

TITLE: Perspectives on the International Classification of Diseases, 11th Revision (ICD-11); an international qualitative study to Understand and improve mental health Diagnosis using expertise by Experience: INCLUDE Study

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ABSTRACT

Developed in collaboration with the WHO Department of Mental Health and Substance Abuse, this study conducted in the UK, India, and the US, integrated feedback from mental health service users into the development of the chapter on mental, behavioural, and neurodevelopmental disorders for the Eleventh Revision of the International Classification of Diseases and Related Health Problems (ICD-11). The ICD-11 is set for approval by the World Health Assembly in May, 2019. As a reporting standard and diagnostic classification system it will be highly influential on the policy, clinical practice, and research that affect mental health service users; yet this is the first study to systematically seek and collate service user perspectives on a major classification and diagnostic guideline. Focus groups were used to collect feedback on five diagnoses: depressive episode, generalised anxiety disorder, schizophrenia, bipolar type 1 disorder, and personality disorder. Participants were given the official draft diagnostic guidelines and a parallel lay translation. Data were thematically analysed. This formed the basis of co-produced recommendations for the WHO, which included features that could be added or revised to better reflect lived experience and changes to language that was confusing or objectionable to service users. The findings also indicated that an accessible lay language version of the ICD-11 could be beneficial for service users and their supporters.

INTRODUCTION

The ICD-11 will be used for health reporting by WHO's 194 member states beginning in January, 2022. The chapter on Mental and Behavioural Disorders in the current version (ICD-10) is the most widely used classification system for mental disorders globally.¹ The WHO Department of Mental Health and Substance Abuse (MSD) has developed detailed diagnostic guidelines for ICD-11 Mental, Behavioural, and Neurodevelopmental Disorders to be used by health professionals in clinical settings. Priorities for MSD have included enhancing the clinical utility and global applicability of the ICD-11 diagnostic guidelines.¹ This will be highly influential on the mental health (MH) policy and service provision that affect the lives of people who experience MH difficulties. This study represents the first systematic and programmatic research study of MH service users during the revision process of a major diagnostic guideline (including the ICD and the Diagnostic and Statistical Manual of Mental Disorders, DSM of the American Psychiatric Association).

The Lancet Commission on Global Mental Health² has identified the critical importance of service users as experts by experience in the global development and provision of MH innovation and services; reaffirming the MH recovery and disability rights philosophy of *nothing about us without us*. The value of expertise by experience in innovation, service provision, and research is increasingly recognised by policy makers, service providers, and researchers.³⁻⁵

Classification and diagnostic guidelines are designed to offer guidance to clinicians and researchers, and the language and terminology is often technical. Despite this, the diagnostic features are easily accessed via the internet. Receiving a diagnosis can be beneficial to service users but it has also been reported to have negative consequences. These include feeling labelled, reduced, and stigmatised.⁶⁻⁹ It is therefore essential to gain understanding of the way that service users respond to the content of the major diagnostic systems as this could enhance clinical utility and help avoid potential unintended negative consequences.

Aims

This study aimed to gain perspective from service users across international contexts. With agreement from the WHO, five diagnoses were selected: schizophrenia, bipolar disorder type 1 (BPD1), depressive episode (DE), personality disorder (PD), and generalised anxiety disorder (GAD). These diagnoses were selected to include a wide range of symptom phenomena, include diagnoses with high disease burden¹⁰, and experienced as stigmatising.^{11,12} The UK and India sites sought feedback on the five diagnoses. The US site implemented the protocol for DE, Schizophrenia, and BPD1. This study aimed to systematically collate feedback on a) the draft content of the ICD-11, b) whether the features fit with lived-experience, and c) the language.

We also sought feedback in the UK and India from clinicians who routinely use the ICD; including psychiatrists, primary care doctors, and clinical psychologists. We were primarily concerned the perspectives of service users and used the clinician data to triangulate these findings.

Participants were provided with two parallel versions of the relevant diagnostic guidelines to feedback on: a version taken from WHO'S draft Clinical Descriptions and Diagnostic Guideline (CDDG) for ICD-11 mental disorders¹³ and a summary of this in accessible lay language (produced for this project by medical professionals and reviewed by the research team including service users). This study additionally aimed to explore the service user responses to the accessible version of the guidelines.

METHOD

Study Design

All aspects of this study, including the protocol, delivery, and analysis were coproduced by researchers, service users, and clinicians. The INCLUDE study protocol has previously been published.¹⁴

Ethics Committee Approval

All sites received approval from appropriate review bodies. In the UK this was Coventry and Warwickshire HRA Research Ethics Committee (ref 16/WM/0479); Indian approval was from Institute Ethics Committee of All India Institute of Medical Sciences (AIIMS) New Delhi (Ref No. IEC-442/04.08.2017); the US approval was from the New York State Psychiatric Institute Institutional Review Board (Ref Project #7573).

Data were collected through focus group discussions (FGDs), which were considered the most appropriate method to capture opinions via a reflective process facilitated by social interaction.¹⁵⁻¹⁷ In India the draft guidelines and lay summary were provided in both English and Hindi.

Recruitment

We aimed to use purposive sampling to ensure a wide range of viewpoints were captured. Recruitment was, however, essentially pragmatic, with diverse recruitment pathways to ensure maximum inclusivity and heterogeneity in each context. In the UK and India, clinical staff in a MH service approached service users who met inclusion criteria. To allow self-referral, in the UK the study was also promoted via posters in clinical spaces (e.g. waiting rooms) and newsletters to the MH trust membership. Recruitment in the US was via staff with lived experience working in a peer led service and the study was also promoted by flyers circulated to the peer service members. All service users recruited via clinicians or peer-staff were aware of their diagnosis prior to recruitment. Clinicians were recruited via emails to potentially interested parties. In all countries interested people (service users and clinicians) approached the research team to discuss participation and were screened against inclusion criteria; including self-confirming that they had formally received at least one diagnosis under investigation. In order to facilitate engagement and reduce burden on participants, we did not collect standardised self-reported demographic data. To ensure that the samples were broadly mixed, we did gather visual estimated data on gender and age-range (in India this was gathered from medical records which were accessed with consent). We do not report this as permission to share this data was not sought from participants. Informed consent was taken for all participants. Participants in the UK and US received a £10 voucher and \$20 respectively to thank them for their participation. Participants in India did not receive reimbursement as this is standard practice.

Sample

The number of FGDs was based on findings for using standardised topic guides or interviews for qualitative research.¹⁸ The FGD size was chosen to allow participants opportunity to discuss detailed views and experiences, whilst maximising recruitment feasibility.¹⁹ The sample size and number of FGDS was deemed sufficient to provide data to meet the research aims.²⁰

Table 1, shows the number of participants and FGDs for each country. Adult service users (≥ 18 years) were included if they had formally received at least one of the five diagnoses, were accessing MH services currently

or within the last five years, able to take part in a FGD in English (or Hindi in India), and had capacity to consent. Those with multiple diagnoses were limited to one FGD. Clinicians in the FGDs had experience of using the diagnoses under investigation. In order to triangulate the outputs of the analyses and co-produce recommendations for revisions to the ICD-11, feedback groups were run with seven additional service users and four clinicians in the UK.

TABLE 1 HERE

Data Collection

Handouts including the draft ICD-11 guidelines and a lay summary were used to inform all participants (service users and clinicians) of the proposed ICD-11 features. The ICD guidelines were divided into set discussion points for the FGDs in all countries (developed by the UK team including clinicians and service users). This included feedback on the proposed features and language. The same FGD materials, including set discussion points, were used for all sites and participants (with questions and handouts available in Hindi in India). Each FGD lasted between 60-120 minutes. The FGDs were all facilitated by an experienced lead facilitator. All lead facilitators were members of the research team; who were clinicians, peer providers, and/or researchers.

Data Analysis

A critical realist epistemological stance was adopted for the analysis.²¹ This approach was selected to capture the nuance of individual experience and develop useful feedback for the WHO.²²

All FGDs were audio-recorded and transcribed verbatim. Thematic analysis²³ was used to identify patterns within the data relating to perceptions of the draft content of the guidelines. This was supported by qualitative data management software (NVivo-11/Dedoose). We inductively coded patterns (or themes) that reoccurred (a cut-off of a minimum of 3 codes was applied) or appeared salient.^{22,23} The transcripts were initially read and open coded (using the same language as participants where possible); a minimum of 25% of the transcripts were independently coded by a second researcher. These codes were compared and discussed until consensus was reached. As the codes were descriptive of the data, consensus was reached with minimal disagreement and without involving a third analyst. This process was used to develop coding frames of key themes for each diagnosis for service users and clinicians for all countries before making comparisons among countries; ensuring that the findings from each context were not influenced by other contexts. When the coding frames were complete, 50% of codes were validity checked by independently analysing the codes against the themes. A high level of inter-rater agreement was found for all sites (UK 0.79, India 0.84, US 0.82). In order to triangulate the service user findings, we compared the coding frames developed from the service user and clinician data. We found that there was a good level of superordinate theme co-occurrence (with the exception of themes relating to the lay summaries and the addition of themes relating to the utility of the ICD-11 system in the coding frames developed from the clinician data). The analysis output was overarching superordinate themes (reflecting broad conceptual categories), containing more nuanced subsidiary themes.

RESULTS

Table 2 shows the key superordinate and subsidiary themes found for service users for all countries. These themes were developed from the analysis outlined above.

TABLE 2 HERE

Additional Features

The most frequently occurring theme was features that participants, based on their lived experience, felt had been omitted from the draft ICD-11. The majority of these additional features reflected internal or “felt-experience” (as described by the UK feedback group). This mainly comprised emotional, psychological, and somatic experience.

The diagnosis with the largest number of additional features was schizophrenia. This included anger, fear and memory difficulties.

“I always misplace things or lose things, because I have a very bad short-term memory.” (US, schizophrenia FGD)

Additionally the schizophrenia FGDs identified that their experience of interpersonal difficulties (feelings of distance, isolation, or alienation from other people) and difficulties communicating internal experiences were not reflected in the proposed ICD-11.

“I like to do things my way. My father and my brother criticise some of my actions... They may not understand the reason, but there is a reason for it that I can’t explain to anyone” (India, schizophrenia FGD).

Additional features for BPD1 included anxiety, anger, nausea, and sickness. Participants reported that they felt that the proposed features reflected negative aspects of BPD1 and identified increased levels of creativity as a positive aspect.

“I do feel it should have something about creativity in it because I think that an important aspect of mania” (UK, BPD1 FGD)

Fewer missing features were identified for GAD and DE. Nausea and anger were identified for GAD, anxiety and pain were identified for DE.

The PD FGDs reported that the proposed features did not reflect their internal felt-experience; including distress and difficulty. The features do include vulnerability in relationships, but the participants additionally identified that they did not explicitly include that people with PD may be vulnerable to exploitation from others.

“A lot of this stuff is one-sided; it problematises the sufferer, it doesn’t talk about their vulnerabilities, nothing about them being open to exploitation or predation, nothing like that. Nothing about how potentially their fears, and suspiciousness, and avoidance might be caused by previous abuse.” (UK, PD FGD)

There were parallels between the clinician and service user data in terms of additional features; however, far fewer additional features were identified by clinicians. They noted the omission of anxiety from the features of DE and vulnerability to exploitation by others from PD. In the ICD-11 there are qualifiers for the features of depression that include anxiety symptoms. These qualifiers were considered out of scope for the material presented to participants.

Participants in the FGDs for schizophrenia, PD and BPD1 identified that features tended to reflect an external perspective rather than the internal or felt-experience of features. This aligns with the finding that the majority of additional features reflected internal experience.

“It’s the internal experience that’s getting missed again, this is all rated on what’s being seen outside” (UK, PD FGD)

Features that do not resonate

Another superordinate theme was features that were identified as not resonating with lived experience. These were identified for schizophrenia, BPD1 and PD.

Participants in the schizophrenia FGD in India and the UK objected to the word “disorganised” (as in, thinking and behaviour). Participants reported the felt-experience of psychotic symptoms (including thought disorder and delusions) may appear disorganised but is often linked to a felt-experience of patterns or connections between things or experiences that may feel particularly significant (this was also found for psychotic phenomena in BPD1). Therefore, thinking or behaviour that appears disorganised may actually be goal-directed in ways that are hard for people to explain (this also relates to the findings of communication difficulties).

“What appears meaningless or disorganized to you may not be so for me... it can have a very clear meaning for me... I may not be able to explain every action (India, Schizophrenia FGD)

In the PD FGDs, participants reported that the word ‘maladaptive’ (as in, “maladaptive patterns of cognition, emotional experience, emotional expression, and behaviour”) did not fit with their experience.

“I absolutely hate the word maladaptive... It’s somebody else’s judgement if it’s a bad adaption or not, but it’s an adaptation that somebody has had to make to survive their circumstances, so therefore it’s actually a very valid adaption for that person in the situation.” (UK, PD FGD)

The clinicians also reported that the concept of maladaptive is culturally defined.

The proposed ICD-11 features for BPD1 include “decreased need for sleep” as distinct from insomnia. Participants in the US reported that their lived experience was that they could not sleep but did not necessarily need less sleep.

“I didn’t sleep because I was thinking about other things, but I didn’t necessarily feel less need for sleep” (US, BPD1 FGD)

Language

There was a superordinate theme of language that service users disliked. This was found for schizophrenia, DE and PD. For the descriptions of schizophrenia, participants disliked the words “bizarre” (as in, “behaviour that appears bizarre or purposeless”) and “disorganised” (as previously discussed) as these were perceived to be negative descriptions of the phenomena.

“Terms such as disorganized or bizarre are negative terms. These terms should not be there.” (India, Schizophrenia FGD)

There were also technical terms that participants misunderstood or interpreted in a negative way. This included “retardation” and “neuro-vegetative” in DE. The clinicians also felt that neuro-vegetative could be confusing to service users and felt that the use of the term ‘maladaptive’ for PD may be objectionable to service users.

“When you say “retardation,” it gives the idea that we can’t actually halfway defend ourselves or we’re helpless or we need to actually – someone needs to be watching us every five seconds” (US, DE FGD)

Specific Themes for Personality Disorder

Harm to others is included in the proposed ICD-11 (e.g. “Severe Personality Disorder is often associated with harm to self or others”). Service users reported that they were concerned that it might be interpreted that harm to others is always a feature of PD.

“I don’t agree with some of the content written here, especially that the person with personality disorder person can kill or harm others. If you describe personality disorder like this, I would hesitate in disclosing my illness to others.” (India PD, FGD)

There was feedback on the move to a dimensional approach. It was reported that the inclusion of a milder diagnosis may risk people exhibiting more severe symptoms in order to obtain a diagnosis that validated their perceived level of difficulty or to gain access to care or treatment.

“You’re invalidating people who score at a particular point, as mild... you’re not getting rid of the stigma; you’re adding what I used to call a “meta-stigma,” which is a stigma of not being ill enough.” (UK, PD FGD)

Lay Summaries

Positive feedback on the lay summaries was a superordinate theme that was found for all diagnoses, across all countries. Participants reported that the lay summaries were clearer, more accessible, and easier to understand; consequently, they were reported to be more resonant with, and descriptive of, lived-experience.

“It just seems to be much easier to associate with this (lay summary) than all this (official ICD-11 text).” (US, Schizophrenia FGD)

Participants also reported that the lay summaries would be a beneficial resource for service users and may support a shared language with friends and family and shared decision-making with clinicians.

“I want to keep a copy of this document to share it with my family.” (India, GAD FGD)

“Is the idea of this now it’s going to be more shared? When the diagnosis is done it’s a shared experience, so you’re looking at this? (lay summary) Because you never actually get shown anything” (UK, DE FGD)

Exploration between Countries

As shown by Figure 1, there were differences between the three research contexts but these did not appear to follow a particular pattern. For example, the ICD-11 proposed content for DE states that “In some cultural contexts, mood changes are more readily expressed in the form of bodily symptoms (e.g. pain, fatigue, weakness)”. Despite this, pain was reported for DE by participants in both India and the US.

Participants in India reported that for BPD1 and GAD, the proposed descriptions did not necessarily reflect their experience as well as local words or idioms.

“It would be easy to understand if you can call it as an illness of udaasi and tezi” (India, BPAD1 FGD)

The data from the US included more references to the impact of substance use. This was not discussed in the FGDs in the other two countries but was coded for all diagnoses in the US.

“Drugs and alcohol can... trigger it, activate it.” (US, schizophrenia FGD)

There were similarities between the countries; e.g. service users in the schizophrenia FGDs in all three countries reported that the ICD-11 features did not reflect their experience of interpersonal difficulties and anxiety was universally reported as a feature of depression.

DISCUSSION

This is the first study to systematically seek service user perspectives on a major diagnostic guideline. Participants identified additional features for all diagnoses. These mainly reflected internal experience (e.g. pain or distress). Many additional features could be externally observed (e.g. interpersonal difficulties) but even for these features, much of the feedback centred on felt-experience. Participants identified instances where features

did not resonate with lived experience. This included disorganised and maladaptive behaviour in schizophrenia and PD respectively. The feedback suggested that this may not reflect the internal experience. Participants also identified that features tended to reflect an external perspective. Classification systems operationalise features and prioritise what can be described from an external perspective to enhance reliability and support clinical use.¹ Our data suggests that this may have the potential unintended consequences for service users of feeling alienated, misunderstood or invalidated.

There were commonalities between the service user and clinician findings. Clinicians identified some overlapping additional features (e.g. vulnerability to others in PD and anxiety in DE) but far fewer than service users. There were also overlaps in language identified as potentially confusing or objectionable to service users (e.g. ‘neuro-vegetative’ and ‘maladaptive’). The superordinate theme of positive feedback on the lay summaries was not coded from the clinician data. The clinician data did include superordinate themes relating to the utility of the ICD system for all diagnoses. These are not discussed in this paper as this has been comprehensively covered elsewhere in the ICD-11 development.¹

Participants identified that language is important and offered feedback on words or terms that were confusing, misinterpreted or objectionable. In the draft ICD-11 guidelines, terms such as ‘retardation’ and ‘neuro-vegetative’ were misinterpreted, while ‘bizarre’, ‘disorganised’, and ‘maladaptive’ were objectionable. Participants in India reported that there are words or idioms in their native language that better resonate with lived experience. This finding aligns with the ICD-11 commitment to provide latitude in the diagnostic system that allows for cultural difference² Cultural considerations were not included in the materials evaluated in the study.

A second goal of this study was to explore responses to the lay language summaries. Service users across all sites and diagnoses offered positive feedback; the data suggests that such summaries could aid understanding, offer a common language or explanation, and potentially facilitate a “shared” or collaborative diagnostic process. Findings also suggest that explanatory information received during the diagnostic process can aid understanding.^{24,25}

CONCLUSION

This study was developed in collaboration with the WHO and offers a unique insight into the views of service users on the proposed ICD-11. Coproduced recommendations, based on the themes described above, were included in a report written by the research team and submitted to the WHO; which has established a process of review and consideration of incorporation into revisions of the CDDG for ICD-11 Mental, Behavioural and Neurodevelopmental Disorders. This includes the finding that service users may benefit from a version of the ICD-11 system that is understandable to them and includes more information about the felt-experience underlying the operationalised features.

This study was limited by the number of included diagnoses, participants, countries, and languages. This limits generalisability of the findings. However, as a qualitative study, the findings present both useful recommendations and a transferable methodology for the systematic integration of the perspectives of service users into current and future iterations of the ICD. Future feedback from service users could incorporate a wider range of countries and service contexts; particularly in low and middle income countries. The lack of reportable demographic data is also a limitation of the current study.

From the perspective of service users, diagnosis can validate and help make sense of distressing and complex MH experiences.^{25,26} However, our findings suggest that one unintended consequence of major classification systems is that the operationalised features do not always reflect internal or felt experience. Diagnosis can also offer a shared language for service users, families, and clinicians but we found that the technical and medical language in major systems can be confusing or alienating for people who are not professionally trained, which may reinforce power imbalance.²⁷ Diagnosis may also support a shared understanding between service users, families and clinicians. This is best achieved when there is understanding between service user and clinician of both the clinician’s reasoning and service user’s experience.

One future direction is to co-produce with service users, carers, and clinicians, shared summaries of the diagnostic features and related phenomena for collaborative use by clinicians and service users. This could offer a shared language that captures additional aspects of lived experience, avoids medical terminology, provides lay understanding of the operational features, and enriches these features with the underlying felt-experience. We hope that this could encourage a reciprocal and collaborative diagnostic process and sharing of power between clinicians and service users. There is evidence that this facilitates rapport and engagement, and may support recovery.²⁴ Coproduced shared summaries could also allow greater elaboration of contextually situated lived and felt-experience and the local language and idioms used to describe MH phenomena. These shared summaries could also be used for public engagement, health education, and clinical training.

This study represents an overdue milestone and watershed moment in MH research. It is the first time that service users have participated in systematic research to provide review and recommendations on proposed diagnostic guidelines for a major system. Given this, it is worth remarking that the proposed guidelines were in many cases perceived as useful and relevant to lived experience. It is also profoundly important to acknowledge and document the recommendations that this study generated. Critically, this study validates the essential engagement of service users and the essential role of co-production. As demonstrated herein, such practices have the potential to enhance the descriptive accuracy and maximise the acceptability of the guidelines from the service user perspective, a key constituent group for whom the system is critically relevant.

Author's contributions

CH, CN, GMR, JW, TS contributed to the study conceptualisation and original protocol; YPSB, KC, PBN, KMP, PS, MSR, JS, and MS developed protocols in their respective countries (with support from CH); CH, YPSB, KC, PBN, CN, KP, PS, JS, MS, MSR, JW, and TS delivered recruitment and data collection in respective countries; CH, YPSB, KC, PBN, CN, KP, PS, JS, MS, MSR, and HZ analysed and combined the data. All authors contributed to writing or revising the paper.

Conflict of Interest Statement

We declare no competing interests.

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Country	Focus group discussion	Number of focus groups	Total Number of participants
UK	Schizophrenia	2	7
	Bipolar disorder	2	8
	Depressive episode	2	8
	Generalised anxiety disorder	2	4
	Personality disorder	2	6
	Physicians	2	11
	Clinical psychologists	1	6
India	Schizophrenia	2	8
	Bipolar disorder	2	7
	Depressive episode	2	9
	Generalised anxiety disorder	1	9
	Personality disorder	2	4
	Psychiatrists	1	6
	Clinical psychologists	1	7
US	Schizophrenia	4	18
	Bipolar disorder	4	20
	Depressive episode	3	19
Total		35	157

Table 1, Number of participants and focus groups for each country

Diagnosis	Superordinate theme	Subsidiary theme	Number of times theme was coded*		
			UK	India	US
Schizophrenia	Additional features	Difficulty communicating	18	11	1
		Interpersonal difficulties	15	7	5
		Fear/distress	17	0	2
		Psychotic features feel 'real'	10	0	7
		Irritability/sensitivity	0	7	0
		Psychotic features: pattern, significance	5	0	0
		Memory difficulties	1	0	7
	Disliked language	"Disorganised"	0	5	0
		"Bizarre"	0	3	0
	Non-resonant features	Disorganised thinking/behaviour	9	0	2
Lay summary	Positive feedback	11	6	8	
BPD1	Additional features	Anxiety/distress	8	1	4
		Anger	6	5	0
		Frequent mood fluctuations	0	8	0
		Interpersonal sensitivity	0	6	0
		Psychotic features: pattern, significance	5	0	0
		Creativity	3	0	0
	Non-resonant features	Sleep difficulties include insomnia	0	0	4
	Cultural description	Native language/idioms are better	0	5	0
Lay summary	Positive feedback	3	6	30	
DE	Missing features	Anxiety/tension	6	6	2
		Pain	0	6	5
	Disliked/confusing language	"Psychomotor retardation"	1	0	11
		"Neuro-vegetative"	3	0	0
Lay summary	Positive feedback	18	4	8	
PD	Additional features	Distress	11	0	n/a
		Vulnerability to others	5	0	n/a
	Non-resonant features	Harm to others	6	6	n/a
		Maladaptive cognition and behaviour	3	0	n/a
	Disliked language	"Maladaptive"	4	0	n/a
Lay summary	Positive feedback	7	7	n/a	
GAD	Additional features	Anger	12	0	n/a
		Pain	0	5	n/a
	Cultural description	Native language/idioms are better	0	6	n/a
	Lay summary	Positive feedback	10	6	n/a

Table 2, Superordinate and subsidiary themes for all countries

*Themes discussed in this manuscript were coded a minimum of 3 times