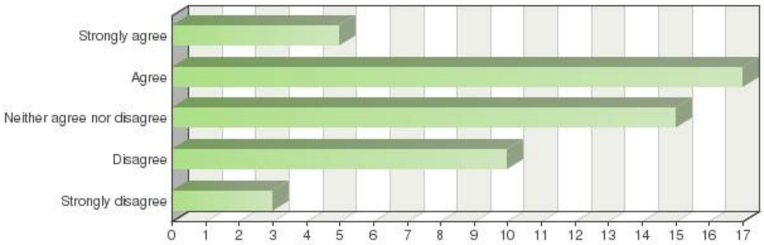
Question 33 Please state to which extent you agree or disagree with the following statements:

Levels GPs have low expectations regarding the recovery of patients diagnosed with schizophrenia/psychosis

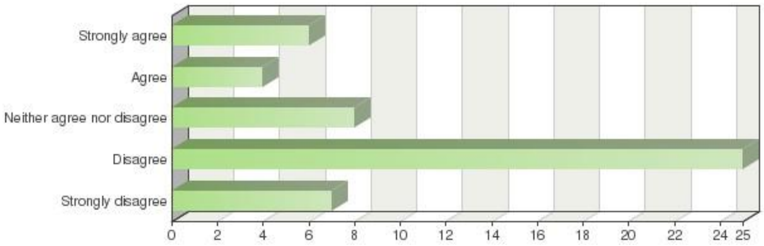


Frequency table

Levels	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Strongly agree	5	5	4.85%	4.85%	10%	10%
Agree	17	22	16.5%	21.36%	34%	44%
Neither agree nor disagree	15	37	14.56%	35.92%	30%	74%
Disagree	10	47	9.71%	45.63%	20%	94%
Strongly disagree	3	50	2.91%	48.54%	6%	100%
Sum:	50	-	48.54%	-	100%	-
Not answered:	53	-	51.46%	-	-	-
Average: 2.78	Minimum:	1	Variance:		1.15	
Median: 3	Maximum:	5	Std. deviation:		1.07	

Total answered: 50

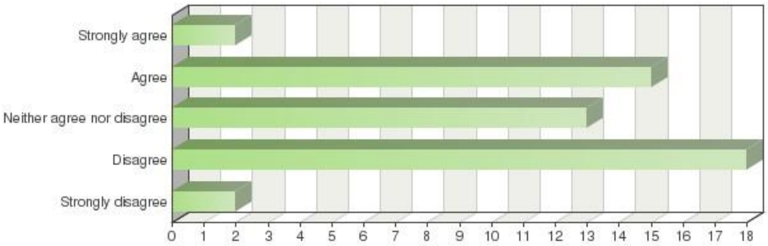
Levels I feel hopeless (meaning you felt there was nothing else you can do) regarding treatment and recovery for patients diagnosed with schizophrenia/psychosis.


Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
0
2
4
6
8
10
12
14
16
18
20
22
24
25

	6	6	5.83%	5.83%	12%	12%
	4	10	3.88%	9.71%	8%	20%
	8	18	7.77%	17.48%	16%	36%
Disagree	25	43	24.27%	41.75%	50%	86%
Strongly disagree	7	50	6.8%	48.54%	14%	100%
Sum:	50	-	48.54%	-	100%	-
Not answered:	53	-	51.46%	-	-	-
Average: 3.46	Minimum:	1	Variance:		1.44	
Median: 4	Maximum:	5	Std. deviation:		1.2	

Total answered: 50

Levels I experience difficulties when discussing antipsychotic medication with patients diagnosed with schizophrenia or psychosis

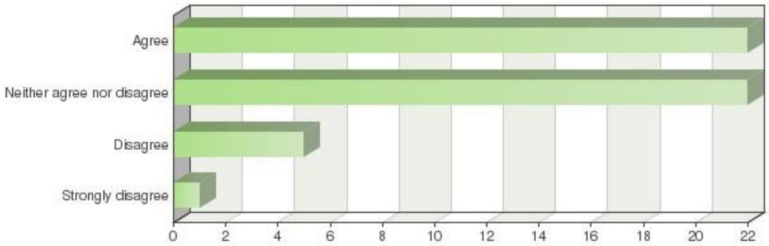


Frequency table

Levels	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Strongly agree	2	2	1.94%	1.94%	4%	4%
Agree	15	17	14.56%	16.5%	30%	34%
Neither agree nor disagree	13	30	12.62%	29.13%	26%	60%
Disagree	18	48	17.48%	46.6%	36%	96%
Strongly disagree	2	50	1.94%	48.54%	4%	100%
Sum:	50	-	48.54%	-	100%	-
Not answered:	53	-	51.46%	-	-	-
Average: 3.06	Minimum:	1	Variance:		1	
Median: 3	Maximum:	5	Std. deviation:		1	

Total answered: 50

Levels Patients diagnosed with schizophrenia/psychosis understand the need for antipsychotic medication.

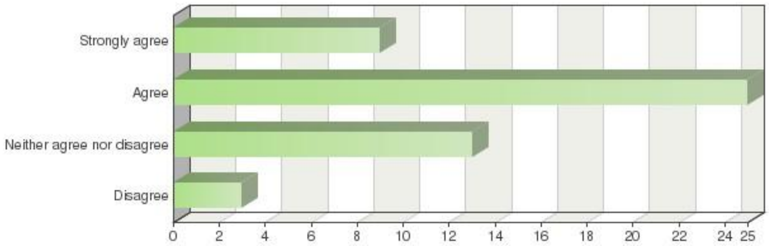


Frequency table

Levels	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Agree	22	22	21.36%	21.36%	44%	44%
Neither agree nor disagree	22	44	21.36%	42.72%	44%	88%
Disagree	5	49	4.85%	47.57%	10%	98%
Strongly disagree	1	50	0.97%	48.54%	2%	100%
Sum:	50	-	48.54%	-	100%	-
Not answered:	53	-	51.46%	-	-	-
Average: 2.7	Minimum:	2	Variance:		0.54	
Median: 3	Maximum:	5	Std. deviation:		0.74	

Total answered: 50

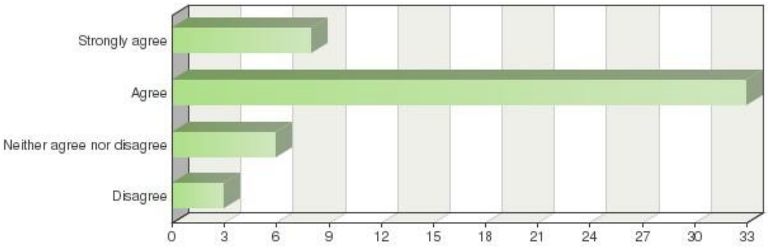
Levels There is pressure on GPs to ensure adherence of antipsychotics in order to prevent relapse.



	9	9	8.74%	8.74%	18%	18%
	25	34	24.27%	33.01%	50%	68%
	13	47	12.62%	45.63%	26%	94%
Disagree	3	50	2.91%	48.54%	6%	100%
Sum:	50	-	48.54%	-	100%	-
Not answered:	53	-	51.46%	-	-	-
Average: 2.2	Minimum:	1	Variance:		0.65	
Median: 2	Maximum:	4	Std. deviation:		0.81	

Total answered: 50

Levels A lack of information about the nature of antipsychotic medication, meant that patients do not see the importance of physical health checks and potentially do not attend yearly reviews.

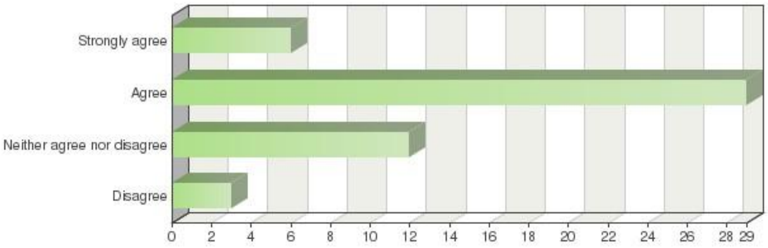


Frequency table

Levels	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Strongly agree	8	8	7.77%	7.77%	16%	16%
Agree	33	41	32.04%	39.81%	66%	82%
Neither agree nor disagree	6	47	5.83%	45.63%	12%	94%
Disagree	3	50	2.91%	48.54%	6%	100%
Sum:	50	-	48.54%	-	100%	-
Not answered:	53	-	51.46%	-	-	-
Average: 2.08	Minimum:	1	Variance:		0.52	
Median: 2	Maximum:	4	Std. deviation:		0.72	

Total answered: 50

Levels Patients will discontinue their medication if they experience side effects that they were not advised of before.



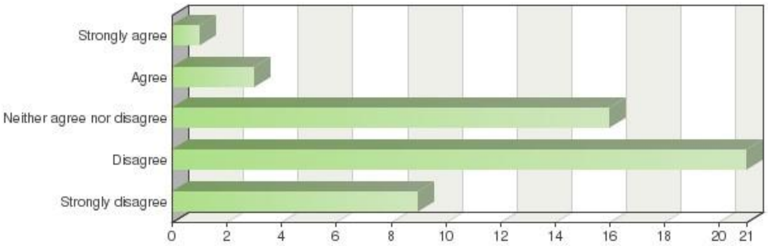
Frequency table

Levels	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Strongly agree	6	6	5.83%	5.83%	12%	12%
Agree	29	35	28.16%	33.98%	58%	70%

Neither agree nor disagree		12	47	11.65%	45.63%	24%	94%
Disagree		3	50	2.91%	48.54%	6%	100%
Sum:		50	-	48.54%	-	100%	-
Not answered:		53	-	51.46%	-	-	-
Average:	2.24	Minimum:	1	Variance:		0.55	
Median:	2	Maximum:	4	Std. deviation:		0.74	

Total answered: 50

Levels Most patients diagnosed with psychosis or schizophrenia lack capacity or insight regarding their treatment

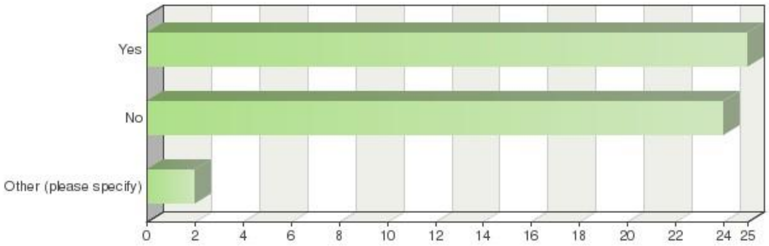


		1	1	0.97%	0.97%	2%	2%
		3	4	2.91%	3.88%	6%	8%
		16	20	15.53%	19.42%	32%	40%
Disagree		21	41	20.39%	39.81%	42%	82%
Strongly disagree		9	50	8.74%	48.54%	18%	100%
Sum:		50	-	48.54%	-	100%	-
Not answered:		53	-	51.46%	-	-	-
Average:	3.68	Minimum:	1	Variance:		0.83	
Median:	4	Maximum:	5	Std. deviation:		0.91	

Total answered: 50

Question 34

Have you experienced communication difficulties with people with a diagnosis of schizophrenia or psychosis?



Frequency table

Choices		Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency
Yes		25	25	24.27%	24.27%	49.02%	49.02%
No		24	49	23.3%	47.57%	47.06%	96.08%
Other (please specify)		2	51	1.94%	49.51%	3.92%	100%
Sum:		51	-	49.51%	-	100%	-
Not answered:		52	-	50.49%	-	-	-
Average:	1.55	Minimum:	1	Variance:		0.33	
Median:	2	Maximum:	3	Std. deviation:		0.58	

Total answered: 51

Last choice text input

sometimes when actuely unwell, not at other times.

A minority

Levels	Absolute frequency	Cum. absolute frequency	Relative frequency	Cum. relative frequency	Adjusted relative frequency	Cum. adjusted relative frequency

Frequency table

Strongly agree
Agree
Neither agree nor disagree

Question 35

If you experienced any communication difficulties with people with a diagnosis with schizophrenia or psychosis, please describe those:

Text input

During an acute episode but no issues with patients stable on medication
clear aids to help understand risks
Patient's lack of comprehension, poor listening, paranoia, passivity
Lack of rapport
Lack of Insight (despite disagreeing with statement above, due to generalisation) Poor English
difficulties due to language, speech processing, acute MH presentation
A rational explanation that the patient could understand was possible after the patient was given medication in a hospital setting. If it related to simply using the patient's language I have found language line effective
Aggressive, abusive and violent on occasion Repetitive consultations, with patients who have no insight Family difficulties with patients and unable to support the patients
they can ignore phone calls and letters, sometimes they sofa surf.
Often these patients have difficulty expressing themselves clearly and/or associated learning difficulties

Understanding, trust issues

only if they have been unwell and not able to hold a rational conversation

Withdrawal and lack of insight

Long waiting times in secondary care

mainly in acute phase

Communication difficulties with a particular case who had LD

Sometimes lack insight which means a discussion about

Communication is very difficult if their symptoms are returning. Also there is very little we can do in a 10 minute appointment with other patients waiting.

Only occasionally an issue. eg patients with very longstanding illness, often living in supported accommodation and carers very good at supporting communication

Language barrier usually

Poor compliance, sometimes aggressive Difficult to contact

Question 36

Any further comments?

Thank you for taking part. If you have any questions, please contact lisa.gruenwald.17@ucl.ac.uk

Text input

Annual SMI reviews are now part of QoF from April 21 onwards. This involves a comprehensive mental and physical health review, blood test and medication review using a template. Mostly medication is left unchanged if no side effects. Referral back to secondary care if side effects.

Very important study. Thank you.

I think any antipsychotic prescription should come with a deprescribing/exit plan, and GP timely access to psychiatric advice/secondary care input when needed. Unfortunately that is almost never in place!

As an out of hours GP I encounter the acute exacerbations more. If medications are changed this is usually done with advise of a psychiatric team.

Patients who suffers psychoses do present a challengeAs they have high DNA rates, are less engaging, may have periods of non-compliance. Very often carers, relatives, support workers, medication management teams and local pharmacies are recruited to repeat messages about blood tests, medication monitoring and reviews as well as physical health checks.

---

getting it right can be rewarding too! Difficult when CMHT says they have nothing to offer but the patient is not coping and all concerns from neighbours etc come to GP.

Several of your questions are still set up to demand answers even if they are not relevant based on the response to the question above - try setting up conditional parameters on these questions! Also question 29 needs an n/a option - if you did not have any patients diagnosed with these conditions in the last year you shouldnâ€™t answer this one!

Some of the yes / no questions are somewhere between yes and no. There should be a sometimes, all the times, never type scale. CMHTs should try and give a plan about stopping the meds if they see fit. I’ve never seen a letter from a CMHT where they have stopped any meds or advised when or how to.

Health improvement workers (HIWs) were recently appointed by the local NHS. Their role was supposed to be to engage patients in primary care with severe mental illness in their physical and mental health checks. However, they have been working mostly in secondary care out patient clinics. This is an example of how the NHS cynically creates posts and takes funding but spends it in secondary care. The money was supposed to re-engage SMI patients in primary care and prevent their non-engagement with their physical and mental health.

There has been a continual increase in mental health services discharging patients with all diagnoses and increasing expectation that GPs can, somehow, provide the same input as mental health services. For example, urgent telephone appointments for patients who are expressing suicidal thoughts/deterioration of psychotic symptoms - there is nothing I can do as GP in a 10 minute appointment other than signpost to crisis line/call 999 - which would have been better done at the point the patient/relative(it is usually relatives that make this type of call) makes contact ie at reception/triage stage, rather than wait for a call back in 4-6 hours. We do not have the capacity in GP to deal with complex mental health issues/crises.

---

secondary care are very slow to respond when we ask for help. I have only tried to admit 2 patients to hospital acutely in the past 20years or so (and have asked for lots of urgent OP reviews) but with the 2 patients it took about 3 hours of negotiating with the secondary care team and they seemed reluctant to admit but on both occasions the patient was an inpatient for 6-7 months so clearly my requests were justified.

This is very interesting. I have been a GP a very long time. I don't think I have considered that it is my role to reduce/stop anti-psychotics. I usually discuss it if the patient brings it up. I would only reduce if the patient and carers agree good idea and monitor carefully. unfortunately I have had a few relapsed patients but maybe that is a price worth paying.

---

no

Appendix 12 SPSS outputs

1) Recruitment study
2) GET
3) FILE='\\ad.ucl.ac.uk\homeg\uctvlmg\Documents\PhD\recruitment study\Interview study 08.09_new.sav'
4) PASSWORD='=P/(#K/(!l'.
5) DATASET NAME DataSet1 WINDOW=FRONT.
6) SORT CASES BY MEDS_LONGTERM_NOOTHER (A).
7) RECODE MEDS_LONGTERM_NOOTHER (1=1) (2=1) (3=1) (4=2) INTO meds_binary_longterm.
8) EXECUTE.
9) SORT CASES BY MEDS_REDUCE_NOOTHER (A).
10) SORT CASES BY MEDS_STOP_FINAL (A).
11) RECODE MEDS_REDUCE_NOOTHER (1=1) (2=1) (3=1) (4=2) INTO meds_binary_reduce.
12) EXECUTE.
13) RECODE MEDS_STOP_FINAL (1=1) (2=1) (4=1) (3=2) INTO meds_binary_stop.
14) EXECUTE.
15) CROSSTABS
16) /TABLES=meds_binary_longterm meds_binary_reduce meds_binary_stop BY PRIM_SECON_CARE
17) /FORMAT=AVALUE TABLES
18) /STATISTICS=CHISQ PHI
19) /CELLS=COUNT ROW COLUMN TOTAL
20) /COUNT ROUND CELL.
21)
22)
23)
24)
25) **Crosstabs**
26)
27)
28)

Notes

Output Created		01-MAY-2022 09:43:31
Comments		
Input	Data	\\ad.ucl.ac.uk\homeg\uctvlmg\Documents\PhD\recruitment study\Interview study 08.09_new.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>

	Split File	<none>
	N of Rows in Working Data File	269
Missing Value Handling	Definition of Missing	User-defined missing values are treated as missing.
	Cases Used	Statistics for each table are based on all the cases with valid data in the specified range(s) for all variables in each table.
Syntax		CROSSTABS /TABLES=meds_binary_longterm meds_binary_reduce meds_binary_stop BY PRIM_SECON_CARE /FORMAT=AVALUE TABLES /STATISTICS=CHISQ PHI /CELLS=COUNT ROW COLUMN TOTAL /COUNT ROUND CELL.
Resources	Processor Time	00:00:00.03
	Elapsed Time	00:00:00.03
	Dimensions Requested	2
	Cells Available	524245

29)
30)
31) [DataSet1] \\ad.ucl.ac.uk\homeg\uctvlmg\Documents\PhD\recruitment study\Interview study 08.09_new.sav
32)
33)
34)

Case Processing Summary

	Cases		
	Valid	Missing	Total

	N	Percent	N	Percent	N	Percent
meds_binary_longterm * PRIM_SECON_CARE	249	92.6%	20	7.4%	269	100.0%
meds_binary_reduce * PRIM_SECON_CARE	248	92.2%	21	7.8%	269	100.0%
meds_binary_stop * PRIM_SECON_CARE	260	96.7%	9	3.3%	269	100.0%

35)

36)

37)

38) meds_binary_longterm * PRIM_SECON_CARE

39)

40)

41)

Crosstab

			PRIM_SECON_CARE		
			primary care	secondary care	
meds_binary_longterm	1.00	Count	32	170	
		% within meds_binary_longterm	15.8%	84.2%	
		% within PRIM_SECON_CARE	84.2%	80.6%	
		% of Total	12.9%	68.3%	
	2.00	Count	6	41	
		% within meds_binary_longterm	12.8%	87.2%	
		% within PRIM_SECON_CARE	15.8%	19.4%	
		% of Total	2.4%	16.5%	
Total		Count	38	211	
		% within meds_binary_longterm	15.3%	84.7%	

	% within PRIM_SECON_CARE	100.0%	100.0%	
	% of Total	15.3%	84.7%	

42)

43)

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.279[a]	1	.597		
Continuity Correction[b]	.092	1	.762		
Likelihood Ratio	.289	1	.591		
Fisher's Exact Test				.822	.393
Linear-by-Linear Association	.278	1	.598		
N of Valid Cases	249				

44)

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 7.17.

b. Computed only for a 2x2 table

45)

46)

Symmetric Measures

		Value	Approximate Significance
Nominal by Nominal	Phi	.033	.597
	Cramer's V	.033	.597
N of Valid Cases		249	

47)

48)

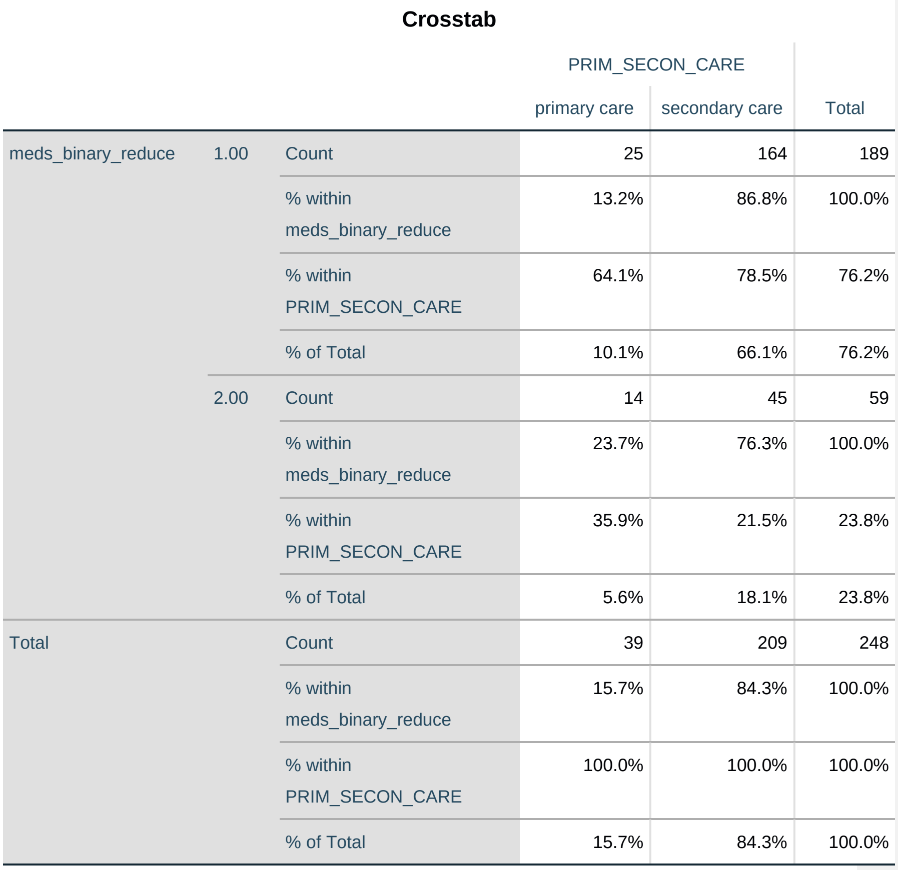
49)

50) meds_binary_reduce * PRIM_SECON_CARE

51)

52)

53)

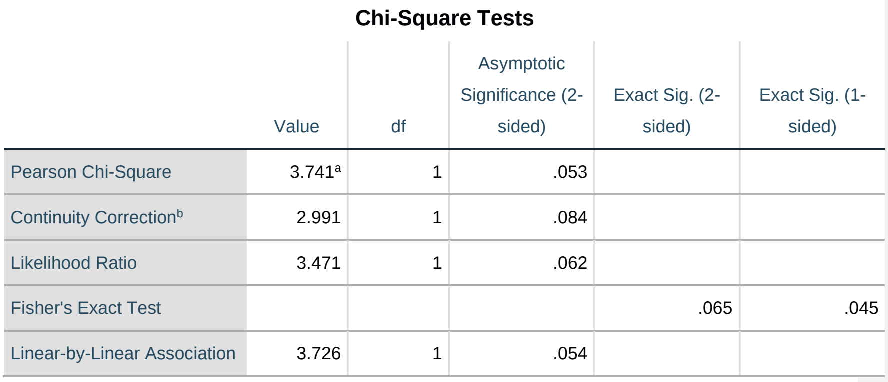


Crosstab

			PRIM_SECON_CARE		
			primary care	secondary care	Total
meds_binary_reduce	1.00	Count	25	164	189
		% within meds_binary_reduce	13.2%	86.8%	100.0%
		% within PRIM_SECON_CARE	64.1%	78.5%	76.2%
		% of Total	10.1%	66.1%	76.2%
	2.00	Count	14	45	59
		% within meds_binary_reduce	23.7%	76.3%	100.0%
		% within PRIM_SECON_CARE	35.9%	21.5%	23.8%
		% of Total	5.6%	18.1%	23.8%
Total		Count	39	209	248
		% within meds_binary_reduce	15.7%	84.3%	100.0%
		% within PRIM_SECON_CARE	100.0%	100.0%	100.0%
		% of Total	15.7%	84.3%	100.0%

54)

55)



Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	3.741[a]	1	.053		
Continuity Correction[b]	2.991	1	.084		
Likelihood Ratio	3.471	1	.062		
Fisher's Exact Test				.065	.045
Linear-by-Linear Association	3.726	1	.054		

N of Valid Cases	248				

56)

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 9.28.

b. Computed only for a 2x2 table

57)

58)

Symmetric Measures

		Value	Approximate Significance
Nominal by Nominal	Phi	-.123	.053
	Cramer's V	.123	.053
N of Valid Cases		248	

59)

60)

61)

62) meds_binary_stop * PRIM_SECON_CARE

63)

64)

65)

Crosstab

			PRIM_SECON_CARE		
			primary care	secondary care	Total
meds_binary_stop	1.00	Count	25	169	194
		% within meds_binary_stop	12.9%	87.1%	100.0%
		% within PRIM_SECON_CARE	62.5%	76.8%	74.6%
		% of Total	9.6%	65.0%	74.6%
	2.00	Count	15	51	66
		% within meds_binary_stop	22.7%	77.3%	100.0%
		% within PRIM_SECON_CARE	37.5%	23.2%	25.4%
		% of Total	5.8%	19.6%	25.4%

Total	Count	40	220	260
	% within meds_binary_stop	15.4%	84.6%	100.0%
	% within PRIM_SECON_CARE	100.0%	100.0%	100.0%
	% of Total	15.4%	84.6%	100.0%

66)

67)

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	3.663[a]	1	.056		
Continuity Correction[b]	2.946	1	.086		
Likelihood Ratio	3.422	1	.064		
Fisher's Exact Test				.074	.046
Linear-by-Linear Association	3.649	1	.056		
N of Valid Cases	260				

68)

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 10.15.

b. Computed only for a 2x2 table

69)

70)

Symmetric Measures

		Value	Approximate Significance
Nominal by Nominal	Phi	-.119	.056
	Cramer's V	.119	.056
N of Valid Cases		260	

71)

72) SORT CASES BY MEDS_REDUCE_NOOTHER (A).

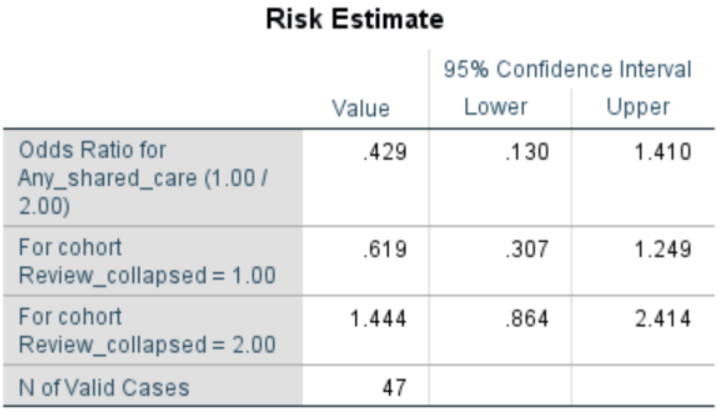
73)

74)

75) GP survey

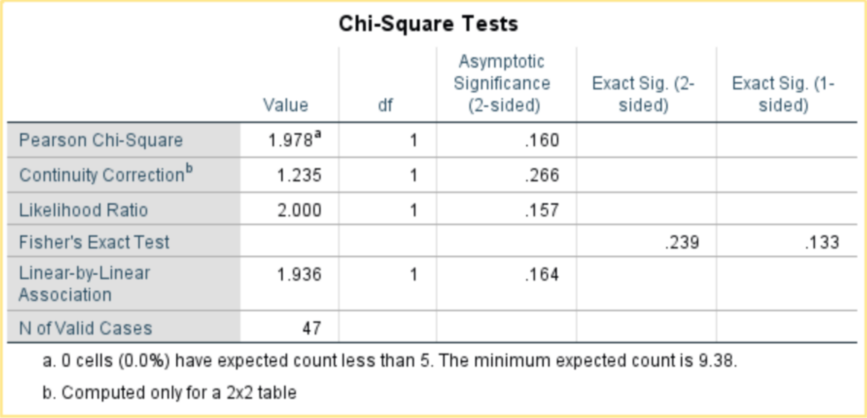
Access to shared care

	Not comfortable to review	Comfortable and very comfortable to review
Any access to shared care	7	14
No Access to shared care	14	12
	Not comfortable to reduce	Comfortable (+v comf) to reduce
Any access to shared care	8	13
No Access to shared care	14	11
	Not comfortable	Comfortable(+v comf)
Yes	10	15
No	12	12
Other	2	0



Risk Estimate

	Value	95% Confidence Interval Lower	95% Confidence Interval Upper
Odds Ratio for Any_shared_care (1.00 / 2.00)	.429	.130	1.410
For cohort Review_collapsed = 1.00	.619	.307	1.249
For cohort Review_collapsed = 2.00	1.444	.864	2.414
N of Valid Cases	47		



Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	1.978[a]	1	.160		
Continuity Correction[b]	1.235	1	.266		
Likelihood Ratio	2.000	1	.157		
Fisher's Exact Test				.239	.133
Linear-by-Linear Association	1.936	1	.164		
N of Valid Cases	47				

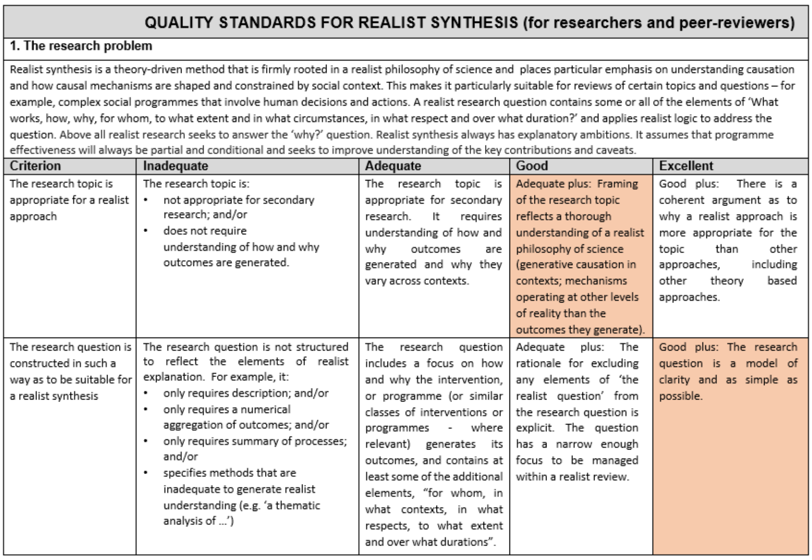
a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 9.38.

b. Computed only for a 2x2 table

Appendix 13: Realist Review Publication

Appendix 14: Realist Synthesis Quality Standards

The following section outlines the quality standards, as defined by RAMESES (2014). The highlighted section illustrate to which extent the PhD has met each quality standard. Justification for this is outlined in the Discussion – section "Realist Synthesis Quality Standards".

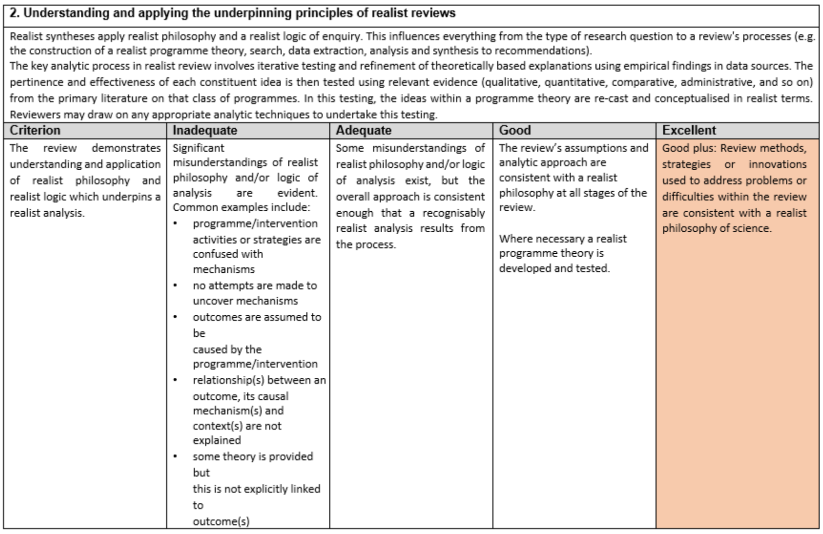


QUALITY STANDARDS FOR REALIST SYNTHESIS (for researchers and peer-reviewers)

1. The research problem

Realist synthesis is a theory-driven method that is firmly rooted in a realist philosophy of science and places particular emphasis on understanding causation and how causal mechanisms are shaped and constrained by social context. This makes it particularly suitable for reviews of certain topics and questions – for example, complex social programmes that involve human decisions and actions. A realist research question contains some or all of the elements of 'What works, how, why, for whom, to what extent and in what circumstances, in what respect and over what duration?' and applies realist logic to address the question. Above all realist research seeks to answer the 'why?' question. Realist synthesis always has explanatory ambitions. It assumes that programme effectiveness will always be partial and conditional and seeks to improve understanding of the key contributions and caveats.

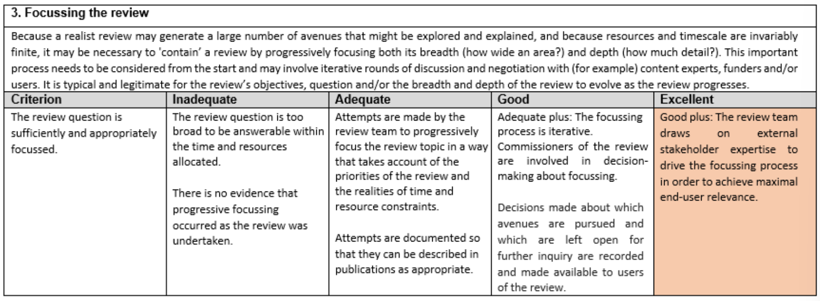
Criterion	Inadequate	Adequate	Good	Excellent
The research topic is appropriate for a realist approach	The research topic is: • not appropriate for secondary research; and/or • does not require understanding of how and why outcomes are generated.	The research topic is appropriate for secondary research. It requires understanding of how and why outcomes are generated and why they vary across contexts.	Adequate plus: Framing of the research topic reflects a thorough understanding of a realist philosophy of science (generative causation in contexts; mechanisms operating at other levels of reality than the outcomes they generate).	Good plus: There is a coherent argument as to why a realist approach is more appropriate for the topic than other approaches, including other theory based approaches.
The research question is constructed in such a way as to be suitable for a realist synthesis	The research question is not structured to reflect the elements of realist explanation. For example, it: • only requires description; and/or • only requires a numerical aggregation of outcomes; and/or • only requires summary of processes; and/or • specifies methods that are inadequate to generate realist understanding (e.g. 'a thematic analysis of …')	The research question includes a focus on how and why the intervention, or programme (or similar classes of interventions or programmes - where relevant) generates its outcomes, and contains at least some of the additional elements, "for whom, in what contexts, in what respects, to what extent and over what durations".	Adequate plus: The rationale for excluding any elements of 'the realist question' from the research question is explicit. The question has a narrow enough focus to be managed within a realist review.	Good plus: The research question is a model of clarity and as simple as possible.



2. Understanding and applying the underpinning principles of realist reviews

Realist syntheses apply realist philosophy and a realist logic of enquiry. This influences everything from the type of research question to a review's processes (e.g. the construction of a realist programme theory, search, data extraction, analysis and synthesis to recommendations).
The key analytic process in realist review involves iterative testing and refinement of theoretically based explanations using empirical findings in data sources. The pertinence and effectiveness of each constituent idea is then tested using relevant evidence (qualitative, quantitative, comparative, administrative, and so on) from the primary literature on that class of programmes. In this testing, the ideas within a programme theory are re-cast and conceptualised in realist terms. Reviewers may draw on any appropriate analytic techniques to undertake this testing.

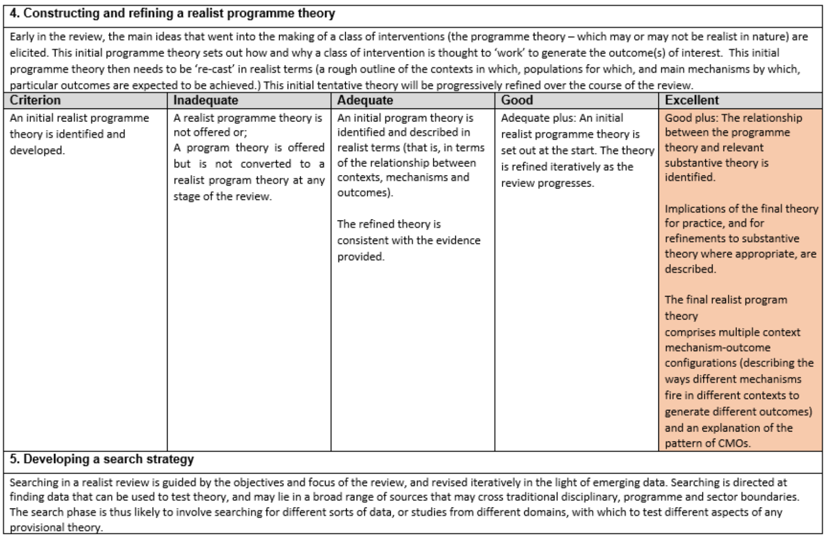
Criterion	Inadequate	Adequate	Good	Excellent
The review demonstrates understanding and application of realist philosophy and realist logic which underpins a realist analysis.	Significant misunderstandings of realist philosophy and/or logic of analysis are evident. Common examples include: • programme/intervention activities or strategies are confused with mechanisms • no attempts are made to uncover mechanisms • outcomes are assumed to be caused by the programme/intervention • relationship(s) between an outcome, its causal mechanism(s) and context(s) are not explained • some theory is provided but this is not explicitly linked to outcome(s)	Some misunderstandings of realist philosophy and/or logic of analysis exist, but the overall approach is consistent enough that a recognisably realist analysis results from the process.	The review's assumptions and analytic approach are consistent with a realist philosophy at all stages of the review. Where necessary a realist programme theory is developed and tested.	Good plus: Review methods, strategies or innovations used to address problems or difficulties within the review are consistent with a realist philosophy of science.



3. Focussing the review

Because a realist review may generate a large number of avenues that might be explored and explained, and because resources and timescale are invariably finite, it may be necessary to 'contain' a review by progressively focusing both its breadth (how wide an area?) and depth (how much detail?). This important process needs to be considered from the start and may involve iterative rounds of discussion and negotiation with (for example) content experts, funders and/or users. It is typical and legitimate for the review's objectives, question and/or the breadth and depth of the review to evolve as the review progresses.

Criterion	Inadequate	Adequate	Good	Excellent
The review question is sufficiently and appropriately focussed.	The review question is too broad to be answerable within the time and resources allocated. There is no evidence that progressive focussing occurred as the review was undertaken.	Attempts are made by the review team to progressively focus the review topic in a way that takes account of the priorities of the review and the realities of time and resource constraints. Attempts are documented so that they can be described in publications as appropriate.	Adequate plus: The focussing process is iterative. Commissioners of the review are involved in decision-making about focussing. Decisions made about which avenues are pursued and which are left open for further inquiry are recorded and made available to users of the review.	Good plus: The review team draws on external stakeholder expertise to drive the focussing process in order to achieve maximal end-user relevance.



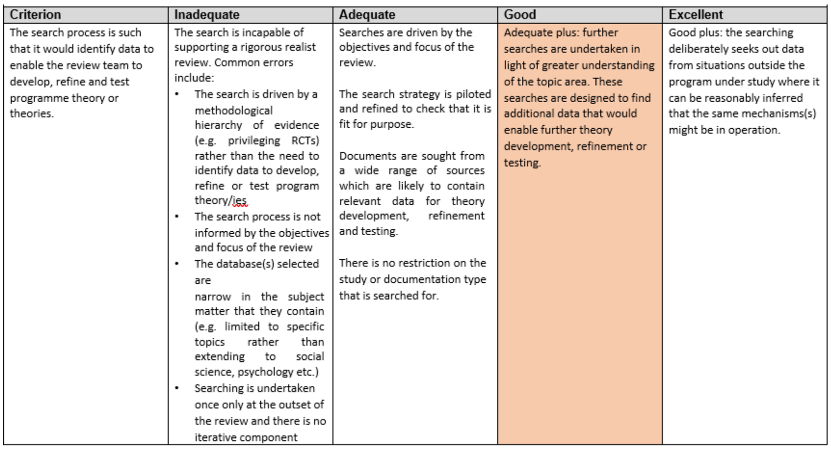
4. Constructing and refining a realist programme theory

Early in the review, the main ideas that went into the making of a class of interventions (the programme theory – which may or may not be realist in nature) are elicited. This initial programme theory sets out how and why a class of intervention is thought to 'work' to generate the outcome(s) of interest. This initial programme theory then needs to be 're-cast' in realist terms (a rough outline of the contexts in which, populations for which, and main mechanisms by which, particular outcomes are expected to be achieved.) This initial tentative theory will be progressively refined over the course of the review.

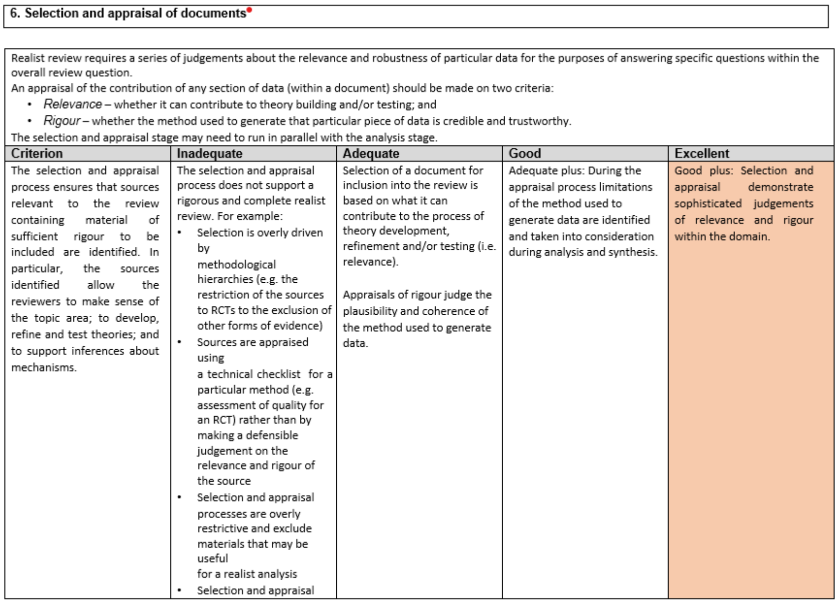
Criterion	Inadequate	Adequate	Good	Excellent
An initial realist programme theory is identified and developed.	A realist programme theory is not offered or; A program theory is offered but is not converted to a realist program theory at any stage of the review.	An initial program theory is identified and described in realist terms (that is, in terms of the relationship between contexts, mechanisms and outcomes). The refined theory is consistent with the evidence provided.	Adequate plus: An initial realist programme theory is set out at the start. The theory is refined iteratively as the review progresses.	Good plus: The relationship between the programme theory and relevant substantive theory is identified. Implications of the final theory for practice, and for refinements to substantive theory where appropriate, are described. The final realist program theory comprises multiple context mechanism-outcome configurations (describing the ways different mechanisms fire in different contexts to generate different outcomes) and an explanation of the pattern of CMOs.

5. Developing a search strategy

Searching in a realist review is guided by the objectives and focus of the review, and revised iteratively in the light of emerging data. Searching is directed at finding data that can be used to test theory, and may lie in a broad range of sources that may cross traditional disciplinary, programme and sector boundaries. The search phase is thus likely to involve searching for different sorts of data, or studies from different domains, with which to test different aspects of any provisional theory.



Criterion	Inadequate	Adequate	Good	Excellent
The search process is such that it would identify data to enable the review team to develop, refine and test programme theory or theories.	The search is incapable of supporting a rigorous realist review. Common errors include: • The search is driven by a methodological hierarchy of evidence (e.g. privileging RCTs) rather than the need to identify data to develop, refine or test program theory/ies • The search process is not informed by the objectives and focus of the review • The database(s) selected are narrow in the subject matter that they contain (e.g. limited to specific topics rather than extending to social science, psychology etc.) • Searching is undertaken once only at the outset of the review and there is no iterative component	Searches are driven by the objectives and focus of the review. The search strategy is piloted and refined to check that it is fit for purpose. Documents are sought from a wide range of sources which are likely to contain relevant data for theory development, refinement and testing. There is no restriction on the study or documentation type that is searched for.	Adequate plus: further searches are undertaken in light of greater understanding of the topic area. These searches are designed to find additional data that would enable further theory development, refinement or testing.	Good plus: the searching deliberately seeks out data from situations outside the program under study where it can be reasonably inferred that the same mechanisms(s) might be in operation.



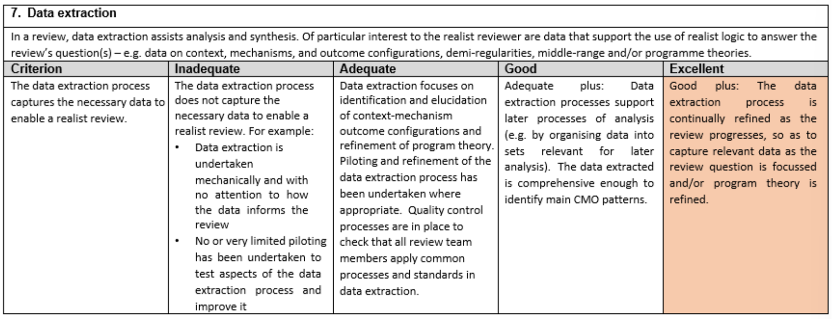
6. Selection and appraisal of documents

Realist review requires a series of judgements about the relevance and robustness of particular data for the purposes of answering specific questions within the overall review question.
An appraisal of the contribution of any section of data (within a document) should be made on two criteria:

- *Relevance* – whether it can contribute to theory building and/or testing; and
- *Rigour* – whether the method used to generate that particular piece of data is credible and trustworthy.

The selection and appraisal stage may need to run in parallel with the analysis stage.

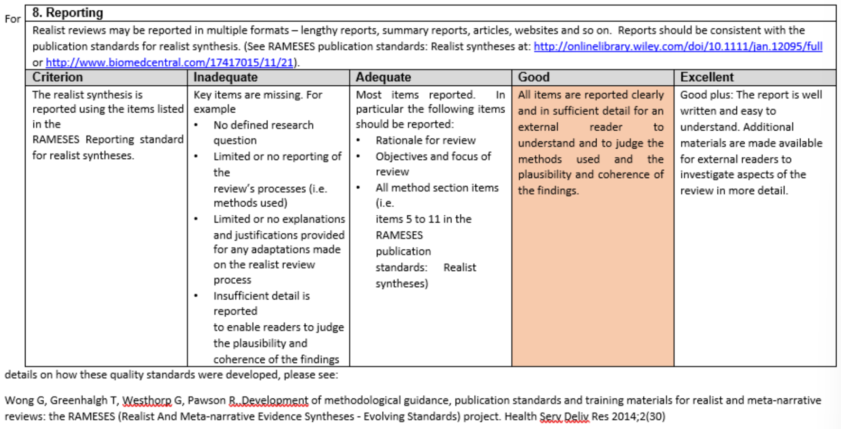
Criterion	Inadequate	Adequate	Good	Excellent
The selection and appraisal process ensures that sources relevant to the review containing material of sufficient rigour to be included are identified. In particular, the sources identified allow the reviewers to make sense of the topic area; to develop, refine and test theories; and to support inferences about mechanisms.	The selection and appraisal process does not support a rigorous and complete realist review. For example: • Selection is overly driven by methodological hierarchies (e.g. the restriction of the sources to RCTs to the exclusion of other forms of evidence) • Sources are appraised using a technical checklist for a particular method (e.g. assessment of quality for an RCT) rather than by making a defensible judgement on the relevance and rigour of the source • Selection and appraisal processes are overly restrictive and exclude materials that may be useful for a realist analysis • Selection and appraisal	Selection of a document for inclusion into the review is based on what it can contribute to the process of theory development, refinement and/or testing (i.e. relevance). Appraisals of rigour judge the plausibility and coherence of the method used to generate data.	Adequate plus: During the appraisal process limitations of the method used to generate data are identified and taken into consideration during analysis and synthesis.	Good plus: Selection and appraisal demonstrate sophisticated judgements of relevance and rigour within the domain.



7. Data extraction

In a review, data extraction assists analysis and synthesis. Of particular interest to the realist reviewer are data that support the use of realist logic to answer the review's question(s) – e.g. data on context, mechanisms, and outcome configurations, demi-regularities, middle-range and/or programme theories.

Criterion	Inadequate	Adequate	Good	Excellent
The data extraction process captures the necessary data to enable a realist review.	The data extraction process does not capture the necessary data to enable a realist review. For example: • Data extraction is undertaken mechanically and with no attention to how the data informs the review • No or very limited piloting has been undertaken to test aspects of the data extraction process and improve it	Data extraction focuses on identification and elucidation of context-mechanism outcome configurations and refinement of program theory. Piloting and refinement of the data extraction process has been undertaken where appropriate. Quality control processes are in place to check that all review team members apply common processes and standards in data extraction.	Adequate plus: Data extraction processes support later processes of analysis (e.g. by organising data into sets relevant for later analysis). The data extracted is comprehensive enough to identify main CMO patterns.	Good plus: The data extraction process is continually refined as the review progresses, so as to capture relevant data as the review question is focussed and/or program theory is refined.



8. Reporting

Realist reviews may be reported in multiple formats – lengthy reports, summary reports, articles, websites and so on. Reports should be consistent with the publication standards for realist synthesis. (See RAMESES publication standards: Realist syntheses at: http://onlinelibrary.wiley.com/doi/10.1111/jan.12095/full or http://www.biomedcentral.com/17417015/11/21).

Criterion	Inadequate	Adequate	Good	Excellent
The realist synthesis is reported using the items listed in the RAMESES Reporting standard for realist syntheses.	Key items are missing. For example • No defined research question • Limited or no reporting of the review's processes (i.e. methods used) • Limited or no explanations and justifications provided for any adaptations made on the realist review process • Insufficient detail is reported to enable readers to judge the plausibility and coherence of the findings	Most items reported. In particular the following items should be reported: • Rationale for review • Objectives and focus of review • All method section items (i.e. items 5 to 11 in the RAMESES publication standards: Realist syntheses)	All items are reported clearly and in sufficient detail for an external reader to understand and to judge the methods used and the plausibility and coherence of the findings.	Good plus: The report is well written and easy to understand. Additional materials are made available for external readers to investigate aspects of the review in more detail.

For details on how these quality standards were developed, please see:

Wong G, Greenhalgh T, Westhorp G, Pawson R. Development of methodological guidance, publication standards and training materials for realist and meta-narrative reviews: the RAMESES (Realist And Meta-narrative Evidence Syntheses - Evolving Standards) project. Health Serv Deliv Res 2014;2(30)