



MEDIATE



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Bibliography

MEET THE TEAM 1



Professor Ian Maidment – Chief Investigator

Aston University

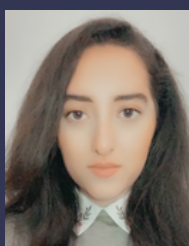
Role: Overall responsibility for all aspects of MEDIATE. Led co-ordination of project team and dissemination. Advised on medication optimisation in severe mental illness, role of pharmacy and realist methods.



Dr Jo Howe – Research Associate

Aston University

Role: Lead RA overseeing delivery of MEDIATE. Screened, coded, analysed and synthesised documents. Developed CMOCs and final programme theory.



Hafsa Habib – Research Assistant

Aston University

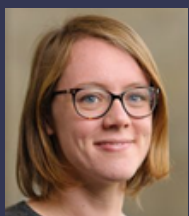
Role: Supported delivery of MEDIATE. Coded, analysed and synthesised documents. Developed CMOCs and final programme theory.



Dr Geoff Wong – Associate Professor & GP

University of Oxford

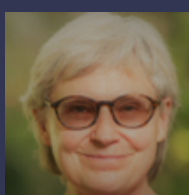
Role: Provided advice and lead on realist methodology, assisted in review processes, data analysis and synthesis, and programme theory development. Also provided advice on the role of primary care and supported dissemination in primary care.



Claire Duddy – Realist Reviewer & NIHR Pre-Doctoral Fellow

University of Oxford

Role: Developed and ran literature searches; advised and assisted on realist methodology. Assisted in review processes, data analysis and synthesis and developing programme theory.



Professor Maura MacPhee – Professor of Nursing, Health Services Researcher

University of British Columbia (Canada)

Role: Screened, coded, analysed and synthesised documents. Developed CMOCs and final programme theory. Provided international perspective to the research findings and expertise on realist methodology.

MEET THE TEAM 2



Dr Sheri Oduola – Lecturer in Mental Health Nursing

University of East Anglia

Role: Led on nursing aspects, supported analysis and interpretation of findings, and dissemination. Advised on Programme Theory and intervention components in relation to ethnic minority communities.



Dr Simon Jacklin – Lecturer in Pharmacy Practice

Keele University

Role: Specialist advisor in community and hospital pharmacy and shared decision making.



Professor Rachel Upthegrove – Professor of Psychiatry & Youth Mental Health, Honorary Consultant Psychiatrist

University of Birmingham

Role: Led on clinical psychiatry aspects. Supported analysis, interpretation and dissemination, particularly in specialist secondary services.



Dr Katherine Allen – Lead: Recovery and Service User, Family and Carer Experience

Birmingham and Solihull Mental Health NHS Foundation Trust

Role: Led and coordinated PPI work, including supporting PPI engagement.



Emma Patterson – Head of Research & Innovation

Birmingham and Solihull Mental Health NHS Foundation Trust

Role: Lead collaborative practice partner. Liaison between Aston University and Birmingham and Solihull Mental Health NHS Foundation Trust.



Max Carlish – Chair of Lived Experience Action Group and NIHR Pre-Doctoral Fellow

Birmingham and Solihull Mental Health NHS Foundation Trust

Role: Lived experience and provided patient perspective.

WHAT IS MEDIATE?

MEDIATE: MEDication optimisATIion in severE mental illness

Medication, particularly anti-psychotics and mood stabilisers, are the main treatment options for people with severe mental illnesses (SMI), such as schizophrenia and bipolar disorder. Whilst helpful in controlling symptoms, these medications can lead to debilitating side effects and the development of additional diagnoses such as diabetes and cardiovascular disease.

People with SMI often receive complex medication regimens to treat their mental and physical health needs. Optimising these regimens can be challenging and the consequences of failing to do so can be devastating, both in terms of untreated mental illness and medication related side-effects, and can, in turn, increase the risk of non-adherence and relapse.

Although collaborative approaches such as shared decision making are thought to positively influence medication optimisation, there is very little published research describing how medication decisions are determined for people living with SMI.

MEDIATE is a 16 month long NIHR funded realist review, starting from November 2021 to March 2023, involving extensive stakeholder engagement with 'experts-by-experience' to make sense of the complexities and identify potential solutions. The protocol for MEDIATE has been published in the BMJ Open. See below:

Link: [MEDIATE PROTOCOL](#)

MEDIATE is funded by the National Institute for Health Research (NIHR).

OUR METHODS

We conducted a realist review, drawing together data from published research to develop a better understanding of how medication optimisation works (or not) for people living with SMI.

The review comprised six stages and encompassed: Focusing the review, developing initial programme theories, developing the search strategy, selection and appraisal of documents, data extraction and synthesis, and programme theory refinement.

Patient and Public Involvement (PPI) was central throughout MEDiate. Two groups of stakeholders were formed, the Lived Experience Group (LEG), comprising people living with SMI, and the Practitioner Group (PG), comprising practitioners caring for people with SMI. These meetings enabled us to better understand the needs of stakeholders. Five one-hour online meetings were held with both groups (the LEG had an additional introductory meeting). LEG and PG feedback influenced the focus of the review, highlighted gaps in research evidence and indicated areas for future research, which, initially informed the realist review, and subsequently the research design and the priorities for further research. Stakeholders represented a diverse population, to explore a range of perspectives and promote equal access for public engagement opportunities.

Our review included 51 documents in total. We used data extracted from these documents to build realist "CMOCs" (context-mechanism-outcome configurations"). A CMOC explains the causal links between contexts (C) and mechanisms (M) which generate outcomes (O), both intended and unintended. Our analysis is drawn together in a refined "programme theory", outlining our understanding of how medication optimisation for people living with SMI works. In realist research, a programme theory offers an explanation as to how programmes (or interventions) are expected to work.

OUR MEDIATE PROGRAMME THEORY

“When individuals with SMI/service users (SU) are first diagnosed with serious mental illness, a diagnosis which is frightening to them, they seek out information about their illness. SUs taking medications want practitioner support and realistic practitioner advice they can understand and apply to their current and ongoing needs. SUs 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 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-judgmental support from family members and their social network, including peer support workers.”

CMOC 1-3

<p>CMOC 1</p> <p>Evidence</p>	<p>When an individual with SMI is first diagnosed, is medicated and experiences coercive, dehumanising experiences from practitioners (C), this often derails the development of trusting therapeutic alliances (O) because of feelings of powerlessness (M) and stigmatisation (M).</p> <p><i>"However, when health professionals did not listen to participants, the relationship was experienced as being unequal, with the professional holding the power. Often, participants did not have the necessary skills to speak up, and rather than being active participants in their health care, became passive recipients. Thus, rather than gaining critical skills of mastering living with mental illness and managing the consequences of poor physical health, participants felt mastered by health professionals."</i>¹</p>
<p>CMOC 2</p> <p>Evidence</p>	<p>When an individual 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.</p> <p><i>"The majority of participants recalled initial relief, hope, and optimism when told by their clinician that their experiences were treatable with medication, as captured in the following statement: I thought ... "something can be done ... it's not just me being a freak, this is a thing that people have and there's a thing for it." [...] Receiving professional explanations of psychosis and treatment gave many participants a way to make sense of their experiences, which fitted with cultural expectations of illness and cure and was both normalising and validating."</i>²</p>
<p>CMOC 3</p> <p>Evidence</p>	<p>When an individual 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.</p> <p><i>"The lack of trust created by previous experiences of coercion or sectioning under the Mental Health Act may also prevent SU from sharing whether they are currently experiencing symptoms [...] If outcomes and options are not discussed and aligned this can have consequences moving forward. SUs may choose not to adhere to treatment plans, which can lead to unsafe medication practices, putting their health at risk."</i>³</p>

CMOC 4-7

<p>CMOC 4</p> <p>Evidence</p>	<p>From the start of their relationship onwards, when an individual 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.</p> <p><i>"The clinician needs to listen to the patient, understand their perspective, including their beliefs and concerns about their illness and medication, and ensure that their preferences regarding treatment are based on fact rather than misperceptions. Involving patients in the choice of their medication increases the likelihood of adherence."</i> ⁴</p>
<p>CMOC 5</p> <p>Evidence</p>	<p>From the start of the therapeutic relationship onwards, when an individual with SMI feels comfortable accessing their clinician 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 mutual respect (M) in each other and in the information being exchanged.</p> <p><i>"Obtaining proper information, either from the treatment provider or from personal reading, and thus becoming knowledgeable about one’s own condition and process, seemed important when moving from the short-term horizon to thinking about living with the challenges over a longer-term perspective [...] Further, information appears to best facilitate successful use when delivered in a manner that supports and sustains the person’s concerns with his or her autonomy and individual efforts. A straightforward and honest use of everyday language can promote a collaborative framework"</i> ⁵</p>
<p>CMOC 6</p> <p>Evidence</p>	<p>Whenever an individual 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 (e.g., 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</p> <p><i>"Most respondents reported using the Internet to review information on medications already prescribed by the psychiatrist. They did so in order to clarify their expectations for a medication’s potential side effects and risks or to check out a current health concern as a side effect."</i> ⁶</p>
<p>CMOC 7</p> <p>Evidence</p>	<p>When an individual with SMI on medications has continuity over time in a trusting, respectful 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.</p> <p><i>"...there’s a lot to be said for having a provider who knows your history, knows where you’ve been. ...He definitely always lets me share my ideas, and his approach is we work things through together and he listens to me, so...that’s the reason I stuck with him."</i> ⁷</p>

CMOC 8-11

<p>CMOC 8</p> <p>Evidence</p>	<p>When individuals 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 (e.g., harm to self or others).</p> <p><i>"Clinicians may resist SDM with patients with serious mental illness because they fear being held liable for any potentially negative outcome that might result from SDM, such as symptom exacerbation, hospitalization, or death [...] For clinicians, safety risks, such as relapse, present high potential for legal liability, particularly if the risk is accompanied by symptoms potentially related to harm, such as suicidality or homicidality."</i> ⁸</p>
<p>CMOC 9</p> <p>Evidence</p>	<p>When an individual with SMI trusts family and social network members to believe in them, want the best for them and to provide non-judgmental support (C), they are apt to feel more confident in following through with prescribed medication plans (O) due to a sense of safety (M) among people looking after their well-being.</p> <p><i>"It was considered important that the social environment supported the participants while they were on medication. Support from the family created a close social network and was described as facilitating motivation to maintain medication. Participants reported that their family took care of their physical and mental needs and facilitated their continuing to medicate (Chang et al., 2013)."</i> ⁹</p>
<p>CMOC 10</p> <p>Evidence</p>	<p>When an individual 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.</p> <p><i>"In Roe et al. (2009) study for example, pressure came from professionals, family and friends and in some cases, participants took medication to maintain the status quo and to please others, especially their families. In addition, one participant stated that access to a rehabilitation service was contingent on their compliance with medication (Roe et al., 2009)"</i> ¹⁰</p>
<p>CMOC 11</p> <p>Evidence</p>	<p>When individuals 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.</p> <p><i>"The reciprocity and feelings of togetherness experienced in peer groups were also pointed out as helpful and meaningful in several ways. Simply getting to know other people who struggled with similar issues made many participants feel more positive toward engagement with services. In these groups, participants usually experienced genuine empathy and understanding as well as instillation of hope from others who had dealt successfully with their own symptoms and distress. Many participants found the groups to be helpful in developing coping strategies and gaining more control over their experience. Helping others was also perceived as an important part of engaging in these groups."</i> ¹¹</p>

KEY FINDINGS

Medication optimisation is possible within the context of shared decision making between SUs and practitioners. The impact of negative initial contacts with healthcare services, such as coercive treatment practices, adversely influences future therapeutic relationships, and ultimately, medication optimisation.

Positive early and ongoing experiences can help SU's form trusting therapeutic relationships, discuss medication concerns with practitioners and negotiate changes to medications based on their lifestyle needs.

SUs frequently access additional sources of information about medication and diagnoses from family, friends, peer support workers and the internet. Peer support workers are an important resource to SUs, given their lived experience with SMI.

CONCLUSIONS

Medication optimisation for people with SMI can be facilitated through shared decision making. Positive early and ongoing encounters with healthcare services and practitioners are instrumental. Although SUs seek out non-clinical sources of information and support, when trusting therapeutic relationships exist, SUs are more apt to openly share information with practitioners and collaboratively manage medication.

WHATS NEXT?

Our stakeholders, both the LEG and the PG, highlighted the potential impact of peer support workers/family/carers on medication optimisation, but limited evidence was found relating to these aspects during the review. Additionally, there was a paucity of evidence explaining how medication can be optimised for people with SMI from ethnically diverse backgrounds. We will submit a programme grant application to further continue this work and propose that any key aspect of future research should focus on these areas.

CONTACT US



For regular updates on our work follow us on Twitter
[@PharMed_](https://twitter.com/PharMed_)



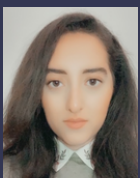
Professor Ian Maidment

i.maidment@aston.ac.uk
[@Prof_Ian_M](https://twitter.com/Prof_Ian_M)



Dr Jo Howe

j.howe1@aston.ac.uk
[@DrJoHowe](https://twitter.com/DrJoHowe)



Hafsah Habib

h.habib2@aston.ac.uk
[@Hafsah_Habib](https://twitter.com/Hafsah_Habib)

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