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## Psychotropic medication for adults with intellectual disability: a multi-stakeholder qualitative exploration of decision-making

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-032861
Article Type:	Research
Date Submitted by the Author:	09-Jul-2019
Complete List of Authors:	Sheehan, Rory; University College London, Division of Psychiatry HASSIOTIS, ANGELA; University College London, Division of Psychiatry Strydom, André; Institute of Psychiatry Psychology and Neuroscience Morant, Nicola; University College London, Division of Psychiatry
Keywords:	intellectual disability, psychotropic medication, QUALITATIVE RESEARCH, shared decision making

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**TITLE PAGE****Psychotropic medication for adults with intellectual disability: a multi-stakeholder qualitative exploration of decision-making**

Dr Rory Sheehan, MSc, Division of Psychiatry, University College London

Professor Angela Hassiotis, PhD, Division of Psychiatry, University College London

Professor André Strydom, PhD, Institute of Psychiatry, Psychology and Neuroscience, King's College London

Dr Nicola Morant, PhD, Division of Psychiatry, University College London

**Corresponding author details**

Dr Rory Sheehan

Division of Psychiatry, University College London, 6<sup>th</sup> Floor Maple House, 149 Tottenham Court Road, London W1T 7NF

Telephone: 0207-679-9201

E-mail: r.sheehan@ucl.ac.uk

**Word count**

5,928

**Number of figures and tables**

1 table

1 figure

**Keywords**

Intellectual disability; psychotropic medication; qualitative research; shared decision making

## **ABSTRACT**

### **Psychotropic medication for adults with intellectual disability: a multi-stakeholder qualitative exploration of decision-making**

**Objectives** Understanding patient and carer perspectives is essential to improving the quality of medication prescribing, and healthcare policies advocate involvement in treatment decisions. The high proportion of people with intellectual disability (ID) prescribed psychotropic medication underpins concerns about inappropriate use in this group. The objective of this study was to explore experiences of psychotropic medication among people with ID and their carers, with a focus on how medication decisions are made.

**Design** Qualitative study using semi-structured interviews on experiences of psychotropic medication and its management with people with ID, family carers, and paid carers. Data were analysed using thematic analysis.

**Participants and setting** 14 people with mild-moderate ID, 12 family carers, and 12 paid carers were recruited from specialist psychiatry services and community organisations in the UK. Purposive sampling ensured a mix of participant characteristics.

**Results** People with ID were highly compliant with prescribed psychotropic medication and were generally not aware of their right to be involved in medication decisions. Paid and family carers reported being closely involved in medication use and monitoring, and felt they possessed important forms of knowledge about the person they care cared for. They valued decision-making in which they felt they had a voice and a genuine role. Lack of

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3 involvement was commonly described and took three forms: being uninformed,  
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5 insufficiently included, and lacking influence. Carers made efforts to democratise the  
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7 decision-making process by gathering information, disrupting power asymmetries, and  
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9 attempting to prove their credibility as informants and valid decision-making partners.  
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13 **Conclusions** Shared decision making is a model that offers people with ID and their carers a  
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15 role in decisions about their care. Further work is needed to develop, evaluate and embed  
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17 shared decision making for medication decisions with people with ID and their carers.  
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### STRENGTHS AND LIMITATIONS OF THIS STUDY

- There are major concerns about the over-use of psychotropic medication for adults with intellectual disability and efforts to improve prescribing are on-going.
- This is the first multi-stakeholder study of patient, paid carer, and family carer experience of psychotropic medication decision-making for people with intellectual disability.
- In-depth qualitative methods allow us to develop a nuanced understanding of the relational and power dynamics underpinning decision-making.
- Our work extends the literature by considering psychotropic medication optimisation within the framework of shared decision making, a model which has become pre-eminent and aspirational but which is under-developed in this setting and in this clinical population.
- The views of prescribers and other health professionals were not included. Adaptations to methodology were made to support people with ID but those with limited or no verbal ability were not able to take part.

## **MANUSCRIPT**

### **Psychotropic medication for adults with intellectual disability: a multi-stakeholder qualitative exploration of decision-making**

#### **INTRODUCTION**

Up to 2% of the global population live with intellectual disability (ID), a lifelong condition characterised by significant deficits in cognitive and adaptive function with early onset.<sup>1, 2</sup> A combination of biological, psychological, social, and developmental factors contribute to a high rate of mental disorder in this group.<sup>3</sup> Recent evidence from epidemiological studies conducted across jurisdictions confirms that people with ID are often prescribed psychotropic medication, in many cases in the absence of a diagnosis for which it is indicated.<sup>4-9</sup> Psychotropic polypharmacy,<sup>10-13</sup> high doses,<sup>11</sup> and increased susceptibility to adverse side-effects<sup>14, 15</sup> are also significant concerns. Thus, people with ID are a key group in whom efforts to improve psychotropic prescribing are required. In England, a national programme, Stopping the Over-Medication of People with ID (STOMP), has been established to reduce inappropriate use of psychotropic medication.<sup>16</sup> Co-produced with people with ID, the programme aims to raise awareness of the issue, develop resources for patients and carers, and act as a stimulus for practice change.<sup>17</sup>

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3 Medication optimisation is a multi-faceted approach to improving the use of prescribed  
4 medication with the aim of enhancing clinical outcomes, improving safety and reducing  
5 waste.<sup>18</sup> While deprescribing (reducing or discontinuing inappropriate medication) may be  
6 one element of optimisation, improving the quality of medication use requires more than a  
7 sole focus on quantitative measures. Understanding people's experience of medication and  
8 encouraging partnership between professionals and patients are also important  
9 components of successful medication optimisation<sup>18, 19</sup> that intersect with the broader  
10 concept of shared decision making (SDM). SDM seeks to replace traditional, paternalistic  
11 models of care with more collaborative approaches to treatment decisions where expertise  
12 and responsibility are owned jointly by doctor and patient.<sup>20</sup> SDM has gained prominence  
13 and become embedded in policy across many areas of healthcare internationally. The aims  
14 of SDM are congruent with longstanding UK government strategy to increase the inclusion  
15 and support the autonomy of people with ID in healthcare decisions and more generally.<sup>21</sup>  
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39 Although psychotropic medication optimisation has become a focus of policy and practice  
40 for people with ID<sup>17, 22</sup> there has been little exploration of experiential aspects of medication  
41 use in this group, and of the processes by which psychotropic medication decisions are  
42 made. It is not clear how, and to what extent, the principles of SDM are applied and how the  
43 model may adapt to the presence of multiple stakeholders, as paid or family carers often  
44 support people with ID in various aspects of their life. In this study, we sought to explore the  
45 experiences and expectations of adults with ID and paid and family carers regarding  
46 psychotropic medication use, and how decisions about this are made with healthcare  
47 professionals.  
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## METHODS

### Participants and setting

People were eligible to participate if they were; adults ( $\geq 18$  years) with ID who were prescribed psychotropic medication; family carers of adults with ID who had been prescribed psychotropic medication; or paid carers who worked with adults with ID who had experience of supporting people with psychotropic medication and who were employed in a variety of settings. The cognitive ability of potential participants with ID was not formally tested but participants were required to have capacity to provide informed consent to take part and sufficient verbal ability to talk about their experiences.

A leaflet advertising the research was offered to potential participants at appointments with specialist psychiatry of intellectual disability services within the National Health Service (NHS). Short presentations by researchers to community third-sector (i.e. non-statutory) and care provider organizations were used to expand the reach of recruitment. People who showed an initial interest were contacted and eligibility was confirmed. Written, informed consent was received before interviews were conducted and participants understood the research to be for an academic project as well as providing insights that could benefit patient care. Purposive sampling was used to select participants with a range of

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3 characteristics that may be related to medication views and experiences, such as age,  
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5 gender, ethnic group, and psychiatric morbidity.  
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11 People with ID and family carers were given a £20 shopping voucher as a token of  
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13 appreciation for donating time to the study. Paid carers were provided with a certificate  
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15 thanking them for their contribution.  
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### 23 **Data collection**

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29 Baseline demographic and descriptive data were collected by participant report. Qualitative  
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31 data were collected in audio-recorded individual in-depth semi-structured interviews  
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33 conducted by the first author, a psychiatrist and clinician researcher with experience of  
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35 working with people with ID and an academic interest in medication use. He did not have  
36  
37 any other contact with participants. A topic guide with open-ended questions was used to  
38  
39 provide a broad structure to the interviews yet allowing points of interest to be pursued as  
40  
41 they arose. We adopted a flexible approach to interviews with people with ID in order to  
42  
43 facilitate their involvement.<sup>23</sup> All study materials for people with ID were available in 'easy-  
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45 read and laminated picture cards were used (where appropriate) as prompts and to  
46  
47 orientate interviewees. Checking and summarising content throughout the interviews gave  
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49 opportunity for clarification and elaboration. Field notes were made to supplement the  
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51 transcripts and provide context for the analysis.  
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## Analysis

Descriptive quantitative data were summarised. Audio-recorded interviews were transcribed verbatim (RS), anonymised and the transcripts then checked for accuracy.

Thematic analysis was used with an inductive orientation in which themes were derived from the data.<sup>24</sup> Transcripts from each group of participants were analysed concurrently to build a unifying coding frame that was developed in an iterative process as additional transcripts were analysed. Independent coding of a subset of transcripts by another researcher in a related field, discussion of analytic techniques and emerging themes between members of the research team, and reflexive memos were used to ensure integrity of the analysis. NVivo qualitative data analysis software (QSR International Pty Ltd. Version 12, 2018) was used to manage the data and facilitate the analytic processes.

## Public involvement

The recruitment strategy, participant materials, and topic guide were informed by discussions with a consultation group consisting of people with ID employed for this work, some of whom had lived experience of mental illness, psychotropic medication use, and contact with mental health services. The group will assist with future targeted dissemination activities to the participants with ID, their families and prescribers.

## RESULTS

### Sample

Thirty-eight people (14 adults with ID; 12 family carers; 12 paid carers) were recruited between December 2017 and May 2018 (table 1). Twenty-nine were recruited from clinical services and nine from third-sector organizations. All participated in face-to-face interviews. 18 interviews were completed at people's home (10 people with ID; 8 family carers), 12 (all paid carers) at their place of work, 7 (3 people with ID; 4 family carers) at a university, and 1 (person with ID) at a community centre. Seven participants with ID preferred to have a companion with them in the interview (in 6 cases this was a relative, in 1 case a professional advocate).

Participants with ID reported having been diagnosed with a range of psychiatric disorders and most had been prescribed psychotropic medication for many years, often decades. None of those who participated were under a legal framework of care (e.g. Community Treatment Order or Guardianship Order).

	<b>People with ID (n=14)</b>	<b>Family carers (n=12)</b>	<b>Paid carers (n=12)</b>
Mean age (SD, range)	46.1 years (12.9, 25-68)	62.7 years (10.5, 42-80)	39.4 years (9.5, 24-55)
Sex (M:F)	9:5	3:9	6:6
Ethnic group	White <i>n</i> =8 Black <i>n</i> =2 Asian <i>n</i> =3 Other/mixed <i>n</i> =1	White <i>n</i> =8 Black <i>n</i> =1 Asian <i>n</i> =3 Other/mixed <i>n</i> =0	White <i>n</i> =7 Black <i>n</i> =3 Asian <i>n</i> =2 Other/mixed <i>n</i> =0
Degree of ID <sup>1</sup>	Mild <i>n</i> =12 Moderate <i>n</i> =2	Mild <i>n</i> =6 Moderate <i>n</i> =4 Severe-profound <i>n</i> =2	N/A <sup>2</sup>
Relationship to person with ID / professional title	N/A	Parent <i>n</i> =10 Sibling <i>n</i> =1 Grandparent <i>n</i> =1	Support worker <i>n</i> =8 Managerial responsibility <i>n</i> =4
Mean time working with people with ID (SD, range)	N/A	N/A	9.4 years (9.0, 0.5-25)
Current living arrangements	Independent <i>n</i> =3 With family <i>n</i> =5 Shared supported living <i>n</i> =6	With family member with ID <i>n</i> =9 Separately from family member with ID <i>n</i> =3	N/A <sup>2</sup>
Self-reported psychiatric diagnosis <sup>1,4</sup>	Severe mental illness <sup>3</sup> <i>n</i> =6 Depression <i>n</i> =6 Anxiety disorder <i>n</i> =5 Other <i>n</i> =2	Severe mental illness <sup>3</sup> <i>n</i> =4 Depression <i>n</i> =4 Anxiety disorder <i>n</i> =6 Other <i>n</i> =0	N/A <sup>2</sup>
Autism <sup>1</sup>	<i>n</i> =3	<i>n</i> =5	N/A <sup>2</sup>
Prescribed medication by group <sup>1,4</sup>	Antipsychotic <i>n</i> =9 Mood stabiliser <i>n</i> =3	Antipsychotic <i>n</i> =10 Mood stabiliser <i>n</i> =2	N/A <sup>2</sup>

	Anti-depressant <i>n</i> =9 Other <i>n</i> =3	Anti-depressant <i>n</i> =9 Other <i>n</i> =4	
Mean duration of psychotropic use (SD, range) <sup>1</sup>	16.8 years (14.0, 3-50)	13.6 years (8.0, 1-27)	N/A <sup>2</sup>
Mean interview duration (SD, range)	24 minutes (9.0, 11-38)	38 minutes (10.9, 19-55)	47 minutes (11.9, 31-73)

ID, intellectual disability; SD, standard deviation; N/A, not applicable

<sup>1</sup>Information provided by family carers relates to the person with ID they cared for

<sup>2</sup>Data for paid carers not collected as each paid carer worked with more than one individual with ID

<sup>3</sup>Severe mental illness includes schizophrenia, other psychotic disorders, and bipolar affective disorder

<sup>4</sup>Cell total exceeds the number in each group as people were able to report more than one diagnosis and may have been prescribed medication from more than one psychotropic class

**Table 1** Sample characteristics NEAR HERE

## Thematic analysis

We developed three major themes in our analysis of the data. The first theme, carer role, draws mainly on the interviews with paid and family carers to describe how the carer identity is constructed and how caring activities are performed. The second theme, medication beliefs and experience, describes the meanings that people give to psychotropic medication and how these can develop over time. Together, these themes provide context to the third major theme, decisional processes, in which the lived experiences of different stakeholders in the medication decision-making process are explored, including the dynamics and struggles that sometimes characterised the interactions with prescribers. Throughout the analysis we aim to provide a sense of the data by using quotes from

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3 anonymised participants who were given a number prefixed with ID (person with ID), FC  
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5 (family carer), or PC (paid carer).  
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### 10 11 12 **Carer role: the “front-line people”** 13

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18 In describing their roles in caring for a person with ID, both paid and family carers placed  
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20 substantial importance on knowing and being close to the person, and the privilege that this  
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22 gave them in evaluating their wellbeing. Carers also spoke of their role as advocates,  
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24 ensuring that processes are centred around the person with ID and their interests are  
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26 upheld.  
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34 In relation to psychotropic medication, in addition to practical, daily tasks such as collecting,  
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36 storing, and giving medication to the person with ID, both family and paid carers spoke of  
37  
38 their “integral” (PC02) role in monitoring and managing people’s health. Carers described  
39  
40 themselves as “the front-line people,” (PC01) a unique position which gave them intimate  
41  
42 knowledge of the person with ID and was contrasted with “short and limited” (PC05)  
43  
44 meetings with medical professionals. Knowing the person with ID closely and over time was  
45  
46 seen as important given the range of problems that was described amongst the group they  
47  
48 supported (including physical illness, developmental disabilities, mental illness and/or  
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50 behavioural problems). Given this complexity, carers perceived value in their ability to  
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52 interpret subtle signs and to “build up a picture of that person and how medication interacts  
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3 *with them*" (PC02). Family carers, in particular, described an intuitive sense of 'knowing' the  
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5 needs of their relative:  
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12 *"I've always had to deal with [son] not being verbal and not being able to tell me, so I*  
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14 *had to read him by body language all through his life. I'm aware of the signs...I know*  
15  
16 *if he has an infection in his nose, in his ears. I know if he has a headache...if he's not*  
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18 *OK...I already know"* (FC04)  
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25 They often took a 'gatekeeping' role in determining when to seek professional advice, and in  
26  
27 mediating interactions between the doctor and the person with ID thereafter. Possibly  
28  
29 owing to differences in the degree of ID of those they cared for, family and paid carers  
30  
31 diverged slightly in how they positioned themselves during these appointments. Family  
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33 carers described taking a more direct approach in speaking with the doctor and acting on  
34  
35 behalf of their relative, including, for example, one mother who attended appointments  
36  
37 with the psychiatrist while her son waited outside the room. Paid carers, meanwhile, framed  
38  
39 their input as *"empowering"* (PC09) and facilitating the person with ID to speak for  
40  
41 themselves, so that *"if there's something the service user wants to say, I can make sure it*  
42  
43 *happens"* (PC04) while taking more of a *"back seat"* (PC06) during the appointment.  
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53 Several carers spoke about a process of two-way *"translating"* (PC09) of information  
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55 between the doctor and the person with ID, again drawing on their knowledge of the person  
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57 with ID in order to relay information in an individualised and more understandable way. This  
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3 role often extended beyond the appointment itself and incorporated “*preparing the service*  
4 *user for the appointment and explaining in a very clear way what might happen*” (PC04) and  
5  
6 afterwards, educating and “*finding stuff out together*” (PC09) with the person with ID:  
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14 *“I always get questioned by my clients “What’s this pill? What’s that pill?” What I’ve*  
15 *done for my key clients is I’ve made a list of all the medication, and I did it in easy*  
16 *read....and I’ve got a table of what they do with picture...if they ever ask me what*  
17 *happens, I just show them and go through it with them...I will stick it up on the fridge*  
18 *to familiarise people with it.” (PC05)*  
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### 30 **Medication beliefs and experience: acceptance and ambivalence**

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36 We developed this theme predominantly from interviews with people with ID and family  
37 carers as we found that paid carers were more hesitant in offering their own opinions about  
38 medication. In this theme, passive compliance of the person with ID emerged, founded on  
39 relatively limited understanding of medication, yet a strong sense of faith in medication and  
40 trust in the doctor. For family carers psychotropic medication was an emotive topic and  
41 many were ambivalent about its use.  
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55 People with ID tended to focus on the tangible aspects of psychotropic medication (the  
56 taste, colour, and size of tablets) and the set of ‘rules’ that constituted the medication  
57 routine; “*I take [the tablets] at night-time, the little mauve ones, my big yellow ones, and my*  
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3 *little white sleeping tablet*" (ID05). There was a tacit belief in medication as important and  
4  
5 necessary, even though in many cases understanding of the indication for medication and  
6  
7 its potential effects was limited. Most people with ID characterised medication benefits in  
8  
9 vague or generic terms (e.g. "[medication] gets me better" (ID01); "it's helpful...for my  
10  
11 health" (ID09); "keeps me steady" (ID13)), although description of adverse side-effects were  
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13 more immediate and vivid (the most commonly mentioned were sedation, weight gain, and  
14  
15 movement side-effects):  
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24 *"My speech got slurred...really terrible and slurred. I just couldn't get the words out"*  
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26 (ID07)  
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30 *"I felt groggy...like I feel like a cabbage sometimes"* (ID08)  
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36 The perceived consequences of not taking medication were often described as frightening  
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38 and unpredictable and included being out-of-control or "*a danger*" (ID10). Some feared they  
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40 would "*probably end up back in hospital*" (ID13) if they stopped medication, experiences of  
41  
42 which (in those who had previous admissions) were universally negative and acted as a  
43  
44 strong motivator to keep well, which people equated with compliance with medication.  
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46 Although a minority of people with ID did express more critical views about medication or  
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48 declared that they did not like taking it, none seriously questioned its use:  
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57 *"I don't want to take it...I don't like taking it, but I have to"* (ID04)  
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3 *"I don't like taking medication at the best of times, but I know I've got to take it"*

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6 (ID10)  
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12 Given the length of time that most carers had been managing medication (average >13  
13 years), they tended to describe their experience as a journey. Their narrative was often  
14 recounted with a strong emotional overlay. Many recalled that medication was first  
15 prescribed during a mental health crisis. In such difficult circumstances, which were often  
16 stressful and sometimes impacting their own mental health, family carers could find it  
17 difficult to make a confident decision about medication; the imperative to act being set  
18 against a fear of psychotropic drugs and their possible side-effects:  
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33 *"In the beginning I was terrified about medication, the side-effects and everything.*  
34 *And also her [daughter's] condition...It's a really dangerous medication...I read lots of*  
35 *information and went on the internet, and it said lots about side-effects...But I didn't*  
36 *have any way out...I was really worried and couldn't make the decision"* (FC08)  
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46 Initial reticence was often overcome when the beneficial effects of medication were  
47 observed and family carers could undergo quite major shifts in attitude:  
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54 *"I'd always been quite resistant [to medication] because I'd heard about chemical*  
55 *coshes and all that stuff...I thought '[son] doesn't need a psychotropic'...but he went*  
56 *onto a very low dose and it noticeably helped...Now I'm at a stage of the psychiatrist*  
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3 *thinking we should reduce the dose, and I'm really resistant to that because it feels so*  
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5 *helpful"* (FC02)  
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11 Others' longer-term experience of medication was less favourable. In these cases  
12 medication was variously described as ineffective, only temporarily effective (the positive  
13 effects "*wearing off*" (FC01) over time was a common complaint), or blighted by adverse  
14 physical side-effects. The potential of psychotropic medication to dull people's cognitive  
15 faculties was expressed in various terms (e.g. "*[relative] was almost like a dead person...the*  
16 *drugs [meant] she was moving away from us...becoming a non-person*" (FC12); and "*they*  
17 *have this vacant kind of look...staring into the horizon*" (PC01)). Fears about psychotropic  
18 medication were occasionally juxtaposed against the sensitivity and exceptionality of the  
19 person with ID:  
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*"Sometimes I don't think these tablets are for people with autism and learning*  
*disabilities at all, you know? That's not the answer...if there's no cure, why are you giving all*  
*this medication?"* (FC03)

Some had witnessed multiple medication changes and had come to view medication as unpredictable ("*like taking pot luck*" FC09) or even an "*experiment*" (FC08 & FC12). Other concerns about medication included medication being used too readily ("*[the doctors are] very quick to put them on but very slow to take them off*" FC06); the absence of alternative, psychosocial interventions which were often considered more appropriate but unavailable

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3 due to resource constraints (*“other things can cost money...so sometimes it’s a control*  
4 *medication”* PC06); and a sense of psychotropic medication as a powerful and extreme  
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6 intervention, a *“sledge hammer treatment”* (PC07) that could render the person incapable.  
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10 Considering these, many carers psychotropic medication use was an ongoing source of  
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12 tension and unease:

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19 *“I’m not happy with medication...The prescription is easy to write out...but*  
20 *medication might not be for [son] at all, for what’s wrong with him, and they’re*  
21 *writing out prescriptions all the time...He’s got no other support around these*  
22 *issues...it’s always just medication...not enough, err, not enough maybe talking*  
23 *therapy...I think there should be more done than there is”* (FC03)  
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### 35 **Decisional processes relating to psychiatric medication**

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41 In this section we describe the degree of involvement that people with ID, their family  
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43 carers, and paid carers experienced and wanted in medication decisions, and their reactions  
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45 when they found that their expectation did not match reality.  
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#### 52 **a) Unequal power dynamics**

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3 There was a common assumption across stakeholder groups that the psychiatric  
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5 appointment was the nexus of medication decisions and that the psychiatrist has the  
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8 *“ultimate power”* (FC02) and *“final say”* (PC08) in medication decision-making. Interviewees  
9  
10 did not express a desire to challenge this, viewing the psychiatrist as *“the expert”* (FC11)  
11  
12 who *“knows best”* (ID10) and *“does the best for everyone who’s sick”* (FC07). In cases where  
13  
14 people did not share the psychiatrist’s opinion on medication, they relatively quickly  
15  
16 deferred to the doctor (*“the medical profession probably know better....I come on-board”*  
17  
18 (PC06)) and would not act alone to change medication:  
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*“I wouldn’t [change medication] because then if anything happened I’d be the one to  
blame. It says in the leaflet ‘do not stop medication unless you speak to your  
doctor’...sometimes I feel like doing it and I think to myself, ‘no, I’ll leave it and talk to  
[the psychiatrist] first’...they know better than we do”* (FC03)  
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Participants with ID varied in their desire for involvement in medication decisions. Whilst  
some (generally those with more mild ID) obviously wanted to be know and be included in  
discussions about their medication, a greater number did not expect to be involved, holding  
a singular belief in the authority of the doctor that left little room for their own agency:

*“I have to take my medication, I ain’t got no choice...It’s the doctor’s orders to keep  
on the medication...there’s not a lot you can do about it”* (ID11)

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3 *"It's the doctor's decision [about medication]...it's up to them" (ID01)*  
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9 Carers recognised the vulnerability of people with ID to being *"marginalised"* (PC02) and  
10  
11 *"misunderstood"* (PC05) in medication discussions, an observation that gave them  
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14 justification for being more forthright:  
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20 *"I understand that sometimes I come across overbearing, nose-y, and always getting*  
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22 *involved...but I do believe, and this is a firm belief, if I was not behind [son] and*  
23  
24 *asking for him, demanding for him... he would be in a worse place now, mentally... If*  
25  
26 *he didn't have me he would definitely be worse off in all sorts" (FC09)*  
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34 The desire of both paid and family carers to be involved in medication discussions and  
35  
36 decision was obvious through their depictions of positive and negative experiences of  
37  
38 medication decision-making across time and between clinicians. Positive experiences of  
39  
40 medication decision-making were described as collaborations, *"partnerships"* (FC02 & PC02)  
41  
42 and *"negotiations"* (PC08) with the psychiatrist. One woman with ID described how she had  
43  
44 jointly come to a decision about reducing medication, *"[it was] my idea...and theirs [the*  
45  
46 *doctors'] too"* (ID04). In these accounts, people valued *"open discussion"* (PC09), being given  
47  
48 *"time to talk"* (FC10), invited to give their opinion, and being *"welcomed"* (PC12) and *"taken*  
49  
50 *seriously"* (FC02) when doing so:  
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3 *“It’s been a really good partnership trying to get [service user] on the right*  
4 *medication...It’s worked really well...I went along to see the psychiatrist, spoke to him*  
5 *about my concerns...and then he very quickly sent appointments through to see*  
6 *them. And I thought, ‘wow, he listened, took it on board, called those people in,*  
7 *reviewed their medication’... The psychiatrists have been very tolerant, very patient*  
8 *and have listened to what we’ve been saying... So it can work” (PC02)*  
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33 *“A lot of doctors are open to discuss...they ask the [patient] and they ask me...and*  
34 *they listen” (PC06)*  
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Conversely, being excluded from decisions about medication could take an emotional toll, especially on family carers who described feeling *“annoyed”* (FC05), *“frustrated”* (FC04&FC08), *“angry”* (FC12&FC08), or isolated:

*“It’s always a bad experience when you’re not involved...I wasn’t in control of anything really, and there was no-one out there I could turn to” (FC11)*

#### **b) Efforts to democratise medication decisions**

From respondents’ accounts of how medication decisions were made, we identified three related elements of decision-making. These were being informed, being included, and



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2  
3 having influence (figure 1). In any one of these processes, people could find themselves  
4 marginalised and disenfranchised. Many paid and family carers, and a smaller number of  
5 respondents with ID, described making efforts to change the dynamics of medication  
6 decisions with strategies aimed at democratising each of these elements.  
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20 **[Figure 1]** [Elements of involvement in medication decisions described by participants –  
21 NEAR HERE]  
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28 The most fundamental element of involvement in the decision-making process was to be  
29 **informed** about medication, yet several people with ID could not recall that medication was  
30 ever spoken about by their doctor. These experiences reinforced a sense of powerlessness  
31 as medication decisions were perceived to *“just happen”* (ID01). Both paid and family carers  
32 could also be deprived of information (*“hardly ever told when people switch medication”*  
33 (PC09)), that is, not being thought of when medications were discussed and consequently  
34 fining themselves *“not knowing what’s going on”* (FC05). Paid carers, particularly those  
35 working in larger organisations in which numerous people with ID were supported, worried  
36 that being *“out of the loop”* (PC12) left them *“ill-equipped and dangerously exposed”* (PC11),  
37 at once responsible for medication administration and monitoring yet without vital  
38 information of drug changes, doses, or effects.  
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3 In response, both family and paid carers, and occasionally people with ID, had made  
4 attempts to improve their knowledge about medication (and alternative treatments) by  
5 seeking information independently from a variety of sources, including medication leaflets,  
6 television, internet, news media, carer networks, colleagues, and formal training courses.  
7  
8 This knowledge could improve their confidence and go some way to meet and respond to  
9 the technical expertise of the psychiatrist. Many people with ID, and some carers, however,  
10 could struggle with accessing appropriate information and were left in a relatively less  
11 powerful position as a result:  
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*“Me myself is not very good in asking questions or understanding everything, so I just leave it...I can’t go on the internet...I’m not very good in reading and writing, I don’t understand everything, so that’s why I don’t bother” (FC07)*

Secondly, respondent in all groups had experience of being nominally present when medication decisions were made but not **included** in a meaningful sense, and having little to no opportunity to voice their concerns:

*“They said “you will be going on an anti-depressant.” I didn’t know the name, then it all went cold....the next thing I knew it was in my blister pack and I’ve been taking it ever since” (ID06)*

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3 *"I don't think my opinion was asked...I was in the review but I wasn't asked the big*  
4 *questions about treatment"* (PC10)  
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11 Family and paid carers spoke of trying to shape the discourse in conversations with the  
12 psychiatrist and the need to be assertive and to have confidence to challenge their authority  
13 in order to gain visibility and ensure their views were heard. One relative described her  
14 typical approach was to *"not muck about...If I think the doctor's wrong, I tell 'em, just like*  
15 *that"* (FC01). Sometimes a dramatic *"bust up"* (FC09) or *"battle"* (FC12) with the clinical  
16 team was considered necessary and could 'reset' the interaction in favour of a greater role  
17 for the family carer in medication decisions, although paid carers tended to shun overt  
18 conflict. At other times tenacity and *"pushing to be involved"* (PC09) spoke of ongoing effort  
19 to develop and maintain involvement:  
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37 *"I always have to be chasing. I'm still chasing now...It shouldn't be like that, but*  
38 *that's the way it works...I think [the doctors] respect me more after, I kind of, put my*  
39 *foot down"* (FC04)  
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49 Carers used their knowledge of the healthcare system to navigate to a position where they  
50 had the greatest chance of being heard. One paid carer described the strategy involved in  
51 arranging an appointment with the psychiatrist:  
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3 *"I'll have to write [to the psychiatrist] and copy in the GP...I'll have to be quite forceful*  
4 *about it. And then I'll actually ring [the psychiatrist] and I'll follow it up with an e-*  
5 *mail...We can ring the learning disability [team] secretary because we've got a very*  
6 *good relationship with her...I will actually sometimes say to her, "it's quite a complex*  
7 *case this is, it's probably worth us seeing the consultant"" (PC08)*  
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19 The final element to being involved described by respondents was the ability to **influence**  
20 decisions about medication. This constituted moving beyond merely exchanging information  
21 to becoming a meaningful participant in a collaborative decision, whose opinions were  
22 heard and shaped decisions. Although there were instances where this had been achieved,  
23 all three stakeholder groups described situations in which this had not happened. Some also  
24 described strategies they had used in attempts to increase their decisional influence.  
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38 Of the minority of people with ID who had tried to question their medication, some  
39 described receiving evasive answers that served solely to reinforce the importance of taking  
40 medication:  
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49 *"I just get ignored, I feel like I'm getting ignored...when I say something about*  
50 *[medication], it's basically 'you just have to take the medication'" (ID08)*  
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3 Similarly, carers reported that their concerns were “not believed” (FC09) or “dismissed as  
4  
5 trivial and unimportant” (PC09). Some carers had proposed their own ideas about  
6  
7 medication only to be given a sense that it was not their place to do so:  
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14 “The consultant was like “you’re talking rubbish”...it was like, ‘what does she know?’”  
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16 (PC02)

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23 “I suggested a medication which had been mentioned previously and I had looked up  
24  
25 the research on it. It’s something that’s very useful for people with high levels of  
26  
27 anxiety and I thought it might be worth trying but umm... there was a small flicker  
28  
29 and then, like, “no, I don’t think so, where did you hear about this?” sort of thing”  
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32 (FC05)  
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39 Given their perception of being ‘low ranked’ in the hierarchy of stakeholders (“just a  
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41 provider” (PC08) and “not seen as a professional or intellectual resource” (PC11)), paid  
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43 carers often felt the need to prove the credibility of their knowledge in order to be heard or  
44  
45 effect change. Investing in the relationship with the psychiatrist was felt to make this easier  
46  
47 (“because they know me, they know my information is really important” (PC05)), and paid  
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49 carers sometimes sought legitimacy by presenting themselves as objective, collecting ‘data’,  
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51 and taking “a paper trail ... [of] evidence” (PC08) to appointments to support their views.  
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3 The minority of people with ID who had tried to assert themselves were generally not  
4  
5 successful in gaining the greater involvement and influence they wanted. Some described  
6  
7 having recruited a carer to advocate on their behalf but it was more common for people  
8  
9 with ID to quickly acquiesce:  
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17 *"I don't get heard out properly... [The doctor says] "Is [the medication] keeping you*  
18 *right?" and I just say "yeah", but I don't think it is. But I don't want to argue. I don't*  
19 *want to argue with them so I just say "yeah, it works on me"...I've asked [the*  
20 *psychiatrist] before to [change medication] but she wouldn't let me so I just let [the*  
21 *psychiatrist] get on with it...I just don't say nothing 'cos I feel like I'm not heard out"*  
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29 *(ID08)*  
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35 Family carers, too, could become burnt-out and resign themselves to a subordinate position  
36  
37 after trying and failing to be heard. After a long fight and a number of "terrible" experiences,  
38  
39 one mother reluctantly stepped back from taking a more active role in treatment decisions,  
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41 stating "we're [now] leaving it to them, I think that's the best way" (FC06).  
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## 48 **DISCUSSION**

### 49 **Principal findings**

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3 People with ID reported having very few opportunities to become involved in the  
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5 psychotropic medication decision-making process. Only a minority described consciously  
6  
7 ceding control to others, with most either unaware they were entitled to a role in deciding  
8  
9 medication, or had been unsuccessful in involving themselves despite their best efforts. Lack  
10  
11 of knowledge about medication, a strong belief in medication as necessary and important,  
12  
13 fear of the consequences of not taking medication (particularly admission to hospital), trust  
14  
15 in the doctor as expert, and deference towards authority figures all underpinned a passive  
16  
17 compliance and largely unquestioning stance towards medication. In this regard, our  
18  
19 analysis supports the 'model of compliance' proposed by Crossley and Withers in their  
20  
21 exploration of the experiences of people with ID prescribed antipsychotic medication<sup>25</sup>, and  
22  
23 calls for greater efforts to inform and involve people with ID about their medication.  
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34 Family and paid carer groups, meanwhile, clearly had an expectation of being involved in  
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36 medication decision-making which was related to their self-identity as the "front line  
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38 people" and advocates for those they supported. They strongly believed in the value of the  
39  
40 contribution they could make to medication decisions, and considered their involvement  
41  
42 essential to achieving the best outcome for the individual they supported. Positive  
43  
44 experiences were described in terms compatible with collaborative and negotiated models  
45  
46 of decision-making, albeit with the over-riding assumption that the psychiatrist would take  
47  
48 final responsibility for prescribing decisions. While experiences of shared decision-making  
49  
50 undoubtedly did exist, this was by no means the default, and many participants felt they  
51  
52 were/had been denied the opportunity to contribute to decision-making. Underpinning this  
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54 was the devaluing of their knowledge (based heavily on relational lived experience) in  
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3 comparison to that of the psychiatrist. This 'epistemic injustice'<sup>26</sup> prompted numerous  
4 attempts to rebalance the power asymmetry in consultations as people tried to leverage  
5 influence or strengthen their voice. Although these could be successful to an extent, they  
6 required resources and added to the emotional toll of caring. These findings echo other  
7 work which highlights family carers' sense of marginalisation in medication decisions<sup>27, 28</sup>  
8 and how they often struggle to get their views recognised as valid by health professionals.<sup>29-</sup>  
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### 24 **Clinical implications**

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30 The over-use of psychotropic medication in services for people with ID is now well-  
31 evidenced. Off-label prescribing, psychotropic polypharmacy, and lengthy durations of  
32 medication treatment were all reported by the participants recruited for this study. The  
33 average duration of psychotropic in our sample was 16 years, and antipsychotic use far  
34 outweighed the presence of severe mental illness according to participant report. The  
35 STOMP programme in England, established to address these issues, has not yet achieved  
36 wholesale reductions in use of antipsychotic medication<sup>32</sup> but the measurement of  
37 medication optimisation must include more than a crude count of prescriptions. Improving  
38 medication outcomes for individuals requires a person-centred approach to prescribing that  
39 includes partnership between stakeholders and consideration of patients' values and goals  
40 on an equal footing to the expertise and opinion of mental health professionals. These  
41 elements are embodied in shared decision making (SDM).  
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6 The adoption of SDM in routine mental healthcare has been slow<sup>33</sup> despite accumulating  
7  
8 evidence that the approach is associated with patient benefit.<sup>34</sup> Although psychiatrists  
9  
10 explicitly endorse the SDM model,<sup>35</sup> micro-analytic studies of psychiatric consultations show  
11  
12 that its principles are infrequently applied.<sup>36-38</sup> Issues of insight, fluctuating mental capacity,  
13  
14 power differentials between patient and professional, and the background threat of  
15  
16 compulsory treatment have been identified as implementation barriers that are especially  
17  
18 pertinent in psychiatric clinics.<sup>39</sup> Arguably the challenges to SDM are compounded in people  
19  
20 with ID<sup>40, 41</sup> due to the fixed cognitive deficit, additional communication needs, and people's  
21  
22 lack of experience and confidence in making choices about their healthcare or, indeed, more  
23  
24 generally.<sup>42, 43</sup> Shifting the paradigm to SDM seems likely to represent a significant role  
25  
26 change for all stakeholders. Clinicians, who currently hold the majority of the decision-  
27  
28 making power in these clinical encounters, will need to find ways of making conversations  
29  
30 more inclusive as SDM becomes a legal as well as an ethical imperative.<sup>44</sup> People with ID  
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32 must be appropriately supported in contributing to healthcare decisions, if we are to avoid  
33  
34 making unreasonable demands that further alienate them from professionals. Integrating  
35  
36 the views of other stakeholders, including paid and family carers, can add complexity to  
37  
38 negotiations, especially where the relative lack of scientific evidence base for the use of  
39  
40 psychotropic medication in this group adds ambiguity and uncertainty about the most  
41  
42 appropriate course of action. Furthermore, the processes of SDM may be compromised in  
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44 resource-constrained health systems with a focus on throughput and financial targets.  
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### Strengths and limitations of this study

This study is unique in providing a multi-stakeholder analysis of accounts of the use of psychotropic medications in people with ID. It extends the existing qualitative literature in this field which has typically focused solely on antipsychotic drugs<sup>25</sup> or medication used for behaviour that challenges.<sup>27, 28, 45</sup> Synthesising the results of interviews with patients, family carers, and paid carers allowed us to develop broad, over-arching themes, and helps us to understand the interactions and dynamics involved in the complex process of medication decision-making. Adaptations to the research method enabled us to gain meaningful insights into the experiences of people with ID, a group who are often excluded from research participation and may be considered inappropriate for in-depth qualitative investigation.<sup>46</sup> A relatively large sample size, with respondents purposively sampled from different locations and according to demographic and clinical characteristics, adds to the breadth of our findings.

In prioritising the views of people with ID and their carers, this research did not include general practitioners, pharmacists, or psychiatrists. Participants were self-selecting and may have included only those with greater confidence. Their views are not necessarily representative of a wider group of people with ID and their carers. We only interviewed people (and carers of people) who were currently prescribed psychotropic medication and under the care of specialist psychiatry teams, thereby excluding those who may have previously taken medication, been managed solely in primary care, or who have chosen not

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3 to take medication for mental health problems. People in any of these groups may possess  
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5 different and equally-valid perspectives on psychotropic medication and its prescribing.  
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## 11 **Future work**

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18 Observing interactions within real-world consultations in ethnographic work could lead to a  
19  
20 more nuanced understanding of how medication discussions happen, and help further  
21  
22 develop theoretical models of healthcare decision-making in people with ID. Developing  
23  
24 scalable interventions to improve opportunities for SDM with adults with ID and their carers  
25  
26 also requires further investment. Several such interventions have been developed for use in  
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28 people with mental health problems without ID,<sup>47-51</sup> the principles of which may be  
29  
30 applicable to wider patient groups. Finally, it will be necessary to demonstrate that  
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32 incorporating SDM principles in routine care is associated with improved patient-reported  
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34 and objective outcomes.  
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## 44 **Conclusion**

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50 Achieving optimal use of psychotropic medication is a health service priority and can only  
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52 occur by working in partnership with people with ID and their carers. SDM embodies the  
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54 values of autonomy and choice that are advocated in policy for people with ID and offers a  
55  
56 means of ensuring that all stakeholders are represented in important decisions. Our study  
57  
58 suggests that shared medication decisions are achievable, and sometimes practised, but are  
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3 far from the norm for people with ID. Further research to develop interventions that  
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5 support patient and carer involvement, and practice change to embed SDM are needed to  
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7 ensure people with ID and their carers have a voice in medication discussions and decisions.  
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## Acknowledgements

The authors would like to thank those who agreed to take part in the study and the organisations and individuals that assisted with recruitment, and Restu Handoyo, who contributed to the analysis. We also thank members of the service user consultation group, Jackie McMorrow and Jill Huntlesmith.

## Contributors

RS, AH, AS, and NM designed the study. RS recruited to the study and carried out the interviews. RS, AH, AS, and NM undertook the analysis. RS and NM drafted the manuscript with input from AH and AS. All authors approved the final version.

## Funding

This study was funded by a Doctoral Research Fellowship awarded to RS from the National Institute for Health Research (NIHR) (Ref: DRF-2016-09-140).

## Disclaimer

The views expressed in this article and those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. The funder had no role in study design, analysis, decision to publish, or preparation of the manuscript.

## Competing interests

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9 **Data sharing**  
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For peer review only

## REFERENCES

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®): American Psychiatric Publishing; 2013.
2. Maulik P, Mascarenhas M, Mathers C, et al. Prevalence of intellectual disability: A meta-analysis of population-based studies. *Res Dev Disabil* 2011;32(2):419-36.
3. Cooper S-A, Smiley E, Morrison J, et al. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry* 2007;190(1):27-35.
4. Sheehan R, Hassiotis A, Walters K, et al. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. *BMJ* 2015;351:h4326.
5. Lunskey Y, Khoo W, Tadrous M, et al. Antipsychotic use with and without comorbid psychiatric diagnosis among adults with intellectual and developmental disabilities. *Can J Psychiatry* 2018;63(6):361-9.
6. De Kuijper G, Hoekstra P, Visser F, et al. Use of antipsychotic drugs in individuals with intellectual disability (ID) in the Netherlands: prevalence and reasons for prescription. *J Intellect Disabil Res* 2010;54(7):659-67.
7. Doan TN, Lennox NG, Taylor-Gomez M, et al. Medication use among Australian adults with intellectual disability in primary healthcare settings: a cross-sectional study. *J Intellect Dev Disabil* 2013;38(2):177-81.
8. Holden B, Gitlesen JP. Psychotropic medication in adults with mental retardation: prevalence, and prescription practices. *Res Dev Disabil* 2004;25(6):509-21.
9. Hsu S-W, Chiang P-H, Chang Y-C, et al. Trends in the use of psychotropic drugs in people with intellectual disability in Taiwan: a nationwide outpatient service study, 1997–2007. *Res Dev Disabil* 2014;35(2):364-72.
10. Lunskey Y, Modi M. Predictors of Psychotropic Polypharmacy Among Outpatients With Psychiatric Disorders and Intellectual Disability. *Psychiatr Serv* 2017;69(2):242-6.
11. Bowring D, Totsika V, Hastings R, et al. Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study. *J Intellect Disabil Res* 2017;61(6):604-17.

12. O'Dwyer M, Peklar J, Mulryan N, et al. Prevalence, patterns and factors associated with psychotropic use in older adults with intellectual disabilities in Ireland. *J Intellect Disabil Res* 2017;61(10):969-83.
13. Lott I, McGregor M, Engelman L, et al. Longitudinal prescribing patterns for psychoactive medications in community-based individuals with developmental disabilities: utilization of pharmacy records. *Journal of Intellectual Disability Research* 2004;48(6):563-71.
14. O'Dwyer M, McCallion P, McCarron M, et al. Medication use and potentially inappropriate prescribing in older adults with intellectual disabilities: a neglected area of research. *Ther Adv Drug Saf* 2018;9(9):535-57.
15. Sheehan R, Horsfall L, Strydom A, et al. Movement side effects of antipsychotic drugs in adults with and without intellectual disability: UK population-based cohort study. *BMJ Open* 2017;7(8):e017406.
16. Branford D, Gerrard D, Saleem N, et al. Stopping over-medication of people with intellectual disability, Autism or both (STOMP) in England part 1—history and background of STOMP. *Advances in Mental Health and Intellectual Disability* 2019;13(1):31-40.
17. Branford D, Gerrard D, Saleem N, et al. Stopping over-medication of people with an intellectual disability, autism or both (STOMP) in England part 2—the story so far. *Advances in Mental Health and Intellectual Disability* 2019;13(1):41-51.
18. Royal Pharmaceutical Society. Medicines Optimisation: helping patients to make the most of medicines. London, UK: Royal Pharmaceutical Society; 2013.
19. Cutler S, Fattah L, Shaw M, et al. What does medicines optimisation mean for pharmacy professionals? *Pharm J* 2011;287(7680):606.
20. Charles C, Gafni A, Whelan T. Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med* 1999;49(5):651-61.
21. Department of Health. Valuing People Now: a new three-year strategy for people with learning disabilities. London, UK: Department of Health,; 2010.
22. Sheehan R, Strydom A, Morant N, et al. Psychotropic prescribing in people with intellectual disability and challenging behaviour. *BMJ* 2017.
23. Hollomotz A. Successful interviews with people with intellectual disability. *Qual Res* 2018;18(2):153-70.



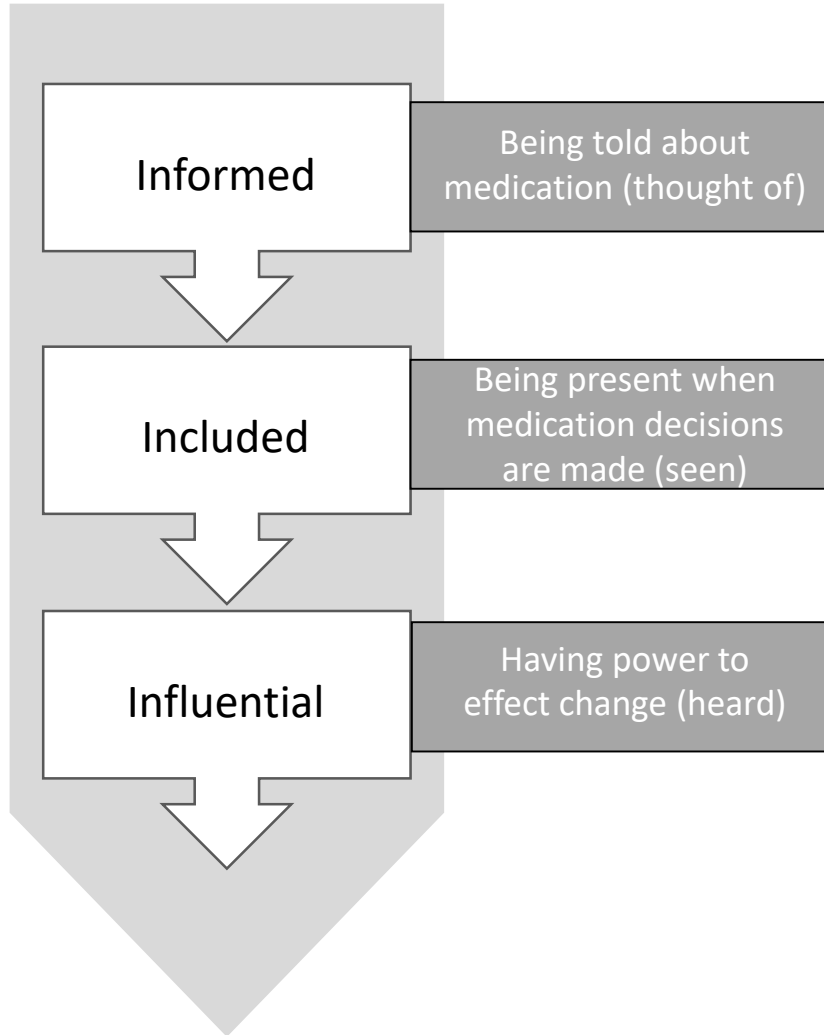
- 1
- 2
- 3 24. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*
- 4 2006;3(2):77-101.
- 5
- 6
- 7 25. Crossley R, Withers P. Antipsychotic medication and people with intellectual
- 8 disabilities: their knowledge and experiences. *J Appl Res Intellect Disabil* 2009;22(1):77-86.
- 9
- 10 26. Newbigging K, Ridley J. Epistemic struggles: The role of advocacy in promoting
- 11 epistemic justice and rights in mental health. *Soc Sci Med* 2018;219:36-44.
- 12
- 13 27. Sheehan R, Kimona K, Giles A, et al. Findings from an online survey of family carer
- 14 experience of the management of challenging behaviour in people with intellectual
- 15 disabilities, with a focus on the use of psychotropic medication. *Br J Learn Disabil*
- 16 2018;46(2):82-91.
- 17
- 18 28. Edwards N, King J, Watling H, et al. Qualitative exploration of psychotropic
- 19 medication to manage challenging behaviour in adults with intellectual disability: views of
- 20 family members. *Advances in Mental Health and Intellectual Disability* 2017;11(5/6):207-18.
- 21
- 22 29. James N. The formal support experiences of family carers of people with an
- 23 intellectual disability who also display challenging behaviour and/or mental health issues:
- 24 What do carers say? *J Intellect Disabil* 2013;17(1):6-23.
- 25
- 26 30. Knox M. Family control: The views of families who have a child with an intellectual
- 27 disability. *J Appl Res Intellect Disabil* 2000;13(1):17-28.
- 28
- 29 31. Griffith GM, Hastings R. 'He's hard work, but he's worth it'. The Experience of
- 30 Caregivers of Individuals with Intellectual Disabilities and Challenging Behaviour: A
- 31 Meta-Synthesis of Qualitative Research. *J Appl Res Intellect Disabil* 2014;27(5):401-19.
- 32
- 33 32. Mehta H, Glover G. Psychotropic drugs and people with learning disabilities or
- 34 autism. 2019.
- 35
- 36 33. Slade M. Implementing shared decision making in routine mental health care. *World*
- 37 *Psychiatry* 2017;16(2):146-53.
- 38
- 39 34. Joosten E, DeFuentes-Merillas L, de Weert G, et al. Systematic review of the effects
- 40 of shared decision-making on patient satisfaction, treatment adherence and health status.
- 41 *Psychother Psychosom* 2008;77:219-26.
- 42
- 43 35. Seale C, Chaplin R, Lelliott P, et al. Sharing decisions in consultations involving anti-
- 44 psychotic medication: a qualitative study of psychiatrists' experiences. *Soc Sci Med*
- 45 2006;62(11):2861-73.
- 46
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- 49
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- 60

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2  
3 36. McCabe R, Skelton J, Heath C, et al. Engagement of patients with psychosis in the  
4 consultation: conversation analytic study. *BMJ* 2002;325(7373):1148-51.  
5  
6
- 7 37. McCabe R, Khanom H, Bailey P, et al. Shared decision-making in ongoing outpatient  
8 psychiatric treatment. *Patient Educ Couns* 2013;91(3):326-8.  
9
- 10 38. Dooley J, Bass N, Livingston G, et al. Involving patients with dementia in decisions to  
11 initiate treatment: effect on patient acceptance, satisfaction and medication prescription. *Br*  
12 *J Psychiatry* 2019;214(4):213-7.  
13  
14
- 15 39. Morant N, Kaminskiy E, Ramon S. Shared decision making for psychiatric medication  
16 management: beyond the micro-social. *Health Expect* 2015;19:1002-14.  
17  
18
- 19 40. Goldsmith L, Woodward V, Jackson L, et al. Informed consent for blood tests in  
20 people with a learning disability. *J Adv Nurs* 2013;69(9):1966-76.  
21  
22
- 23 41. Sullivan WF, Heng J. Supporting adults with intellectual and developmental  
24 disabilities to participate in health care decision making. *Can Fam Physician* 2018;64(Suppl  
25 2):S32-S6.  
26  
27
- 28 42. Fovargue SJ, Keywood K, Flynn M. Participation in health care decision-making by  
29 adults with learning disabilities. *Mental Health Care* 2000;3(10):341-4.  
30  
31
- 32 43. Myron R, Gillespie S, Swift P, et al. Whose decision? Preparation for and  
33 implementation of the Mental Capacity Act in statutory and non-statutory services in  
34 England and Wales. London; 2008.  
35  
36
- 37 44. Adshead G, Crepez-Keay D, Deshpande M, et al. Montgomery and shared decision-  
38 making: implications for good psychiatric practice. *Br J Psychiatry* 2018;213(5):630-2.  
39  
40
- 41 45. Hall S, Deb S. A qualitative study on the knowledge and views that people with  
42 learning disabilities and their carers have of psychotropic medication prescribed for  
43 behaviour problems. *Advances in Mental Health and Intellectual Disability* 2008;2(1):29-37.  
44  
45
- 46 46. Coons KD, Watson SL. Conducting research with individuals who have intellectual  
47 disabilities: Ethical and practical implications for qualitative research. *Journal on*  
48 *Developmental Disabilities* 2013;19(2):14.  
49  
50
- 51 47. Harris N, Lovell K, Day J, et al. An evaluation of a medication management training  
52 programme for community mental health professionals; service user level outcomes: a  
53 cluster randomised controlled trial. *Int J Nurs Stud* 2009;46(5):645-52.  
54  
55
- 56 48. Stead U, Morant N, Ramon S. Shared decision-making in medication management:  
57 development of a training intervention. *BJPsych Bull* 2017;41(4):221-7.  
58  
59  
60

1  
2  
3 49. Loh A, Simon D, Wills CE, et al. The effects of a shared decision-making intervention  
4 in primary care of depression: a cluster-randomized controlled trial. *Patient Educ Couns*  
5 2007;67(3):324-32.  
6  
7

8  
9 50. Deegan PE. A Web application to support recovery and shared decision making in  
10 psychiatric medication clinics. *Psychiatr Rehabil J* 2010;34(1):23.  
11

12 51. Priebe S, McCabe R, Bullenkamp J, et al. Structured patient–clinician communication  
13 and 1-year outcome in community mental healthcare: cluster randomised controlled trial.  
14 *Br J Psychiatry* 2007;191(5):420-6.  
15  
16  
17  
18  
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21  
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## COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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# BMJ Open

## Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multi-stakeholder qualitative study in the UK

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-032861.R1
Article Type:	Original research
Date Submitted by the Author:	27-Sep-2019
Complete List of Authors:	Sheehan, Rory; University College London, Division of Psychiatry HASSIOTIS, ANGELA; University College London, Division of Psychiatry Strydom, André; Institute of Psychiatry Psychology and Neuroscience Morant, Nicola; University College London, Division of Psychiatry
<b>Primary Subject Heading</b>:	Mental health
Secondary Subject Heading:	Qualitative research
Keywords:	intellectual disability, psychotropic medication, QUALITATIVE RESEARCH, shared decision making

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**TITLE PAGE****Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multi-stakeholder qualitative study in the UK**

Dr Rory Sheehan, MSc, Division of Psychiatry, University College London

Professor Angela Hassiotis, PhD, Division of Psychiatry, University College London

Professor André Strydom, PhD, Institute of Psychiatry, Psychology and Neuroscience, King's College London

Dr Nicola Morant, PhD, Division of Psychiatry, University College London

**Corresponding author details**

Dr Rory Sheehan

Division of Psychiatry, University College London, 6<sup>th</sup> Floor Maple House, 149 Tottenham Court Road, London W1T 7NF

Telephone: 0207-679-9201

E-mail: r.sheehan@ucl.ac.uk

**Word count**

7,115

**Number of figures and tables**

1 table

1 figure

**Keywords**

Intellectual disability; psychotropic medication; qualitative research; shared decision making



## **ABSTRACT**

### **Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multi-stakeholder qualitative study in the UK**

**Objectives** Understanding patient and carer perspectives is essential to improving the quality of medication prescribing. This study aimed to explore experiences of psychotropic medication use among people with intellectual disability (ID) and their carers, with a focus on how medication decisions are made.

**Design** Thematic analysis of data collected in individual semi-structured interviews.

**Participants and setting** Fourteen adults with ID, twelve family carers, and twelve paid carers were recruited from specialist psychiatry services, community groups, care providers, and training organisations in the UK.

**Results** People with ID reported being highly compliant with psychotropic medication, based on a largely unquestioned view of medication as important and necessary, and belief in the authority of the psychiatrist. Though they sometimes experienced medication negatively, they were generally not aware of their right to be involved in medication decisions. Paid and family carers reported undertaking a number of medication-related activities. Their 'front-line' status and longevity of relationships meant that carers felt they possessed important forms of knowledge relevant to medication decisions. Both groups of carers valued decision-making in which they felt they had a voice and a genuine role. While some in each group described making joint decisions about medication with psychiatrists, lack of involvement

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3 was often described. This took three forms in participants' accounts: being uninformed of  
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5 important facts, insufficiently included in discussions, and lacking influence to shape  
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7 decisions. Participants described efforts to democratise the decision-making process by  
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9 gathering information, acting to disrupt perceived power asymmetries, and attempting to  
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11 prove their credibility as valid decision-making partners.  
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16 **Conclusions** Stakeholder involvement is a key element of medication optimisation that is  
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18 not always experienced in decisions about psychotropic medication for people with ID.  
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20 Forms of shared decision-making could be developed to promote collaboration and offer  
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22 people with ID and their carers greater involvement in medication decisions.  
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## STRENGTHS AND LIMITATIONS OF THIS STUDY

- This is the first multi-stakeholder study of patient, family carer, and paid carer experiences of psychotropic medication use and the decision-making processes surrounding this for people with intellectual disability.
- Adaptations to qualitative methodology were made that allowed us to obtain meaningful data from people with intellectual disability.
- Using in-depth qualitative methods allowed us to develop a nuanced understanding of the relational and power dynamics underpinning decision-making about psychotropic medication.
- The views of prescribers and other health professionals are not included in this report.
- Those with limited or no verbal ability were not able to take part.

## **MANUSCRIPT**

### **Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multi-stakeholder qualitative study in the UK**

#### **INTRODUCTION**

Up to 2% of the global population live with intellectual disability (ID), a lifelong condition characterised by significant deficits in cognitive and adaptive function with early onset.<sup>1, 2</sup> A combination of biological, psychological, social, and developmental factors contribute to a high rate of mental disorder in this group.<sup>3</sup> Recent evidence from epidemiological studies conducted across jurisdictions confirms that people with ID are often prescribed psychotropic medication, in many cases in the absence of a diagnosis for which it is indicated.<sup>4-9</sup> Psychotropic polypharmacy,<sup>10-13</sup> high doses,<sup>11</sup> and increased susceptibility to adverse side-effects<sup>14, 15</sup> are also significant concerns. Thus, people with ID are a key group in whom efforts to improve psychotropic prescribing are required. In England, a national programme, Stopping the Over-Medication of People with ID (STOMP), has been established to reduce inappropriate use of psychotropic medication.<sup>16</sup> Co-produced with people with ID, the programme aims to raise awareness of the issue, develop resources for patients and carers, and act as a stimulus for practice change.<sup>17</sup>

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3 Medication optimisation is a multi-faceted approach to improving the use of prescribed  
4 medication with the aim of enhancing clinical outcomes, improving safety and reducing  
5 waste.<sup>18</sup> While deprescribing (reducing or discontinuing inappropriate medication) may be  
6 one element of optimisation, improving the quality of medication use requires more than a  
7 sole focus on quantitative measures. Understanding people's experience of medication and  
8 encouraging partnership between professionals and patients are also important  
9 components of successful medication optimisation.<sup>18, 19</sup> As such, there are clear overlaps  
10 with several broader ideals and principles that are increasingly embedded in healthcare  
11 policies and clinical guidelines across health and social care internationally, including  
12 person-centred care, personalised medicine, and shared decision making (SDM). In relation  
13 to how decisions are reached about treatment options or courses of action, including use,  
14 choice and dose of medication, SDM seeks to replace traditional, paternalistic models with  
15 more collaborative approaches to treatment decisions where expertise and responsibility  
16 are owned jointly by the health professional and the patient.<sup>20</sup> The aims of SDM are  
17 congruent with longstanding UK government strategy to increase the inclusion and support  
18 the autonomy of people with ID in healthcare decisions and more generally.<sup>21</sup> As well as  
19 being an ethical ideal, evidence suggests that SDM is associated with a range of measurable  
20 benefits including improved understanding, patient satisfaction, and trust.<sup>22, 23</sup>

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51 However, people with ID are not routinely placed at the centre of healthcare decisions<sup>24</sup> and  
52 carers of people with ID have reported that their views are not heard or that they are  
53 insufficiently involved by services.<sup>25, 26</sup> The literature relating specifically to psychotropic  
54 medication in people with ID is less developed, though a small body of evidence shows that  
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3 both people with ID and their carers often lack knowledge about psychotropic medication  
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5 and experience few opportunities for involvement in medication decision-making.<sup>27-30</sup> It  
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7 remains unclear how, and to what extent, the principles of SDM are applied in psychotropic  
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9 medication decisions in contemporary UK settings. Additionally, how and between whom  
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11 decisions are 'shared' in the clinical context of ID needs further exploration, as there are  
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13 often multiple stakeholders in the form of family carers and those with paid caring  
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15 responsibilities. In this study, we sought to explore the experiences and expectations of  
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17 adults with ID and paid and family carers regarding psychotropic medication use, and how  
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19 decisions about this are made with healthcare professionals.  
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## 29 **METHODS**

### 31 **Participants and setting**

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41 People were eligible to participate if they were, adults ( $\geq 18$  years) with ID who were  
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43 currently prescribed psychotropic medication and were under the care of a specialist  
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45 psychiatry of intellectual disability team, family carers of adults with ID who had been  
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47 prescribed psychotropic medication, or paid carers who worked with adults with ID and who  
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49 had experience of supporting people with psychotropic medication. Paid carers may have be  
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51 employed in a variety of settings including residential homes, supported living projects, or  
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53 as peripatetic community support workers. Psychotropic medication was defined as any  
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55 drug listed in the British National Formulary as being used for mental health disorders.<sup>31</sup>  
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6 The study was conducted in the south-east of England. Two methods of recruitment were  
7  
8 used. In one, a leaflet advertising the research was offered to potential participants (people  
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10 with ID, family carers, paid carers) by clinicians at appointments with specialist psychiatry of  
11  
12 intellectual disability services within the National Health Service (NHS). These clinicians  
13  
14 made a first assessment of eligibility to take part in the research. The other recruitment  
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16 method included short presentations by researchers to community third-sector (i.e. non-  
17  
18 statutory), care provider, and training organizations, with leaflets about the research also  
19  
20 available. After hearing about the research, the contact details of those who showed an  
21  
22 initial interest in taking part were passed to the research team, either directly from the  
23  
24 person themselves or, with permission, via clinical staff. Potential participants were then  
25  
26 contacted and eligibility was confirmed by liaison with people with ID and/or carers prior to  
27  
28 interviews being held. The cognitive ability of potential participants with ID was not formally  
29  
30 tested. Capacity to consent to taking part in the research was assessed immediately before  
31  
32 the interview as part of the procedure of obtaining valid informed consent. This process was  
33  
34 undertaken in accordance with the principles of the Mental Capacity Act<sup>32</sup> by a researcher  
35  
36 with professional experience and training in assessing capacity. It was made clear to  
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38 participants that their contribution was voluntary, that they could decline to take part  
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40 without prejudice, and they may end an interview at any time. Written consent was  
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42 received from all participants before interviews were conducted. Purposive sampling was  
43  
44 used to select participants with a range of characteristics that may be related to medication  
45  
46 views and experiences. For people with ID this included age, gender, ethnic group,  
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48 indication for psychotropic medication and medication class; for family carers, age, gender,  
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3 ethnic group, degree of ID in their relative, indication for and class of medication; and for  
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5 paid carers, age, gender, ethnic group, duration working with people with ID, and seniority.  
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11 People with ID and family carers were given a £20 shopping voucher as a token of  
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13 appreciation for donating time to the study. Paid carers were provided with a certificate  
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15 thanking them for their contribution.  
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### 23 **Ethical approval**

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29 The study was approved by the London-Surrey NHS Research Ethics Committee (reference  
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31 17/LO/1365). Local Research and Development approvals were obtained prior to any  
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33 research activities being undertaken.  
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### 40 **Data collection**

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46 Baseline demographic and descriptive data were collected by participant report; we did not  
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48 cross-check these with other sources of information. Qualitative data were collected in  
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50 audio-recorded individual in-depth semi-structured interviews conducted by the first  
51  
52 author, who is a psychiatrist and clinician researcher with experience of working with  
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54 people with ID and an academic interest in medication use. He did not have any other  
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56 contact with participants. All interviews were conducted face-to-face. Participants were able  
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3 to bring other people to their interview, if they wished, and interviews were held at a time  
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5 and place preferred by participants. A topic guide with open-ended questions was  
6  
7 developed and used to provide a broad structure to the interviews whilst allowing points of  
8  
9 interest to be pursued as they arose. Included topics were, people's experiences of using  
10  
11 psychotropic medication, discussions medication with health professionals, and how  
12  
13 decisions about medication are made (see supplementary material). Paid carers reported  
14  
15 experiences and attitudes formed from supporting several different people. We adopted a  
16  
17 flexible approach to interviews with people with ID in order to facilitate their involvement,  
18  
19 including adapting the depth of questioning as appropriate to their ability.<sup>33</sup> All study  
20  
21 materials for people with ID were available in 'easy-read' format and laminated picture  
22  
23 cards were used (where appropriate) as prompts and to orientate interviewees. Checking  
24  
25 and summarising content throughout the interviews gave opportunity for clarification and  
26  
27 elaboration. Reflective field notes were made to supplement the transcripts and assist with  
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29 reflexive practice and data analysis.  
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## 41 **Analysis**

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47 Descriptive data were summarised and tabulated. Audio-recorded interviews were  
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49 transcribed verbatim by the first author, anonymised, and the transcripts checked for  
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51 accuracy. As a research team we are interested in medication optimisation for people with  
52  
53 ID and in how shared decision-making processes can impact this. Given the relative lack of  
54  
55 literature in the field, thematic analysis was used with an inductive orientation in which  
56  
57 themes were derived from the data.<sup>34</sup> Transcripts from each group of participants were  
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3 analysed concurrently to build a unifying coding frame that was developed in an iterative  
4  
5 process as additional transcripts were analysed. Independent coding of a subset of six  
6  
7 transcripts by members of the research team early in the analytic process, regular discussion  
8  
9 of emerging themes and the conceptual coherence of the findings, and reflexive memos  
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11 were used to enhance integrity of the analysis. NVivo qualitative data analysis software  
12  
13 (QSR International Pty Ltd. Version 12, 2018) was used to manage the data and facilitate the  
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15 analytic processes.  
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### 24 **Patient and public involvement**

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30 The development of the recruitment strategy, and the design of participant materials and  
31  
32 the interview topic guide were informed by discussions with a consultation group consisting  
33  
34 of people with ID employed for this work, some of whom had lived experience of mental  
35  
36 illness, psychotropic medication use, and contact with mental health services. The group will  
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38 assist with future targeted dissemination activities to the participants with ID, their families  
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40 and prescribers.  
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## 49 **RESULTS**

### 50 51 52 53 54 55 **Sample** 56 57 58 59 60

Thirty-eight people (14 adults with ID; 12 family carers; 12 paid carers) were recruited between December 2017 and May 2018 (table 1). Twenty-nine were recruited from clinical services and nine from third-sector organizations. 18 interviews were completed at people's home (10 people with ID; 8 family carers), 12 (all paid carers) at their place of work, 7 (3 people with ID; 4 family carers) at a university, and 1 (person with ID) at a community centre. Seven participants with ID preferred to have a companion with them in the interview (in 6 cases this was a relative, in 1 case a professional advocate).

Participants with ID reported having been diagnosed with a range of psychiatric disorders and most had been prescribed psychotropic medication for many years and in some cases for decades. None of those who participated were under a legal framework of care (e.g. Community Treatment Order or Guardianship Order).

	People with ID ( <i>n</i> =14)	Family carers ( <i>n</i> =12)	Paid carers ( <i>n</i> =12)
Mean age (SD, range)	46.1 years (12.9, 25-68)	62.7 years (10.5, 42-80)	39.4 years (9.5, 24-55)
Sex (M:F)	9:5	3:9	6:6
Ethnic group	White <i>n</i> =8 Black <i>n</i> =2 Asian <i>n</i> =3 Other/mixed <i>n</i> =1	White <i>n</i> =8 Black <i>n</i> =1 Asian <i>n</i> =3 Other/mixed <i>n</i> =0	White <i>n</i> =7 Black <i>n</i> =3 Asian <i>n</i> =2 Other/mixed <i>n</i> =0
Degree of ID <sup>1</sup>	Mild <i>n</i> =12 Moderate <i>n</i> =2	Mild <i>n</i> =6 Moderate <i>n</i> =4 Severe-profound <i>n</i> =2	N/A <sup>2</sup>
Relationship to person	N/A	Parent <i>n</i> =10	Support worker <i>n</i> =8

with ID / professional title		Other relative <i>n</i> =2	Managerial responsibility <i>n</i> =4
Mean time working with people with ID (SD, range)	N/A	N/A	9.4 years (9.0, 0.5-25)
Current living arrangements	Independent <i>n</i> =3 With family <i>n</i> =5 Shared supported living <i>n</i> =6	With family member with ID <i>n</i> =9 Separately from family member with ID <i>n</i> =3	N/A <sup>2</sup>
Self-reported psychiatric diagnosis <sup>1 4</sup>	Severe mental illness <sup>3</sup> <i>n</i> =6 Depression <i>n</i> =6 Anxiety disorder <i>n</i> =5 Other <i>n</i> =2	Severe mental illness <sup>3</sup> <i>n</i> =4 Depression <i>n</i> =4 Anxiety disorder <i>n</i> =6 Other <i>n</i> =0	N/A <sup>2</sup>
Autism <sup>1</sup>	<i>n</i> =3	<i>n</i> =5	N/A <sup>2</sup>
Prescribed medication by group <sup>1 4</sup>	Antipsychotic <i>n</i> =9 Mood stabiliser <i>n</i> =3 Anti-depressant <i>n</i> =9 Other <i>n</i> =3	Antipsychotic <i>n</i> =10 Mood stabiliser <i>n</i> =2 Anti-depressant <i>n</i> =9 Other <i>n</i> =4	N/A <sup>2</sup>
Mean duration of psychotropic use (SD, range) <sup>1</sup>	16.8 years (14.0, 3-50)	13.6 years (8.0, 1-27)	N/A <sup>2</sup>
Mean interview duration (SD, range)	24 minutes (9.0, 11-38)	38 minutes (10.9, 19-55)	47 minutes (11.9, 31-73)

ID, intellectual disability; SD, standard deviation; N/A, not applicable

<sup>1</sup>Information provided by family carers relates to the person with ID they cared for

<sup>2</sup>Data for paid carers were not collected as each paid carer worked with more than one individual with ID

<sup>3</sup>Severe mental illness includes schizophrenia spectrum disorders and bipolar affective disorder

<sup>4</sup>Cell total exceeds the number in each group as people were able to report more than one diagnosis and may have been prescribed medication from more than one psychotropic class

**Table 1** Sample characteristics**Thematic analysis**

We developed three major themes in our analysis of the data, and present these in each sub-section below. The first theme, medication beliefs and experience, describes the meanings that people give to psychotropic medication, and how these can develop over time. The second theme, carer role, draws mainly on the interviews with paid and family carers to describe how the carer identity is constructed and how caring activities are performed. Together, these themes provide context to the third major theme about decisional processes, in which the lived experiences of different stakeholders in the medication decision-making process are explored, including the dynamics and struggles that sometimes characterised interactions with prescribers. Throughout the analysis we aim to provide a sense of the data by using quotes from anonymised participants who were given a number prefixed with ID (person with ID), FC (family carer), or PC (paid carer).

**Medication beliefs and experience: acceptance and ambivalence**

We developed this theme predominantly from interviews with people with ID and family carers as we found that paid carers were generally more hesitant in offering their personal opinions about medication. In this theme, passive compliance of the person with ID emerged, founded on relatively limited understanding of medication, yet a strong sense of

1  
2  
3 faith in medication and trust in the doctor. For family carers psychotropic medication was an  
4  
5 emotive topic and many were ambivalent about its use. A minority of paid carers expressed  
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7 concerns about inappropriate psychotropic use.  
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14 People with ID tended to focus on the tangible aspects of psychotropic medication (the  
15  
16 taste, colour, and size of tablets) and the set of 'rules' that constituted their current  
17  
18 medication routine, for example, *"I take [the tablets] at night-time, the little mauve ones,*  
19  
20 *my big yellow ones, and my little white sleeping tablet"* (ID05). There was a tacit belief in  
21  
22 medication as important and necessary, even though in many cases understanding of the  
23  
24 indication for medication and its potential effects was limited. Most people with ID  
25  
26 characterised medication benefits in vague or generic terms (e.g. *"[medication] gets me*  
27  
28 *better"* (ID01); *"it's helpful...for my health"* (ID09); *"keeps me steady"* (ID13)), whilst  
29  
30 describing of adverse side-effects with more immediate and vivid language (the most  
31  
32 commonly mentioned were sedation, weight gain, and movement side-effects):  
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42 *"My speech got slurred...really terrible and slurred. I just couldn't get the words out"*  
43  
44 (ID07)  
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46

47  
48 *"I felt groggy...like I feel like a cabbage sometimes"* (ID08)  
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54 The perceived consequences of not taking medication were often described as frightening  
55  
56 and unpredictable and included being out-of-control or *"a danger"* (ID10). Some feared they  
57  
58 would *"probably end up back in hospital"* (ID13) if they stopped medication, experiences of  
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3 which (in those who had previous admissions) were universally negative and acted as a  
4 strong motivator to keep well, which people equated with medication compliance. Although  
5 a minority of people with ID did express more critical views about medication or declared  
6 that they did not like taking it, none seriously questioned its use or believed there was an  
7 alternative:  
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*“I don’t want to take it...I don’t like taking it, but I have to” (ID04)*

*“I don’t like taking medication at the best of times, but I know I’ve got to take it”*

(ID10)

31 Given the length of time that most family carers had been managing medication (average  
32 >13 years), they tended to describe their experience as a journey and their narrative was  
33 often recounted with a strong emotional overlay. Many recalled that medication was first  
34 prescribed during a mental health crisis. In these difficult and stressful circumstances, which  
35 sometimes impacted their own mental health, family carers could find it difficult to make a  
36 confident decision about medication; the imperative to act being set against a fear of  
37 psychotropic drugs and their possible side-effects:  
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*“In the beginning I was terrified about medication, the side-effects and everything.*

*And also her [daughter’s] condition...It’s a really dangerous medication...I read lots of  
54 information and went on the internet, and it said lots about side-effects...But I didn’t  
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3 *have any way out...I was really worried and couldn't make the decision" (FC08)*  
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9 Initial reticence was often overcome when the beneficial effects of medication were  
10  
11 observed and family carers could undergo quite major shifts in attitude:  
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17 *"I'd always been quite resistant [to medication] because I'd heard about chemical*  
18 *coshes and all that stuff...I thought '[son] doesn't need a psychotropic'...but he went*  
19 *onto a very low dose and it noticeably helped...Now I'm at a stage of the psychiatrist*  
20 *thinking we should reduce the dose, and I'm really resistant to that because it feels so*  
21 *helpful" (FC02)*  
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33 Others' longer-term experience of medication was less favourable. In these cases  
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35 medication was variously described as ineffective, only temporarily effective (the positive  
36 effects "*wearing off*" (FC01) over time was a common complaint), or blighted by adverse  
37  
38 physical side-effects. The potential of psychotropic medication to dull people's cognitive  
39  
40 faculties and render them almost incapable was expressed in various terms (e.g. "*relative*  
41 *was almost like a dead person...the drugs [meant] she was moving away from us...becoming*  
42 *a non-person*" (FC12); "*they have this vacant kind of look...staring into the horizon*" (PC01)  
43  
44 "*a sledge hammer treatment*" (PC07)). Fears about psychotropic medication were  
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53 occasionally juxtaposed against the sensitivity and exceptionality of the person with ID:  
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3 *“Sometimes I don’t think these tablets are for people with autism and learning*  
4 *disabilities at all, you know? That’s not the answer...if there’s no cure, why are you*  
5 *giving all this medication?” (FC03)*  
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14 Some carers had witnessed multiple medication changes and had come to view medication  
15 with scepticism, as unpredictable (*“like taking pot luck”* FC09) or even an *“experiment”*  
16 (FC08 & FC12). Other concerns about medication included medication being used too  
17 readily (*“[the doctors are] very quick to put them on but very slow to take them off”* FC06);  
18 the absence of alternative, psychosocial interventions which were often considered more  
19 appropriate but unavailable due to resource constraints (*“other things can cost money...so*  
20 *sometimes it’s a control medication”* PC06). Considering these concerns, for many carers  
21 psychotropic medication use was an ongoing source of tension and unease:  
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37 *“I’m not happy with medication...The prescription is easy to write out...but*  
38 *medication might not be for [son] at all, for what’s wrong with him, and they’re*  
39 *writing out prescriptions all the time...He’s got no other support around these*  
40 *issues...it’s always just medication...not enough, err, not enough maybe talking*  
41 *therapy...I think there should be more done than there is” (FC03)*  
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53 *“Hopefully [relative will need] less medication in the future...I’m worried about the*  
54 *side-effects but also that she will become unwell if she stops [medication]...it’s*  
55 *difficult, I don’t know what will happen. There could be many problems” (FC07)*  
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### Carer role: the “front-line people”

In describing their roles in caring for a person with ID, both paid and family carers placed substantial importance on knowing and being close to the person, and the privilege that this gave them in evaluating their wellbeing. Carers also spoke of their role as advocates, ensuring that processes are centred around the person with ID and their interests are upheld.

In relation to psychotropic medication, in addition to practical, daily tasks such as collecting, storing, and giving medication to the person with ID, both family and paid carers spoke of their “integral” (PC02) role in monitoring and managing people’s health. Carers described themselves as “the front-line people,” (PC01) a unique position which gave them intimate knowledge of the person with ID and was contrasted with “short and limited” (PC05) meetings with medical professionals. Knowing the person with ID closely and over time was seen as important in view of the range of problems that were described amongst the group they supported (including physical illness, developmental disabilities, mental illness and/or behavioural problems). Given this complexity, carers perceived value in their ability to interpret subtle signs and to “build up a picture of that person and how medication interacts with them” (PC02). Family carers, in particular, described an intuitive sense of ‘knowing’ the needs of their relative:

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3 *“I’ve always had to deal with [son] not being verbal and not being able to tell me, so I*  
4 *had to read him by body language all through his life. I’m aware of the signs...I know*  
5 *if he has an infection in his nose, in his ears. I know if he has a headache...if he’s not*  
6 *OK...I already know” (FC04)*  
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17 Carers often took a ‘gatekeeping’ role in determining when to seek professional advice, and  
18 in mediating interactions between the doctor and the person with ID thereafter. Family and  
19 paid carers diverged slightly in how they positioned themselves during medical  
20 appointments. Family carers described taking a more direct approach in speaking with the  
21 doctor and acting on behalf of their relative, including, for example, one mother who  
22 attended appointments with the psychiatrist while her son waited outside the room. Paid  
23 carers, meanwhile, framed their input as *“empowering”* (PC09) and facilitating the person  
24 with ID to speak for themselves, so that *“if there’s something the service user wants to say, I*  
25 *can make sure it happens”* (PC04) while preferring to take more of a *“back seat”* (PC06).  
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43 Several carers spoke about a process of *“translating”* (PC09) information between the  
44 doctor and the person with ID, again drawing on their familiarity of the person with ID in  
45 order to relay information in an individualised and more understandable way. This role  
46 often incorporated *“preparing the service user for the appointment and explaining in a very*  
47 *clear way what might happen”* (PC04) and afterwards, reflecting with and educating the  
48 person with ID after the appointment:  
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*"[My relative] usually says [to the psychiatrist] "it's best if you explain this to my mum or sister because they're good at explaining it to me"" (FC08)*

*"I always get questioned by my clients "What's this pill? What's that pill?" What I've done for my key clients is I've made a list of all the medication, and I did it in easy read....and I've got a table of what they do with picture...if they ever ask me what happens, I just show them and go through it with them...I will stick it up on the fridge to familiarise people with it." (PC05)*

In summary, carers viewed their role with respect to medication as both broad in scope and vital to the life of the person they supported:

*"I understand that sometimes I come across overbearing, nousey, and always getting involved...but I do believe, and this is a firm belief, if I was not behind [son] and asking for him, demanding for him... he would be in a worse place now, mentally... If he didn't have me he would definitely be worse off in all sorts" (FC09)*

## **Decisional processes relating to psychotropic medication**

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3 In this section we describe the forms of involvement that people with ID, their family carers,  
4  
5 and paid carers experienced and desired in medication decisions, and their feelings and  
6  
7 responses when these differed from the decisional processes they experienced.  
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### 10 11 12 13 14 **a) Power dynamics** 15 16

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20 There was a common assumption across stakeholder groups that the psychiatric  
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22 appointment was the nexus of medication decisions and that the psychiatrist has the  
23  
24 “ultimate power” (FC02) and “final say” (PC08) in medication decision-making. Interviewees  
25  
26 did not express a desire to challenge this, viewing the psychiatrist as “the expert” (FC11)  
27  
28 who “knows best” (ID10) and “does the best for everyone who’s sick” (FC07). In cases where  
29  
30 people did not share the psychiatrist’s opinion on medication, they relatively quickly  
31  
32 deferred (“the medical profession probably know better....I come on-board” (PC06)) and  
33  
34 would not act alone to change medication:  
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44 *“I wouldn’t [change medication] because then if anything happened I’d be the one to*  
45  
46 *blame. It says in the leaflet ‘do not stop medication unless you speak to your*  
47  
48 *doctor’...sometimes I feel like doing it and I think to myself, ‘no, I’ll leave it and talk to*  
49  
50 *[the psychiatrist] first’...they know better than we do” (FC03)*  
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3 For many with ID the authority of the doctor was absolute and left little room for their own  
4 agency. Based on their lived experience, medication decisions were a part of life over which  
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6 could exert little influence:  
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14 *"I have to take my medication, I ain't got no choice...It's the doctor's orders to keep*  
15 *on the medication...there's not a lot you can do about it"* (ID11)  
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23 *"It's the doctor's decision [about medication]...it's up to them"* (ID01)  
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29 Some people with ID were satisfied with the psychiatrist assuming control over medication  
30 decisions:  
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34 *"Doctors should make the decisions about medicine...they have more experience...[I*  
35 *prefer to] leave it to the doctor"* (ID14)  
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43 However others (generally those with more mild ID) obviously wanted to be involved in the  
44 process (e.g. *"Explain what [the medication] is supposed to do...Tell me what's going on!"*  
45 ID06). Congruent with these wishes, there were some descriptions of shared medication  
46 decisions. One woman with ID, for example, described how she had jointly reached a  
47  
48 decision about reducing her medication, explaining that *"[it was] my idea...and theirs [the*  
49 *doctors'] too"* (ID04).  
50  
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3 The desire of both paid and family carers to be involved in medication discussions and  
4 decisions was more obvious and evident through their depictions of both positive and  
5 negative experiences of medication decision-making across time and between clinicians.  
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9  
10 Positive experiences of medication decision-making were described as collaborations,  
11  
12  
13 *“partnerships”* (FC02 & PC02) and *“negotiations”* (PC08) and participants often made  
14  
15 reference to having a good working relationship with the psychiatrist. In these accounts,  
16  
17  
18 people valued *“open discussion”* (PC09), being given *“time to talk”* (FC10), invited to give  
19  
20 their opinion, and being *“welcomed”* (PC12) and *“taken seriously”* (FC02) when doing so:  
21  
22  
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26  
27 *“It’s been a really good partnership trying to get [service user] on the right*  
28  
29 *medication...It’s worked really well...I went along to see the psychiatrist, spoke to him*  
30  
31 *about my concerns...and then he very quickly sent appointments through to see*  
32  
33 *them. And I thought, ‘wow, he listened, took it on board, called those people in,*  
34  
35 *reviewed their medication’... The psychiatrists have been very tolerant, very patient*  
36  
37 *and have listened to what we’ve been saying... So it can work”* (PC02)  
38  
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45 *“A lot of doctors are open to discuss...they ask the [patient] and they ask me...and*  
46  
47 *they listen”* (PC06)  
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55 *“[The doctor] was utterly supportive [and] took seriously what I’d said, so I trusted*  
56  
57 *her...She suggested medication...it was made very clear to me what the long-term*  
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3 *side-effects are...I wanted to give it a try, see how it goes. [I felt] no pressure...I think*  
4  
5 *the professionals are very good at consulting” (FC02)*  
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12 Conversely, being excluded from decisions about medication could take an emotional toll,  
13  
14 especially on family carers who described feeling “*annoyed*” (FC05), “*frustrated*”  
15  
16 (FC04&FC08), “*angry*” (FC12&FC08), or isolated:  
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23 *“It’s always a bad experience when you’re not involved...I wasn’t in control of*  
24  
25 *anything really, and there was no-one out there I could turn to” (FC11)*  
26  
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31 *“It’s been extremely stressful...When you find out somebody’s been fiddling [with*  
32  
33 *medication] behind your back and you haven’t known about it” (FC05)*  
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#### 40 ***b) Efforts to democratise medication decisions***

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46 From respondents’ accounts of how medication decisions were made, we identified three  
47  
48 related elements of decision-making. These were being informed, being included, and  
49  
50 having influence (figure 1). In any one of these processes, patients and carers could find  
51  
52 themselves marginalised. Many paid and family carers, and a smaller number of  
53  
54 respondents with ID, described making efforts to change the dynamics of medication  
55  
56 decisions with strategies aimed at democratising each of these elements.  
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6 **[Figure 1]** [Elements of involvement in medication decisions described by participants –  
7  
8 NEAR HERE]  
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14 A pre-requisite to involvement in the decision-making process was to be **informed** about  
15 medication, yet several people with ID could not recall that medication was ever spoken  
16 about by their doctor (*"I don't think [the psychiatrist] talks about medication...I ain't got a*  
17 *clue"* (ID02)). These experiences reinforced a sense of powerlessness as medication  
18 decisions were perceived to *"just happen"* (ID01). Both paid and family carers reported  
19 lacking information (*"hardly ever told when people switch medication"* (PC09))and  
20 sometimes not *"not knowing what's going on"* (FC05). Paid carers, particularly those  
21 working in larger organisations in which numerous people with ID were supported, worried  
22 that being *"out of the loop"* (PC12) left them *"ill-equipped and dangerously exposed"* (PC11),  
23 at once responsible for medication administration and monitoring yet without vital  
24 information of drug changes, doses, or effects.  
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45 In response, both family and paid carers, and occasionally people with ID, had made  
46 attempts to improve their knowledge about medication (and alternative treatments) by  
47 seeking information independently from a variety of sources, including medication leaflets,  
48 television, internet, news media, carer networks, colleagues, and formal training courses.  
49  
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55 People with ID were often reliant on carers to help them with this in a way which recalled  
56 the 'carer role' that carers themselves had described:  
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*“My sister can come, we can look up what [the medication’s] supposed to do so at least I get a better picture” (ID06)*

Acquiring knowledge was reported by participants to improve their confidence and go some way to meet and respond to the technical expertise of the psychiatrist. Many people with ID, and some carers, however, could struggle with accessing appropriate information and were left in a relatively less powerful position as a result. None of the participants mentioned having used accessible medication information.

*“Because I’ve got the learning difficulties, I’m not able to understand a lot...I’m not very good with a lot of the terms and conditions on there. It’s really hard for me to read one of those [medication information] leaflets...I don’t know much about it so I can’t say yes and I can’t say no” (ID10)*

*“Me myself is not very good in asking questions or understanding everything, so I just leave it...I can’t go on the internet...I’m not very good in reading and writing, I don’t understand everything, so that’s why I don’t bother” (FC07)*

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3 Respondents in all groups had experience of being nominally present when medication  
4  
5 decisions were made but not **included** in discussions in a meaningful sense, and having little  
6  
7 to no opportunity to voice their concerns:  
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14 *“They said “you will be going on an anti-depressant.” I didn’t know the name, then it*  
15  
16 *all went cold....the next thing I knew it was in my blister pack and I’ve been taking it*  
17  
18 *ever since” (ID06)*  
19  
20

21  
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24  
25 *“I don’t think my opinion was asked...I was in the review but I wasn’t asked the big*  
26  
27 *questions about treatment” (PC10)*  
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34 Family and paid carers spoke of trying to shape the discourse in conversations with the  
35  
36 psychiatrist and needing to have confidence to challenge their authority in order to ensure  
37  
38 their views were heard. One relative described her assertive approach as *“not muck[ing]*  
39  
40 *about...If I think the doctor’s wrong, I tell ‘em, just like that” (FC01)*. Sometimes a dramatic  
41  
42 *“bust up” (FC09) or “battle” (FC12)* with the clinical team was considered necessary and  
43  
44 could ‘reset’ the interaction in favour of a greater role for the family carer in medication  
45  
46 decisions. At other times tenacity and *“pushing to be involved” (PC09)* spoke of ongoing  
47  
48 effort to develop and maintain involvement:  
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3 *"I always have to be chasing. I'm still chasing now...It shouldn't be like that, but*  
4 *that's the way it works...I think [the doctors] respect me more after, I kind of, put my*  
5 *foot down"* (FC04)  
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14 Paid carers tended to avoid overt conflict. Instead they often relied on their accumulated  
15  
16 knowledge of the healthcare system to navigate to a position where they stood the greatest  
17  
18 chance of being heard. One paid carer described the strategy involved in arranging an  
19  
20 appointment with the psychiatrist:  
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28 *"I'll have to write [to the psychiatrist] and copy in the GP...I'll have to be quite forceful*  
29 *about it. And then I'll actually ring [the psychiatrist] and I'll follow it up with an e-*  
30 *mail...We can ring the learning disability [team] secretary because we've got a very*  
31 *good relationship with her...I will actually sometimes say to her, "it's quite a complex*  
32 *case this is, it's probably worth us seeing the consultant"*" (PC08)  
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44 The final element to being involved that was described by respondents was the ability to  
45  
46 **influence** decisions about medication. This constituted moving beyond merely exchanging  
47  
48 information to becoming a meaningful collaboration partner, whose opinions were heard  
49  
50 and shaped decisions. Although there were clear instances where this had been achieved,  
51  
52 all three stakeholder groups described situations in which this had not happened. Some also  
53  
54 described strategies they had used in attempts to increase their decisional influence.  
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3 The minority of people with ID who had attempted to assert themselves were generally not  
4  
5 successful in gaining the greater involvement and influence they wanted. In response to  
6  
7 questioning their medication, some people with ID described receiving evasive answers that  
8  
9 served solely to reinforce the importance of taking medication as directed:  
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17 *"I just get ignored, I feel like I'm getting ignored...when I say something about*  
18  
19 *[medication], it's basically 'you just have to take the medication'" (ID08)*  
20  
21

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24  
25 *"Sometimes I do [talk to the doctor about medication] but they tend to, like, they say*  
26  
27 *"we can't really say nothing because you've got to take it" and they don't really say*  
28  
29 *why" (ID10)*  
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36 One described having recruited a carer to advocate on their behalf but it was more common  
37  
38 for people with ID to quickly acquiesce:  
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44  
45 *"I don't get heard out properly... [The doctor says] "Is [the medication] keeping you*  
46  
47 *right?" and I just say "yeah", but I don't think it is. But I don't want to argue. I don't*  
48  
49 *want to argue with them so I just say "yeah, it works on me"...I've asked [the*  
50  
51 *psychiatrist] before to [change medication] but she wouldn't let me so I just let [the*  
52  
53 *psychiatrist] get on with it...I just don't say nothing 'cos I feel like I'm not heard out"*  
54  
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56  
57 (ID08)  
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6 Similarly, carers reported that their concerns had been “not believed” (FC09) or “dismissed  
7  
8 as trivial and unimportant” (PC09). Having proposed their own ideas about medication,  
9  
10 some carers were given a sense that it was not their place to do so:  
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17 *“The consultant was like “you’re talking rubbish”...it was like, ‘what does she know?’”*

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19  
20 (PC02)  
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26 *“I suggested a medication which had been mentioned previously and I had looked up*  
27  
28 *the research on it. It’s something that’s very useful for people with high levels of*  
29  
30 *anxiety and I thought it might be worth trying but umm... there was a small flicker*  
31  
32 *and then, like, “no, I don’t think so, where did you hear about this?” sort of thing”*

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35  
36 (FC05)  
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42 Such experiences could lead family carers to become burnt-out and resign themselves to a  
43  
44 subordinate position. After what she described as a long and turbulent relationship with her  
45  
46 relative’s care team, one mother reluctantly stepped back from taking a more active role in  
47  
48 treatment decisions, stating “we’re [now] leaving it to them, I think that’s the best way”  
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50  
51 (FC06).  
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3 Given their perception of being 'low ranked' in the hierarchy of stakeholders (*"just a*  
4 *provider"* (PC08) and *"not seen as a professional or intellectual resource"* (PC11)), paid  
5  
6 carers often felt the need to prove the credibility of their knowledge in order to be heard  
7  
8 and have influence. Investing in the relationship with the psychiatrist was felt to make this  
9  
10 easier (*"because they know me, they know my information is really important"* (PC05)), and  
11  
12 paid carers sometimes sought legitimacy by presenting themselves as objective, collecting  
13  
14 data, and taking *"a paper trail ... [of] evidence"* (PC08) to appointments to support their  
15  
16 views.  
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## 28 **DISCUSSION**

### 29 **Principal findings**

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39 The qualitative techniques used in this study enabled us to gain a deep understanding of the  
40  
41 views and experiences of people with ID and their carers about psychotropic drug use, a  
42  
43 topic which is highly relevant given the prevalence of psychotropic use in this group.

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45  
46 Psychotropic medication decision-making is a complex process, and made more so by the  
47  
48 presence of multiple stakeholders. Although preferences towards involvement varied  
49  
50 between individuals, most participants in this study valued having a place in decision-  
51  
52 making; experiences that were not aligned with expectations could lead to a range of  
53  
54 emotional responses and prompt various efforts to gain position.  
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3 People with ID reported having few opportunities to become involved in the psychotropic  
4 medication decision-making process. Only a minority described consciously ceding control  
5  
6 to others, with most either unaware they were entitled to a role in deciding medication, or  
7  
8 having been unsuccessful in involving themselves despite their efforts. Lack of knowledge  
9  
10 about medication, a strong belief in medication as necessary and important, fear of the  
11  
12 consequences of not taking medication (particularly admission to hospital), trust in the  
13  
14 doctor as an expert, and deference towards authority figures all underpinned a passive  
15  
16 compliance and largely unquestioning stance towards medication. In this regard, our  
17  
18 analysis supports the 'model of compliance' proposed by Crossley and Withers in their  
19  
20 exploration of the experiences of people with ID prescribed antipsychotic medication<sup>28</sup>, and  
21  
22 renews calls for greater efforts to inform and involve people with ID about their medication.  
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34 Family and paid carer groups, meanwhile, clearly had a desire to be involved in medication  
35  
36 decision-making. This was related to a self-identity as the "front line people" and was  
37  
38 intertwined with their often ambivalent attitude towards psychotropic medication. The  
39  
40 carers strongly believed in the value of the contribution they could make to medication  
41  
42 decisions, and considered their involvement essential to achieving the best outcome for the  
43  
44 individual they supported. Positive experiences were described in terms compatible with  
45  
46 collaborative and negotiated models of decision-making, albeit with the over-riding  
47  
48 assumption that the psychiatrist would take final responsibility for prescribing decisions.  
49  
50  
51 While experiences of SDM undoubtedly did exist, these could not be taken for granted, and  
52  
53 many study participants felt they had been denied a place in decision-making. Beneath this  
54  
55 could be the devaluing of carer knowledge (based heavily on relational lived experience) in  
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3 comparison to the technical knowledge and scientific expertise of the psychiatrist. This  
4  
5 'epistemic injustice'<sup>35</sup> prompted numerous attempts to rebalance the perceived power  
6  
7 asymmetry in consultations as people tried to leverage influence or strengthen their voice.  
8  
9  
10 Although these could be successful to an extent, they required resources that were not  
11  
12 available to all, added to the emotional toll of caring, and had caused some to lose faith in  
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15 services.  
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### 21 **Clinical implications**

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28 The over-use of psychotropic medication for people with ID is now well-evidenced and is the  
29  
30 focus of national attention. Off-label prescribing, psychotropic polypharmacy, and lengthy  
31  
32 durations of medication treatment were all reported by the participants recruited for this  
33  
34 study. The average duration of psychotropic use in our sample was 16 years, and the  
35  
36 prevalence of antipsychotic use far outweighed the presence of severe mental illness. The  
37  
38 STOMP programme in England, established to address these issues, has not yet achieved  
39  
40 wholesale reductions in use of antipsychotic medication<sup>36</sup> but an assessment of medication  
41  
42 optimisation must include more than a crude count of prescriptions. Improving medication  
43  
44 outcomes for individuals requires a person-centred approach to prescribing that includes  
45  
46 partnership between stakeholders and consideration of patients' values and goals on an  
47  
48 equal footing to the expertise and opinion of mental health professionals. These elements  
49  
50 are part of broader attempts to support patient autonomy, and are embodied in the shared  
51  
52 decision making (SDM) model.  
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6 The adoption of SDM in routine mental healthcare has been slow<sup>37</sup> and although  
7  
8 psychiatrists explicitly endorse the model,<sup>38</sup> micro-analytic studies of routine psychiatric  
9  
10 consultations show that its principles are infrequently applied.<sup>39-41</sup> Issues of insight,  
11  
12 fluctuating mental capacity associated with episodes of acute and severe mental ill-health,  
13  
14 power differentials between patient and professional, and the background threat of  
15  
16 compulsory treatment, have all been identified as implementation barriers that are  
17  
18 especially pertinent in psychiatric practise.<sup>42</sup> Arguably the challenges to SDM are  
19  
20 compounded in people with ID<sup>43, 44</sup> due to the fixed cognitive deficit, additional  
21  
22 communication needs, and people's lack of experience and confidence in making choices  
23  
24 about their healthcare or, indeed, more generally.<sup>45, 46</sup>  
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34 The presence of multiple stakeholders adds an extra dimension to the SDM model, which  
35  
36 has largely been developed apropos dyadic doctor-patient interactions and may not  
37  
38 adequately account for complex decisions that are distributed within social networks.<sup>42</sup>  
39  
40 Defining roles and responsibilities, and balancing the relative influence of different (and  
41  
42 possibly conflicting) views adds to the challenges of achieving shared decisions in this group.  
43  
44 Thus, if we are to achieve successful SDM, and in so doing, obtain its benefits, the model  
45  
46 may need to be broadened.  
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55 A parallel concept of *supported* decision-making has been advanced for those with cognitive  
56  
57 impairment,<sup>47</sup> and is similarly predicated on the principles of autonomy and self-  
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3 determination. Supported decision-making formalises the place of a network of individuals,  
4  
5 which may consist of family members, friends, or other trusted people, who are able to help  
6  
7 the person to formulate and express their preferences and thus exercise their autonomy.  
8  
9 This may include assistance in gathering information, understanding their options, and/or  
10  
11 communicating their choice. Clearly, such tasks were often undertaken by carers  
12  
13 interviewed in the present study and suggests that elements of the framework could be  
14  
15 incorporated to an adapted model of SDM.  
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24 Increasing inclusion of people with ID and their paid and/or family carers in decisions (under  
25  
26 whatever model this is branded), may represent a significant role change for all  
27  
28 stakeholders. Clinicians, which our study indicates hold the majority of the decision-making  
29  
30 power in these clinical encounters, will need to find ways of making conversations more  
31  
32 accessible and collaborative as patient involvement becomes a legal as well as an ethical  
33  
34 imperative.<sup>48</sup> People with ID must be made aware of their rights and appropriately  
35  
36 supported in contributing to healthcare decisions to a level which they are comfortable  
37  
38 with, if we are to avoid making unreasonable demands that risk alienating them from  
39  
40 professionals. As we have reported, carers can play a pivotal role in contributing to this  
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42 involvement, and this should be recognised and itself supported.  
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## 52 **Future work**

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3 Observing interactions within real-world consultations could lead to a more nuanced  
4  
5 understanding of how medication discussions happen, and help to further develop  
6  
7 theoretical models of healthcare decision-making in people with ID. Developing scalable  
8  
9 interventions based on this understanding could improve opportunities for involvement of  
10  
11 adults with ID and their carers. Several interventions have been developed and evaluated in  
12  
13 people with mental health problems without ID.<sup>49-53</sup> Exploring the views of prescribers and  
14  
15 other health professionals also is important and could uncover other factors that influence  
16  
17 patient and carer involvement and which themselves be a target for intervention. Finally, it  
18  
19 will be necessary to demonstrate that incorporating SDM principles in routine care in this  
20  
21 group is associated with improved patient-reported and objective outcomes.  
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### 31 **Strengths and limitations of this study**

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37 This study is unique in providing a multi-stakeholder analysis of accounts of the use of  
38  
39 psychotropic medications in people with ID. It extends the existing qualitative literature in  
40  
41 this field which has typically focused solely on antipsychotic drugs<sup>28</sup> or medication used for  
42  
43 behaviour that challenges.<sup>29, 54, 55</sup> Synthesising the results of interviews with patients, family  
44  
45 carers, and paid carers allowed us to develop broad, over-arching themes, and helps us to  
46  
47 understand the interactions and dynamics involved in the complex process of medication  
48  
49 decision-making. Adaptations to the research method enabled us to gain meaningful  
50  
51 insights into the experiences of people with ID, a group who are often excluded from  
52  
53 research participation and may be considered inappropriate for in-depth qualitative  
54  
55 investigation.<sup>56</sup> A relatively large sample size, with respondents purposively sampled from  
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3 different locations and according to demographic and clinical characteristics, adds to the  
4  
5 breadth of our findings.  
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11 The views of people with ID and their carers are difficult to obtain and seldom heard in the  
12 research literature. In prioritising their accounts, this research report does not include the  
13 views of general practitioners, pharmacists, or psychiatrists. Participants were self-selecting  
14 and may have included only those with greater confidence. Their views are not necessarily  
15 representative of a wider group of people with ID and their carers. We only interviewed  
16 people (and carers of people) who were currently prescribed psychotropic medication and  
17 under the care of specialist psychiatry teams, thereby excluding those who may have  
18 previously taken medication, been managed solely in primary care, or who have chosen not  
19 to take medication for mental health problems. People in any of these groups may possess  
20 different and equally-valid perspectives on psychotropic medication and its prescribing.  
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## 40 **Conclusion**

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46 Achieving optimal use of psychotropic medication is a health service priority and can only  
47 occur when working in partnership with people with ID and their carers. Frameworks such  
48 as SDM which are based on the principles of personalisation and collaboration offer a  
49 possible means of ensuring that stakeholders are represented in important decisions. Our  
50 study suggests that successful collaborative decisions regarding medication are achievable  
51 but are not always experienced. Further research to understand how medication decisions  
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3 are made from the perspective of prescribers and how other stakeholders can be  
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5 meaningfully and productively brought into this is necessary to inform the development of  
6  
7 interventions that ensure people with ID and their carers have a true voice in medication  
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9 discussions and decisions.  
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## Acknowledgements

The authors would like to thank those who agreed to take part in the study and the organisations and individuals that assisted with recruitment, and Restu Handoyo, who contributed to the analysis. We also thank members of the service user consultation group, Jackie McMorrow and Jill Huntlesmith.

## Contributors

RS, AH, AS, and NM designed the study. RS recruited to the study and carried out the interviews. RS, AH, AS, and NM undertook the analysis. RS and NM drafted the manuscript with input from AH and AS. All authors approved the final version.

## Funding

This study was funded by a Doctoral Research Fellowship awarded to RS from the National Institute for Health Research (NIHR) (Ref: DRF-2016-09-140).

## Disclaimer

The views expressed in this article and those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. The funder had no role in study design, analysis, decision to publish, or preparation of the manuscript.

## Competing interests

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9 **Data sharing**  
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## REFERENCES

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®). Arlington, VA: American Psychiatric Publishing; 2013.
2. Maulik P, Mascarenhas M, Mathers C, *et al*. Prevalence of intellectual disability: A meta-analysis of population-based studies. *Res Dev Disabil* 2011;32:419-36.
3. Cooper S-A, Smiley E, Morrison J, *et al*. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry* 2007;190:27-35.
4. Sheehan R, Hassiotis A, Walters K, *et al*. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. *BMJ* 2015;351:h4326.
5. Lunskey Y, Khuu W, Tadrous M, *et al*. Antipsychotic use with and without comorbid psychiatric diagnosis among adults with intellectual and developmental disabilities. *Can J Psychiatry* 2018;63:361-9.
6. De Kuijper G, Hoekstra P, Visser F, *et al*. Use of antipsychotic drugs in individuals with intellectual disability (ID) in the Netherlands: prevalence and reasons for prescription. *J Intellect Disabil Res* 2010;54:659-67.
7. Doan TN, Lennox NG, Taylor-Gomez M, *et al*. Medication use among Australian adults with intellectual disability in primary healthcare settings: a cross-sectional study. *J Intellect Dev Disabil* 2013;38:177-81.
8. Holden B, Gitlesen JP. Psychotropic medication in adults with mental retardation: prevalence, and prescription practices. *Res Dev Disabil* 2004;25:509-21.
9. Hsu S-W, Chiang P-H, Chang Y-C, *et al*. Trends in the use of psychotropic drugs in people with intellectual disability in Taiwan: a nationwide outpatient service study, 1997–2007. *Res Dev Disabil* 2014;35:364-72.
10. Lunskey Y, Modi M. Predictors of Psychotropic Polypharmacy Among Outpatients With Psychiatric Disorders and Intellectual Disability. *Psychiatr Serv* 2017;69:242-6.
11. Bowring D, Totsika V, Hastings R, *et al*. Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study. *J Intellect Disabil Res* 2017;61:604-17.
12. O'Dwyer M, Peklar J, Mulryan N, *et al*. Prevalence, patterns and factors associated with psychotropic use in older adults with intellectual disabilities in Ireland. *J Intellect Disabil Res* 2017;61:969-83.
13. Lott I, McGregor M, Engelman L, *et al*. Longitudinal prescribing patterns for psychoactive medications in community-based individuals with developmental disabilities: utilization of pharmacy records. *J Intellect Disabil Res* 2004;48:563-71.
14. O'Dwyer M, McCallion P, McCarron M, *et al*. Medication use and potentially inappropriate prescribing in older adults with intellectual disabilities: a neglected area of research. *Ther Adv Drug Saf* 2018;9:535-57.
15. Sheehan R, Horsfall L, Strydom A, *et al*. Movement side effects of antipsychotic drugs in adults with and without intellectual disability: UK population-based cohort study. *BMJ Open* 2017;7:e017406.

16. Branford D, Gerrard D, Saleem N, *et al.* Stopping over-medication of people with intellectual disability, Autism or both (STOMP) in England part 1—history and background of STOMP. *Advances in Mental Health and Intellectual Disability* 2019;13:31-40.
17. Branford D, Gerrard D, Saleem N, *et al.* Stopping over-medication of people with an intellectual disability, autism or both (STOMP) in England part 2—the story so far. *Advances in Mental Health and Intellectual Disability* 2019;13:41-51.
18. Royal Pharmaceutical Society. Medicines Optimisation: helping patients to make the most of medicines. London, UK: Royal Pharmaceutical Society; 2013.
19. Cutler S, Fattah L, Shaw M, *et al.* What does medicines optimisation mean for pharmacy professionals? *Pharm J* 2011;287:606.
20. Charles C, Gafni A, Whelan T. Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med* 1999;49:651-61.
21. Department of Health. Valuing People Now: a new three-year strategy for people with learning disabilities. London, UK: Department of Health; 2010.
22. Shay LA, Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making* 2015;35:114-31.
23. Joosten E, DeFuentes-Merillas L, de Weert G, *et al.* Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychother Psychosom* 2008;77:219-26.
24. Keywood K, Fovargue S, Flynn M. Best Practice? Health care decision-making by, with and for adults with learning disabilities. Manchester, UK: National Development Team; 1999.
25. Chadwick DD, Mannan H, Garcia Iriarte E, *et al.* Family voices: life for family carers of people with intellectual disabilities in Ireland. *J Appl Res Intellect Disabil* 2013;26:119-32.
26. Tuffrey-Wijne I, Giatras N, Goulding L, *et al.* Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study. *Health Serv Deliv Res* 2013;1-224
27. Heslop P, Folkes L, Rodgers J. The knowledge people with learning disabilities and their carers have about psychotropic medication. *Tizard Learning Disability Review* 2005;10:10-8.
28. Crossley R, Withers P. Antipsychotic medication and people with intellectual disabilities: their knowledge and experiences. *J Appl Res Intellect Disabil* 2009;22:77-86.
29. Edwards N, King J, Watling H, *et al.* Qualitative exploration of psychotropic medication to manage challenging behaviour in adults with intellectual disability: views of family members. *Advances in Mental Health and Intellectual Disability* 2017;11:207-18.
30. Lalor J, Poulson L. Psychotropic medications and adults with intellectual disabilities: care staff perspectives. *Advances in Mental Health and Intellectual Disability* 2013;7:333-45.
31. Joint Formulary Committee. British National Formulary. London, UK: Pharmaceutical Press; 2019.
32. Department of Health. Mental Capacity Act. London, UK: The Stationery Office; 2005.
33. Hollomotz A. Successful interviews with people with intellectual disability. *Qual Res* 2018;18:153-70.
34. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101.
35. Newbigging K, Ridley J. Epistemic struggles: The role of advocacy in promoting epistemic justice and rights in mental health. *Soc Sci Med* 2018;219:36-44.

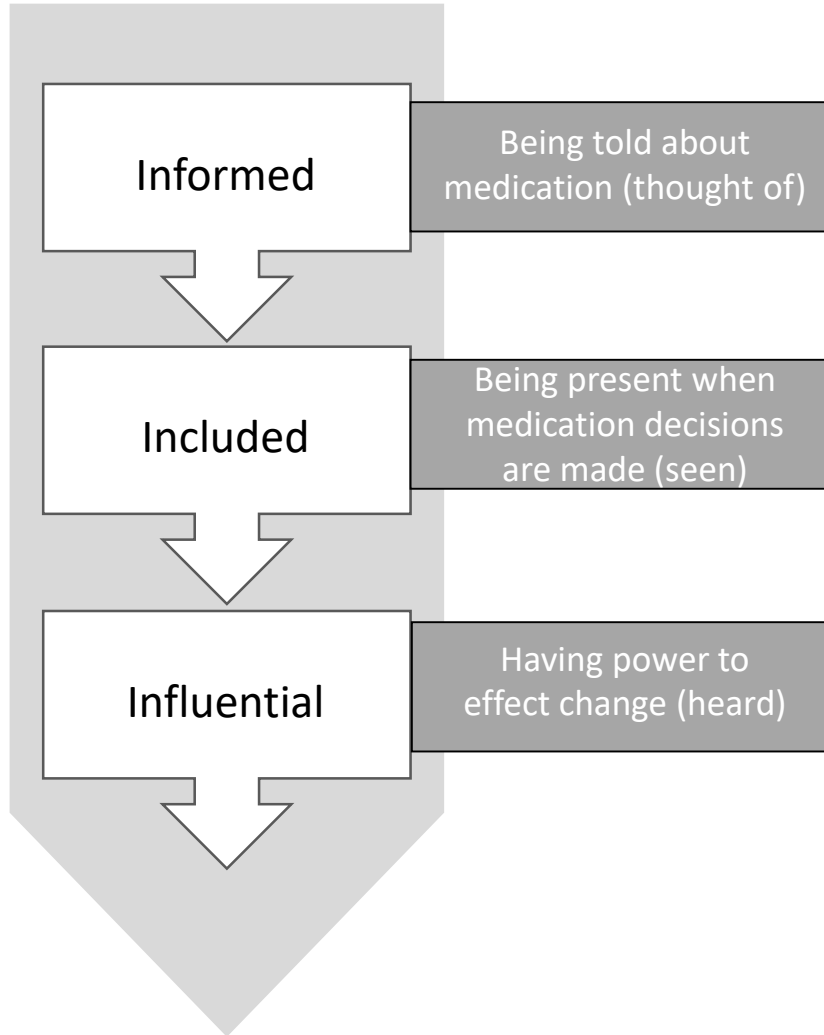
- 1  
2  
3 36. Mehta H, Glover G. Psychotropic drugs and people with learning disabilities or autism. 2019.  
4 Public Health England.  
5
- 6 37. Slade M. Implementing shared decision making in routine mental health care. *World*  
7 *Psychiatry* 2017;16:146-53.  
8
- 9 38. Seale C, Chaplin R, Lelliott P, *et al.* Sharing decisions in consultations involving anti-psychotic  
10 medication: a qualitative study of psychiatrists' experiences. *Soc Sci Med* 2006;62:2861-73.  
11
- 12 39. McCabe R, Skelton J, Heath C, *et al.* Engagement of patients with psychosis in the  
13 consultation: conversation analytic study. *BMJ* 2002;325:1148-51.  
14
- 15 40. McCabe R, Khanom H, Bailey P, *et al.* Shared decision-making in ongoing outpatient  
16 psychiatric treatment. *Patient Educ Couns* 2013;91:326-8.  
17
- 18 41. Dooley J, Bass N, Livingston G, *et al.* Involving patients with dementia in decisions to initiate  
19 treatment: effect on patient acceptance, satisfaction and medication prescription. *Br J Psychiatry*  
20 2019;214:213-7.  
21
- 22 42. Morant N, Kaminskiy E, Ramon S. Shared decision making for psychiatric medication  
23 management: beyond the micro-social. *Health Expect* 2015;19:1002-14.  
24
- 25 43. Goldsmith L, Woodward V, Jackson L, *et al.* Informed consent for blood tests in people with a  
26 learning disability. *J Adv Nurs* 2013;69:1966-76.  
27
- 28 44. Sullivan WF, Heng J. Supporting adults with intellectual and developmental disabilities to  
29 participate in health care decision making. *Can Fam Physician* 2018;64:S32-S6.  
30
- 31 45. Fovargue SJ, Keywood K, Flynn M. Participation in health care decision-making by adults with  
32 learning disabilities. *Mental Health Care* 2000;3:341-4.  
33
- 34 46. Myron R, Gillespie S, Swift P, *et al.* Whose decision? Preparation for and implementation of  
35 the Mental Capacity Act in statutory and non-statutory services in England and Wales. London, UK:  
36 Mental Health Foundation; 2008.  
37
- 38 47. Devi N, Bickenbach J, Stucki G. Moving towards substituted or supported decision-making?  
39 Article 12 of the Convention on the Rights of Persons with Disabilities. *Alter* 2011;5:249-64.  
40
- 41 48. Adshead G, Crepez-Keay D, Deshpande M, *et al.* Montgomery and shared decision-making:  
42 implications for good psychiatric practice. *Br J Psychiatry* 2018;213:630-2.  
43
- 44 49. Harris N, Lovell K, Day J, *et al.* An evaluation of a medication management training  
45 programme for community mental health professionals; service user level outcomes: a cluster  
46 randomised controlled trial. *Int J Nurs Stud* 2009;46:645-52.  
47
- 48 50. Stead U, Morant N, Ramon S. Shared decision-making in medication management:  
49 development of a training intervention. *BJPsych Bull* 2017;41:221-7.  
50
- 51 51. Loh A, Simon D, Wills CE, *et al.* The effects of a shared decision-making intervention in  
52 primary care of depression: a cluster-randomized controlled trial. *Patient Educ Couns* 2007;67:324-  
53 32.  
54
- 55 52. Deegan PE. A Web application to support recovery and shared decision making in psychiatric  
56 medication clinics. *Psychiatr Rehabil J* 2010;34:23.  
57
- 58 53. Priebe S, McCabe R, Bullenkamp J, *et al.* Structured patient-clinician communication and 1-  
59 year outcome in community mental healthcare: cluster randomised controlled trial. *Br J Psychiatry*  
60 2007;191:420-6.

1  
2  
3 54. Sheehan R, Kimona K, Giles A, *et al*. Findings from an online survey of family carer  
4 experience of the management of challenging behaviour in people with intellectual disabilities, with  
5 a focus on the use of psychotropic medication. *Br J Learn Disabil* 2018;46:82-91.  
6

7 55. Hall S, Deb S. A qualitative study on the knowledge and views that people with learning  
8 disabilities and their carers have of psychotropic medication prescribed for behaviour problems.  
9 *Advances in Mental Health and Intellectual Disability* 2008;2:29-37.  
10

11 56. Coons KD, Watson SL. Conducting research with individuals who have intellectual disabilities:  
12 Ethical and practical implications for qualitative research. *Journal on Developmental Disabilities*  
13 2013;19:14.  
14  
15  
16  
17  
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19  
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21  
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### **Topic guide – people with ID**

\*To be supplemented with visual information and prompts\*

- What do you think about the medication you take for mental health?
- Do you talk about psychotropic medication with the psychiatrist?
  - What has this been like?
  - Do they ask what has been good about taking medication?
  - Do they ask what has been bad about medication?
- Who is involved in decisions about psychotropic medication?
  - Do you want to be involved?
  - Are you involved?
    - If not, why?
  - Is anyone else involved (e.g. carer, family member)?
    - How are they involved?
    - What do you think about them being involved?
- Do you feel that you have a choice about medication?
  - Does the psychiatrist ask you what you want to do with medication?
  - Have they listened to your views?
- What if you were worried about your medication?
  - What if you had a problem with your medication?
- What should the doctor think about when they are prescribing medication for you?
  - What is important to you?
  - What do you want to know about the medicine?
- What would make it easier to talk to the doctor about medication?

### **Topic guide – family carers**

- What has been your experience when psychotropic medication has been prescribed for your relative?
  
- Who is involved in decisions about psychotropic medication?
  - How is your relative involved in the decision?
  - Are you involved?
  - Who else is involved?
  - Is/was your level of involvement what you would like?
  
- Is medication reviewed after it has been prescribed?
  - How?
  - What was the review like?
  - Are you involved in this?
  - Is the review effective?
  
- How were/are decisions to continue, stop, or change medication made?
  - Have you and your relative been given a choice about medication?
  
- Do you discuss medication with the psychiatrist at appointments?
  - Do you think that you know enough about the medications?
  - How would you know if medication is working or not working?
  - Do you have a method for recording the positive and negative effects of medication (e.g. rating scales)?
  - What if there is a problem with medication?
  
- What should be thought about when medication is reviewed?
  
- What might make it easier for you or your relative to give your views about medication?

### **Topic guide – paid carers**

- What has been your experience when psychotropic medication has been prescribed for the people you support?
- Who is involved in decisions about psychotropic medication?
  - How is the person you support involved in the decision?
  - Are you involved?
  - Should you be involved?
- Is medication reviewed after it has been prescribed?
  - How?
  - What happens in the review?
  - Are you involved in this?
  - Is the review effective?
- Who makes decisions to continue, stop, or change medication?
  - How are these decisions made?
  - Have you and the person you support been given a choice about medication?
- Do you discuss medication with the psychiatrist at appointments?
  - How able do you feel to contribute to this discussion?
  - Do you think that you know enough about the medications?
  - How would you know if medication is working or not working?
  - Do you have a method for recording the positive and negative effects of medication (e.g. rating scales)?
  - What if there is a problem with medication?
- What should be thought about when medication is reviewed?
- What might make it easier for you or the person you support to give your views about medication?



## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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# BMJ Open

## Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multi-stakeholder qualitative study in the UK

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-032861.R2
Article Type:	Original research
Date Submitted by the Author:	30-Oct-2019
Complete List of Authors:	Sheehan, Rory; University College London, Division of Psychiatry HASSIOTIS, ANGELA; University College London, Division of Psychiatry Strydom, André; Institute of Psychiatry Psychology and Neuroscience Morant, Nicola; University College London, Division of Psychiatry
<b>Primary Subject Heading</b>:	Mental health
Secondary Subject Heading:	Qualitative research
Keywords:	intellectual disability, psychotropic medication, QUALITATIVE RESEARCH, shared decision making

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**TITLE PAGE****Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multi-stakeholder qualitative study in the UK**

Dr Rory Sheehan, MSc, Division of Psychiatry, University College London

Professor Angela Hassiotis, PhD, Division of Psychiatry, University College London

Professor André Strydom, PhD, Institute of Psychiatry, Psychology and Neuroscience, King's College London

Dr Nicola Morant, PhD, Division of Psychiatry, University College London

**Corresponding author details**

Dr Rory Sheehan

Division of Psychiatry, University College London, 6<sup>th</sup> Floor Maple House, 149 Tottenham Court Road, London W1T 7NF

Telephone: 0207-679-9201

E-mail: r.sheehan@ucl.ac.uk

**Word count**

7,137

**Number of figures and tables**

1 table

1 figure

**Keywords**

Intellectual disability; psychotropic medication; qualitative research; shared decision making

## **ABSTRACT**

### **Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multi-stakeholder qualitative study in the UK**

**Objectives** Understanding patient and carer perspectives is essential to improving the quality of medication prescribing. This study aimed to explore experiences of psychotropic medication use among people with intellectual disability (ID) and their carers, with a focus on how medication decisions are made.

**Design** Thematic analysis of data collected in individual semi-structured interviews.

**Participants and setting** Fourteen adults with ID, twelve family carers, and twelve paid carers were recruited from specialist psychiatry services, community groups, care providers, and training organisations in the UK.

**Results** People with ID reported being highly compliant with psychotropic medication, based on a largely unquestioned view of medication as important and necessary, and belief in the authority of the psychiatrist. Though they sometimes experienced medication negatively, they were generally not aware of their right to be involved in medication decisions. Paid and family carers reported undertaking a number of medication-related activities. Their 'front-line' status and longevity of relationships meant that carers felt they possessed important forms of knowledge relevant to medication decisions. Both groups of carers valued decision-making in which they felt they had a voice and a genuine role. While some in each group described making joint decisions about medication with psychiatrists, lack of involvement

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3 was often described. This took three forms in participants' accounts: being uninformed of  
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5 important facts, insufficiently included in discussions, and lacking influence to shape  
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7 decisions. Participants described efforts to democratise the decision-making process by  
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9 gathering information, acting to disrupt perceived power asymmetries, and attempting to  
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11 prove their credibility as valid decision-making partners.  
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16 **Conclusions** Stakeholder involvement is a key element of medication optimisation that is  
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18 not always experienced in decisions about psychotropic medication for people with ID.  
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20 Forms of shared decision-making could be developed to promote collaboration and offer  
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22 people with ID and their carers greater involvement in medication decisions.  
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## STRENGTHS AND LIMITATIONS OF THIS STUDY

- This is the first multi-stakeholder study of patient, family carer, and paid carer experiences of psychotropic medication use and the decision-making processes surrounding this for people with intellectual disability.
- Adaptations to qualitative methodology were made that allowed us to obtain meaningful data from people with intellectual disability.
- Using in-depth qualitative methods allowed us to develop a nuanced understanding of the relational and power dynamics underpinning decision-making about psychotropic medication.
- The views of prescribers and other health professionals are not included in this report.
- Those with limited or no verbal ability were not able to take part.

## **MANUSCRIPT**

### **Experiences of psychotropic medication use and decision-making for adults with intellectual disability: a multi-stakeholder qualitative study in the UK**

#### **INTRODUCTION**

Up to 2% of the global population live with intellectual disability (ID), a lifelong condition characterised by significant deficits in cognitive and adaptive function with early onset.<sup>1, 2</sup> A combination of biological, psychological, social, and developmental factors contribute to a high rate of mental disorder in this group.<sup>3</sup> Recent evidence from epidemiological studies conducted across jurisdictions confirms that people with ID are often prescribed psychotropic medication, in many cases in the absence of a diagnosis for which it is indicated.<sup>4-9</sup> Psychotropic polypharmacy,<sup>10-13</sup> high doses,<sup>11</sup> and increased susceptibility to adverse side-effects<sup>14, 15</sup> are also significant concerns. Thus, people with ID are a key group in whom efforts to improve psychotropic prescribing are required. In England, a national programme, Stopping the Over-Medication of People with ID (STOMP), has been established to reduce inappropriate use of psychotropic medication.<sup>16</sup> Co-produced with people with ID, the programme aims to raise awareness of the issue, develop resources for patients and carers, and act as a stimulus for practice change.<sup>17</sup>



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3 Medication optimisation is a multi-faceted approach to improving the use of prescribed  
4 medication with the aim of enhancing clinical outcomes, improving safety and reducing  
5 waste.<sup>18</sup> While deprescribing (reducing or discontinuing inappropriate medication) may be  
6 one element of optimisation, improving the quality of medication use requires more than a  
7 sole focus on quantitative measures. Understanding people's experience of medication and  
8 encouraging partnership between professionals and patients are also important  
9 components of successful medication optimisation.<sup>18, 19</sup> As such, there are clear overlaps  
10 with several broader ideals and principles that are increasingly embedded in healthcare  
11 policies and clinical guidelines across health and social care internationally, including  
12 person-centred care, personalised medicine, and shared decision making (SDM). In relation  
13 to how decisions are reached about treatment options or courses of action, including use,  
14 choice and dose of medication, SDM seeks to replace traditional, paternalistic models with  
15 more collaborative approaches to treatment decisions where expertise and responsibility  
16 are owned jointly by the health professional and the patient.<sup>20</sup> The aims of SDM are  
17 congruent with longstanding UK government strategy to increase the inclusion and support  
18 the autonomy of people with ID in healthcare decisions and more generally.<sup>21</sup> As well as  
19 being an ethical ideal, evidence suggests that SDM is associated with a range of measurable  
20 benefits including improved understanding, patient satisfaction, and trust.<sup>22, 23</sup>

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51 However, evidence indicates that people with ID may not routinely be placed placed at the  
52 centre of healthcare decisions<sup>24</sup> and carers of people with ID have reported that their views  
53 are not heard or that they are insufficiently involved by services.<sup>25, 26</sup> The literature relating  
54 specifically to psychotropic medication in people with ID is less developed, though a small  
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3 body of evidence shows that both people with ID and their carers often lack knowledge  
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5 about psychotropic medication and experience few opportunities for involvement in  
6  
7 medication decision-making.<sup>27-30</sup> It remains unclear how, and to what extent, the principles  
8  
9 of SDM are applied in psychotropic medication decisions in contemporary UK settings.  
10  
11 Additionally, how and between whom decisions are 'shared' in the clinical context of ID  
12  
13 needs further exploration, as there are often multiple stakeholders in the form of family  
14  
15 carers and those with paid caring responsibilities. In this study, we sought to explore the  
16  
17 experiences and expectations of adults with ID and paid and family carers regarding  
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19 psychotropic medication use, and how decisions about this are made with healthcare  
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21 professionals.  
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## 31 **METHODS**

### 32 33 34 35 36 37 **Participants and setting**

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43 People were eligible to participate if they were, adults ( $\geq 18$  years) with ID who were  
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45 currently prescribed psychotropic medication and were under the care of a specialist  
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47 psychiatry of intellectual disability team, family carers of adults with ID who had been  
48  
49 prescribed psychotropic medication, or paid carers who worked with adults with ID and who  
50  
51 had experience of supporting people with psychotropic medication. Paid carers may have be  
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53 employed in a variety of settings including residential homes, supported living projects, or  
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3 as peripatetic community support workers. Psychotropic medication was defined as any  
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5 drug listed in the British National Formulary as being used for mental health disorders.<sup>31</sup>  
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11 The study was conducted in the south-east of England. Two methods of recruitment were  
12  
13 used. In one, a leaflet advertising the research was offered to potential participants (people  
14  
15 with ID, family carers, paid carers) by clinicians at appointments with specialist psychiatry of  
16  
17 intellectual disability services within the National Health Service (NHS). These clinicians  
18  
19 made a first assessment of eligibility to take part in the research. The other recruitment  
20  
21 method included short presentations by researchers to community third-sector (i.e. non-  
22  
23 statutory), care provider, and training organizations, with leaflets about the research also  
24  
25 available. After hearing about the research, the contact details of those who showed an  
26  
27 initial interest in taking part were passed to the research team, either directly from the  
28  
29 person themselves or, with permission, via clinical staff. Potential participants were then  
30  
31 contacted and eligibility was confirmed by liaison with people with ID and/or carers prior to  
32  
33 interviews being held. The cognitive ability of potential participants with ID was not formally  
34  
35 tested. Capacity to consent to taking part in the research was assessed immediately before  
36  
37 the interview as part of the procedure of obtaining valid informed consent. This process was  
38  
39 undertaken in accordance with the principles of the Mental Capacity Act<sup>32</sup> by a researcher  
40  
41 with professional experience and training in assessing capacity. It was made clear to  
42  
43 participants that their contribution was voluntary, that they could decline to take part  
44  
45 without prejudice, and they may end an interview at any time. Written consent was  
46  
47 received from all participants before interviews were conducted. Purposive sampling was  
48  
49 used to select participants with a range of characteristics that may be related to medication  
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3 views and experiences. For people with ID this included age, gender, ethnic group,  
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5 indication for psychotropic medication and medication class; for family carers, age, gender,  
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7 ethnic group, degree of ID in their relative, indication for and class of medication; and for  
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9 paid carers, age, gender, ethnic group, duration working with people with ID, and seniority.  
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17 People with ID and family carers were given a £20 shopping voucher as a token of  
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19 appreciation for donating time to the study. Paid carers were provided with a certificate  
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21 thanking them for their contribution.  
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### 28 **Ethical approval**

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34 The study was approved by the London-Surrey NHS Research Ethics Committee (reference  
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36 17/LO/1365). Local Research and Development approvals were obtained prior to any  
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38 research activities being undertaken.  
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### 45 **Data collection**

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51 Baseline demographic and descriptive data were collected by participant report; we did not  
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53 cross-check these with other sources of information. Qualitative data were collected in  
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55 audio-recorded individual in-depth semi-structured interviews conducted by the first  
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57 author, who is a psychiatrist and clinician researcher with experience of working with  
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3 people with ID and an academic interest in medication use. He did not have any other  
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5 contact with participants. All interviews were conducted face-to-face. Participants were able  
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7 to bring other people to their interview, if they wished, and interviews were held at a time  
8  
9 and place preferred by participants. A topic guide with open-ended questions was  
10  
11 developed and used to provide a broad structure to the interviews whilst allowing points of  
12  
13 interest to be pursued as they arose. Interview topics included, people's experiences of  
14  
15 using psychotropic medication, discussions medication with health professionals, and how  
16  
17 decisions about medication are made (see supplementary material). Paid carers reported  
18  
19 experiences and attitudes formed from supporting several different people. We adopted a  
20  
21 flexible approach to interviews with people with ID in order to facilitate their involvement,  
22  
23 including adapting the depth of questioning as appropriate to their ability.<sup>33</sup> All study  
24  
25 materials for people with ID were available in 'easy-read' format and laminated picture  
26  
27 cards were used (where appropriate) as prompts and to orientate interviewees. Checking  
28  
29 and summarising content throughout the interviews gave opportunity for clarification and  
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31 elaboration. Reflective field notes were made to supplement the transcripts and assist with  
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33 reflexive practice and data analysis.  
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## 46 **Analysis**

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52 Descriptive data were summarised and tabulated. Audio-recorded interviews were  
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54 transcribed verbatim by the first author, anonymised, and the transcripts checked for  
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56 accuracy. As a research team we are interested in medication optimisation for people with  
57  
58 ID and in how shared decision-making processes can impact this. Given the relative lack of  
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3 literature in the field, thematic analysis was used with an inductive orientation in which  
4  
5 themes were derived from the data.<sup>34</sup> Transcripts from each group of participants were  
6  
7 analysed concurrently to build a unifying coding frame that was developed in an iterative  
8  
9 process as additional transcripts were analysed. Independent coding of a subset of six  
10  
11 transcripts by members of the research team early in the analytic process, regular discussion  
12  
13 of emerging themes and the conceptual coherence of the findings, and reflexive memos  
14  
15 were used to enhance integrity of the analysis. NVivo qualitative data analysis software  
16  
17 (QSR International Pty Ltd. Version 12, 2018) was used to manage the data and facilitate the  
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19 analytic processes.  
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### 29 **Patient and public involvement**

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35 The development of the recruitment strategy, and the design of participant materials and  
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37 the interview topic guide were informed by discussions with a consultation group consisting  
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39 of people with ID employed for this work, some of whom had lived experience of mental  
40  
41 illness, psychotropic medication use, and contact with mental health services. The group will  
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43 assist with future targeted dissemination activities to the participants with ID, their families  
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45 and prescribers.  
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## 53 **RESULTS**

### 54 **Sample**

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Thirty-eight people (14 adults with ID; 12 family carers; 12 paid carers) were recruited between December 2017 and May 2018 (table 1). Twenty-nine were recruited from clinical services and nine from third-sector organizations. 18 interviews were completed at peoples homes (10 people with ID; 8 family carers), 12 (all paid carers) at their place of work, 7 (3 people with ID; 4 family carers) at a university, and 1 (person with ID) at a community centre. Seven participants with ID preferred to have a companion with them in the interview (in 6 cases this was a relative, in 1 case a professional advocate).

Participants with ID reported having been diagnosed with a range of psychiatric disorders and most had been prescribed psychotropic medication for many years and in some cases for decades. None of those who participated were under a legal framework of care (e.g. Community Treatment Order or Guardianship Order).

	People with ID (n=14)	Family carers (n=12)	Paid carers (n=12)
Mean age (SD, range)	46.1 years (12.9, 25-68)	62.7 years (10.5, 42-80)	39.4 years (9.5, 24-55)
Sex (M:F)	9:5	3:9	6:6
Ethnic group	White n=8 Black n=2 Asian n=3 Other/mixed n=1	White n=8 Black n=1 Asian n=3 Other/mixed n=0	White n=7 Black n=3 Asian n=2 Other n=0
Degree of ID <sup>1</sup>	Mild n=12 Moderate n=2	Mild n=6 Moderate n=4	N/A <sup>3</sup>

		Severe-profound <i>n</i> =2	
Relationship to person with ID / professional title	N/A	Parent <i>n</i> =10 Other relative <i>n</i> =2	Support worker <i>n</i> =8 Managerial responsibility <i>n</i> =4
Mean time working with people with ID (SD, range)	N/A	N/A	9.4 years (9.0, 0.5-25)
Current living arrangements	Independent <i>n</i> =3 With family <i>n</i> =5 Shared supported living <i>n</i> =6	With family member with ID <i>n</i> =9 Separately from family member with ID <i>n</i> =3	N/A <sup>2</sup>
Self-reported psychiatric diagnosis <sup>1,4</sup>	Severe mental illness <sup>3</sup> <i>n</i> =6 Depression <i>n</i> =6 Anxiety disorder <i>n</i> =5 Other <i>n</i> =2	Severe mental illness <sup>3</sup> <i>n</i> =4 Depression <i>n</i> =4 Anxiety disorder <i>n</i> =6 Other <i>n</i> =0	N/A <sup>2</sup>
Autism <sup>1</sup>	<i>n</i> =3	<i>n</i> =5	N/A <sup>2</sup>
Prescribed medication by group <sup>1,4</sup>	Antipsychotic <i>n</i> =9 Mood stabiliser <i>n</i> =3 Anti-depressant <i>n</i> =9 Other <i>n</i> =3	Antipsychotic <i>n</i> =10 Mood stabiliser <i>n</i> =2 Anti-depressant <i>n</i> =9 Other <i>n</i> =4	N/A <sup>2</sup>
Mean duration of psychotropic use (SD, range) <sup>1</sup>	16.8 years (14.0, 3-50)	13.6 years (8.0, 1-27)	N/A <sup>2</sup>
Mean interview duration (SD, range)	24 minutes (9.0, 11-38)	38 minutes (10.9, 19-55)	47 minutes (11.9, 31-73)

ID, intellectual disability; SD, standard deviation; N/A, not applicable

<sup>1</sup>Information provided by family carers relates to the person with ID they cared for

<sup>2</sup>Data for paid carers were not collected as each paid carer worked with more than one individual with ID

<sup>3</sup>Severe mental illness includes schizophrenia spectrum disorders and bipolar affective disorder

<sup>4</sup>Cell total exceeds the number in each group as people were able to report more than one diagnosis and may have been prescribed medication from more than one psychotropic class



**Table 1** Sample characteristics**Thematic analysis**

We developed three major themes in our analysis of the data, and present these in each sub-section below. The first theme, medication beliefs and experience, describes the meanings that people give to psychotropic medication, and how these can develop over time. The second theme, carer role, draws mainly on the interviews with paid and family carers to describe how the carer identity is constructed and how caring activities are performed. Together, these themes provide context to the third major theme about decisional processes, in which the lived experiences of different stakeholders in the medication decision-making process are explored, including the dynamics and struggles that sometimes characterised interactions with prescribers. Throughout the analysis we aim to provide a sense of the data by using quotes from anonymised participants who were given a number prefixed with ID (person with ID), FC (family carer), or PC (paid carer).

**Medication beliefs and experience: acceptance and ambivalence**

We developed this theme predominantly from interviews with people with ID and family carers as we found that paid carers were generally more hesitant in offering their personal opinions about medication. In this theme, passive compliance of the person with ID

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2  
3 emerged, founded on relatively limited understanding of medication, yet a strong sense of  
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5 faith in medication and trust in the doctor. For family carers psychotropic medication was an  
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7 emotive topic and many were ambivalent about its use. A minority of paid carers expressed  
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9 concerns about inappropriate psychotropic use.  
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17 People with ID tended to focus on the tangible aspects of psychotropic medication (the  
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19 taste, colour, and size of tablets) and the set of 'rules' that constituted their current  
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21 medication routine, for example, *"I take [the tablets] at night-time, the little mauve ones,*  
22  
23 *my big yellow ones, and my little white sleeping tablet"* (ID05). There was a tacit belief in  
24  
25 medication as important and necessary, even though in many cases understanding of the  
26  
27 indication for medication and its potential effects was limited. Most people with ID  
28  
29 characterised medication benefits in vague or generic terms (e.g. *"[medication] gets me*  
30  
31 *better"* (ID01); *"it's helpful...for my health"* (ID09); *"keeps me steady"* (ID13)), whilst  
32  
33 describing adverse side-effects using more immediate and vivid language (the most  
34  
35 commonly mentioned were sedation, weight gain, and movement side-effects):  
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45 *"My speech got slurred...really terrible and slurred. I just couldn't get the words out"*  
46  
47 (ID07)  
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50 *"I felt groggy...like I feel like a cabbage sometimes"* (ID08)  
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56 The perceived consequences of not taking medication were often described as frightening  
57  
58 and unpredictable and included being out-of-control or *"a danger"* (ID10). Some feared they  
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3 would “*probably end up back in hospital*” (ID13) if they stopped medication, experiences of  
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5 which (in those who had previous admissions) were universally negative and acted as a  
6  
7 strong motivator to keep well, which people equated with medication compliance. Although  
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9 a minority of people with ID did express more critical views about medication or declared  
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11 that they did not like taking it, none seriously questioned its use or believed there was an  
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13 alternative:  
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22 *“I don’t want to take it...I don’t like taking it, but I have to”* (ID04)

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25 *“I don’t like taking medication at the best of times, but I know I’ve got to take it”*  
26  
27 (ID10)  
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34 Given the length of time that most family carers had been managing medication (average  
35  
36 >13 years), they tended to describe their experience as a journey and their narrative was  
37  
38 often recounted with a strong emotional overlay. Many recalled that medication was first  
39  
40 prescribed during a mental health crisis. In these difficult and stressful circumstances, which  
41  
42 sometimes impacted their own mental health, family carers could find it difficult to make a  
43  
44 confident decision about medication; the imperative to act being set against a fear of  
45  
46 psychotropic drugs and their possible side-effects:  
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55 *“In the beginning I was terrified about medication, the side-effects and everything.*  
56  
57 *And also her [daughter’s] condition...It’s a really dangerous medication...I read lots of*  
58  
59 *information and went on the internet, and it said lots about side-effects...But I didn’t*  
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3 *have any way out...I was really worried and couldn't make the decision" (FC08)*  
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9 Initial reticence was often overcome when the beneficial effects of medication were  
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11 observed and family carers could undergo quite major shifts in attitude:  
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17 *"I'd always been quite resistant [to medication] because I'd heard about chemical*  
18 *coshes and all that stuff...I thought '[son] doesn't need a psychotropic'...but he went*  
19 *onto a very low dose and it noticeably helped...Now I'm at a stage of the psychiatrist*  
20 *thinking we should reduce the dose, and I'm really resistant to that because it feels so*  
21 *helpful" (FC02)*  
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33 Others' longer-term experience of medication was less favourable. In these cases  
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35 medication was variously described as ineffective, only temporarily effective (the positive  
36 effects *"wearing off"* (FC01) over time was a common complaint), or blighted by adverse  
37  
38 physical side-effects. The potential of psychotropic medication to dull people's cognitive  
39  
40 faculties was expressed in various terms (e.g. *"[relative] was almost like a dead person...the*  
41 *drugs [meant] she was moving away from us...becoming a non-person" (FC12); "they have*  
42 *this vacant kind of look...staring into the horizon" (PC01) "a sledge hammer treatment"*  
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(PC07)). Fears about psychotropic medication were occasionally juxtaposed against the  
sensitivity and exceptionality of the person with ID:

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3 *“Sometimes I don’t think these tablets are for people with autism and learning*  
4 *disabilities at all, you know? That’s not the answer...if there’s no cure, why are you*  
5 *giving all this medication?” (FC03)*  
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14 Some carers spoke of witnessing multiple medication changes and had come to view  
15 medication with scepticism, as unpredictable (*“like taking pot luck”* FC09) or even an  
16 *“experiment”* (FC08 & FC12). Other concerns about medication included medication being  
17 used too readily (*“[the doctors are] very quick to put them on but very slow to take them off”*  
18 FC06); the absence of alternative, psychosocial interventions which were often considered  
19 more appropriate but unavailable due to resource constraints (*“other things can cost*  
20 *money...so sometimes it’s a control medication”* PC06). Considering these concerns, for many  
21 carers psychotropic medication use was an ongoing source of tension and unease:  
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37 *“I’m not happy with medication...The prescription is easy to write out...but*  
38 *medication might not be for [son] at all, for what’s wrong with him, and they’re*  
39 *writing out prescriptions all the time...He’s got no other support around these*  
40 *issues...it’s always just medication...not enough, err, not enough maybe talking*  
41 *therapy...I think there should be more done than there is” (FC03)*  
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53 *“Hopefully [relative will need] less medication in the future...I’m worried about the*  
54 *side-effects but also that she will become unwell if she stops [medication]...it’s*  
55 *difficult, I don’t know what will happen. There could be many problems” (FC07)*  
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### Carer role: the “front-line people”

In describing their roles in caring for a person with ID, both paid and family carers placed substantial importance on knowing and being close to the person, and the privilege that this gave them in evaluating their wellbeing. Carers also spoke of their role as advocates, ensuring that processes are centred around the person with ID and their interests are upheld.

In relation to psychotropic medication, in addition to practical, daily tasks such as collecting, storing, and giving medication to the person with ID, both family and paid carers explained their “integral” (PC02) role in monitoring and managing people’s health. Carers described themselves as “the front-line people,” (PC01) a unique position which gave them intimate knowledge of the person with ID and was contrasted with “short and limited” (PC05) meetings with medical professionals. Knowing the person with ID closely and over time was seen as important in view of the range of problems that were described amongst the group they supported (including physical illness, developmental disabilities, mental illness and/or behavioural problems). Given this complexity, carers perceived value in their ability to interpret subtle signs and to “build up a picture of that person and how medication interacts with them” (PC02). Family carers, in particular, described an intuitive sense of ‘knowing’ the needs of their relative:

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3           *"I've always had to deal with [son] not being verbal and not being able to tell me, so I*  
4           *had to read him by body language all through his life. I'm aware of the signs...I know*  
5           *if he has an infection in his nose, in his ears. I know if he has a headache...if he's not*  
6           *OK...I already know"* (FC04)  
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17 Carers often took a 'gatekeeping' role in determining when to seek professional advice, and  
18 in mediating interactions between the doctor and the person with ID thereafter. Family and  
19 paid carers diverged slightly in how they positioned themselves during medical  
20 appointments. Family carers described taking a more direct approach in speaking with the  
21 doctor and acting on behalf of their relative, including, for example, one mother who  
22 attended appointments with the psychiatrist while her son waited outside the room. Paid  
23 carers, meanwhile, framed their input as *"empowering"* (PC09) and facilitating the person  
24 with ID to speak for themselves, so that *"if there's something the service user wants to say, I*  
25 *can make sure it happens"* (PC04) while preferring to take more of a *"back seat"* (PC06).  
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43 Several carers spoke about a process of *"translating"* (PC09) information between the  
44 doctor and the person with ID, again drawing on their familiarity of the person with ID in  
45 order to relay information in an individualised and more understandable way. This role  
46 often incorporated *"preparing the service user for the appointment and explaining in a very*  
47 *clear way what might happen"* (PC04) and afterwards, reflecting with and educating the  
48 person with ID after the appointment:  
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*"[My relative] usually says [to the psychiatrist] "it's best if you explain this to my mum or sister because they're good at explaining it to me"" (FC08)*

*"I always get questioned by my clients "What's this pill? What's that pill?" What I've done for my key clients is I've made a list of all the medication, and I did it in easy read....and I've got a table of what they do with picture...if they ever ask me what happens, I just show them and go through it with them...I will stick it up on the fridge to familiarise people with it." (PC05)*

In summary, carers viewed their role with respect to medication as both broad in scope and vital to the life of the person they supported:

*"I understand that sometimes I come across overbearing, nosey, and always getting involved...but I do believe, and this is a firm belief, if I was not behind [son] and asking for him, demanding for him... he would be in a worse place now, mentally... If he didn't have me he would definitely be worse off in all sorts" (FC09)*

## **Decisional processes relating to psychotropic medication**



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3 In this section we describe the forms of involvement that people with ID, their family carers,  
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5 and paid carers experienced and desired in medication decisions, and their feelings and  
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7 responses when these differed from the decisional processes they experienced.  
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### 10 11 12 13 14 **a) Power dynamics** 15 16

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20 There was a common assumption across stakeholder groups that the psychiatric  
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22 appointment was the nexus of medication decisions and that the psychiatrist has the  
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24 “ultimate power” (FC02) and “final say” (PC08) in medication decision-making. Interviewees  
25  
26 did not express a desire to challenge this, viewing the psychiatrist as “the expert” (FC11)  
27  
28 who “knows best” (ID10) and “does the best for everyone who’s sick” (FC07). In cases where  
29  
30 people did not share the psychiatrist’s opinion on medication, they relatively quickly  
31  
32 deferred (“the medical profession probably know better....I come on-board” (PC06)) and  
33  
34 would not act alone to change medication:  
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43  
44 *“I wouldn’t [change medication] because then if anything happened I’d be the one to*  
45  
46 *blame. It says in the leaflet ‘do not stop medication unless you speak to your*  
47  
48 *doctor’...sometimes I feel like doing it and I think to myself, ‘no, I’ll leave it and talk to*  
49  
50 *[the psychiatrist] first’...they know better than we do” (FC03)*  
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3 For many with ID the authority of the doctor was seen to be absolute and left little room for  
4  
5 their own agency. Based on their lived experience, medication decisions were a part of life  
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7 over which could exert little influence:  
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13  
14 *"I have to take my medication, I ain't got no choice...It's the doctor's orders to keep*  
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16 *on the medication...there's not a lot you can do about it"* (ID11)  
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23 *"It's the doctor's decision [about medication]...it's up to them"* (ID01)  
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29 Some people with ID were satisfied with the psychiatrist assuming control over medication  
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31 decisions:  
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38 *"Doctors should make the decisions about medicine...they have more experience...[I*  
39  
40 *prefer to] leave it to the doctor"* (ID14)  
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46 However others (generally those with more mild ID) wanted to be involved in the process  
47  
48 (e.g. *"Explain what [the medication] is supposed to do...Tell me what's going on!"* ID06).

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51 Congruent with these wishes, there were some descriptions of shared medication decisions.

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54 One woman with ID, for example, described how she had jointly reached a decision about  
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56 reducing her medication, explaining that *"[it was] my idea...and theirs [the doctors'] too"*  
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58 (ID04).  
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6 The desire of both paid and family carers to be involved in medication discussions and  
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8 decisions was more obvious and evident through their depictions of both positive and  
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10 negative experiences of medication decision-making across time and between clinicians.  
11  
12  
13 Positive experiences of medication decision-making were described as collaborations,  
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15  
16 *“partnerships”* (FC02 & PC02) and *“negotiations”* (PC08) and participants often made  
17  
18 reference to having a good working relationship with the psychiatrist. In these accounts,  
19  
20 people valued *“open discussion”* (PC09), being given *“time to talk”* (FC10), invited to give  
21  
22 their opinion, and being *“welcomed”* (PC12) and *“taken seriously”* (FC02) when doing so:  
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30 *“It’s been a really good partnership trying to get [service user] on the right*  
31  
32 *medication...It’s worked really well...I went along to see the psychiatrist, spoke to him*  
33  
34 *about my concerns...and then he very quickly sent appointments through to see*  
35  
36 *them. And I thought, ‘wow, he listened, took it on board, called those people in,*  
37  
38 *reviewed their medication’... The psychiatrists have been very tolerant, very patient*  
39  
40 *and have listened to what we’ve been saying... So it can work”* (PC02)  
41  
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48 *“A lot of doctors are open to discuss...they ask the [patient] and they ask me...and*  
49  
50 *they listen”* (PC06)  
51  
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56 *“[The doctor] was utterly supportive [and] took seriously what I’d said, so I trusted*  
57  
58 *her...She suggested medication...it was made very clear to me what the long-term*  
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3 *side-effects are...I wanted to give it a try, see how it goes. [I felt] no pressure...I think*  
4  
5 *the professionals are very good at consulting” (FC02)*  
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12 Conversely, being excluded from decisions about medication could take an emotional toll,  
13  
14 especially on family carers who described feeling “*annoyed*” (FC05), “*frustrated*”  
15  
16 (FC04&FC08), “*angry*” (FC12&FC08), or isolated:  
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23 *“It’s always a bad experience when you’re not involved...I wasn’t in control of*  
24  
25 *anything really, and there was no-one out there I could turn to” (FC11)*  
26  
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31 *“It’s been extremely stressful...When you find out somebody’s been fiddling [with*  
32  
33 *medication] behind your back and you haven’t known about it” (FC05)*  
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#### 40 ***b) Efforts to democratise medication decisions***

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46 From respondents’ accounts of how medication decisions were made, we identified three  
47  
48 related elements of decision-making. These were being informed, being included, and  
49  
50 having influence (figure 1). In any one of these processes, patients and carers could find  
51  
52 themselves marginalised. Many paid and family carers, and a smaller number of  
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54 respondents with ID, described making efforts to change the dynamics of medication  
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56 decisions with strategies aimed at democratising each of these elements.  
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6 **[Figure 1]** [Elements of involvement in medication decisions described by participants –  
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8 NEAR HERE]  
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14 A pre-requisite to involvement in the decision-making process was to be **informed** about  
15 medication, yet several people with ID could not recall that medication was ever spoken  
16 about by their doctor (*"I don't think [the psychiatrist] talks about medication...I ain't got a*  
17 *clue"* (ID02)). These experiences reinforced a sense of powerlessness as medication  
18 decisions were perceived to *"just happen"* (ID01). Both paid and family carers reported  
19 lacking information (*"hardly ever told when people switch medication"* (PC09))and  
20 sometimes *"not knowing what's going on"* (FC05). Paid carers, particularly those working in  
21 larger organisations in which numerous people with ID were supported, worried that being  
22 *"out of the loop"* (PC12) left them *"ill-equipped and dangerously exposed"* (PC11), at once  
23 responsible for medication administration and monitoring yet without vital information of  
24 drug changes, doses, or effects.  
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45 In response, both family and paid carers, and occasionally people with ID, had made  
46 attempts to improve their knowledge about medication (and alternative treatments) by  
47 seeking information independently from a variety of sources, including medication leaflets,  
48 television, internet, news media, carer networks, colleagues, and formal training courses.  
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55 People with ID were often reliant on carers to help them gain further information:  
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3                    *“My sister can come, we can look up what [the medication’s] supposed to do so at*  
4  
5                    *least I get a better picture” (ID06)*  
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12   Acquiring knowledge was reported by participants to improve their confidence and go some  
13  
14   way to meet and respond to the technical expertise of the psychiatrist. Many people with  
15  
16   ID, and some carers, however, could struggle with accessing appropriate information and  
17  
18   were left in a relatively less powerful position as a result. None of the participants  
19  
20   mentioned having used accessible medication information.  
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23

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28                    *“Because I’ve got the learning difficulties, I’m not able to understand a lot...I’m not*  
29  
30                    *very good with a lot of the terms and conditions on there. It’s really hard for me to*  
31  
32                    *read one of those [medication information] leaflets...I don’t know much about it so I*  
33  
34                    *can’t say yes and I can’t say no” (ID10)*  
35  
36  
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41                    *“Me myself is not very good in asking questions or understanding everything, so I just*  
42  
43                    *leave it...I can’t go on the internet...I’m not very good in reading and writing, I don’t*  
44  
45                    *understand everything, so that’s why I don’t bother” (FC07)*  
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52   Respondents in all groups had experience of being nominally present when medication  
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54   decisions were made but not **included** in discussions in a meaningful sense, and reported  
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56   having little to no opportunity to voice their concerns:  
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*“They said “you will be going on an anti-depressant.” I didn’t know the name, then it all went cold....the next thing I knew it was in my blister pack and I’ve been taking it ever since” (ID06)*

*“I don’t think my opinion was asked...I was in the review but I wasn’t asked the big questions about treatment” (PC10)*

Family and paid carers spoke of trying to shape the discourse in conversations with the psychiatrist and needing to have confidence to challenge their authority in order to ensure their views were heard. One relative described her assertive approach as *“not muck[ing] about...If I think the doctor’s wrong, I tell ‘em, just like that” (FC01)*. Sometimes a dramatic *“bust up” (FC09)* or *“battle” (FC12)* with the clinical team was considered necessary and could ‘reset’ the interaction in favour of a greater role for the family carer in medication decisions. At other times tenacity and *“pushing to be involved” (PC09)* spoke of ongoing effort to develop and maintain involvement:

*“I always have to be chasing. I’m still chasing now...It shouldn’t be like that, but that’s the way it works...I think [the doctors] respect me more after, I kind of, put my foot down” (FC04)*

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3 Paid carers tended to avoid overt conflict. Instead they often relied on their accumulated  
4  
5 knowledge of the healthcare system to navigate to a position where they stood the greatest  
6  
7 chance of being heard. One paid carer described the strategy involved in arranging an  
8  
9 appointment with the psychiatrist:  
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17 *“I’ll have to write [to the psychiatrist] and copy in the GP...I’ll have to be quite forceful*  
18  
19 *about it. And then I’ll actually ring [the psychiatrist] and I’ll follow it up with an e-*  
20  
21 *mail...We can ring the learning disability [team] secretary because we’ve got a very*  
22  
23 *good relationship with her...I will actually sometimes say to her, “it’s quite a complex*  
24  
25 *case this is, it’s probably worth us seeing the consultant”” (PC08)*  
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33 The final element to being involved that was described by respondents was the ability to  
34  
35 **influence** decisions about medication. This constituted moving beyond merely exchanging  
36  
37 information to becoming a meaningful collaboration partner, whose opinions were heard  
38  
39 and shaped decisions. Although there were clear instances where this had been achieved,  
40  
41 all three stakeholder groups described situations in which this had not happened. Some also  
42  
43 described strategies they had used in attempts to increase their decisional influence.  
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51 The minority of people with ID who had attempted to assert themselves were generally not  
52  
53 successful in gaining the greater involvement and influence they wanted. In response to  
54  
55 questioning their medication, some people with ID described receiving evasive answers that  
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57 served solely to reinforce the importance of taking medication as directed:  
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*"I just get ignored, I feel like I'm getting ignored...when I say something about [medication], it's basically 'you just have to take the medication'" (ID08)*

*"Sometimes I do [talk to the doctor about medication] but they tend to, like, they say "we can't really say nothing because you've got to take it" and they don't really say why" (ID10)*

One described having recruited a carer to advocate on their behalf but it was more common for people with ID to quickly acquiesce:

*"I don't get heard out properly... [The doctor says] "Is [the medication] keeping you right?" and I just say "yeah", but I don't think it is. But I don't want to argue. I don't want to argue with them so I just say "yeah, it works on me"...I've asked [the psychiatrist] before to [change medication] but she wouldn't let me so I just let [the psychiatrist] get on with it...I just don't say nothing 'cos I feel like I'm not heard out" (ID08)*

Similarly, some carers reported that their concerns had been *"not believed"* (FC09) or *"dismissed as trivial and unimportant"* (PC09). Having proposed their own ideas about medication, some carers reported being given a sense that it was not their place to do so:

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*"The consultant was like "you're talking rubbish"...it was like, 'what does she know?'"*

(PC02)

*"I suggested a medication which had been mentioned previously and I had looked up the research on it. It's something that's very useful for people with high levels of anxiety and I thought it might be worth trying but umm... there was a small flicker and then, like, "no, I don't think so, where did you hear about this?" sort of thing"*

(FC05)

Such experiences were reported to have contributed to family carers becoming burnt-out and resigning themselves to a subordinate position with respect to medication decisions. After what she described as a long and turbulent relationship with her relative's care team, one mother reluctantly stepped back from taking a more active role in treatment decisions, stating *"we're [now] leaving it to them, I think that's the best way"* (FC06).

Given their perception of being 'low ranked' in the hierarchy of stakeholders (*"just a provider"* (PC08) and *"not seen as a professional or intellectual resource"* (PC11)), paid carers often felt the need to prove the credibility of their knowledge in order to be heard and have influence. Investing in the relationship with the psychiatrist was felt to make this easier (*"because they know me, they know my information is really important"* (PC05)), and paid carers sometimes sought legitimacy by presenting themselves as objective, collecting

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3 data, and taking “a paper trail ... [of] evidence” (PC08) to appointments to support their  
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5 views.  
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## 10 11 **DISCUSSION**

### 12 13 14 15 16 17 18 **Principal findings**

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24 This qualitative study has enabled us to gain a deep understanding of the views and  
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26 experiences of people with ID and their carers about psychotropic drug use and decision-  
27  
28 making. Though highly topical given the prevalence of psychotropic prescribing in this  
29  
30 group, the subject has been relatively little studied using qualitative approaches. The  
31  
32 inclusion of multiple stakeholders adds an additional dimension to medication decision-  
33  
34 making which we have been able to explore. . Although preferences for involvement varied  
35  
36 between individuals, most participants in our study valued having a place in decision-  
37  
38 making. Experiences that were not aligned with expectation of involvement could lead to a  
39  
40 range of emotional responses and prompt various efforts to gain position and influence.  
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50 People with ID reported having few opportunities to become involved in the psychotropic  
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52 medication decision-making process. Only a minority described consciously ceding control  
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54 to others, with most either unaware they were entitled to a role in deciding medication, or  
55  
56 having been unsuccessful in involving themselves despite their efforts. Lack of knowledge  
57  
58 about medication, a strong belief in medication as necessary and important, fear of the  
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3 consequences of not taking medication (particularly admission to hospital), trust in the  
4 doctor as an expert, and deference towards authority figures all underpinned a passive  
5 compliance and largely unquestioning stance towards medication. In this regard, our  
6 analysis supports the 'model of compliance' proposed by Crossley and Withers in their  
7 exploration of the experiences of people with ID prescribed antipsychotic medication<sup>28</sup>, and  
8 renews calls for greater efforts to inform and involve people with ID about their medication.  
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22 Family and paid carer groups, meanwhile, clearly expressed a desire to be involved in  
23 medication decision-making. This was related to a self-identity as the "front line people"  
24 and was intertwined with their often conflicted or uneasy attitude towards psychotropic  
25 medication. The carers strongly believed in the value of the contribution they could make to  
26 medication decisions, and considered their involvement essential to achieving the best  
27 outcome for the individual they supported. Positive experiences were described in terms  
28 compatible with collaborative and negotiated models of decision-making, albeit with the  
29 over-riding assumption that the psychiatrist would take final responsibility for prescribing  
30 decisions. While experiences of SDM undoubtedly did exist, these could not be taken for  
31 granted, and many study participants felt they had been denied a place in decision-making.  
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3 resources that were not available to all, added to the emotional toll of caring, and had  
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5 caused some to lose faith in services.  
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## 10 11 **Clinical implications**

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18 The over-use of psychotropic medication for people with ID is now well-evidenced and is the  
19  
20 focus of national attention. Off-label prescribing, psychotropic polypharmacy, and lengthy  
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22 durations of medication treatment were all reported by the participants recruited for this  
23  
24 study. The average duration of psychotropic use in our sample was 16 years, and the  
25  
26 prevalence of antipsychotic use far outweighed the presence of severe mental illness. The  
27  
28 STOMP programme in England, established to address these issues, has not yet achieved  
29  
30 wholesale reductions in use of antipsychotic medication<sup>36</sup> but an assessment of medication  
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32 optimisation must include more than a crude count of prescriptions. Improving medication  
33  
34 outcomes for individuals requires a person-centred approach to prescribing that includes  
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36 partnership between stakeholders and consideration of patients' values and goals on an  
37  
38 equal footing to the expertise and opinion of mental health professionals. These elements  
39  
40 are part of broader attempts to support patient autonomy, and are embodied in the shared  
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42 decision making (SDM) model.  
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53 The adoption of SDM in routine mental healthcare has been slow<sup>37</sup> and although  
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55 psychiatrists explicitly endorse the model,<sup>38</sup> micro-analytic studies of routine psychiatric  
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57 consultations show that its principles are infrequently applied.<sup>39-41</sup> Issues of insight,  
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3 fluctuating mental capacity associated with episodes of acute and severe mental ill-health,  
4 power differentials between patient and professional, and the background threat of  
5 compulsory treatment, have all been identified as implementation barriers that are  
6 especially pertinent in psychiatric practise.<sup>42</sup> Arguably the challenges to SDM are  
7 compounded in people with ID<sup>43, 44</sup> due to the fixed cognitive deficit, additional  
8 communication needs, and people's lack of experience and confidence in making choices  
9 about their healthcare or, indeed, more generally.<sup>45, 46</sup>

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24 The presence of multiple stakeholders adds an extra dimension to the SDM model, which  
25 has largely been developed with reference to dyadic doctor-patient interactions and may  
26 not adequately account for complex decisions that are distributed within social networks.<sup>42</sup>  
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Defining roles and responsibilities, and balancing the relative influence of different (and possibly conflicting) views adds to the challenges of achieving shared decisions in this group. Thus, if we are to achieve successful SDM, and in so doing, obtain its benefits, the model may need to be broadened.

A parallel concept of *supported* decision-making has been advanced for those with cognitive impairment,<sup>47</sup> and is similarly predicated on the principles of autonomy and self-determination. Supported decision-making formalises the place of a network of individuals, which may consist of family members, friends, or other trusted people, who are able to help the person to formulate and express their preferences and thus exercise their autonomy. This may include assistance in gathering information, understanding their options, and/or communicating their choice. Clearly, such tasks were often undertaken by carers

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3 interviewed in the present study and suggests that elements of the framework could be  
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5 incorporated to an adapted model of SDM.  
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11 Increasing inclusion of people with ID and their paid and/or family carers in decisions (under  
12 whatever model this is branded), may represent a significant role change for all  
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14 stakeholders. Clinicians, which our study indicates hold the majority of the decision-making  
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16 power in these clinical encounters, will need to find ways of making conversations more  
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18 accessible and collaborative as patient involvement becomes a legal as well as an ethical  
19  
20 imperative.<sup>48</sup> People with ID must be made aware of their rights and appropriately  
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22 supported in contributing to healthcare decisions to a level which they are comfortable  
23  
24 with, if we are to avoid making unreasonable demands that risk alienating them from  
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26 professionals. As we have reported, carers can play a pivotal role in contributing to this  
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28 involvement, and this should be recognised and itself supported.  
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#### 40 **Future work**

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46 Observing interactions within real-world consultations could lead to a more nuanced  
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48 understanding of how medication discussions happen, and help to further develop  
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50 theoretical models of healthcare decision-making in people with ID. Developing scalable  
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52 interventions based on this understanding could improve opportunities for involvement of  
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54 adults with ID and their carers. Several interventions have been developed and evaluated in  
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56 people with mental health problems without ID.<sup>49-53</sup> Exploring the views of prescribers and  
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3 other health professionals also is important and could uncover other factors that influence  
4 patient and carer involvement and which themselves could be a target for intervention.  
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8 Finally, it will be necessary to demonstrate that incorporating SDM principles in routine care  
9 in this group is associated with improved patient-reported and objective outcomes.  
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### 13 14 15 16 17 **Strengths and limitations of this study** 18

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23 This study is unique in providing a multi-stakeholder analysis of accounts of the use of  
24 psychotropic medications in people with ID. It extends the existing qualitative literature in  
25 this field which has typically focused solely on antipsychotic drugs<sup>28</sup> or medication used for  
26 behaviour that challenges.<sup>29, 54, 55</sup> Synthesising the results of interviews with patients, family  
27 carers, and paid carers allowed us to develop broad, over-arching themes, and helps us to  
28 understand the interactions and dynamics involved in the complex process of medication  
29 decision-making. Adaptations to the research method enabled us to gain meaningful  
30 insights into the experiences of people with ID, a group who are often excluded from  
31 research participation and may be considered inappropriate for in-depth qualitative  
32 investigation.<sup>56</sup> A relatively large sample size, with respondents purposively sampled from  
33 different locations and according to demographic and clinical characteristics, adds to the  
34 breadth of our findings.  
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56 The views of people with ID and their carers are difficult to obtain and seldom heard in the  
57 research literature. In prioritising their accounts, this research report does not include the  
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3 views of general practitioners, pharmacists, or psychiatrists. Participants were self-selecting  
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5 and may have included only those with greater confidence. Their views are not necessarily  
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7 representative of a wider group of people with ID and their carers. We only interviewed  
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9 people (and carers of people) who were currently prescribed psychotropic medication and  
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11 under the care of specialist psychiatry teams, thereby excluding those who may have  
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13 previously taken medication, been managed solely in primary care, or who have chosen not  
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15 to take medication for mental health problems. People in any of these groups may possess  
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17 different and equally-valid perspectives on psychotropic medication and its prescribing.  
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## 27 **Conclusion**

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32 Achieving optimal use of psychotropic medication is a health service priority and can only  
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34 occur when working in partnership with people with ID and their carers. Frameworks such  
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36 as SDM which are based on the principles of personalisation and collaboration offer a  
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38 possible means of ensuring that stakeholders are represented in important decisions. Our  
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40 study suggests that successful collaborative decisions regarding medication are achievable  
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42 but are not always experienced. Further research to understand how medication decisions  
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44 are made from the perspective of prescribers and how other stakeholders can be  
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46 meaningfully and productively included is necessary to inform the development of  
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48 interventions that help ensure people with ID and their carers have a true voice in  
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50 medication discussions and decisions.  
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## Acknowledgements

The authors would like to thank those who agreed to take part in the study and the organisations and individuals that assisted with recruitment, and Restu Handoyo, who contributed to the analysis. We also thank members of the service user consultation group, Jackie McMorrow and Jill Huntlesmith.

## Contributors

RS, AH, AS, and NM designed the study. RS recruited to the study and carried out the interviews. RS, AH, AS, and NM undertook the analysis. RS and NM drafted the manuscript with input from AH and AS. All authors approved the final version.

## Funding

This study was funded by a Doctoral Research Fellowship awarded to RS from the National Institute for Health Research (NIHR) (Ref: DRF-2016-09-140).

## Disclaimer

The views expressed in this article and those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. The funder had no role in study design, analysis, decision to publish, or preparation of the manuscript.

## Competing interests

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9 **Data sharing**  
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12 No additional data are available  
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For peer review only

## REFERENCES

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®). Arlington, VA: American Psychiatric Publishing; 2013.
2. Maulik P, Mascarenhas M, Mathers C, *et al*. Prevalence of intellectual disability: A meta-analysis of population-based studies. *Res Dev Disabil* 2011;32:419-36.
3. Cooper S-A, Smiley E, Morrison J, *et al*. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry* 2007;190:27-35.
4. Sheehan R, Hassiotis A, Walters K, *et al*. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. *BMJ* 2015;351:h4326.
5. Lunskey Y, Khuu W, Tadrous M, *et al*. Antipsychotic use with and without comorbid psychiatric diagnosis among adults with intellectual and developmental disabilities. *Can J Psychiatry* 2018;63:361-9.
6. De Kuijper G, Hoekstra P, Visser F, *et al*. Use of antipsychotic drugs in individuals with intellectual disability (ID) in the Netherlands: prevalence and reasons for prescription. *J Intellect Disabil Res* 2010;54:659-67.
7. Doan TN, Lennox NG, Taylor-Gomez M, *et al*. Medication use among Australian adults with intellectual disability in primary healthcare settings: a cross-sectional study. *J Intellect Dev Disabil* 2013;38:177-81.
8. Holden B, Gitlesen JP. Psychotropic medication in adults with mental retardation: prevalence, and prescription practices. *Res Dev Disabil* 2004;25:509-21.
9. Hsu S-W, Chiang P-H, Chang Y-C, *et al*. Trends in the use of psychotropic drugs in people with intellectual disability in Taiwan: a nationwide outpatient service study, 1997–2007. *Res Dev Disabil* 2014;35:364-72.
10. Lunskey Y, Modi M. Predictors of Psychotropic Polypharmacy Among Outpatients With Psychiatric Disorders and Intellectual Disability. *Psychiatr Serv* 2017;69:242-6.
11. Bowring D, Totsika V, Hastings R, *et al*. Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study. *J Intellect Disabil Res* 2017;61:604-17.
12. O'Dwyer M, Peklar J, Mulryan N, *et al*. Prevalence, patterns and factors associated with psychotropic use in older adults with intellectual disabilities in Ireland. *J Intellect Disabil Res* 2017;61:969-83.
13. Lott I, McGregor M, Engelman L, *et al*. Longitudinal prescribing patterns for psychoactive medications in community-based individuals with developmental disabilities: utilization of pharmacy records. *J Intellect Disabil Res* 2004;48:563-71.
14. O'Dwyer M, McCallion P, McCarron M, *et al*. Medication use and potentially inappropriate prescribing in older adults with intellectual disabilities: a neglected area of research. *Ther Adv Drug Saf* 2018;9:535-57.
15. Sheehan R, Horsfall L, Strydom A, *et al*. Movement side effects of antipsychotic drugs in adults with and without intellectual disability: UK population-based cohort study. *BMJ Open* 2017;7:e017406.

16. Branford D, Gerrard D, Saleem N, *et al*. Stopping over-medication of people with intellectual disability, Autism or both (STOMP) in England part 1—history and background of STOMP. *Advances in Mental Health and Intellectual Disability* 2019;13:31-40.
17. Branford D, Gerrard D, Saleem N, *et al*. Stopping over-medication of people with an intellectual disability, autism or both (STOMP) in England part 2—the story so far. *Advances in Mental Health and Intellectual Disability* 2019;13:41-51.
18. Royal Pharmaceutical Society. Medicines Optimisation: helping patients to make the most of medicines. London, UK: Royal Pharmaceutical Society; 2013.
19. Cutler S, Fattah L, Shaw M, *et al*. What does medicines optimisation mean for pharmacy professionals? *Pharm J* 2011;287:606.
20. Charles C, Gafni A, Whelan T. Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med* 1999;49:651-61.
21. Department of Health. Valuing People Now: a new three-year strategy for people with learning disabilities. London, UK: Department of Health; 2010.
22. Shay LA, Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making* 2015;35:114-31.
23. Joosten E, DeFuentes-Merillas L, de Weert G, *et al*. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychother Psychosom* 2008;77:219-26.
24. Keywood K, Fovargue S, Flynn M. Best Practice? Health care decision-making by, with and for adults with learning disabilities. Manchester, UK: National Development Team; 1999.
25. Chadwick DD, Mannan H, Garcia Iriarte E, *et al*. Family voices: life for family carers of people with intellectual disabilities in Ireland. *J Appl Res Intellect Disabil* 2013;26:119-32.
26. Tuffrey-Wijne I, Giatras N, Goulding L, *et al*. Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study. *Health Serv Deliv Res* 2013;1-224
27. Heslop P, Folkes L, Rodgers J. The knowledge people with learning disabilities and their carers have about psychotropic medication. *Tizard Learning Disability Review* 2005;10:10-8.
28. Crossley R, Withers P. Antipsychotic medication and people with intellectual disabilities: their knowledge and experiences. *J Appl Res Intellect Disabil* 2009;22:77-86.
29. Edwards N, King J, Watling H, *et al*. Qualitative exploration of psychotropic medication to manage challenging behaviour in adults with intellectual disability: views of family members. *Advances in Mental Health and Intellectual Disability* 2017;11:207-18.
30. Lalor J, Poulson L. Psychotropic medications and adults with intellectual disabilities: care staff perspectives. *Advances in Mental Health and Intellectual Disability* 2013;7:333-45.
31. Joint Formulary Committee. British National Formulary. London, UK: Pharmaceutical Press; 2019.
32. Department of Health. Mental Capacity Act. London, UK: The Stationery Office; 2005.
33. Hollomotz A. Successful interviews with people with intellectual disability. *Qual Res* 2018;18:153-70.
34. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101.
35. Newbigging K, Ridley J. Epistemic struggles: The role of advocacy in promoting epistemic justice and rights in mental health. *Soc Sci Med* 2018;219:36-44.

- 1  
2  
3 36. Mehta H, Glover G. Psychotropic drugs and people with learning disabilities or autism. 2019.  
4 Public Health England.  
5
- 6 37. Slade M. Implementing shared decision making in routine mental health care. *World*  
7 *Psychiatry* 2017;16:146-53.  
8
- 9 38. Seale C, Chaplin R, Lelliott P, *et al.* Sharing decisions in consultations involving anti-psychotic  
10 medication: a qualitative study of psychiatrists' experiences. *Soc Sci Med* 2006;62:2861-73.  
11
- 12 39. McCabe R, Skelton J, Heath C, *et al.* Engagement of patients with psychosis in the  
13 consultation: conversation analytic study. *BMJ* 2002;325:1148-51.  
14
- 15 40. McCabe R, Khanom H, Bailey P, *et al.* Shared decision-making in ongoing outpatient  
16 psychiatric treatment. *Patient Educ Couns* 2013;91:326-8.  
17
- 18 41. Dooley J, Bass N, Livingston G, *et al.* Involving patients with dementia in decisions to initiate  
19 treatment: effect on patient acceptance, satisfaction and medication prescription. *Br J Psychiatry*  
20 2019;214:213-7.  
21
- 22 42. Morant N, Kaminskiy E, Ramon S. Shared decision making for psychiatric medication  
23 management: beyond the micro-social. *Health Expect* 2015;19:1002-14.  
24
- 25 43. Goldsmith L, Woodward V, Jackson L, *et al.* Informed consent for blood tests in people with a  
26 learning disability. *J Adv Nurs* 2013;69:1966-76.  
27
- 28 44. Sullivan WF, Heng J. Supporting adults with intellectual and developmental disabilities to  
29 participate in health care decision making. *Can Fam Physician* 2018;64:S32-S6.  
30
- 31 45. Fovargue SJ, Keywood K, Flynn M. Participation in health care decision-making by adults with  
32 learning disabilities. *Mental Health Care* 2000;3:341-4.  
33
- 34 46. Myron R, Gillespie S, Swift P, *et al.* Whose decision? Preparation for and implementation of  
35 the Mental Capacity Act in statutory and non-statutory services in England and Wales. London, UK:  
36 Mental Health Foundation; 2008.  
37
- 38 47. Devi N, Bickenbach J, Stucki G. Moving towards substituted or supported decision-making?  
39 Article 12 of the Convention on the Rights of Persons with Disabilities. *Alter* 2011;5:249-64.  
40
- 41 48. Adshead G, Crepez-Keay D, Deshpande M, *et al.* Montgomery and shared decision-making:  
42 implications for good psychiatric practice. *Br J Psychiatry* 2018;213:630-2.  
43
- 44 49. Harris N, Lovell K, Day J, *et al.* An evaluation of a medication management training  
45 programme for community mental health professionals; service user level outcomes: a cluster  
46 randomised controlled trial. *Int J Nurs Stud* 2009;46:645-52.  
47
- 48 50. Stead U, Morant N, Ramon S. Shared decision-making in medication management:  
49 development of a training intervention. *BJPsych Bull* 2017;41:221-7.  
50
- 51 51. Loh A, Simon D, Wills CE, *et al.* The effects of a shared decision-making intervention in  
52 primary care of depression: a cluster-randomized controlled trial. *Patient Educ Couns* 2007;67:324-  
53 32.  
54
- 55 52. Deegan PE. A Web application to support recovery and shared decision making in psychiatric  
56 medication clinics. *Psychiatr Rehabil J* 2010;34:23.  
57
- 58 53. Priebe S, McCabe R, Bullenkamp J, *et al.* Structured patient-clinician communication and 1-  
59 year outcome in community mental healthcare: cluster randomised controlled trial. *Br J Psychiatry*  
60 2007;191:420-6.

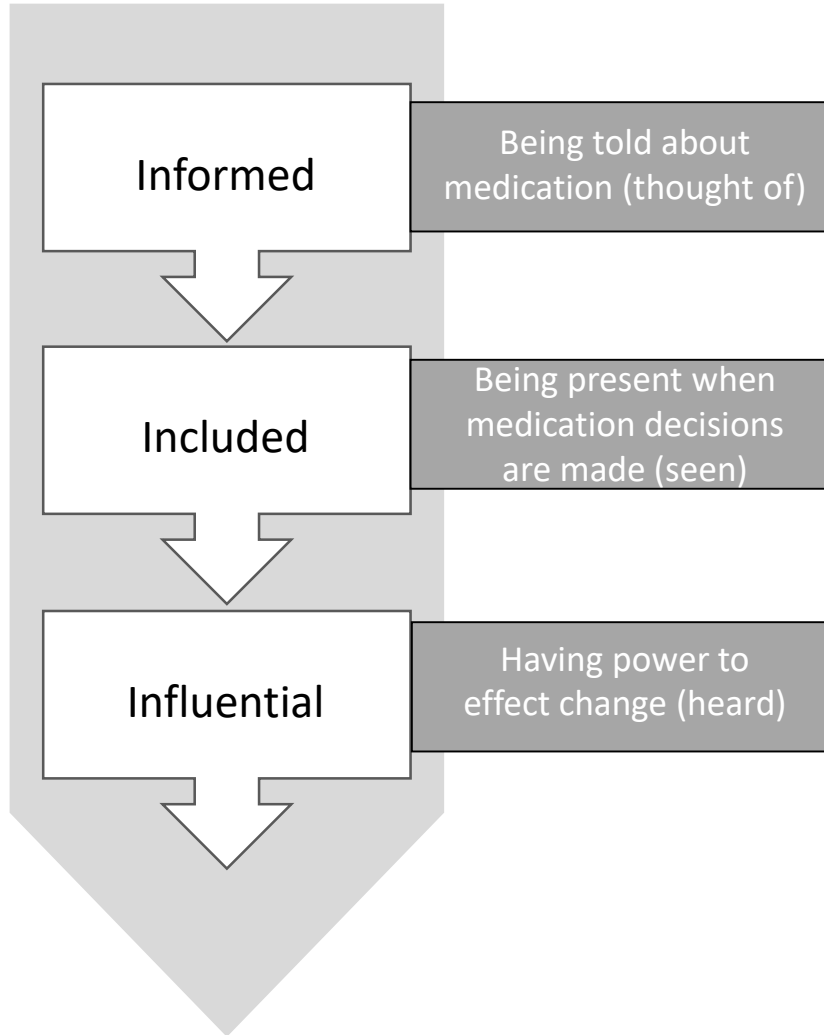
1  
2  
3 54. Sheehan R, Kimona K, Giles A, *et al*. Findings from an online survey of family carer  
4 experience of the management of challenging behaviour in people with intellectual disabilities, with  
5 a focus on the use of psychotropic medication. *Br J Learn Disabil* 2018;46:82-91.  
6

7 55. Hall S, Deb S. A qualitative study on the knowledge and views that people with learning  
8 disabilities and their carers have of psychotropic medication prescribed for behaviour problems.  
9 *Advances in Mental Health and Intellectual Disability* 2008;2:29-37.  
10

11 56. Coons KD, Watson SL. Conducting research with individuals who have intellectual disabilities:  
12 Ethical and practical implications for qualitative research. *Journal on Developmental Disabilities*  
13 2013;19:14.  
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15  
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### **Topic guide – people with ID**

\*To be supplemented with visual information and prompts\*

- What do you think about the medication you take for mental health?
- Do you talk about psychotropic medication with the psychiatrist?
  - What has this been like?
  - Do they ask what has been good about taking medication?
  - Do they ask what has been bad about medication?
- Who is involved in decisions about psychotropic medication?
  - Do you want to be involved?
  - Are you involved?
    - If not, why?
  - Is anyone else involved (e.g. carer, family member)?
    - How are they involved?
    - What do you think about them being involved?
- Do you feel that you have a choice about medication?
  - Does the psychiatrist ask you what you want to do with medication?
  - Have they listened to your views?
- What if you were worried about your medication?
  - What if you had a problem with your medication?
- What should the doctor think about when they are prescribing medication for you?
  - What is important to you?
  - What do you want to know about the medicine?
- What would make it easier to talk to the doctor about medication?

### **Topic guide – family carers**

- What has been your experience when psychotropic medication has been prescribed for your relative?
- Who is involved in decisions about psychotropic medication?
  - How is your relative involved in the decision?
  - Are you involved?
  - Who else is involved?
  - Is/was your level of involvement what you would like?
- Is medication reviewed after it has been prescribed?
  - How?
  - What was the review like?
  - Are you involved in this?
  - Is the review effective?
- How were/are decisions to continue, stop, or change medication made?
  - Have you and your relative been given a choice about medication?
- Do you discuss medication with the psychiatrist at appointments?
  - Do you think that you know enough about the medications?
  - How would you know if medication is working or not working?
  - Do you have a method for recording the positive and negative effects of medication (e.g. rating scales)?
  - What if there is a problem with medication?
- What should be thought about when medication is reviewed?
- What might make it easier for you or your relative to give your views about medication?

### **Topic guide – paid carers**

- What has been your experience when psychotropic medication has been prescribed for the people you support?
- Who is involved in decisions about psychotropic medication?
  - How is the person you support involved in the decision?
  - Are you involved?
  - Should you be involved?
- Is medication reviewed after it has been prescribed?
  - How?
  - What happens in the review?
  - Are you involved in this?
  - Is the review effective?
- Who makes decisions to continue, stop, or change medication?
  - How are these decisions made?
  - Have you and the person you support been given a choice about medication?
- Do you discuss medication with the psychiatrist at appointments?
  - How able do you feel to contribute to this discussion?
  - Do you think that you know enough about the medications?
  - How would you know if medication is working or not working?
  - Do you have a method for recording the positive and negative effects of medication (e.g. rating scales)?
  - What if there is a problem with medication?
- What should be thought about when medication is reviewed?
- What might make it easier for you or the person you support to give your views about medication?

## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**