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A realist review of medication optimisation of community dwelling service users with serious mental illness

Jo Howe ,¹ Maura MacPhee,² Claire Duddy,³ Hafsa Habib,⁴ Geoff Wong ,³ Simon Jacklin,⁵ Sheri Oduola,⁶ Rachel Upthegrove,^{7,8} Max Carlsh,⁹ Katherine Allen,⁹ Emma Patterson,⁹ Ian Maidment ¹

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For numbered affiliations see end of article.

Correspondence to

Dr Jo Howe, Pharmacy, Aston University, Birmingham B4 7ET, UK; j.howe1@aston.ac.uk

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ABSTRACT

Background Severe mental illness (SMI) incorporates schizophrenia, bipolar disorder, non-organic psychosis, personality disorder or any other severe and enduring mental health illness. Medication, particularly antipsychotics and mood stabilisers are the main treatment options. Medication optimisation is a hallmark of medication safety, characterised by the use of collaborative, person-centred approaches. There is very little published research describing medication optimisation with people living with SMI.

Objective Published literature and two stakeholder groups were employed to answer: What works for whom and in what circumstances to optimise medication use with people living with SMI in the community?

Methods A five-stage realist review was co-conducted with a lived experience group of individuals living with SMI and a practitioner group caring for individuals with SMI. An initial programme theory was developed. A formal literature search was conducted across eight bibliographic databases, and literature were screened for relevance to programme theory refinement. In total 60 papers contributed to the review. 42 papers were from the original database search with 18 papers identified from additional database searches and citation searches conducted based on stakeholder recommendations.

Results Our programme theory represents a continuum from a service user's initial diagnosis of SMI to therapeutic alliance development with practitioners, followed by mutual exchange of information, shared decision-making and medication optimisation.

Accompanying the programme theory are 11 context-mechanism-outcome configurations that propose evidence-informed contextual factors and mechanisms that either facilitate or impede medication optimisation. Two mid-range theories highlighted in this review are supported decision-making and trust formation.

Conclusions Supported decision-making and trust are foundational to overcoming stigma and establishing 'safety' and comfort between service users and practitioners. Avenues for future research include the influence of stigma and equity across cultural and ethnic groups with individuals with SMI; and use of trained supports, such as peer support workers.

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WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Medication optimisation is challenging for both people living with severe mental illness and their prescribing clinicians; medication non-adherence is common.

WHAT THIS STUDY ADDS

⇒ Effective optimisation of medication requires a person-centred approach embedded throughout a service user's journey from initial diagnosis to effective medication co-management with practitioners.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Research is needed in multiple aspects of medication optimisation, including transition from acute care to community, the role of trained peer support workers and practitioner awareness of unique needs for individuals from ethnic and cultural minority groups.

INTRODUCTION

Medication optimisation

Severe mental illness (SMI) is a significant global healthcare burden with rates increasing throughout the world.¹ The term SMI includes diagnoses of schizophrenia, non-organic psychosis, bipolar disorder, personality disorder and any other severe and enduring mental illness.² Medications are a key treatment for SMI, but medication side effects can contribute to chronic physical illness (eg, diabetes, cardiovascular disease), a diminished

quality of life and a decreased lifespan.^{3 4} Complex medication regimens are often used to treat SMI; dosing can be a delicate balance between overprescribing and underprescribing, based on individual service user's (SUs) unique needs.⁵

Given the complex nature of SMI medication management and the need to consider issues such as risk of relapse, serious side-effect profiles and potential drug-drug interactions, medication safety is of paramount importance to SUs and practitioners.⁶⁻⁸ Psychotropics have many safety challenges. Metabolic adverse events including weight gain, changes in cholesterol and triglyceride levels and increases in blood sugar are a particular concern.⁹ Many psychotropics have anticholinergic effects; these include constipation, falls and confusion.^{10 11} This confusion could potentially worsen the negative and cognitive symptoms of schizophrenia and increase the risk of medication errors.⁷

Since 2008, the global Institute for Healthcare Improvement (IHI) and its country affiliates, such as the UK's Health Foundation, have advocated for inclusion of SUs and person-centred care approaches when identifying best practices, strategies pertaining to patient safety and quality of care delivery¹² as well as promoting shared decision-making (SDM) in healthcare systems.¹³ The original Triple Aim IHI framework consisted of three pillars for advancing quality and safety: enhanced population health, positive SU experiences and cost-effectiveness.¹² The original framework has expanded to Quadruple Aim, including staff experience.¹² These IHI frameworks highlight how the SU voice is an integral component of all healthcare quality and safety initiatives. Medication optimisation, a hallmark of medication safety, is defined as 'a person-centred approach to safe and effective medicines use, to ensure people obtain the best possible outcomes from their medicines'.¹⁴ Effective medication optimisation involves the perspectives of SUs with lived experience of taking medications.¹⁵ Multidisciplinary care delivery for SMI is more effective when SUs play a central role in medication decision-making.¹⁶

Failure to optimise medication is often attributed to SU non-adherence, practitioner underprescribing or overprescribing or overtreatment, including polypharmacy.^{2 16-18} Management of SMI is particularly challenging with reported non-adherence rates as high as 50%.^{19 20} Non-adherence²¹ and overprescribing occur more frequently in ethnic minority communities, as do physical illnesses, such as diabetes and cardiovascular disease.^{14 22} In general, the lowest possible medication dose is recommended to control SMI symptoms,²³ however higher doses are often prescribed by practitioners concerned about relapse.²⁴ Poorly managed SMI increases relapse rates, hospitalisation and is associated with unemployment, homelessness, disrupted education, substance misuse, physical health problems, self-harm and excess mortality.^{2 17 18 25} A systematic

review and meta-analysis of studies from Asia, Europe and North America found that non-adherence within the SMI population is the strongest predictor of relapse.²⁶

Shared decision-making

Person-centred approaches, such as SDM between key practitioner groups (eg, pharmacy, medicine, nursing), SUs with SMI and family carers, are associated with increased SU medication adherence and improved practitioner prescribing practices.^{7 17 19 20} There is, however, limited research on what needs to happen, how and when in the SU-practitioner relationship to promote person-centred SDM and ultimately, medication optimisation for SUs with SMI.^{4 17 27} Assumptions are often made about intervention effectiveness only from practitioner's viewpoints.²⁸ The implementation of SDM can be hindered by practitioners' beliefs about SDM. A Netherlands-based study compared practitioner reports of SDM use with direct observations of their SU interactions.²⁹ Practitioners reported using SDM as their usual decision-making style, but in observations, there was low engagement with SUs. The authors described practitioners as 'unconsciously incompetent in SDM'. Therefore, developing knowledge on how to implement effective person-centred approaches that promote medication optimisation is needed.

Present research

We conducted a realist review on medication optimisation with community dwelling SUs living with SMI. We focused on community dwelling as most SMI SUs live in the community, where there are greater opportunities for them to exercise control over their medication regime (eg, by omitting doses or via non-adherence).

We synthesised data from academic literature and drew on perspectives of community-based stakeholders with lived experience of SMI, informal (family) carers and mental health practitioners caring for SUs with SMI. A realist review can uncover important contextual factors affecting outcomes.³⁰ We constructed a programme theory comprising a series of testable hypotheses, known as context-mechanism-outcome configurations (CMOCs), to explain a potential SU-practitioner journey from initial diagnosis to trusting therapeutic alliance, SDM and medication optimisation.

Realist reviews have become increasingly popular within the quality and safety literature to explain how and why interventions work. Realist reviews have been used to investigate junior doctors' antimicrobial prescribing³¹; safety-netting practices in primary care³² and medication management for community dwelling seniors on complex medication regimens.³³ Realist reviews address research questions about what works, for whom, under what circumstances and how, and are a valuable methodological alternative or complement

to other forms of evidence synthesis, such as systematic reviews.^{30 34}

Research objectives

The overall objective for this realist review was to use published literature, alongside lived experience and practitioner stakeholder groups to understand: What works for whom and in what circumstances to optimise medication for community dwelling SUs with SMI.

METHODS

We conducted a five-stage realist review. Our review protocol was published³⁵ and registered a priori with PROSPERO (CRD42021280980). We used academic literature as well as feedback and advice from our stakeholder groups (lived experience group (LEG) and practitioner group (PG) to refine our programme theory, and create a series of testable CMOCs.³⁶ The LEG comprised six lived experience stakeholders from Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT) Lived Experience Advisory Research (LEAR) Group and two additional individuals with lived experience from outside LEAR (who were recruited to facilitate discussions). The PG comprised healthcare practitioners from the UK caring for SUs with SMI. The practitioners were recruited from personal networks and via social media advertisements.

Our CMOCs describe specific contexts associated with important outcomes related to medication optimisation, such as therapeutic alliance formation, and they articulate the mechanisms that trigger these outcomes. In this project, we have defined the following:

Setting: adults with SMI taking medication living in the community.

Intervention: any intervention to optimise medication usage for SUs living with SMI.

Context: situational factors that create conditions necessary to trigger underlying mechanisms.

Mechanisms: hidden, psychological processes that link specific contexts to intended outcomes.

Outcomes: quality of life, adherence, adverse events, disease symptoms, economic.

Stage 1: objectives, initial programme theory

Objectives

To conduct a realist review using published literature alongside lived experience and practitioner stakeholder input to understand: What works for whom and in what circumstances to optimise medication use for community dwelling SUs with SMI.

Development of initial programme theory

We developed an initial programme theory (IPT), a testable explanation of how and why medication optimisation is supposed to work for people living with SMI. Prior to the application for funding, IM initially

consulted with stakeholders with lived experience from BSMHFT. These conversations helped shape the initial funding application and formed the tentative foundations for the IPT. Through retelling accounts of their own experiences of SDM within mental health services, stakeholders stressed the importance of the therapeutic relationship in generating positive outcomes. Once the project started, JH liaised with subject matter experts known to the project team to gain a wider understanding of SMI, medication utilisation and SU-practitioner SDM. Additionally, an informal literature search primarily using Google Scholar was conducted. This step was used to gain an understanding of the factors influencing SDM within SMI. Additional publications recommended by the project team were also considered. The IPT was developed from these sources.

Stage 2: literature search

A formal literature search was conducted in January 2022 by CD across eight bibliographic databases (MEDLINE, Embase, PsycINFO, CINAHL, Cochrane Library, Scopus, Web of Science Core Citation Indexes (Science Citation Index Expanded, Social Sciences Citation Index, Arts & Humanities Citation Index, Emerging Sources Citation Index, Conference Proceedings Citation Index, Book Citation Index) and Sociological Abstracts). Our searches combined free text and subject heading terms for SMI, with terms describing medication or medication optimisation, and a comprehensive list of terms reflecting our project focus on SDM and SU-practitioner relationships. The LEG and PG helped to identify key concepts used in our search strategy. Our original protocol indicated that we would run searches in Google Scholar, but this was deemed unnecessary following screening, in light of the volume of literature already retrieved. In response to PG and LEG feedback, additional targeted searches were conducted in June 2022 to identify material relating to internet use, peer support and tapering medication.

Full details of our search strategies are available in online supplemental file 1.

Stage 3: screening and inclusion

Inclusion criteria focused on community dwelling adults (aged 18+ years) living with SMI and taking antipsychotic medication. Studies limited to inpatient settings or focused on diagnoses outside of SMI were excluded. Full details of the inclusion/exclusion criteria can be found in [table 1](#).

Screening

The results of the main search were screened by title and abstract by JH using RAYYAN (a web-based tool designed to assist with screening of title and abstract). In line with realist methodology, titles and abstracts were screened to determine relevance to the

Table 1 Review: inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Community dwelling adults living with SMI, using medication Their family or carers Practitioners involved in their care	Inpatient settings only
Interventions to optimise medication usage Or Experience of medication management and use	SDM tools
All study designs	No focus on the SDM process
All countries	Not SMI
English language	Eating disorders
SDM, shared decision-making; SMI, severe mental illness.	

developing programme theory. A random 10% sample was screened in duplicate by MMP. Uncertainties were resolved via discussions with JH and MMP. Full-text screening was initially completed in EndNote X9 by JH on documents published from 2014 onwards. The decision to focus on this timepoint was based on a significant increase in documents with SDM content during this time period. For full-text articles to be included at this stage, they had to contain data relevant to the developing programme theory with details on the SDM process in relation to prescribing, switching, tapering and taking antipsychotic medication. All full-text documents were assigned a star rating of one to five in EndNote by JH, based on a global judgement of each document's likely relevance, richness and rigour to confirm or dispute the developing programme theory. One-star documents were deemed irrelevant and rejected. Two-star documents were deemed 'unsure', and these were subsequently discussed with MMP and reallocated. Three-star documents were deemed irrelevant for programme theory development but potentially useful for background material. Four-star documents were deemed relevant to CMOC development and programme theory refinement. Five-star documents were deemed the most conceptually rich and relevant to CMOC development and programme theory refinement.

Pre-2014 documents and documents obtained via citation searching and personal networks were purposively screened and analysed by CD, JH, MMP and HH but were not categorised with a star rating as they were chosen due to perceived high relevance, richness and rigour.

Stage 4: data extraction, analysis

Data extraction

Document characteristics were extracted to an Excel spreadsheet by HH (online supplemental file 2).

Data analysis

A coding framework was iteratively and inductively developed and tested by MMP, JH and HH to organise

relevant data. The coding framework was developed in conjunction with the LEG and PG. The framework was tested using a subset of papers from the review. MMP, HH and JH tested each iteration of the framework, and codes were added to ensure the framework encapsulated all relevant data. The framework comprised three conceptual buckets that reflected a more abstracted level of data, for example, decision-making, medication management interventions and therapeutic alliance. In total, there were nine revisions to the framework. The final framework in online supplemental file 3 demonstrates the different levels of abstraction.

Coding of post-2014 five-star full-text documents was completed in NVivo by MMP and HH with a 10% check in duplicate by JH. Extracts of data were coded to nodes (termed parent nodes in NVivo) reflecting conceptual buckets. Extracts of data were coded against subnodes (called child nodes in NVivo) and multiple nodes if appropriate.

Once all five-star papers were coded and discussed with the PG and LEG, a pragmatic decision was made to focus the review on decision-making and therapeutic alliance. Coded data based on the coding framework were initially extracted and imported in Microsoft Word by MMP and HH. Tentative CMOCs were developed and refined through ongoing discussions with JH, MMP and HH. Approximately 30 hours of collaborative discussion took place over MS Teams.

Stage 5: data synthesis, CMOC development and programme theory refinement

Each tentative CMOC was individually reviewed, verified against the underpinning evidence and refined. Similar CMOCs were amalgamated where appropriate. These CMOCs were iteratively refined by checking remaining data from NVivo nodes and extracting relevant examples. Further refinement of the programme theory and CMOCs occurred using data from relevant four-star papers, pre-2014 papers, papers from additional searches and discussions with the project team, LEG and PG. The finalised set of CMOCs and a refined programme theory were discussed and validated with the PG, the LEG and the wider project team. The refined CMOCs, supporting evidence and document origin (eg, post-2014, via citation search or personal networks) can be found in online supplemental file 4.

RESULTS

Our main search identified 1118 unique results. After title and abstract screening, 144 documents published from 2014 onwards were screened in full text. Twenty-nine papers were assigned a five-star rating and coded in NVivo. Thirty-three papers were assigned a four-star rating. Following the decision to narrow the focus, of these 62 papers, 27 were rejected leaving a total of 35 four-star and five-star papers in the review. Eighteen papers were identified via additional

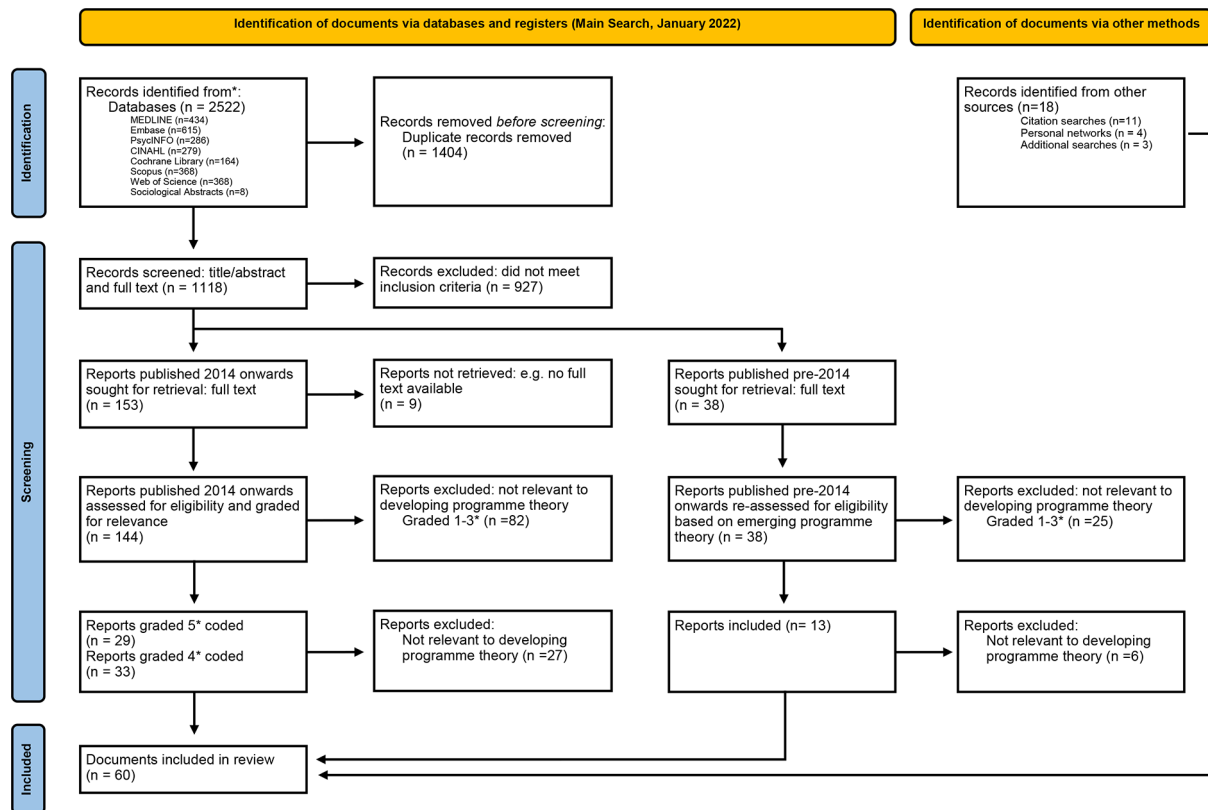


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources. Adapted from Page *et al.*¹¹⁴

searches, citation searches and personal contacts. Seven of the pre-2014 papers were deemed relevant taking the total number of papers contributing to the review to 60 (35+18+7). The inclusion criteria associated with SMI varied between the included papers. Twenty-eight papers included schizophrenia or schizoaffective disorder,^{37–64} 3 papers included borderline personality disorder,^{38 58 59} 9 papers included bipolar disorder,^{43 49 51 54 59–61 65 66} 19 papers included psychosis/psychotic illness,^{38 40 43–45 51 59 61 67–77} 20 papers had a broad definition, for example, SMI or people taking antipsychotic/psychotropic medication,^{37 38 66 75 78–93} 3 papers included less severe forms of mental illness alongside SMI in their population samples,^{51 60 66} 2 papers did not have a patient population and focused on consultant psychiatrists⁹⁴ and secondary care mental health pharmacists.⁹⁵ Several papers included more than one type of SMI. Our searching and screening processes are summarised in figure 1.

Table 2 includes our refined programme theory and 11 CMOCs underpinning the theory. Our refined programme theory describes a journey of medication optimisation for SUs with SMI that begins with initial diagnosis and culminates in a therapeutic alliance characterised by underlying trust, mutual information exchange and SDM. There are potential barriers and facilitators along the way, represented by positive and negative CMOCs. The journey includes practitioners,

SUs with their family and social network and other information sources (eg, internet, peer support workers).

In table 2, CMOCs 1 (first contact) and 2 (relief) are associated with initial diagnosis. The literature highlights the importance of positive first encounters with healthcare services. Negative, coercive experiences can derail practitioner-SU trust formation, while positive experiences can decrease internalised stigma and reassure SUs that their condition is treatable.

CMOC 3 (dismissal) depicts how dismissal and devaluing of SUs by practitioners impedes the establishment of trust, which is a foundational component to therapeutic relationships.

CMOC 4 (being heard) illustrates how development of the therapeutic alliance is dependent on respectful, supportive practitioners willing to listen to and seriously consider SUs' needs and concerns.

CMOCs 5 (practitioner information exchange) and 6 (seeking more information) represent SUs' desire for credible, trustworthy information about diagnosis and medication that is personalised to them and the role of medication in treating their illness, including possible side effects. Regardless of information obtained from practitioners, SUs typically seek out additional information to obtain new knowledge, a greater sense of reassurance and more control over medication and life decisions.

Table 2 Refined programme theory and underpinning context-mechanism-outcome (CMOC) configurations

Refined programme theory	Evidence sources
<p>When service users (SU) are first diagnosed with serious mental illness (SMI), a diagnosis which is frightening to them, they seek out information about their illness. SUs' medication management and practitioner support and advice they can understand and apply to their current and ongoing needs. SUs may seek out individuals with lived experience to validate the experiences they are having, and to learn how others effectively manage living with SMI. As SUs gather information from diverse sources (practitioners, social supports, internet), they are constantly weighing up the pros and cons of medication decisions. It is important to SUs to forge positive working relationships with practitioners who will listen to them, respectfully consider their needs and support their medication decisions whenever possible. SUs are regularly facing lifestyle challenges, some with high stakes, such as pregnancy or serious health side effects. If and when SUs have established therapeutic relationships with practitioners who have their best interests at heart and are competent in their field of expertise, SUs are more apt to seek them out for shared information exchange and decision-making. Regardless of the strength of the SU-practitioner relationship, in high stakes situations, trust is fragile; trust is based on ongoing evidence of practitioners' motivations to support them. Similarly, SUs need ongoing and non-judgemental support from family members and their social network, including peer support workers.</p>	
CMOC	
CMOC 1: first contact	38 44 45 68 74 77 79 81 88 95
When an SU with SMI is first diagnosed, is medicated and has coercive, dehumanising* experiences with practitioners (C), this often details the development of trusting therapeutic alliances (O) because of feelings of powerlessness (M) and stigmatisation (M).	
CMOC 2: relief	43 62 68 71 74 88
When an SU with SMI is first diagnosed and is medicated, validation and normalisation of their condition by a respectful, supportive practitioner (C) results in increased relief, hope and optimism (O) due to decreased stigmatisation of living with SMI (M) and increased reassurance (M) that they have a treatable condition.	
CMOC 3: dismissal	40 43 45 59 62 67 68 71 76 77 79 81 83 88 90
When an SU with SMI on medications realises practitioners are withholding medication information, and/or excluding, ignoring or dismissing them from medication decisions (C), they are apt to withdraw from the practitioner relationship and make their own medication decisions (O), due to mistrust (M) in the practitioners' interest in them and their need for more control (M) over decisions affecting their lives.	
CMOC 4: being heard	39 43 46 47 53 57 60 62 68 70 78 81 83 88 89
From the start of their relationship onwards, when an SU with SMI on medications is actively engaged by a respectful, supportive practitioner who takes an interest in them and their issues and concerns about their illness, medication and side effects (C), they are more apt to forge a therapeutic alliance with their practitioner (O), because they feel heard and listened to (M) and they trust (M) in the practitioner's motivations to help them better manage their medications and illness.	
CMOC 5: practitioner information exchange	43 44 50 52 56 62 67 70 75 80 83 86 90 94
From the start of the therapeutic relationship onwards, when an SU with SMI feels comfortable accessing their practitioner for honest, easy-to-understand and personalised information about their medications (C), they are apt to use the information to prepare for and to cope better with medications and side effects (O), due to development of mutual trust (M) and respect (M) in each other and in the information being exchanged.	
CMOC 6: seeking more information	37 56 67 68 71 77 78 80 85 86
Whenever an SU with SMI on medications desires additional information about their illness, medications and potential side effects (C), they will often seek out accessible, easy-to-understand information from a variety of non-practitioner sources (eg, peers, internet) they perceive to be trustworthy and credible (O), due to need for increased knowledge (M), increased reassurance (M) and greater control (M) with respect to medication and life decisions.	
CMOC 7: confiding and negotiating in a safe way	38 40 42 44 46 48 50 54 56 58 61 62 67 69 71 72 74 78 81 83
When an SU with SMI on medications has continuity over time in a respectful, trusting therapeutic alliance with practitioners who openly discuss and make collaborative medication decisions with them; even when there are disagreements (C), they are more apt to confide in and to negotiate with their practitioners about their medication issues and management plans (O), due to a sense of safety with their practitioners (M), and increased belief (M) in themselves to manage their lives.	84 89 91 92 94 115
CMOC 8: perceived risks	40 42 45 55 76 83 86 88 90 93 94
When SUs with SMI desire to taper, change or discontinue their medication regimen (C), their clinicians may resist sharing information with them and may not support them (O) because they judge that doing so may put themselves, the patient and others at risk (M) if adverse outcomes occur (eg, harm to self or others).	
CMOC 9: family and social supports	54 57 61 64 66 72 73 84 86
When an SU with SMI has support from family and social network members who believe in them and want the best for them (C), they are apt to feel more confident in following through with prescribed medication plans (O) due to increased belief (M) in their capacity to handle ongoing challenges and a sense of safety (M) among people looking after their well-being.	
CMOC 10: fear and guilt	51 54 57 61 63 68 73 80 84 85 88
When an SU with SMI is aware that their family members are fearful about the consequences from medication changes and want them to maintain medications as prescribed (C), they may continue on the medications against their will or secretly discontinue/change their medications (O) to avoid conflict (M) and/or withdrawal of their family's support (M) for them.	
CMOC 11: peer support workers	39 41 65 69 81 86
When SUs with SMI have access to peer support workers with shared lived experiences who talk with them about SMI and life skills management, including medications and side effects (C), they are apt to experience a positive impact on their mental, physical and social-emotional health (O) because they feel validated (M), less stigmatised (M) and reassured (M) that they can have a productive, fulfilling lives with SMI.	
*Our lived experience group asked us to include 'dehumanising', based on their initial experiences with SMI diagnosis and management.	

As described in CMOC 7 (confiding and negotiating in a safe way), a hallmark of strong and effective therapeutic alliances is the ability of practitioners to support SUs, even if they disagree with their medication decisions. SUs feel safe in this type of alliance and are more apt to collaboratively plan their care with a trusted practitioner.

In contrast, CMOC 8 (perceived risks) illustrates why some practitioners might find it challenging to meet SUs' wishes to taper their medication due to risk about potential adverse outcomes, such as relapse and its consequences.

CMOCs 9 (family and social supports), 10 (fear and guilt) and 11 (peer supports) are related to non-practitioner sources of support for individuals with SMI. The family can be a safety net and positive support for SUs (CMOC 9), or the family can be fearful of making medication changes (CMOC 10), resulting in negative SU emotions, such as fear and guilt. In these situations, SUs may feel pressured to conform to family wishes to avoid conflict and ensure that family support is not withdrawn. Peer support workers (CMOC 11) are a promising source of support to SUs, because they validate SUs' feelings, given their lived experience with SMI. However, research on peer support worker roles in medication optimisation was lacking.

DISCUSSION

The patient safety literature has demonstrated that higher levels of safety are achievable by ensuring the voice of SUs and other stakeholders are part of quality improvement efforts.⁹⁶ Medication optimisation is an important component of patient safety, especially for SUs with SMI, where medication is a key treatment strategy.¹⁶ Our programme theory and CMOCs highlight how person-centred care approaches such as providing relevant, useful information and support through practitioners and others can lead to safe medication use (ie, medication optimisation). The CMOCs outlined above provide testable, causal explanations for outcomes, detailing by whom, when and how these happen.

Comparisons with existing literature and theory

A valuable aspect of the realist approach is the potential to use formal or substantive theories to further explain and buttress inferences about underlying mechanisms or drivers for individuals' actions.³⁰ Based on our reading of the included documents and recommendations from our stakeholder groups, we discuss below two theories of particular importance to the development of a therapeutic alliance, which is a necessary condition for effective optimisation of medication.

Supported decision-making theory

Supported decision-making theory emphasises practitioners' roles in assisting SUs with decision-making based on their needs and preferences. Supported

decision-making theory has legal and ethical associations with the 2006 United Nations Convention of Individuals' Rights and Disabilities, which stipulated that no person should be appointed as a decision-maker for an individual who has the capacity to make their own decisions with appropriate supports.⁹⁷ Supported decision-making encompasses person-centred planning, advocacy, communications, interpretive supports and representational supports (eg, peer support workers, family and social networks). The central question practitioners should ask themselves is: 'What supports are needed to ensure this person can best exercise their rights?'⁹⁷

Although research into supported decision-making and SMI is rare, qualitative researchers found that the timing and types of practitioner supports made a difference to individuals with SMI, particularly with respect to confidence and self-control.^{98 99} Researchers from one study created different thematic labels for SUs: SUs with capacity to make their own cogent decisions were 'inward experts', while SUs during periods of acute unwellness were 'outward entrustors', entrusting practitioners to guide their care management. SUs' variable needs for supported decision-making required different practitioner roles, such as practitioners as facilitators (eg, sharing information openly and honestly) and as collaborators (eg, promoting SDM).⁹⁸

In a recent systematic review of supported decision-making for SUs with SMI in clinical practice settings,¹⁰⁰ a limited number of papers included in the review examined stakeholders' perspectives of supported decision-making. Stakeholders, including SUs, family members and practitioners, all agreed to the importance of supported decision-making. Practitioner misconceptions about differences between SUs' rights and preferences, however, were barriers to implementation success. If supported decision-making is a necessary condition for SU-practitioner SDM and medication optimisation, practitioners will need to understand SUs' legal rights, and to engage in roles (eg, facilitator, collaborator) that promote SUs' decision-making autonomy.⁹⁸

Trust formation theory

Our findings make clear that, for SUs with SMI, ongoing alliance-building and confidence in their capacity to share in decisions and manage their lives depends on trust: trust in practitioners and trust/belief in themselves. Trust formation theory defines trust as 'a psychological state comprising the intention to accept vulnerability based on positive expectations of the intentions or behaviour of another'.¹⁰¹ Our programme theory proposes that trust between SUs and practitioners evolves with the development of the therapeutic alliance. An exploratory study of the role of trust in medication management within mental health services¹⁰² supported our realist review findings that practitioners' reluctance to share useful information

in an open and honest way can create mistrust and worsen medication adherence. Ultimately, mistrust obstructs collaborative medication management.^{102 103}

The wider literature provides some evidence of how mutual trust formation enables engagement, disclosure and collaboration in mental healthcare. Corroborating our findings, a qualitative study from the UK found that practitioners' open communications and therapeutic listening promoted and sustained the development of mutual trust over time.¹⁰⁴ More recent literature suggests that the development of a trusting therapeutic alliance is enhanced by practitioners' awareness and respect for SU preferences, such as types of treatment options (eg, medications or psychotherapy), and influenced by the characteristics of practitioners they work with (eg, professional background, gender, age and ethnicity).¹⁰⁵ Even when all preferences cannot be accommodated, eliciting, discussing and acknowledging SU preferences is associated with stronger alliances.¹⁰⁵

The relationship between SDM, trust and information

CMOCs (4, 5, 7) associate SDM with active engagement of SUs and practitioners in open, transparent discussions and collaborative treatment planning based on mutual trust. CMOC 8, however, addresses the negative emotions and risks associated with the SU-practitioner relationship. The literature in our review focused predominantly on practitioner risks, such as concern for SU medication non-adherence and adverse SU outcomes. A recent review of qualitative studies¹⁰⁶ discussed risk-taking from the perspectives of SUs and practitioners. With shared risk-taking, both parties jointly reflect and address inherent risks to any decision, particularly from a safety perspective. Some evidence suggests that mutually identifying and preventing or mitigating risks can actually strengthen the alliance and deepen trust.¹⁰⁷ In the UK, the National Health Service recommends that risk assessment and management should be explained to SUs with SMI as soon as possible as part of SDM.¹⁰⁸

CMOCs (6, 9, 11) pertain to non-practitioner sources of information and support, including the internet and social media, family and friends and peer supports with similar lived experience, although we identified very limited academic literature on how peer support workers can be used to optimise medication management.^{39 41 65 69 81 86} Questions exist with respect to peer support workers' capacity to give accurate medication advice.¹⁰⁹

Future research directions

Future research needs to address non-practitioner sources of information and supports, (eg, peer support workers, families and friends, internet and social media). Our LEG and PG stakeholders both endorsed the importance of peer support workers and their potential roles in medication optimisation.

An area of burgeoning interest is online decision support tools to improve information sharing and communication between SUs and practitioners. A recent systematic review found mixed evidence for the effectiveness of decision support tools with SUs with SMI.¹¹⁰ This review included tools to assist with prioritising treatment preferences, crisis planning and advanced directives. More conclusive research is needed to evaluate the efficacy of online support tools, especially how they help or hinder therapeutic alliance development, SDM and medication optimisation for SUs with SMI.

Our review has highlighted an important evidence gap relating to equity, diversity and inclusivity (EDI) for SUs with SMI from racial and ethnic minority groups, seniors and other vulnerable populations. These groups were rarely mentioned in our review's included papers. When SUs with SMI are members of minority groups and/or vulnerable populations, stigma can be compounded.^{27 111} Ultimately, the success of SU-practitioner relationships depends on reducing mistrust among SUs who have been stigmatised by SMI and by race/ethnicity, while enhancing practitioners' awareness and commitment to EDI. In England, the Race Equality Foundation is a national charity that tracks and reports racial inequality in public services (<https://raceequalityfoundation.org.uk/>). Researchers working with this charity identified persistent healthcare inequalities for English minority groups. 'Traumatic, inappropriate and discriminatory experiences of services can have a detrimental impact on chances for recovery, particularly if the same risk factors of bereavement, family breakdown, incarceration, poverty and exposure to racism continue to be present'.²⁷

Community-based care models may be a more cost-effective way of caring for complex and vulnerable patients. Only a limited number of new care models (eg, team-based care, integrated care) have been well-described or evaluated for SUs with SMI.¹¹² In one mapping review of integrated physical-mental care models for SUs with SMI, a number of concerns were identified, including practitioners' negative biases and stigma towards SMI.¹¹³ As our review illustrates, the initial context, particularly the presence of any negative biases towards SMI, can derail the development of a therapeutic alliance between SUs and practitioners.

Another important consideration for future research centres around the skill and knowledge of individual practitioners to be able to fully engage in SDM. Our practitioner stakeholders informed us that they are often not taught how to have difficult conversations with SUs, leaving them underconfident with some of the more challenging aspects associated with engaging in SDM with this population. However, none of the papers included within this review discussed these issues.

Strengths and limitations

We conducted our realist review within a 1-year timeline. To be as efficient as possible, we focused on the largest body of relevant literature published from 2014 onwards. We returned to pre-2014 literature after developing our CMOCs from the more recent literature to identify earlier data relating to the CMOCs.

Our research team were English speakers only, therefore we excluded any non-English documents from our searches. We adopted an inclusive approach to the population and used a broad definition of SMI. However, there may be differences in the approach to medication optimisation in the different diagnoses (eg, bipolar, psychosis, personality disorder). Future research should consider a more granular approach and compare and contrast across different types of SMI. We focused on SDM between SUs and practitioners. As such, documents pertaining solely to practitioner clinical decision-making were excluded from the review. We accept that we excluded papers pertaining to the dilemmas practitioners face when making unilateral medication decisions due to situations, such as SU acute unwellness.

A strength of this review was the engagement with PG and LEG stakeholders throughout the review process. Their engagement supported our interpretations of data, ensured our findings reflected their real-world experiences and highlighted gaps in the literature. Our review identified evidence gaps in relation to the relationship between race, ethnicity, vulnerable groups and medication optimisation in SMI and in the role of peer support workers. Realist reviews are an iterative process of developing theory and CMOCs, which may then be confirmed, refuted or refined by future research, including, for example, realist evaluation. This review's programme theory and CMOCs produced testable hypotheses for future research with SUs with SMI and community-based practitioners who serve them. In the papers included in this review, there was a lack of information on the contextual factors and mechanisms influencing clinical decision-making in challenging circumstances, such as SU acute unwellness. This was also highlighted by Martínez-Hernández *et al*⁸⁸ who stated that are still differences between models of concordance, described as therapeutic alliance building, and real-life practice situations.

CONCLUSIONS

Medication optimisation is a person-centred approach that begins at time of initial diagnosis and ensures optimal information and supports are accessible to SUs, based on their needs and preferences. At the beginning of the journey and during periods of relapse, supported decision-making is necessary to overcome stigma and establish trust between SUs and practitioners. Practitioners engaging in SDM must ensure that the voice of the SU is present throughout the recovery journey in order to optimise medication.

Author affiliations

¹Pharmacy School, College of Health and Life Sciences, Aston University, Birmingham, UK

²School of Nursing, The University of British Columbia, Vancouver, British Columbia, Canada

³Primary Care Health Sciences, University of Oxford, Oxford, UK

⁴Pharmacy School, Aston University College of Health and Life Sciences, Birmingham, UK

⁵School of Pharmacy and Bioengineering, Keele University, Keele, UK

⁶School of Health Sciences, University of East Anglia, Norwich, UK

⁷Institute for Mental Health, University of Birmingham, Birmingham, UK

⁸Birmingham Early Intervention Service, Birmingham Women's and Children's NHS Foundation Trust, Birmingham, UK

⁹Birmingham and Solihull Mental Health NHS Foundation Trust, Birmingham, UK

Twitter Jo Howe @DrJoHowe and Ian Maidment @maidment_dr

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ORCID iDs

Jo Howe <http://orcid.org/0000-0002-7567-075X>
Geoff Wong <http://orcid.org/0000-0002-5384-4157>
Ian Maidment <http://orcid.org/0000-0003-4152-9704>

REFERENCES

- Jaeschke K, Hanna F, Ali S, *et al.* Global estimates of service coverage for severe mental disorders: findings from the WHO Mental Health Atlas 2017 - Addendum. *Glob Ment Health (Camb)* 2021;8:e28.
- NHS England. Improving physical Healthcare for people living with severe mental illness (SMI) in primary care: guidance for CCGs. 2018. Available: www.england.nhs.uk/wp-content/uploads/2018/02/improving-physical-health-care-for-smi-in-primary-care.pdf. 18
- Carolan A, Keating D, Strawbridge J, *et al.* Optimising prescribing for patients with severe mental illness: the need for criteria. *Evid Based Ment Health* 2019;22:139–41.
- National Institute for Health and Care Excellence. Psychosis and schizophrenia in adults: prevention and management. In: *NICE guideline CG178*. 2014. Available: <https://www.nice.org.uk/guidance/cg178>
- Ostuzzi G, Vita G, Bertolini F, *et al.* Continuing, reducing, switching, or stopping antipsychotics in individuals with schizophrenia-spectrum disorders who are clinically stable: a systematic review and network meta-analysis. *Lancet Psychiatry* 2022;9:614–24.
- Davis KAS, Farooq S, Hayes JF, *et al.* Pharmacoepidemiology research: delivering evidence about drug safety and effectiveness in mental health. *Lancet Psychiatry* 2020;7:363–70.
- Maidment ID, Lelliott P, Paton C. Medication errors in mental healthcare: a systematic review. *Qual Saf Health Care* 2006;15:409–13.
- Roughead L, Procter N, Westaway K, *et al.* *Medication safety in mental health*. Sydney: Australian Commission on Safety and Quality in Health Care, 2017.
- Pillinger T, McCutcheon RA, Vano L, *et al.* Comparative effects of 18 antipsychotics on metabolic function in patients with schizophrenia, predictors of metabolic dysregulation, and association with psychopathology: a systematic review and network meta-analysis. *Lancet Psychiatry* 2020;7:64–77.
- Richardson K, Fox C, Maidment I, *et al.* Anticholinergic drugs and risk of dementia: case-control study. *BMJ* 2018;361:k1315.
- Green AR, Reifler LM, Bayliss EA, *et al.* Drugs contributing to anticholinergic burden and risk of fall or fall-related injury among older adults with mild cognitive impairment, dementia and multiple chronic conditions: a retrospective cohort study. *Drugs Aging* 2019;36:289–97.
- Obucina M, Harris N, Fitzgerald JA, *et al.* The application of triple aim framework in the context of primary healthcare: a systematic literature review. *Health Policy* 2018;122:900–7.
- The Health Foundation. *Person-centered care: from ideas to action. Bringing together the evidence on shared decision making and self-management support*. London, 2014.
- National Institute for Health and Care Excellence. Medicines Optimisation: the safe and effective use of medicines to enable the best possible outcomes. In: *NICE guideline NG5*. 2015. Available: <https://www.nice.org.uk/guidance/ng5>
- Lee JL, Dy SM, Gurses AP, *et al.* Towards a more patient-centered approach to medication safety. *J Patient Exp* 2018;5:83–7.
- Maidment I, Sud D, Chew-Graham C. Challenge of optimising medication in people with severe mental illness. *BMJ Qual Saf* 2022;31:337–9.
- Mental Health Taskforce. *The five year forward view for mental health*. 2016.
- Robotham D, Wykes T, Rose D, *et al.* Service user and carer priorities in a BIOMEDICAL research centre for mental health. *J Ment Health* 2016;25:185–8.
- National Institute for health and Clinical Excellence. Medicines adherence: involving Patients in decisions about prescribed medicines and supporting adherence. In: *Nice guideline CG76*. 2009. Available: <https://www.nice.org.uk/guidance/cg76>
- Semahegn A, Torpey K, Manu A, *et al.* Psychotropic medication non-adherence and its associated factors among patients with major psychiatric disorders: a systematic review and meta-analysis. *Syst Rev* 2020;9:17.
- Opolka JL, Rascati KL, Brown CM, *et al.* Role of ethnicity in predicting antipsychotic medication adherence. *Ann Pharmacother* 2003;37:625–30.
- Sud D, Loughton E, McAskill R, *et al.* The role of pharmacy in the management of cardiometabolic risk, metabolic syndrome and related diseases in severe mental illness: a mixed-methods systematic literature review. *Syst Rev* 2021;10:92.
- Correll CU, Martin A, Patel C, *et al.* Systematic literature review of schizophrenia clinical practice guidelines on acute and maintenance management with antipsychotics. *Schizophrenia (Heidelb)* 2022;8:5.
- Rodolico A, Sifias S, Bighelli I, *et al.* Antipsychotic dose reduction compared to dose continuation for people with schizophrenia. *Cochrane Database Syst Rev* 2022;11:CD014384.
- Weinmann S, Read J, Aderhold V. Influence of antipsychotics on mortality in schizophrenia: systematic review. *Schizophr Res* 2009;113:1–11.
- Loots E, Goossens E, Vanwesemael T, *et al.* Interventions to improve medication adherence in patients with schizophrenia or bipolar disorders: a systematic review and meta-analysis. *Int J Environ Res Public Health* 2021;18:10213.
- Bignall T, Jeraj S, Helsby E, *et al.* *Racial disparities in mental health: literature and evidence review*. London: Race Equality Foundation, 2019.

- 28 Haverfield MC, Tierney A, Schwartz R, *et al.* Can patient-provider interpersonal interventions achieve the quadruple aim of healthcare. *J Gen Intern Med* 2020;35:2107–17.
- 29 Driever EM, Stiggelbout AM, Brand PLP. Do consultants do what they say they do? Observational study of the extent to which clinicians involve their patients in the decision-making process. *BMJ Open* 2022;12:e056471.
- 30 Duddy C, Wong G. Grand rounds in methodology: when are realist reviews useful, and what does a 'good' realist review look like. *BMJ Qual Saf* 2023;32:173–80.
- 31 Papoutsi C, Mattick K, Pearson M, *et al.* Social and professional influences on antimicrobial prescribing for doctors-in-training: a realist review. *J Antimicrob Chemother* 2017;72:2418–30.
- 32 Friedemann Smith C, Lunn H, Wong G, *et al.* Optimising Gps' communication of advice to facilitate patients' self-care and prompt follow-up when the diagnosis is uncertain: a realist review of 'safety-netting' in primary care. *BMJ Qual Saf* 2022;31:541–54.
- 33 Maidment I, Lawson S, Wong G, *et al.* Medication management in older people: the MEMORABLE realist synthesis. Contract No.: 26. 2020.
- 34 Peytremann-Bridevaux I, MacPhee M. Moving forward with integrated care: the use of realist approaches to understand what works, how, for whom and under which circumstances. *Public Health Rev* 2022;43:1605082.
- 35 Maidment I, Wong G, Duddy C, *et al.* Medication optimisation in severe mental illness (MEDIATE): protocol for a realist review. *BMJ Open* 2022;12:e058524.
- 36 Wong G, Westhorp G, Manzano A, *et al.* RAMESSES II reporting standards for realist evaluations. *BMC Med* 2016;14:96.
- 37 Alguera-Lara V, Dowsey MM, Ride J, *et al.* Shared decision making in mental health: the importance for current clinical practice. *Australas Psychiatry* 2017;25:578–82.
- 38 Carrick R, Mitchell A, Powell RA, *et al.* The quest for well-being: a qualitative study of the experience of taking antipsychotic medication. *Psychol Psychother* 2004;77:19–33.
- 39 Clifford L, Crabb S, Turnbull D, *et al.* A qualitative study of medication adherence amongst people with schizophrenia. *Arch Psychiatr Nurs* 2020;34:194–9.
- 40 Crellin NE, Priebe S, Morant N, *et al.* An analysis of views about supported reduction or discontinuation of antipsychotic treatment among people with schizophrenia and other psychotic disorders. *BMC Psychiatry* 2022;22:185.
- 41 Evans M, Barker H, Peddiredy S, *et al.* Peer-delivered services and peer support reaching people with schizophrenia: a scoping review. *International Journal of Mental Health* 2021;2021:1–23.
- 42 Fiorillo A, Barlati S, Bellomo A, *et al.* The role of shared decision-making in improving adherence to pharmacological treatments in patients with schizophrenia: a clinical review. *Ann Gen Psychiatry* 2020;19:43.
- 43 Green CA, Polen MR, Janoff SL, *et al.* Understanding how clinician-patient relationships and relational continuity of care affect recovery from serious mental illness: STARS study results. *Psychiatr Rehabil J* 2008;32:9–22.
- 44 Grünwald LM, Duddy C, Byng R, *et al.* The role of trust and hope in antipsychotic medication reviews between Gps and service users a realist review. *BMC Psychiatry* 2021;21:390.
- 45 Grünwald LM, Thompson J. Re-starting the conversation: improving shared decision making in antipsychotic prescribing. *Psychosis* 2021;13:373–7.
- 46 Haddad PM, Brain C, Scott J. Nonadherence with antipsychotic medication in schizophrenia: challenges and management strategies. *Patient Relat Outcome Meas* 2014;5:43–62.
- 47 Jakovljević M. Long-acting Injectable (depot) antipsychotics and changing treatment philosophy: possible contribution to integrative care and personal recovery of schizophrenia. *Psychiatr Danub* 2014;26:304–7.
- 48 Lim M, Li Z, Xie H, *et al.* The effect of therapeutic alliance on attitudes toward psychiatric medications in schizophrenia. *J Clin Psychopharmacol* 2021;41:551–60.
- 49 García S, Martínez-Cengotitabengoa M, López-Zurbano S, *et al.* Adherence to antipsychotic medication in bipolar disorder and schizophrenic patients: a systematic review. *J Clin Psychopharmacol* 2016;36:355–71.
- 50 Mahone IH, Maphis CF, Snow DE. Effective strategies for nurses empowering clients with schizophrenia: medication use as a tool in recovery. *Issues Ment Health Nurs* 2016;37:372–9.
- 51 Ostrow L, Croft B, Weaver A, *et al.* An exploratory analysis of the role of social supports in psychiatric medication discontinuation: results related to family involvement. *Psychosis* 2019;11:212–22.
- 52 Phan SV. Medication adherence in patients with schizophrenia. *Int J Psychiatry Med* 2016;51:211–9.
- 53 Pietrini F, Albert U, Ballerini A, *et al.* The modern perspective for long-acting Injectables antipsychotics in the patient-centered care of schizophrenia. *Neuropsychiatr Dis Treat* 2019;15:1045–60.
- 54 Pinfold V, Dare C, Hamilton S, *et al.* Anti-psychotic medication decision making during pregnancy: a co-produced research study. *MHRJ* 2019;24:69–84.
- 55 Roberts R, Neasham A, Lambrinudi C, *et al.* A thematic analysis assessing clinical decision-making in antipsychotic prescribing for schizophrenia. *BMC Psychiatry* 2018;18:290.
- 56 Rungruangsiripan M, Sitthimongkol Y, Maneesriwongul W, *et al.* Mediating role of illness representation among social support, therapeutic alliance, experience of medication side effects, and medication adherence in persons with schizophrenia. *Arch Psychiatr Nurs* 2011;25:269–83.
- 57 Salzmänn-Erikson M, Sjödin M. A narrative meta-synthesis of how people with schizophrenia experience facilitators and barriers in using antipsychotic medication: implications for healthcare professionals. *Int J Nurs Stud* 2018;85:7–18.
- 58 Steingard S. Five year outcomes of tapering antipsychotic drug doses in a community mental health center. *Community Ment Health J* 2018;54:1097–100.
- 59 Thompson J, Stansfeld JL, Cooper RE, *et al.* Experiences of taking neuroleptic medication and impacts on symptoms, sense of self and agency: a systematic review and thematic synthesis of qualitative data. *Soc Psychiatry Psychiatr Epidemiol* 2020;55:151–64.
- 60 Velligan DI, Sajatovic M, Hatch A, *et al.* Why do psychiatric patients stop antipsychotic medication? A systematic review of reasons for nonadherence to medication in patients with serious mental illness. *Patient Prefer Adherence* 2017;11:449–68.
- 61 Watts M Dr, Murphy E, Keogh B Dr, *et al.* Deciding to discontinue prescribed psychotropic medication: a qualitative study of service users' experiences. *Int J Ment Health Nurs* 2021;30 Suppl 1:1395–406.
- 62 Weiden PJ. Redefining medication adherence in the treatment of schizophrenia: how current approaches to adherence lead

- to misinformation and threaten therapeutic relationships. *Psychiatr Clin North Am* 2016;39:199–216.
- 63 Zhou Y, Rosenheck R, Mohamed S, *et al.* Factors associated with complete discontinuation of medication among patients with schizophrenia in the year after hospital discharge. *Psychiatry Res* 2017;250:129–35.
- 64 Zipursky RB, Odejayi G, Agid O, *et al.* You say "schizophrenia" and I say "psychosis": just tell me when I can come off this medication. *Schizophr Res* 2020;225:39–46.
- 65 Coulthard K, Patel D, Brizzolara C, *et al.* A feasibility study of expert patient and community mental health team led bipolar psychoeducation groups: implementing an evidence based practice. *BMC Psychiatry* 2013;13:301.
- 66 Larsen-Barr M, Seymour F. Service-user efforts to maintain their wellbeing during and after successful withdrawal from antipsychotic medication. *Ther Adv Psychopharmacol* 2021;11:2045125321989133.
- 67 Aref-Adib G, O'Hanlon P, Fullarton K, *et al.* A qualitative study of online mental health information seeking behaviour by those with psychosis. *BMC Psychiatry* 2016;16:232.
- 68 Geyt GL, Awenat Y, Tai S, *et al.* Personal accounts of discontinuing neuroleptic medication for psychosis. *Qual Health Res* 2017;27:559–72.
- 69 Hansen H, Stige SH, Davidson L, *et al.* How do people experience early intervention services for psychosis? A meta-synthesis. *Qual Health Res* 2018;28:259–72.
- 70 Haugom EW, Stensrud B, Beston G, *et al.* Mental health professionals' experiences with shared decision-making for patients with psychotic disorders: a qualitative study. *BMC Health Serv Res* 2020;20:1093.
- 71 Kaar SJ, Gobjila C, Butler E, *et al.* Making decisions about antipsychotics: a qualitative study of patient experience and the development of a decision aid. *BMC Psychiatry* 2019;19:309.
- 72 Leclerc E, Noto C, Bressan RA, *et al.* Determinants of adherence to treatment in first-episode psychosis: a comprehensive review. *Braz J Psychiatry* 2015;37:168–76.
- 73 Lewins A, Morant N, Akther-Robertson J, *et al.* A qualitative exploration of family members' perspectives on reducing and discontinuing antipsychotic medication. *J Ment Health* 2022;2022:1–8.
- 74 Maj M, van Os J, De Hert M, *et al.* The clinical characterization of the patient with primary psychosis aimed at personalization of management. *World Psychiatry* 2021;20:4–33.
- 75 Morant N, Azam K, Johnson S, *et al.* The least worst option: user experiences of antipsychotic medication and lack of involvement in medication decisions in a UK community sample. *J Ment Health* 2018;27:322–8.
- 76 Opler LA, Ramirez PM, Dominguez LM, *et al.* Rethinking medication prescribing practices in an inner-city Hispanic mental health clinic. *J Psychiatr Pract* 2004;10:134–40.
- 77 Yeisen RAH, Bjornestad J, Joa I, *et al.* Experiences of antipsychotic use in patients with early psychosis: a two-year follow-up study. *BMC Psychiatry* 2017;17:299.
- 78 Bjornestad J, Lavik KO, Davidson L, *et al.* Antipsychotic treatment – a systematic literature review and meta-analysis of qualitative studies. *J Ment Health* 2020;29:513–23.
- 79 Bolden GB, Angell B, Hepburn A. How clients solicit medication changes in psychiatry. *Sociol Health Illn* 2019;41:411–26.
- 80 Delman J, Clark JA, Eisen SV, *et al.* Facilitators and barriers to the active participation of clients with serious mental illnesses in medication decision making: the perceptions of young adult clients. *J Behav Health Serv Res* 2015;42:238–53.
- 81 Ehrlich C, Dannapfel P. Shared decision making: people with severe mental illness experiences of involvement in the care of their physical health. *Mental Health & Prevention* 2017;5:21–6.
- 82 Fiore G, Bertani DE, Marchi M, *et al.* Patient subjective experience of treatment with long-acting Injectable antipsychotics: a systematic review of qualitative studies. *J Bras Psiquiatr* 2021;70:68–77.
- 83 Kaminskiy E, Zisman-Ilani Y, Morant N, *et al.* Corrigendum: barriers and enablers to shared decision making in psychiatric medication management: a qualitative investigation of clinician and service users' views. *Front Psychiatry* 2021;12:789916.
- 84 Katz S, Goldblatt H, Hasson-Ohayon I, *et al.* Retrospective accounts of the process of using and discontinuing psychiatric medication. *Qual Health Res* 2019;29:198–210.
- 85 Keogh B, Murphy E, Doyle L, *et al.* Mental health service users experiences of medication discontinuation: a systematic review of qualitative studies. *J Ment Health* 2022;31:227–38.
- 86 King SR, Allan M, Lindsey L. I found hundreds of other people... but I still wasn't Believed"—an exploratory study on lived experiences of antipsychotic withdrawal. *Psychosis* 2022;1–13.
- 87 Larsen-Barr M, Seymour F, Read J, *et al.* Attempting to discontinue antipsychotic medication: withdrawal methods, relapse and success. *Psychiatry Res* 2018;270:365–74.
- 88 Martínez-Hernández Á, Pié-Balaguer A, Serrano-Miguel M, *et al.* The collaborative management of antipsychotic medication and its obstacles: a qualitative study. *Soc Sci Med* 2020;247:112811.
- 89 Matthias MS, Salyers MP, Rollins AL, *et al.* Decision making in recovery-oriented mental health care. *Psychiatr Rehabil J* 2012;35:305–14.
- 90 Pedley R, McWilliams C, Lovell K, *et al.* Qualitative systematic review of barriers and facilitators to patient-involved antipsychotic prescribing. *BJPsych Open* 2018;4:5–14.
- 91 Sowerby C, Taylor D. Cross-sector user and provider perceptions on experiences of shared-care clozapine: a qualitative study. *BMJ Open* 2017;7:e017183.
- 92 Quirk A, Chaplin R, Hamilton S, *et al.* Communication about adherence to long-term antipsychotic prescribing: an observational study of psychiatric practice. *Soc Psychiatry Psychiatr Epidemiol* 2013;48:639–47.
- 93 Zisman-Ilani Y, Lysaker PH, Hasson-Ohayon I. Shared risk taking: shared decision making in serious mental illness. *Psychiatr Serv* 2021;72:461–3.
- 94 Seale C, Chaplin R, Lelliott P, *et al.* Sharing decisions in consultations involving anti-psychotic medication: a qualitative study of psychiatrists' experiences. *Soc Sci Med* 2006;62:2861–73.
- 95 Younas M, Bradley E, Holmes N, *et al.* Mental health pharmacists views on shared decision-making for antipsychotics in serious mental illness. *Int J Clin Pharm* 2016;38:1191–9.
- 96 Rossiter C, Levett-Jones T, Pich J. The impact of person-centred care on patient safety: an umbrella review of systematic reviews. *Int J Nurs Stud* 2020;109:103658.
- 97 Davidson G, Kelly B, Macdonald G, *et al.* Supported decision making: a review of the International literature. *Int J Law Psychiatry* 2015;38:61–7.

- 98 Knight F, Kokanović R, Ridge D, *et al.* Supported decision-making: the expectations held by people with experience of mental illness. *Qual Health Res* 2018;28:1002–15.
- 99 Kokanović R, Brophy L, McSherry B, *et al.* Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners. *Aust N Z J Psychiatry* 2018;52:826–33.
- 100 Penzenstadler L, Molodynski A, Khazaal Y. Supported decision making for people with mental health disorders in clinical practice: a systematic review. *Int J Psychiatry Clin Pract* 2020;24:3–9.
- 101 Lewicki RJ, Tomlinson EC, Gillespie N. Models of interpersonal trust development: theoretical approaches, empirical evidence, and future directions. *Journal of Management* 2006;32:991–1022.
- 102 Maidment ID, Brown P, Calnan M. An exploratory study of the role of trust in medication management within mental health services. *Int J Clin Pharm* 2011;33:614–20.
- 103 Brown P, Calnan M. Trust as a means of bridging the management of risk and the meeting of need: a case study in mental health service provision. *Social Policy & Administration* 2013;47:242–61.
- 104 Brown P, Calnan M, Scrivener A, *et al.* Trust in mental health services: a neglected concept. *Journal of Mental Health* 2009;18:449–58.
- 105 Trusty WT, Penix EA, Dimmick AA, *et al.* Shared decision-making in mental and behavioural health interventions. *J Eval Clin Pract* 2019;25:1210–6.
- 106 Ahmed N, Barlow S, Reynolds L, *et al.* Mental health professionals' perceived barriers and enablers to shared decision-making in risk assessment and risk management: a qualitative systematic review. *BMC Psychiatry* 2021;21:594.
- 107 Markham S. Collaborative risk assessment in secure and forensic mental health settings in the UK. *Gen Psychiatr* 2020;33:e100291.
- 108 Department of Health. *Best practice in managing risk: principles and evidence for practice in the assessment and management of risk to self and others in mental health services*. London, UK, 2009.
- 109 Shalaby RAH, Agyapong VIO. Peer support in mental health: literature review. *JMIR Ment Health* 2020;7:e15572.
- 110 Thomas EC, Ben-David S, Treichler E, *et al.* A systematic review of shared decision-making interventions for service users with serious mental illnesses: state of the science and future directions. *PS* 2021;72:1288–300.
- 111 Kapadia D, Zhang J, Salway S, *et al.* *Ethnic inequalities in healthcare: a rapid evidence review*. NHS Race & Health Observatory, 2022.
- 112 Baborik AL, Satre DD, Kline-Simon AH, *et al.* Serious mental illness and medical comorbidities: findings from an integrated health care system. *J Psychosom Res* 2017;100:35–45.
- 113 Rodgers M, Dalton J, Harden M, *et al.* Integrated care to address the physical health needs of people with severe mental illness: a mapping review of the recent evidence on barriers, facilitators and evaluations. *Int J Integr Care* 2018;18:9.
- 114 Page MJ, McKenzie JE, Bossuyt PM, *et al.* The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71.
- 115 Jawad I, Watson S, Haddad PM, *et al.* Medication nonadherence in bipolar disorder: a narrative review. *Ther Adv Psychopharmacol* 2018;8:349–63.