



## Service user experiences of care recommendations from the 2014 NICE guideline for bipolar disorder: a survey

James Roe, Adele Cresswell, Shweta Mittal, Mohammed Al-Uzri, James Tanner, Matthew Moore, Sandra Simpson, Boliang Guo & Richard Morriss

To cite this article: James Roe, Adele Cresswell, Shweta Mittal, Mohammed Al-Uzri, James Tanner, Matthew Moore, Sandra Simpson, Boliang Guo & Richard Morriss (2022): Service user experiences of care recommendations from the 2014 NICE guideline for bipolar disorder: a survey, Journal of Mental Health, DOI: [10.1080/09638237.2021.2022614](https://doi.org/10.1080/09638237.2021.2022614)

To link to this article: <https://doi.org/10.1080/09638237.2021.2022614>



© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 24 Jan 2022.



Submit your article to this journal [↗](#)



Article views: 299



View related articles [↗](#)



View Crossmark data [↗](#)

## Service user experiences of care recommendations from the 2014 NICE guideline for bipolar disorder: a survey

James Roe<sup>a</sup>, Adele Cresswell<sup>a</sup>, Shweta Mittal<sup>b</sup>, Mohammed Al-Uzri<sup>c</sup>, James Tanner<sup>d</sup>, Matthew Moore<sup>a</sup>, Sandra Simpson<sup>b</sup>, Boliang Guo<sup>a</sup> and Richard Morriss<sup>a</sup>

<sup>a</sup>National Institute for Health Research: Applied Research Collaboration (ARC) East Midlands, University of Nottingham, Nottingham, UK;

<sup>b</sup>Nottinghamshire HealthCare NHS Foundation Trust, Nottingham, UK; <sup>c</sup>Leicestershire Partnership NHS Trust, Leicester, UK;

<sup>d</sup>Northamptonshire Healthcare NHS Foundation Trust, Kettering, UK

### ABSTRACT

Clinical guidelines for mental health disorders produced by the National Institute of Care Excellence (NICE) emphasise a recovery-based approach clinical care with collaborative decision-making. The aim of the study was to explore service user experience of collaborative decision-making and recovery focussed care in relation to a NICE clinical guideline for bipolar disorder four years after publication. Participants with a clinical diagnosis of bipolar disorder were recruited from adult mental health services in four specialist mental health NHS Trusts through health professional or self-referral following advertisement. An online or written survey was designed with service user input to cover 40 NICE recommendations on recovery based or collaborative care. Participants completed the survey anonymously and independent of any health professional involvement. Of 222 participants, 72 (33.5%) reported to a great extent care was delivered in line with a positive recovery message; 55 (25.5%) reported that not much or no care was recovery based. Only four items (10%) on medication or the offer of crisis services were endorsed as collaborative decision-making with a health professional by >70% service users. Most decision-making in relation to the NICE clinical guideline for bipolar disorder was not delivered collaboratively and only some care was recovery focussed.

### ARTICLE HISTORY

Received 16 December 2020

Revised 20 July 2021

Accepted 29 September 2021

Published online 24 December 2021

### KEYWORDS

Bipolar disorder; clinical guidelines; collaborative care; recovery

## Background

Bipolar disorder (BPD) is a severe long-term mental health problem that is characterised by recurrent episodes of mania/hypomania (such as elevated mood or irritability, grandiosity, lasting at least four days) and depressed mood (lasting for two weeks) that is often severe. BPD affects approximately 1–2% of the population with a peak onset between 15 and 19 years of age and is the 18th leading cause of years lost due to disability (Vos et al., 2012). It is estimated that BPD results in annual costs to the economy (both clinical and loss of earnings) of £5.2 billion (McCrone et al., 2008).

NICE Guidelines provide the most up to date and cost-effective clinical care in England and often guide care internationally. The first NICE Guideline for bipolar disorder was published in 2006 (NICE, 2006) and it was updated in 2014 (NICE, 2014). NICE guidelines are not mandatory in England but must “be carefully considered when developing strategies, planning services and prioritising resources” (NHS Commissioning Board, 2013). They are developed after a thorough systematic review and meta-analysis of the evidence from research, economic modelling of key recommendations in the NICE guideline, and extensive iterative

consultation with service users, carers, a multidisciplinary group of primary and secondary care clinicians, iteration with national and international academic experts, and iteration with national organisations (NICE, 2012). Similar input goes into the development of care pathways, information for the public and quality standards to provide a suite of tools that mental health services might utilise to help implement NICE guidance. As well as developing guidance for the management of specific mental health conditions, NICE has also developed guidance on principles of how health professionals and health organisations should manage service users with mental health disorders (NICE, 2012). The recommendations encouraged information giving, collaborative decision-making between the health professional and service user, and recovery in the sense of maintenance of hope and optimism, social inclusion such as involvement in employment, education, maintenance of independence and self-efficacy.

A number of benefits of implementing clinical guidelines have been proposed (Morriss, 2015). They establish benchmarks and standards of care for professionals and NHS-funded healthcare that service users can reasonably expect to receive. They might improve outcomes by promoting interventions of benefit and discouraging ineffective

**CONTACT** James Roe  james.roe@nottingham.ac.uk  Institute of Mental Health, Triumph Road, Nottingham, NG7 2TU, UK

© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

interventions. If they were widely adhered to, there would be reduced variation in care. They would enable collaborative care and continuity of care to be provided to service users across health care organisations through greater clarity about the care pathway offered to people with bipolar disorder. There might be reduced costs of care through greater consistency, increased efficiency, and fewer avoidable adverse incidents as evidence-based care was followed. Most importantly they inform service users, carers, and the public about health conditions and care to improve their decision-making when self-managing, or seeking care, and empowering collaborative decision-making when discussing care with health professionals.

However, there are concerns about the use of clinical guidelines to direct clinical care (Armstrong, 2002; Lenzer, 2013; Morriss, 2015; Samalin & Llorca, 2012; Woolf et al., 1999; Ziebland et al., 2014). Sometimes clinical guidelines make poor recommendations because scientific evidence may be lacking, misleading or misinterpreted. Recommendations may be influenced by personal opinion of key members of clinical guideline, professional interest, financial or professional conflict of interest. There is sometimes a lack of consistency in recommendations between national clinical guidelines for the same condition. If poor recommendations are made by clinical guidelines, then delivery of ineffective, harmful, or wasteful interventions may be institutionalised. Professionals and health care organisations may be unfairly judged by quality standards or other measures that are not in their control. There might be uncertainty over cost and impact of clinical guidelines if there are unanticipated effects, for example, care becomes more costlier if more patients are referred to secondary care without any improvement in outcome. There is a perceived threat to independence of health professionals and their ability to personalise care of people with atypical presentations, comorbidities or important contextual factors. 8. NICE clinical guidelines discount learning from clinical practice and non-random controlled trial evidence on interventions that nevertheless may be informative for practice. They discourage individual innovation that is inconsistent with NICE clinical guideline care except in research. Complexity of information in NICE clinical guidelines may be a potential barrier to obtaining care by some patients who lack confidence or trust in dealing with NHS professionals or organisations.

Despite rigour in formulating NICE clinical guidelines, implementation into routine practice remains a challenge. They can be ignored if any health care organisation or professional wishes to do so with minimal or no justification, even by hospital consultants specialising in the field of clinical practice covered directly by a NICE clinical guideline. Research shows that NICE Guidelines are rarely fully implemented, and there is great variation in their implementation not only between organisations but also within the same organisation over time (Baker et al., 2001; Price et al., 2012). In particular, NICE recommendations that require changes in the organisation of care, or are counter to established practice, are poorly implemented (Morriss, 2008).

In bipolar disorder, there is conflicting evidence whether guideline-supported care improves patient outcomes. In a randomised controlled trial, group psychoeducation in addition to a specialist psychiatric out-patient service offering psychopharmacology as recommended by the British Association of Psychopharmacology was both more effective and reduced the costs of care substantially (Kessing et al., 2013). Reductions in depression but not mania symptoms were seen with physician education in a before and after intervention study aimed at improving adherence to algorithm derived care (Dennehy et al., 2005). However, Freeland et al. (2015) reviewed in-patient care for all in-patients at one mental health unit in United States. Among 294 patients, 58 per cent received evidence-based pharmacotherapy at discharge, but there was no difference in readmission rates compared to those who did not receive guideline care. Fang et al. (2019) carried out a case note audit of 67 participants with BD referred to a tertiary youth mental health service in Australia. Participants with higher Australian guideline-concordant care had worse symptom and functional outcomes at 18 months follow-up. Similarly, Altınbaş et al. (2011) found no effect of concordance to the Turkish treatment guideline for bipolar disorders on time to remission in patients with bipolar depression in a specialised psychiatric out-patient clinic. Both of these were small studies that might have not had the statistical power to detect clinically important change.

Given the attempts to make NICE clinical recommendations patient centred (NICE, 2012), the aim of this study was to survey service users with bipolar disorder in order to ascertain their experience of care in relation to key recommendations within the NICE guideline for bipolar disorder (NICE, 2014). This guideline was selected because it made many new recommendations in relation to medication, physical health checks, psychological management, organisation of care and shared decision-making in comparison to the NICE previous guideline for bipolar disorder (NICE, 2006). The guideline therefore required changes in clinical practice. By 2017, there had been sufficient time for such changes in practice to have become embedded in practice. One of the authors (RM) had chaired the guideline and was therefore extremely familiar with its content and the shared decision-making that was intended.

## Methods

### Study design

A paper and pencil survey, given face to face, posted or performed online was conducted between October 2017 and January 2019 amongst service users with bipolar disorder to assess the experiences of service users with bipolar disorder in relation to each of the key recommendations of the NICE guidelines. Originally, we intended the survey to be completed only online but feedback from patient and public involvement representatives was that some of the most vulnerable service users with bipolar disorder did not have continuing access to online resources, and many would like the assistance of research support staff to complete

questions on the care they received. They also might want additional assurance about confidentiality and to be sure that they were addressing the survey questions accurately. Many regarded the survey as extremely important to them so they wished to ensure their answers were an accurate reflection of their experience.

Participants were recruited through health care professionals with the help of research support staff in four NHS Trusts (organisations providing universal free specialist mental health care in a defined geographical area), three in the East Midlands and one in the North East of England, self-presentation after advertisements in these health care organisation and third sector settings local to them, and through local branches of Bipolar UK, a national third sector organisation run by people with bipolar disorder for people with bipolar disorder and their carers and families in these localities. Letters were sent to eligible participants to introduce the study and explain the nature and purpose of the research before consent was obtained.

### **Participants**

Eligible participants had to be aged 16 or over, have a primary diagnosis of bipolar disorder according to the service user, currently or recently (previous 12 months) in contact with mental health services, and have sufficient understanding of English (spoken and written). Participants were excluded if they did not have the capacity to give informed consent to the study. The diagnosis of bipolar disorder was not clinically checked in order to encourage participation in the study.

### **Ethics**

Ethical Committee approval was obtained (Nottingham Research Ethics Committee 2, 17/EM/0247). All participants gave written and oral informed consent.

### **Setting**

Participants were recruited using a combination of opportunistic and purposive sampling in an attempt to obtain participants from a wide range of mental health service settings. Within each NHS Trust, the survey was publicised on in-patient units, out-patient settings, community settings, settings where psychoeducation and psychological treatments were offered, recovery colleges and written and electronic communications to staff and service users. We utilised personal and research support contacts with people with bipolar disorder and staff, including our service user researcher and members of Bipolar UK, encouraging them to inform others through snowballing.

### **Survey**

The 2014 NICE Guideline for Bipolar Disorder recommendations were divided into those items that might be detected using an audit of case notes, for example, prescription of

medication or blood monitoring that will be separately reported, and those that would require information from a service user. The survey reported here consisted entirely of these latter items which covered collaboration between the health professional and service user in decision-making, for example, about medication, provision of information and choices, crisis and recovery. JR identified the recommendations, and these were checked with RM and MM, a service user researcher. JR developed the original wording of the survey and this was then edited by the service user researcher. It was piloted at one Bipolar UK site where it was completed by some people with bipolar disorder who were not eligible for the study because they had no contact with specialist mental health services in the previous 12 months. Following feedback from the pilot, the survey was offered online or completed on paper face to face or posted back to the research team. The survey was always completed independently of their usual care team. However, feedback from the pilot suggested that some service users may need assistance to complete the survey, particularly in relation to establishing whether some of the items related to them, for example, those items asking about specific medication or psychological treatment. Therefore, participants were offered the assistance of a research assistant or member of the Clinical Research Network (but not any member of staff involved in any aspect of their clinical care). These staff were trained to clarify the service user's questions about the survey but never to answer for the participant or to suggest to the participant what answer to give. Participants were assured that the results would not be passed to their care team so that they could not be identified and be critical of the care team if they wished.

The survey consisted of 40 items based on the key recommendations from the NICE Guideline, one on the overall positive recovery message, six on general care and support, six on support from secondary care in crisis mania and hypomania, three on support from secondary care on depression, twelve on support from secondary care in the longer term, two on returning to primary care, and ten on how to use medication. Apart from overall positive recovery message, all questions were answered "yes", "no" or "don't know". At the end of the survey, there was space for some free text comments if participants wished to make any additional observations.

### **Analysis**

Survey responses were entered into the STATA for analysis. Data were aggregated for all four sites (NHS Trust and third sector in the same locality) and analysed using descriptive statistics. For data protection reasons, we have not analysed the data according to site. Since the survey was delivered online as well as by paper and pen, response rates cannot be given.

### **Results**

#### **Study sample**

A total of 222 respondents completed the survey at four sites. Some participants did not answer all questions in the



**Table 1.** Survey participant demographics.

Characteristics	N (%)
Gender	
Female	157 (73.4)
Male	57 (26.6)
Age	
18–24	11 (5.0)
25–34	33 (14.9)
35–44	48 (21.6)
45–54	51 (23.0)
55–64	45 (20.3)
65+	20 (9.0)
Ethnicity	
White	
English/Welsh/Scottish/Northern Irish/British	155 (69.8)
Irish	3 (1.4)
Any other White background	3 (1.4)
Mixed/Multiple ethnic groups	
White and Black Caribbean	1 (0.5)
White and Asian	1 (0.5)
Any other Mixed/Multiple ethnic background	14 (6.3)
Asian/Asian British	
Indian	2 (0.9)
Pakistani	1 (0.5)
Any other Asian background	2 (0.9)
Black/African/Caribbean/Black British	
African	1 (0.5)
Caribbean	2 (0.9)
Any other Black / African / Caribbean background	1 (0.5)
Unknown ethnic group	36 (16.2)

survey because they related to a setting or treatment that they did not receive or they preferred not to disclose this information. The mean age of participants was 46.8 (sd = 13.9) years. 73.4% ( $n = 157$ ) of participants were female and 26.6% ( $n = 57$ ) were males, with eight participants who did not provide data. In terms of ethnicity, 25 (11.3%) were not white British or European. Table 1 shows the demographic features of the sample.

A benchmark of 70 percent has been proposed as concordance with most guideline recommendations (Goodwin, 2003). In answer to the question based on NICE bipolar disorder guideline key recommendation 1.1 “To what extent throughout your care did you feel that a positive recovery message was given?”, 215 service users responded; 72 (33.5%) reported to a great extent, 88 (40.93%) to some extent, 42 (19.5%) not much and 13 (6.1%) not at all.

Table 2 shows the results of the 39 remaining questions in the survey in the order of key recommendations in the NICE Guideline for Bipolar Disorder (NICE 2014). Examples of the questions that were asked included “Were you offered assistance with daily living tasks, education, financial and employment problems? (Such as dressing, eating, paying bills etc.)” and “Was it discussed with you how best to manage and monitor your mood in the long term after an episode of mania or bipolar depression?” Only four of 39 (10.3%) items were endorsed by 70 per cent or more of service users: choice of medication decided collaboratively, offer of crisis services during a crisis, opportunity to ask questions about longer term medication, and appropriate information to take lithium safely. In contrast, 17 of 39 (43.6%) items were endorsed by 50 per cent or less service users, including five (12.8%) by under 30 per cent; advance statements, calming environment for mania, family intervention, support for combined healthy eating and physical

activity, and a care plan agreed for return to primary care. There were 19 items in the survey concerning or mentioning medication involving information giving, tailoring of interventions or collaborative decision-making. More than 50 per cent of service users endorsed 17 (89.5%) of these 19 items concerning medication (all except having a care plan and seeking medical attention if vomiting, diarrhoea or ill with lithium). Of the remaining items not concerning medication, only four (20%) were indicated by 50 per cent or more service users and all of these were tailored interventions: full psychiatric assessment as outlined by NICE, offer of crisis services if in crisis, maintaining relationships with carer if in mania, and monitoring mood after an episode of mania or depression. Less than 50 per cent of service users reported collaborative decision-making on non-medication issues, for example, on care plan, risk management or care plan for return to primary care; access to non-medication interventions e.g. psychological intervention for depression, psychological intervention for bipolar disorder in the long-term, family interventions access to a programme of structured activity and health eating, assistance with activities of daily living, education or employment; non-medication management of mania, for example, access to calming environment, not to make important decisions until recovered from mania; and information giving on nonmedication, for example, written information on bipolar disorder.

Free text comments on the survey and also shared directly with researchers were frequently on the lines that people with bipolar disorder should be offered the opportunity to complete such a survey on their experience of care and their involvement in decision-making routinely, not just as a one-off research project such as this.

## Discussion

To our knowledge, this is the first survey of service users with a mental health condition of their experience of the implementation of a NICE clinical guideline for that condition (in this case bipolar disorder) in secondary mental health care in line with the guideline itself and the NICE service user mental health guideline (National Collaborating Centre for Mental Health, 2011). There is to our knowledge no similar service user survey for any clinical guideline in bipolar disorder. We found that only a third of service users reported care that was in line with a positive recovery-based message and a quarter reported that not much or none at all was recovery based. There was evidence of collaborative decision-making, information giving and tailoring of medication to service user needs in 89 per cent of items concerning medication. However, even here there was still room for improvement with only four items (10%) on medication management or the offer of crisis services endorsed by 70 per cent or more of service users. While there is no benchmark set by NICE or any other organisation for a high standard to follow in NICE recommendations, a benchmark of 70 per cent concordance has been suggested as reasonable for most guideline recommendations (Goodwin, 2003). Only four (20%) items that were not concerning medication were

Table 2. Survey responses.

NICE Guidelines for Bipolar Disorder Reference	Question	Yes N (%)	No N (%)	Don't know N (%)	Total Respondents
	<b>General care &amp; support from secondary care services</b>				
1.1.9	Were you offered assistance with daily living tasks, education, financial and employment problems? (Such as dressing, eating, paying bills etc.)	72 (33.6)	130 (60.8)	12 (5.6)	214
1.1.10	Were advance statements (a general statement about anything that is important to you in relation to your future treatment and wellbeing) developed with carers?	63 (29.2)	117 (54.2)	36 (16.7)	216
1.3.2	Did you receive a full psychiatric assessment at point of diagnosis? (In which you would have been asked about your life and experiences, mental and physical health symptoms/experiences, relationships, social circumstances, hopes and aspirations etc.)	149 (69.3)	40 (18.6)	26 (12.1)	215
1.3.4	Do you have a care plan? (Sets out what support you'll get day to day and who will give it to you – including medicines, help with housing, risks etc.)	90 (41.3)	93 (42.7)	35 (16.1)	218
1.1.12	Was your care plan developed in collaboration with you and/or carers?	83 (42.4)	69 (35.2)	44 (22.5)	196
1.4.1	Was a risk management plan developed in collaboration with you and/or carers?	97 (45.1)	81 (37.7)	37 (17.2)	215
	<b>Support from secondary care services – crisis and mania/hypomania</b>				
1.4.2	If you've been in crisis before, were crisis services offered to you? (Such as Crisis Resolution and Home Treatment teams, Crisis Houses, Hospital Admission, Online Support)	153 (79.3)	30 (15.5)	10 (5.2)	193
1.5.1	Were you offered access to calming environments or reduced stimulation when experiencing mania/hypomania?	49 (26.1)	103 (54.8)	36 (19.2)	188
1.5.1	Were you advised not to make important decisions until you had recovered?	90 (46.4)	68 (35.1)	36 (18.6)	194
1.5.1	Were you encouraged to maintain your relationship(s) with your carer(s)?	109 (64.9)	25 (14.9)	34 (20.2)	168
1.5.3 – 1.5.8	Was your preference and previous experience and response to treatment considered?	102 (54.0)	31 (16.4)	56 (29.6)	189
1.5.12	Were the potential benefits of medication for mania or hypomania and the risks, including side effects of medication discussed with you?	133 (66.8)	40 (20.1)	26 (13.1)	199
	<b>Support from secondary care services – depression</b>				
1.6.1	Was a psychological intervention or high-intensity psychological intervention offered for depression? (Such as cognitive behavioural therapy, interpersonal therapy or behavioural couples therapy)	103 (47.9)	86 (40.0)	26 (12.1)	215
1.6.3	Was your preference and previous experience and response to treatment considered?	121 (59.3)	40 (19.6)	43 (21.1)	204
1.6.7	Has the risk of overdosing with medication been raised with you?	110 (51.4)	80 (37.4)	24 (11.2)	214
	<b>Support and advice from services in the longer term</b>				
1.6.8	Were the potential benefits of long-term treatment and the risks, including side effects of medication (relating to depression), discussed with you?	134 (62.3)	62 (28.8)	19 (8.8)	215
1.7.1	Was it discussed with you how best to manage and monitor your mood in the long term after an episode of mania or bipolar depression?	131 (60.4)	66 (30.4)	20 (9.2)	217
1.7.1	Were you given clear written information about bipolar disorder?	103 (47.3)	97 (44.5)	18 (8.3)	218
1.7.2	If you were living with, or close to, family, were you offered a family intervention? (A talking therapy involving you and some family members/carers)	38 (18.4)	150 (72.5)	19 (9.2)	207
1.7.3	Were you offered a structured psychological intervention designed for bipolar disorder? (Individual, group or family talking therapy)	69 (31.8)	115 (53.0)	33 (15.2)	217
1.7.4	Did this intervention provide information about bipolar disorder?	59 (48.4)	34 (27.9)	29 (23.8)	122
1.7.4	Was this programme tailored to your needs?	50 (43.9)	34 (29.8)	30 (26.3)	114
1.7.5	Was there a discussion around whether you'd prefer to continue your existing treatment or switch to lithium, if you were not already on it?	91 (50.3)	67 (37.0)	23 (12.7)	181
1.7.5	Was it explained that lithium is the most effective treatment long term?	109 (51.4)	83 (39.2)	20 (9.4)	212
1.7.7	If long-term medication treatment was stopped, was it discussed with you how to recognise early signs of relapse into mania or depression?	86 (57.7)	40 (26.9)	23 (15.4)	149
1.7.7	Was treatment stopped gradually? (Amount/dose reduced slowly)	64 (57.7)	36 (32.4)	11 (9.9)	111
1.8.2	Was a combined healthy eating and physical activity programme offered?	49 (22.6)	152 (70.1)	16 (7.4)	217
	<b>Returning to primary care</b>				
1.9.3	Was a return to primary care (i.e. your GP) discussed?	72 (38.3)	83 (44.2)	33 (17.6)	188
1.9.4	Was there a care plan agreed with you for your return to primary care?	37 (24.0)	78 (50.7)	39 (25.3)	154

(continued)

Table 2. Continued.

NICE Guidelines for Bipolar Disorder Reference	Question	Yes N (%)	No N (%)	Don't know N (%)	Total Respondents
	<b>How to use medication</b>				
1.10.1	Did you have the opportunity to ask questions	189 (86.7)	12 (5.5)	17 (7.8)	218
1.10.1	Was the choice of medication made in collaboration with you?	155 (71.8)	44 (20.4)	17 (7.9)	216
1.10.2	Was the use of alcohol, tobacco, prescription and non-prescription medication and illegal drugs, and their potential impact on your mood, discussed with you?	142 (66.4)	54 (25.2)	18 (8.4)	214
1.10.14	If starting Lithium: Were you advised that poor adherence or rapid discontinuation may increase the risk of relapse?	58 (55.2)	26 (24.8)	21 (20.0)	105
1.10.14	If starting Lithium: Were you given appropriate information on taking it safely?	79 (75.2)	14 (13.3)	12 (11.4)	105
1.10.17	If taking Lithium: Were you advised to seek medical attention if you developed diarrhoea or vomiting or become very ill for any reason?	49 (46.2)	38 (35.9)	19 (17.9)	106
1.10.17	If taking Lithium: Were you advised to ensure you maintained your fluid intake, particularly when hot and sweating heavily, if you were immobile for long periods or if you developed a chest infection or pneumonia?	70 (64.8)	28 (25.9)	10 (9.3)	108
1.10.17	If taking Lithium: Were you advised to talk to your doctor as soon as possible if you became pregnant or were considering having a family?	44 (61.1)	15 (20.8)	13 (18.1)	72
1.10.37	If taking lamotrigine: Were you advised to contact your doctor immediately if you developed a rash?	59 (63.4)	19 (20.4)	15 (16.1)	93
1.10.37	If taking lamotrigine: Were you advised to inform services if you were pregnant or were planning a pregnancy?	35 (54.7)	18 (28.1)	11 (17.2)	64

endorsed by 50 per cent or more of service users, suggesting that care for service users with bipolar disorder is focussed mostly on medication. Five items, all concerned with non-medication management, namely collaboration on advance statements, agreeing a care plan for return to primary care, offer of calming environments during mania, offer of a family intervention and a programme of combined healthy eating and physical activity were endorsed by less than 30 per cent of service users.

There are few studies of concordance with guidelines on non-medical care guidelines in routine clinical practice. Our results confirm previous surveys highlighting that people with bipolar disorder rarely get help from mental health services with the Mental Capacity Act including advance statements or with similar enablers in other international jurisdictions (Hindley et al, 2019; Morriss et al., 2020). Co-production methods between service users, carers and mental health professionals may produce templates to guide collaborative decision-making around key decisions such as advance decision-making (Stephenson et al 2020) or forthcoming advance choice documents under recent proposals in England to reform the 1983 Mental Health Act (Jankovich et al., 2020). Concordance with Dutch guidelines for bipolar disorder was greater for pharmacological than psychosocial treatment in 839 people with bipolar disorder in a national observational study (Renes et al., 2018). A study of 433 bipolar disorder patients in the United States also showed only 28 per cent of participants had their treatment preferences recorded. Improvements in non-medical interventions care may need more active nationally led strategic policy making such as those that have been enacted for psychological treatment as part of early intervention for psychosis or for the management of common mental health disorders in primary care (NICE, 2017). More systematic attempts to teach guideline care through model consultation might be a way of improving information provision, tailoring

of care and collaborative decision-making for people with bipolar disorder. Compared to usual care, a randomised controlled trial of collaborative care in primary care supported by specialised mental health professionals with psychoeducation increased patient self-management skills along with greater access and continuity of care with professionals improved concordance with medical and non-medical guidance for bipolar disorder (Bauer et al., 2009).

There are many limitations to the survey. There was a considerable under-representation of males, both younger adults and older adults, and of all Black and Minority Ethnic Groups. The NHS Trusts we recruited from covered a range of deprivation in England from some of the most deprived, for example, the cities of Nottingham and Leicester are the 11 and 31<sup>st</sup> most deprived districts in England to some of the least deprived, for example, Rushcliffe, Rutland, and a range of ethnic diversity e.g. the cities of Leicester and Nottingham are 55% and 35% non-white British, respectively (National Statistics, 2019). Unpublished audits of people with mood disorders including bipolar disorder in two of the NHS Trusts found under-representation of men and people from Black and Minority Ethnic Groups, suggesting that the survey might be representative of these NHS Trusts in relation to these characteristics. Many people with bipolar disorder are looked after in primary care which was not examined at all. We recruited from only four NHS Trusts and it is possible that care may be different in other parts of the United Kingdom and internationally. Even in the four NHS Trusts that we carried out the survey, we only recruited a modest sample so it is possible that care may also be different in some parts of these services from what is reported in the current survey. We were unable to establish a denominator in terms of the population of service users with bipolar disorder who might be eligible to take part in the survey.

After discussion with our patient and public involvement representatives and data protection officers, information on demographic factors such as education, social deprivation, current treatment setting, experience with the Mental Health Act was not collected because too much information of this nature might have compromised anonymity and deterred participation. For the same reason, we did not check the self-reported diagnosis of bipolar disorder by standardised psychiatric interview.

There is no overall benchmark of what constitutes satisfactory adherence to a NICE Guidelines, and since guidelines offered tailored care, any benchmark is likely to be different depending on the recommendation e.g. family therapy would not be offered to people who lived alone without any family carer. A benchmark of 70 per cent concordance to core NICE guideline recommendations has been suggested (Morriss, 2008) so it is a concern that only 10 per cent of NICE guideline recommendations for bipolar disorder reached this benchmark. There was no evidence that participants in the survey were inhibited in giving their views about the provision of care in term of either the responses they gave or feedback. However, we do not know how many service users declined the survey because they still had concerns over confidentiality nor can we discount the possibility that those who completed the survey were some of the more dissatisfied service users with bipolar disorder. However, among those who completed the survey, service users frequently expressed their view that after a NICE clinical guideline is implemented, surveys such as this on the standard of care and collaborative decision-making should be routinely administered, not just as a one-off research project. If service users are to be given a loud enough say in their care and decision-making, then surveys such as this might be part of the recommendations of NICE guidelines in mental health.

In summary, a survey on service user experience of the implementation of the NICE clinical guideline for bipolar disorder suggests most respondents did not have an overall positive recovery experience, and that there was still little focus on aspects of care that did not involve medication or crisis provision. There was some evidence that service users were being involved in therapeutic decisions involving medication.

## Acknowledgement

The project was funded by the National Institute for Health Research (NIHR) Applied Research Collaboration East Midlands and supported by the NIHR Clinical Research Network RM was supported by a NIHR Senior Investigator Award, NIHR MindTech MedTech and *In Vitro* Centre and the Nottingham NIHR Biomedical Research Centre.

## Disclosure statement

No financial conflicts of interest. RM chaired the Guideline Development Group for the NICE Guideline for Bipolar Disorder (NICE, 2014).

## Funding

The project was funded by the NIHR Applied Research Collaboration East Midlands.

## Data availability statement

An anonymised database is available from the corresponding author.

## References

- Altınbaş, K., Smith, D., & Oral, E. T. (2011). Adherence to Turkish psychiatric association guideline for bipolar depression treatment in a specialized mood disorders outpatient unit. *Psychiatria Danubina*, 23(2), 189–193.
- Armstrong, D. (2002). Clinical autonomy, individual and collective: the problem of changing doctors' behaviour. *Social Science and Medicine*, 55(10), 1771–1777. [https://doi.org/10.1016/S0277-9536\(01\)00309-4](https://doi.org/10.1016/S0277-9536(01)00309-4)
- Baker, R., Reddish, S., Robertson, N., Hearnshaw, H., & Jones, B. (2001). Randomised controlled trial of tailored strategies to implement guidelines for the management of patients with depression in general practice. *British Journal of General Practice*, 51(470), 737–741.
- Bauer, M. S., Biswas, K., & Kilbourne, A. M. (2009). Enhancing multi-year guideline concordance for bipolar disorder through collaborative care. *The American Journal of Psychiatry*, 166(11), 1244–1250. <https://doi.org/10.1176/appi.ajp.2009.09030342>
- Dennehy, E. B., Suppes, T., Rush, A. J., Miller, A. L., Trivedi, M. H., Crismon, M. L., Carmody, T. J., & Kashner, T. M. (2005). Does provider adherence to a treatment guideline change clinical outcomes for patients with bipolar disorder? Results from the Texas Medication Algorithm Project. *Psychological Medicine*, 35(12), 1695–1706. <https://doi.org/10.1017/S0033291705005933>
- Fang, M., Fila, K., Davey, C., McGorry, P., Berk, M., & Cotton, S. (2019). Poster: Are current guidelines appropriate for youth with early stage Bipolar Disorder? A prospective observational study of the impact of guideline concordant care on 18-month symptomatic and functional outcomes. *Bipolar Disorders*, 21(S1), 66–147. <https://doi.org/10.1111/bdi.12746>
- Freeland, K. N., Cogdill, B. R., Ross, C. A., Sullivan, C. O., Drayton, S. J., VandenBerg, A. M., Short, E. B., & Garrison, K. L. (2015). Adherence to evidence-based treatment guidelines for bipolar depression in an inpatient setting. *American Journal of Health-System Pharmacy: AJHP: official Journal of the American Society of Health-System Pharmacists*, 72(23 Suppl 3), S156–S161. <https://doi.org/10.2146/sp150023>
- Goodwin, G. M, Consensus Group of the British Association for Psychopharmacology (2003). Evidence-based guidelines for treating bipolar disorder: Recommendations from the British Association for Psychopharmacology. *Journal of Psychopharmacology (Oxford, England)*, 17(2), 149–173. <https://doi.org/10.1177/0269881103017002003>
- Hindley, G., Stephenson, L. A., Keene, A. R., Rifkin, L., Gergel, T., & Owen, G. (2019). "Why have I not been told about this?": a survey of experiences of and attitudes to advance decision-making amongst people with bipolar?" *Wellcome Open Research*, 4, 16. <https://doi.org/10.12688/wellcomeopenres.14989.2>
- Jankovich, J., Richards, F., Berrisford, G., & Priebe, S. (2020). Advance statements in adult mental healthcare: an update. *British Journal of Psychiatry Advances*, 26 (2), 109–115.
- Kessing, L. V., Hansen, H. V., Hvenegaard, A., Christensen, E. M., Dam, H., Gluud, C., & Wetterslev, J, Early Intervention Affective Disorders (EIA) Trial Group (2013). Treatment in a specialised outpatient mood disorder clinic v. standard out-patient treatment in the early course of bipolar disorder: randomised clinical trial. *British Journal of Psychiatry*, 202(3), 212–219. <https://doi.org/10.1192/bjp.bp.112.113548>



- Lenzer, J. (2013). Why we can't trust clinical guidelines. *BMJ (Clinical Research ed.)*, 346, f3830. <https://doi.org/10.1136/bmj.f3830>
- McCrone, P., Dhanasiri, S., Patel, A., Knapp, M., & Lawton-Smith, S. (2008). *Paying the price: the cost of mental health care in England to 2026*. King's Fund.
- Morriss, R. (2008). Implementing clinical guidelines for bipolar disorder. *Psychology and Psychotherapy*, 81(Pt 4), 437–458. <https://doi.org/10.1348/147608308X278105>
- Morriss, R. (2015). Mandatory implementation of NICE Guidelines for the care of bipolar disorder and other conditions in England and Wales. *BMC Medicine*, 13(1), 246. <https://doi.org/10.1186/s12916-015-0464-7>
- Morriss, R., Mudigonda, M., Bartlett, P., Chopra, A., & Jones, S. (2020). National survey and analysis of barriers to the utilisation of the 2005 mental capacity act by people with bipolar disorder in England and Wales. *Journal of Mental Health*, 29(2), 131–138. <https://doi.org/10.1080/09638237.2017.1340613>
- National Collaborating Centre for Mental Health (2011). *Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services*. CG136. British Psychological Society and Gaskell.
- National Statistics. 2019. English indices of deprivation 2019 <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019>
- NHS Commissioning Board (2013). *Commissioning policy: Implementation and funding of guidance produced by the National Institute for Health and Clinical Excellence*. NHS Commissioning Board.
- NICE (2006). Bipolar disorder: the management of bipolar disorder in adults, children and adolescents, in primary and secondary care. CG38. British Psychological Society and Gaskell. <https://www.nice.org.uk/guidance/cg38>
- NICE (2012). *The guidelines manual*. PMG6. NICE.
- NICE (2014). *Service user experience in adult mental health: National Institute for Health and Clinical Excellence. Bipolar disorder (update): the management of bipolar disorder in adults, children and adolescents in primary and secondary care*. In NICE (Ed.), Clinical Guideline 185.
- NICE (2017). NICE guidance and current practice report: Mental Health. NICE <https://www.nice.org.uk/media/default/about/what-we-do/into-practice/measuring-uptake/nice-guidance-and-current-practice-report-mental-health.pdf>
- Price, S. J., Whittle, I. R., Ashkan, K., Grundy, P., Cruickshank, G., & Group, U.-H S, UK-HGG Study Group (2012). NICE guidance on the use of carmustine wafers in high grade gliomas: a national study on variation in practice. *British Journal of Neurosurgery*, 26(3), 331–335. <https://doi.org/10.3109/02688697.2012.673651>
- Renes, J. W., Regeer, E. J., Hoogendoorn, A. W., Nolen, W. B., & Kupka, R. W. (2018). A nationwide study on concordance with multimodal treatment guidelines in bipolar disorder. *International Journal of Bipolar Disorders*, 6(1), 22. <https://doi.org/10.1186/s40345-018-0130-z>
- Samalin, L., & Llorca, P. M. (2012). [Methodological approach to inter "guideline" variability in the management of bipolar disorders]". *L'Encephale*, 38(2), 126–132. <https://doi.org/10.1016/j.encep.2011.07.004>
- Stephenson, L. A., Gergel, T., Ruck Keene, A., Rifkin, L., & Owen, G. (2020). The PACT advance decision-making template: preparing for Mental Health Act reforms with co-production, focus groups and consultation. *International Journal of Law and Psychiatry*, 71, 101563. <https://doi.org/10.1016/j.ijlp.2020.101563>
- Vos, T., Flaxman, A. D., Naghavi, M., Lozano, R., Michaud, C., Ezzati, M., Shibuya, K., Salomon, J. A., Abdalla, S., Aboyans, V., Abraham, J., Ackerman, I., Aggarwal, R., Ahn, S. Y., Ali, M. K., Alvarado, M., Anderson, H. R., Anderson, L. M., Andrews, K. G., Memish, Z. A. (2012). Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet (London, England)*, 380(9859), 2163–2196. [https://doi.org/10.1016/S0140-6736\(12\)61729-2](https://doi.org/10.1016/S0140-6736(12)61729-2)
- Woolf, S. H., Grol, R., Hutchinson, A., Eccles, M., & Grimshaw, J. (1999). Clinical guidelines: potential benefits, limitations, and harms of clinical guidelines. *BMJ (Clinical Research ed.)*, 318(7182), 527–530. <https://doi.org/10.1136/bmj.318.7182.527>
- Ziebland, S., Locock, L., Fitzpatrick, R., Stokes, T., Robert, G., O'Flynn, N., Bennert, K., Ryan, S., Thomas, V., & Martin, A. (2014). Informing the development of NICE (National Institute for Health and Care Excellence) quality standards through secondary analysis of qualitative narrative interviews on patients' experiences. NIHR Journals Library. *Health Services and Delivery Research*, 2(45), 1–206. <https://doi.org/10.3310/hsdr02450>