Experiencing mental health diagnosis: a systematic review of service user, clinician, and carer perspectives across clinical settings

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Receiving a mental health diagnosis can be pivotal for service users, and it has been described in both positive and negative terms. What influences service-user experience of the diagnostic process is unclear; consequently, clinicians report uncertainty regarding best practice. This Review aims to understand and inform diagnostic practice through a comprehensive synthesis of qualitative data on views and experiences from key stakeholders (service users, clinicians, carers, and family). We searched five databases and identified 78 papers for inclusion, originating from 13 countries and including 2228 participants. Eligible papers were assessed for quality, and data were coded and then developed into themes, which generated a model representing factors to consider for clinicians conveying, and individuals receiving, mental health diagnoses. Themes included disclosure, information provision, collaboration, timing, stigma, and functional value of diagnosis for recovery. Variations between different stakeholders and clinical contexts are explored. Findings support an individualised, collaborative, and holistic approach to mental health diagnosis.

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Introduction

Receiving a formal diagnosis can have considerable impact.[1] It can help service users to understand their experiences; provide a sense of relief, control, and containment; offer hope for recovery; improve relationships with services; and reduce uncertainty.[2–4] Nonetheless, diagnosis can have unintended consequences, increasing individual and societal burden. These consequences include feelings of hopelessness, disempowerment, and frustration; stigma and discrimination; exacerbated symptoms; and disengagement from services.[5–7]

Qualitative research designs most appropriately capture people's views and experiences.[8] Evidence suggests that the impact of diagnosis depends on various factors, including service delivery. For example, diagnosis was experienced negatively when individuals felt that they received insufficient information from clinicians.[4] Conversely, when people felt knowledgable about their diagnosis, it could foster a sense of control, meaning, and hope.[6] The experience is also affected by the method of communication (eg, a letter *vs* face to face), time taken to decide and disclose a diagnosis, and whether diagnosis is framed as enduring or malleable.[3–5,9–11]

Previous studies that considered service-user experience of mental health diagnosis have focused on a single diagnosis, setting, or stage of the process (eg, disclosure), which limits generalisability. Studies typically explore isolated viewpoints of service users, clinicians, carers, or family. Understanding the process of diagnosis from the perspective of a single stakeholder has restricted usefulness for guiding service provision, which must be implemented at individual, service, and organisational levels. We identified one previous review, but it was limited to whether service users received the information they desired.[12] To our knowledge, no published reviews have yet synthesised data on the entire diagnostic process or included the views of carers and family.

This Review aims to incorporate the views of all key stakeholders, throughout the diagnostic process, across mental health conditions. This broad scope offers opportunity to gain a comprehensive and widely applicable understanding of the factors that influence service-user experience, through which we seek to reveal nuanced consideration of the experiential similarities and differences across contexts, such as diagnosis and service setting. This understanding will support the diagnostic process to improve service-user experience and outcomes. Our Review is timely, considering the upcoming release of the 11th revision of the International Classification of Diseases (ICD-11), which includes a chapter on mental and behavioural disorders.[13] Clinicians have reported uncertainty regarding best practice for the diagnostic process, resulting in discomfort and hesitance in implementing diagnostic manuals.[14–18] We aim to offer practical guidance for clinicians. This Review also seeks to inform service users, as well as carers and family, how to navigate the diagnostic process and support participation of all involved.[19]

Search strategy and selection criteria

We searched PsychINFO, Embase, MEDLINE, and CINAHL from inception to July 20, 2017 (initial search was done in October, 2016, and updated in July, 2017). Our search strategy was as follows: ("experienc* ADJ5 diagno*" or "perspective* ADJ5 diagno*" or "view* ADJ5 diagno*" or "perce* ADJ5 diagno*" or "communicat* ADJ5 diagno*" or "receiv* ADJ5 diagno*" or "deliver* ADJ5 diagno*" or "giv* ADJ5 diagno*" or "process* ADJ5 diagno*" or "news ADJ5 diagno*" or "inform* ADJ5 diagno*" or "disclos* ADJ5 diagno*" or "tell* ADJ5 diagno*" or "breaking ADJ5 news" or "deliver* ADJ5 news") and ("mental health" or "mental illness*" or "psychiatric disorder" or medical subject heading terms relating to psychiatric disorders, adapted for each database [appendix]).

See **Online** for appendix

	Participants	Diagnosis	Country	Setting	Sample size	Data collection	Analysis	Quality rating*	No of codes	Summary of themes
Aref-Adib et al (2016)[20]	Service user	Psychosis	UK	Secondary care	22	Interviews	Thematic analysis	30	19	Provision of information; comprehensiveness and quality of the diagnostic assessment; collaborative and therapeutic relationships
Baik et al (2005)[21]	Clinician	Depression	USA	Primary care	8	Interviews	Grounded theory	30	236	Comprehensiveness and quality of the diagnostic assessment; time to diagnose; stigma, discrimination, and culture; diagnostic accuracy and fit; collaborative and therapeutic relationships; service users' previous experiences and help seeking
Barker (1994)[22]	Service user and clinician	Psychosis	UK	Community	61	Interviews	Not stated	23	60	Provision of information; disclosure; stigma, discrimination, and culture; comprehensiveness and quality of the diagnostic assessment
Barnable et al (2006)[23]	Carer or family	Schizophrenia	Canada	Not stated	6	Interviews	Thematic analysis	29	54	Service users' previous experiences and help seeking; provision of information; disclosure; support from others; involvement of carers, family, and peers
Bartsch et al (2016)[24]	Service user	Borderline personality disorder	Australia	Community	12	Focus groups	Thematic analysis	32	13	Time to diagnose; diagnostic accuracy and fit; service users' previous experiences and help seeking
Bilderbeck et al (2014)[25]	Service user	Mixed	UK	Secondary care	28	Interviews	Framework analysis	32	367	Provision of information; collaborative and therapeutic relationships; stigma, discrimination, and culture; functional value of diagnosis; involvement of family, carers, and peers; service-user identity and recovery; diagnostic accuracy and fit; disclosure; comprehensiveness and quality of the diagnostic assessment; involvement of carers, family, and peers
Black et al (2013)[26]	Service user	Personality disorder	UK	Forensic	10	Interviews	Interpretative phenomenological analysis	32	17	Stigma, discrimination, and culture; functional value of diagnosis
Bonnington and Rose (2014)[27]	Service user	Mixed	UK	Not stated	46	Mixed	Thematic analysis	30	112	Collaborative and therapeutic relationships; provision of information; disclosure; service-user identity and recovery; stigma, discrimination, and culture; diagnostic accuracy and fit; functional value of diagnosis; drivers of diagnosis; ongoing support
Bril-Barniv et al (2017)[28]	Service user	Mixed	Israel	Mixed	29	Interviews	Phenomenological analysis	28	5	Stigma, discrimination, and culture; service-user identity and recovery
Carney et al (1998)[29]	Clinician	Depression	USA	Primary care	21	Focus groups	Content analysis	34	237	Comprehensiveness and quality of the diagnostic assessment; diagnostic accuracy and fit; service users' previous experiences and help seeking; stigma, discrimination, and culture; collaborative and therapeutic relationships; drivers of diagnosis; functional value of diagnosis; disclosure; time to diagnose
Castillo (2000),[30,31] Castillo (2003),[32] Castillo et al (2001),[33] Ramon et al (2001)[34]	Service user	Personality disorder	UK	Not stated	50	Mixed	Quantitative analysis with qualitative component	26	384	Functional value of diagnosis; service-user identity and recovery; stigma, discrimination, and culture; comprehensiveness and quality of the diagnostic assessment; diagnostic accuracy and fit; disclosure; collaborative and therapeutic relationships; support from others; ongoing support
Charles and O'Loughlin (2012)[35]	Service user	Psychosis	USA	Private inpatient	44	Interviews	Unspecified qualitative analysis	19	57	Functional value of diagnosis; service-user identity and recovery; stigma, discrimination, and culture; drivers of diagnosis; disclosure; diagnostic accuracy and fit; collaborative and therapeutic relationships; comprehensiveness and quality of the diagnostic assessment
Clafferty et al (2001)[9]	Clinician	Schizophrenia	UK	Not stated	211	Questionnaires	Not stated	19	42	Disclosure; drivers of diagnosis; collaborative and therapeutic relationships; involvement of family, carers, and peers; stigma, discrimination, and culture; comprehensiveness and quality of the diagnostic assessment; diagnostic accuracy and fit

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	Participants	Diagnosis	Country	Setting	Sample size	Data collection	Analysis	Quality rating*	No of codes	Summary of themes
(Continued from previous page)										
de Oliveira et al (2013)[36]	Service user	Schizophrenia	Brazil	Inpatient	10	Interviews	Thematic analysis	29	28	Disclosure; service-user identity and recovery; time to diagnose; stigma, discrimination, and culture; functional value of diagnosis; provision of information; service users' previous experiences and help seeking
Delmas et al (2012)[37]	Service user and carer or family	Bipolar disorder	Australia	Mixed	26	Interviews	Phenomenological analysis	32	173	Time to diagnose; comprehensiveness and quality of the diagnostic assessment; involvement of family, carers, and peers; diagnostic accuracy and fit; stigma, discrimination, and culture; support from others; involvement of carers, family, and peers; service users' previous experiences and help seeking
Dinos et al (2004)[38]	Service user	Depression	UK	Community	46	Interviews	Thematic analysis	31	29	Stigma, discrimination, and culture; functional value of diagnosis; diagnostic accuracy and fit; provision of information; service users' previous experiences and help seeking
Farzad Nawabi (2004)[39]	Service user	Mixed	USA	Not stated	9	Interviews	Grounded theory	31	339	Stigma, discrimination, and culture; service-user identity and recovery; time to diagnose; support from others; involvement of carers, family, and peers; diagnostic accuracy and fit; functional value of diagnosis; service user's previous experiences and help seeking
Ferriter and Huband (2003)[40]	Carer or family	Schizophrenia	UK	Forensic	26	Interviews	Not stated	23	8	Disclosure; involvement of family, carers, and peers; comprehensiveness and quality of the diagnostic assessment; diagnostic accuracy and fit
Fletcher et al (2008)[41]	Service user	Mixed	Australia	Specialist	110	Questionnaires	Not stated	20	55	Functional value of diagnosis; involvement of family, carers, and peers; collaborative and therapeutic relationships; provision of information; comprehensiveness and quality of the diagnostic assessment; ongoing support
Ford et al (2016)[42]	Clinician	Anxiety disorders	UK	Primary care	17	Interviews	Thematic analysis	34	332	Drivers of diagnosis; comprehensiveness and quality of the diagnostic assessment; diagnostic accuracy and fit; functional value of diagnosis; time to diagnose; collaborative and therapeutic relationships; stigma, discrimination, and culture
Frank and Davidson (2012)[43]	Service user	Psychosis	USA	Secondary community	8	Interviews	Interpretative phenomenological analysis	28	55	Functional value of diagnosis; stigma, discrimination, and culture; time to diagnose; service-user identity and recovery
Frese and Myrick (2010)[44]	Service user	Unspecified mental health diagnosis	USA, Australia, New Zealand, Canada, and UK	Not stated	57	Mixed	Content analysis	20	367	Collaborative and therapeutic relationships; stigma, discrimination, and culture; drivers of diagnosis; diagnostic accuracy and fit; comprehensiveness and quality of the diagnostic assessment; involvement of family, carers, and peers; functional value of diagnosis; service-user identity and recovery
Gallagher et al (2010)[45]	Service user	Unspecified mental health diagnosis	UK	Mixed	10	Interviews	Grounded theory	30	162	Diagnostic accuracy and fit; comprehensiveness and quality of the diagnostic assessment; disclosure; provision of information; functional value of diagnosis; collaborative and therapeutic relationships; stigma, discrimination, and culture
Gammell and Stoppard (1999),[46] Stoppard and Gammell (2003)[47]	Service user	Depression	Canada	Not stated	9	Interviews	Thematic analysis	30	275	Collaborative and therapeutic relationships; service-user identity and recovery; stigma, discrimination, and culture; time to diagnose; diagnostic accuracy and fit; comprehensiveness and quality of the diagnostic assessment; functional value of diagnosis
Giacon and Galera (2013)[48]	Carer or family	Schizophrenia	Brazil	Mixed	23	Interviews	Unspecified qualitative analysis	32	17	Time to diagnose; diagnostic accuracy and fit; stigma, discrimination, and culture; involvement of family, carers, and peers
Goicoechea (2006)[49]	Service user and clinician	Mixed	USA	Inpatient	8	Mixed	Conversational analysis and thematic analysis	28	82	Diagnostic accuracy and fit; service-user identity and recovery; collaborative and therapeutic relationships; comprehensiveness and quality of the diagnostic assessment; drivers of diagnosis; provision of information

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Participants	Diagnosis	Country	Setting	Sample size	Data collection	Analysis	Quality rating*	No of codes	Summary of themes
(Continued from previous page)									
Goldberg (2007)[50] Service user	Bipolar disorder	USA	Not stated	6	Interviews	Thematic analysis	28	1423	Stigma, discrimination, and culture; service-user identity and recovery; diagnostic accuracy and fit; collaborative and therapeutic relationships; drivers of diagnosis; comprehensiveness and quality of the diagnostic assessment; support from others; involvement of carers, family, and peers
Hagen and Nixon (2011)[5] Service user	Psychosis	Canada	Not stated	18	Interviews	Phenomenological analysis	28	207	Provision of information; collaborative and therapeutic relationships; service-user identity and recovery; functional value of diagnosis; diagnostic accuracy and fit; disclosure; comprehensiveness and quality of the diagnostic assessment
Harding et al (2015)[51] Clinician	Unspecified mental health diagnosis	Australia	Primary care	10	Interviews	Thematic analysis	27	49	Collaborative and therapeutic relationships; stigma, discrimination, and culture; service users' previous experiences and help seeking; drivers of diagnosis; comprehensiveness and quality of the diagnostic assessment
Hayne (2003)[2] Service user	Unspecified serious mental health diagnosis	Canada	Not stated	14	Interviews	Thematic analysis	31	376	Drivers of diagnosis; functional value of diagnosis; service-user identity and recovery; stigma, discrimination, and culture; diagnostic accuracy and fit; collaborative and therapeutic relationships; comprehensiveness and quality of the diagnostic assessment; disclosure; provision of information; time to diagnose
Highet et al (2004)[52] Service user	Bipolar disorder	Australia	Not stated	53	Mixed	Thematic analysis	30	114	Diagnostic accuracy and fit; provision of information; time to diagnose; collaborative and therapeutic relationships; disclosure; functional value of diagnosis; comprehensiveness and quality of the diagnostic assessment
Horn et al (2007)[6] Service user	Borderline personality disorder	UK	Not stated	10	Interviews	Interpretative phenomenological analysis	31	646	Stigma, discrimination, and culture; provision of information; functional value of diagnosis; service-user identity and recovery; collaborative and therapeutic relationships; ongoing support; diagnostic accuracy and fit; disclosure; support from others; drivers of diagnosis; time to diagnose
Hunt and Churchill (2013)[53] Clinician	Anorexia nervosa	UK	Primary care	12	Focus groups	Corpus linguistic and discourse analysis	29	129	Comprehensiveness and quality of the diagnostic assessment; drivers of diagnosis; functional value of diagnosis
Hwang (2008)[44] Clinician	Schizophrenia	USA	Secondary community	4	Interviews	Thematic analysis	27	777	Disclosure; stigma, discrimination, and culture; collaborative and therapeutic relationships; functional value of diagnosis; service users' previous experiences and help seeking; provision of information; involvement of family, carers, and peers; diagnostic accuracy and fit; ongoing support; service-user identity and recovery; time to diagnose
Jönsson et al (2008)[54] Service user	Bipolar disorder	Sweden	Outpatient	18	Interviews	Content analysis	31	30	Provision of information; disclosure; service users' previous experiences and help seeking
Karp (1996)[55] Service user	Depression	USA	Not stated	50	Interviews	Unspecified qualitative analysis	24	90	Stigma, discrimination, and culture; functional value of diagnosis; service-user identity and recovery; involvement of family, carers, and peers; time to diagnose
Karp and Tanarugsachock (2000)[56] Carer or family	Mixed	USA	Not stated	50	Interviews	Grounded theory	27	88	Support from others; involvement of carers, family, and peers; comprehensiveness and quality of the diagnostic assessment

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	Participants	Diagnosis	Country	Setting	Sample size	Data collection	Analysis	Quality rating*	No of codes	Summary of themes
(Continued from previous page)										
Keating and Robertson (2004)[57]	Service user, carer or family, and clinician	Unspecified mental health diagnosis	UK	Inpatient and community	93	Mixed	Unspecified qualitative analysis	31	49	Stigma, discrimination, and culture
Krupchanka et al (2016),[58] Krupchanka et al (2017)[59]	Carer or family	Schizophrenia	Belarus	Not stated	20	Interviews	Thematic analysis	30	9	Stigma, discrimination, and culture; involvement of family, carers, and peers
Lampe et al (2012)[15]	Clinician	Mixed	Australia	Primary care	38	Focus groups	Thematic analysis	24	306	Comprehensiveness and quality of the diagnostic assessment; drivers of diagnosis; functional value of diagnosis; time to diagnose; stigma, discrimination, and culture
Leff et al (2017)[60]	Clinician	Depression	Latvia	Primary care	16	Interviews	Thematic analysis	32	114	Service users' previous experiences and help seeking; comprehensiveness and quality of the diagnostic assessment; time to diagnose; collaborative and therapeutic relationships; involvement of family, carers, and peers; service-user identity and recovery; stigma, discrimination, and culture; drivers of diagnosis
Lewis (1995)[61]	Service user	Depression	UK	Not stated	48	Interviews	Thematic analysis	28	151	Diagnostic accuracy and fit; stigma, discrimination, and culture; service-user identity and recovery; functional value of diagnosis; collaborative and therapeutic relationships
Loughland et al (2015)[3]	Service user	Schizophrenia	Australia	Mixed	14	Interviews	Unspecified qualitative analysis	34	256	Provision of information; collaborative and therapeutic relationships; disclosure; service users' previous experiences and help seeking; functional value of diagnosis; ongoing support
Lovell and Hardy (2014)[62]	Service user	Borderline personality disorder	UK	Forensic	8	Interviews	Interpretative phenomenological analysis	31	115	Collaborative and therapeutic relationships; service-user identity and recovery; functional value of diagnosis; stigma, discrimination, and culture; diagnostic accuracy and fit; disclosure
McCormack and Thomson (2017)[63]	Service user	Mixed	Australia	Not stated	5	Interviews	Interpretative phenomenological analysis	30	92	Stigma, discrimination, and culture; functional value of diagnosis; service-user identity and recovery; diagnostic accuracy and fit; collaborative and therapeutic relationships; comprehensiveness and quality of the assessment
McMahon and Lawn (2011)[64,65]	Service user and carer or family	Borderline personality disorder	Australia	Not stated	274	Questionnaires	Not stated	26	219	Disclosure; functional value of diagnosis; stigma, discrimination, and culture; provision of information; collaborative and therapeutic relationships; involvement of family, carers, and peers
Milton and Mullan (2015)[66]	Service user	Unspecified serious mental health diagnosis	Australia	Secondary community	45	Interviews	Thematic analysis	32	514	Time to diagnose; collaborative and therapeutic relationships; disclosure; support from others; involvement of carers, family, and peers; stigma, discrimination, and culture; comprehensiveness and quality of the diagnostic assessment; provision of information; functional value of diagnosis; diagnostic accuracy and fit; involvement of family, carers, and peers; service-user identity and recovery
Milton et al (2016)[10]	Clinician	Unspecified mental health diagnosis	Australia	Mixed	19	Interviews	Thematic analysis	31	619	Involvement of family, carers, and peers; provision of information; diagnostic accuracy and fit; functional value of diagnosis; time to diagnose; disclosure; collaborative and therapeutic relationship; stigma, discrimination, and culture; ongoing support
Mitchell et al (2011)[67]	Clinician	Depression	UK	Primary care	38	Focus groups	Thematic analysis	32	190	Drivers of diagnosis; comprehensiveness and quality of the diagnostic assessment; diagnostic accuracy and fit; time to diagnose; collaborative and therapeutic relationships; stigma, discrimination, and culture; disclosure
Morris et al (2014)[68]	Service user	Borderline personality disorder	UK	General mental health services	9	Interviews	Thematic analysis	30	167	Disclosure; provision of information; functional value of diagnosis; comprehensiveness and quality of the diagnostic assessment; collaborative and therapeutic relationships; service-user identity and recovery

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	Participants	Diagnosis	Country	Setting	Sample size	Data collection	Analysis	Quality rating*	No of codes	Summary of themes
(Continued from previous page)										
Nehls (1999)[69]	Service user	Borderline personality disorder	USA	Inpatient and community	30	Interviews	Interpretative phenomenological analysis	25	106	Functional value of diagnosis; stigma, discrimination, and culture; collaborative and therapeutic relationships; disclosure; provision of information
Outram et al (2014),[16] Outram et al (2015)[70]	Clinician	Schizophrenia	Australia	Mixed	16	Interviews	Thematic analysis	32	826	Disclosure; collaborative and therapeutic relationships; stigma, discrimination, and culture; diagnostic accuracy and fit; time to diagnose; provision of information; involvement of family, carers, and peers; functional value of diagnosis
Petersen and Madsen (2017)[71]	Service user	Depression	Denmark and Norway	Not stated	16	Interviews	Thematic analysis	19	70	Collaborative and therapeutic relationships; comprehensiveness and quality of the diagnostic assessment; time to diagnose; service users' previous experiences and help seeking; functional value of diagnosis; service-user identity and recovery
Pitt et al (2009)[4]	Service user	Mixed	UK	Not stated	8	Interviews	Interpretative phenomenological analysis	33	247	Collaborative and therapeutic relationships; support from others; involvement of carers, family, and peers; comprehensiveness and quality of the diagnostic assessment; functional value of diagnosis; drivers of diagnosis; stigma, discrimination, and culture; service-user identity and recovery; disclosure
Proudfoot et al (2009)[72]	Service user	Bipolar disorder	Australia	Specialist	26	Online observation	Phenomenological and lived experience framework analysis	25	119	Diagnostic accuracy and fit; involvement of carers, family, and peers; stigma, discrimination, and culture; service-user identity and recovery; collaborative and therapeutic relationships; functional value of diagnosis; time to diagnose
Rogers and Dunne (2011),[73] Rogers and Dunne (2013)[74]	Service user	Borderline personality disorder	UK	Specialist	7	Focus groups	Thematic analysis	32	43	Disclosure; collaborative and therapeutic relationships; diagnostic accuracy and fit; functional value of diagnosis; stigma, discrimination, and culture
Rumpza (2015)[75]	Clinician	Borderline personality disorder	USA	Not stated	117	Mixed	Content analysis	29	334	Comprehensiveness and quality of the diagnostic assessment; disclosure; diagnostic accuracy and fit; collaborative and therapeutic relationships
Saver et al (2007)[76]	Service user	Depression	USA	Primary care	15	Interviews	Descriptive analysis	31	185	Provision of information; diagnostic accuracy and fit; collaborative and therapeutic relationships; service-user identity and recovery; service users' previous experiences and help seeking; stigma, discrimination, and culture; comprehensiveness and quality of the diagnostic assessment; time to diagnose
Stalker et al (2005)[7]	Service user and clinician	Personality disorder	UK	Not stated	22	Interviews	Grounded theory	28	112	Stigma, discrimination, and culture; functional value of diagnosis; provision of information; comprehensiveness and quality of the diagnostic assessment; disclosure; diagnostic accuracy and fit
Sulzer (2012),[77] Sulzer et al (2016)[11]	Service user and clinician	Borderline personality disorder	USA	Not stated	64	Mixed	Grounded theory	30	689	Disclosure; service-user identity and recovery; stigma, discrimination, and culture; comprehensiveness and quality of the diagnostic assessment; functional value of diagnosis; diagnostic accuracy and fit; ongoing support
Thomas-MacLean and Stoppard (2004)[78]	Clinician	Depression	Canada	Primary care	20	Interviews	Foucauldian discourse analysis	27	94	Comprehensiveness and quality of the diagnostic assessment; service users' previous experiences and help seeking; diagnostic accuracy and fit; collaborative and therapeutic relationships
Tuck et al (1997)[79]	Carer or family	Schizophrenia	USA	Not stated	9	Interviews	Phenomenological analysis	27	78	Diagnostic accuracy and fit; collaborative and therapeutic relationships; provision of information; disclosure; time to diagnose; involvement of family, carers, and peers; comprehensiveness and quality of the diagnostic assessment
Venhaus (2009)[80]	Service user	Mixed	USA	Inpatient	7	Interviews	Narrative analysis	32	101	Stigma, discrimination, and culture; drivers of diagnosis; time to diagnose; service-user identity and recovery; comprehensiveness and quality of the diagnostic assessment; diagnostic accuracy and fit; functional value of diagnosis

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Participants	Diagnosis	Country	Setting	Sample size	Data collection	Analysis	Quality rating*	No of codes	Summary of themes
(Continued from previous page)									
van Rijswijk et al (2009)[17]	Clinician	Mixed	Netherlands	Primary care	23	Focus groups	Thematic analysis	30	257	Comprehensiveness and quality of the diagnostic assessment; collaborative and therapeutic relationships; functional value of diagnosis; diagnostic accuracy and fit; time to diagnose; drivers of diagnosis
Wheeler (1994)[81]	Carer or family	Schizophrenia	New Zealand	Not stated	4	Interviews	Content analysis	31	138	Involvement of family, carers, and peers; stigma, discrimination, and culture
Wittink et al (2006),[82] Wittink et al (2008)[83]	Service user	Depression	USA	Primary care	48	Interviews	Thematic analysis	31	370	Collaborative and therapeutic relationships; diagnostic accuracy and fit; service users' previous experiences and help seeking; time to diagnose; functional value of diagnosis; comprehensiveness and quality of the diagnostic assessment; provision of information; stigma, discrimination, and culture; disclosure
Wittkampf et al (2008)[84]	Service user and clinician	Depression	Netherlands	Primary care	17	Interviews	Thematic analysis	30	251	Diagnostic accuracy and fit; service users' previous experiences and help seeking; comprehensiveness and quality of the diagnostic assessment; functional value of diagnosis; collaborative and therapeutic relationships; stigma, discrimination, and culture; disclosure

*Ten Critical Appraisal Skills Programme criteria[85] were rated as low (one point), medium (two points), or high quality (three points). A further five points were available to reflect quality determined by narrative appraisal, which considered generalisability and relevancy.

Table: Characteristics of included studies

Inclusion criteria encompassed primary research with a formal qualitative component, gathering data on service-user, clinician, and carer or family views and experiences regarding the process of adult mental health diagnosis. We placed no restrictions on language of publication. Papers not reported in English were translated. We included dissertations, doctoral theses, and non-peer reviewed reports to reduce potential for publication bias. We also searched the first 20 pages of Google Scholar, contacted key authors, and reviewed reference lists of included papers. We excluded developmental disorders, somatoform disorders, substance abuse and dual-diagnosis, dementia, traumatic brain injury, and diagnosis during childhood (under age 18 years). We selected these exclusion criteria because they involve services outside the scope of our Review, and these diagnoses require additional or different processes (eg, further physiological testing and compulsory parent or guardian involvement).

Two authors (AP and JR) independently screened titles and abstracts for eligibility. To establish inter-rater reliability, the first 50 studies were screened together. Full-text articles of potentially eligible studies were screened by AP and JR. If full-text articles were unavail-able, we contacted authors. Uncertainties were resolved by discussion, with involvement of a third reviewer when necessary (GP or CN).

Information extraction

Two reviewers (AP and JR) extracted data. A pre-piloted table was used to extract demographic and methodological information (table). We assessed study quality using the Critical Appraisal Skills Programme qualitative assessment checklist,[85] supplemented with narrative appraisal within which we considered alternative reporting checklists (eg, consolidated criteria for reporting qualitative research [COREQ]).[86] Three reviewers (AP, JR, and DB) assigned quantified quality scores (table). NVivo v.11 software was used to code first-order data (participant quotations) and second-order data (researcher interpre-tations, ie, concepts, themes, and descriptions of findings derived from data) line by line (AP and JR).[87,88] To establish reliability, the first 10% of papers were extracted and coded by two reviewers together (AP and JR). These reviewers independently verified a further 10% subsample of the data extraction and coding.

Thematic synthesis

Thematic synthesis involved the development of descriptive and analytical themes, going beyond initial coding by accounting for transferability to different contexts, relevancy to the research objectives, and frequency of data. Themes were combined into a model representing groups of factors that influence service-user experience of diagnosis. To examine variance across context, we compared themes of papers focused on different stakeholders, diagnoses, service settings,
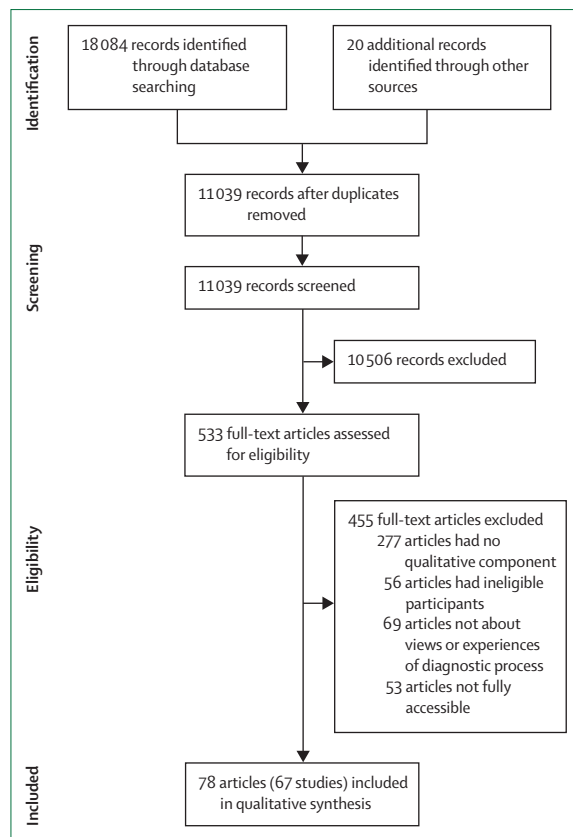
Figure 1: Flow diagram of studies assessed for the Review

countries, time periods, and cultures. We ran a sensitivity analysis to assess the impact of quality appraisal, examining whether including exclusively high-quality studies altered findings. A service user, a clinician, and academics contributed to the analysis.[89,90] Consensus seeking ensured triangulation of different perspectives and minimisation of bias.

The protocol was registered with PROSPERO, number CRD42016047013.

Studies and participants included in the systematic review

Our searches of databases and other sources yielded 18 104 results, of which we screened 533 full-text articles for eligibility (figure 1). We included 67 studies (reported in 78 papers) in thematic synthesis (table). Total sample size was 2228 (mean 33 [SD 44]; median 19 [IQR 10–45]). Studies were done in two middle-income and 11 high-income countries: the UK (21), the USA (17), Australia (13), Canada (five), the Netherlands (two), Brazil (two), Sweden (one), New Zealand (one), Latvia (one), Belarus (one), Norway (one), Denmark (one), and Israel (one). Two studies collected data across several countries (one study collected data from Norway and Denmark, and the other from the USA, Australia, New Zealand, Canada, and the UK). 37 studies involved

service users, 15 involved clinicians, seven involved carers or family, and eight were mixed samples. Diagnoses included psychotic disorders (16), depression (13), personality disorders (12), bipolar disorder (five), anxiety (one), eating disorders (one), mixed (12), and unspecified mental illness (seven). Studies spanned from 1994 to 2017.

Participants were recruited from a range of settings, including primary care, community, specialist, and inpatient services. Research methods included interviews (47), focus groups (seven), questionnaires (three), mixed (nine), and online observations (one).

Inductive thematic synthesis, derived from data of included studies, is represented in a model of considerations of factors identified as influential on service-user experience of diagnosis (figure 2). Themes developed from codes are depicted with their relative weight, demonstrated by the coding frequency of each theme (shown in the key and numeric labels of figure 2). Our model comprises three superordinate categories: service provision, external factors, and internal factors. Service provision factors were most frequently cited and are further divided into three subgroups representing different stages of the diagnostic process: deciding, communicating, and using the diagnosis. We found that the journey through these stages is typically sequential, although there is potential for repetition or circularity of stages. The external and internal factors predate, occur alongside, and postdate service-level influences. They affect service-user experience both directly and in interaction with service provision factors and each other. To illustrate themes, we have displayed quotations from included studies in panels 1–3.

Service provision factors for deciding the diagnosis

Drivers of diagnosis

Whether decisions were driven by service-user need was a major theme contributing to a diagnosis being experienced as accurate and validating. Some service users felt that diagnoses were instead driven by political motives such as power and control; business, financial, and resource affairs (eg, treatment costs); or clinician fears of causing harm (eg, damaging therapeutic relationships). Clinicians reported feeling pressured by these issues during diagnostic decision making.

Comprehensiveness and quality of the diagnostic assessment

Service users found it disconcerting when they perceived a lack of thoughtful and rigorous appraisal preceding diagnosis. Both service users and clinicians felt that the process was more validating and effective when a breadth of factors (ie, biopsychosocial factors) were considered, alongside severity, burden, and chronicity of symptoms. They felt that diagnostic manuals (eg, ICD) could guide assessment, but were sometimes unhelpful because of
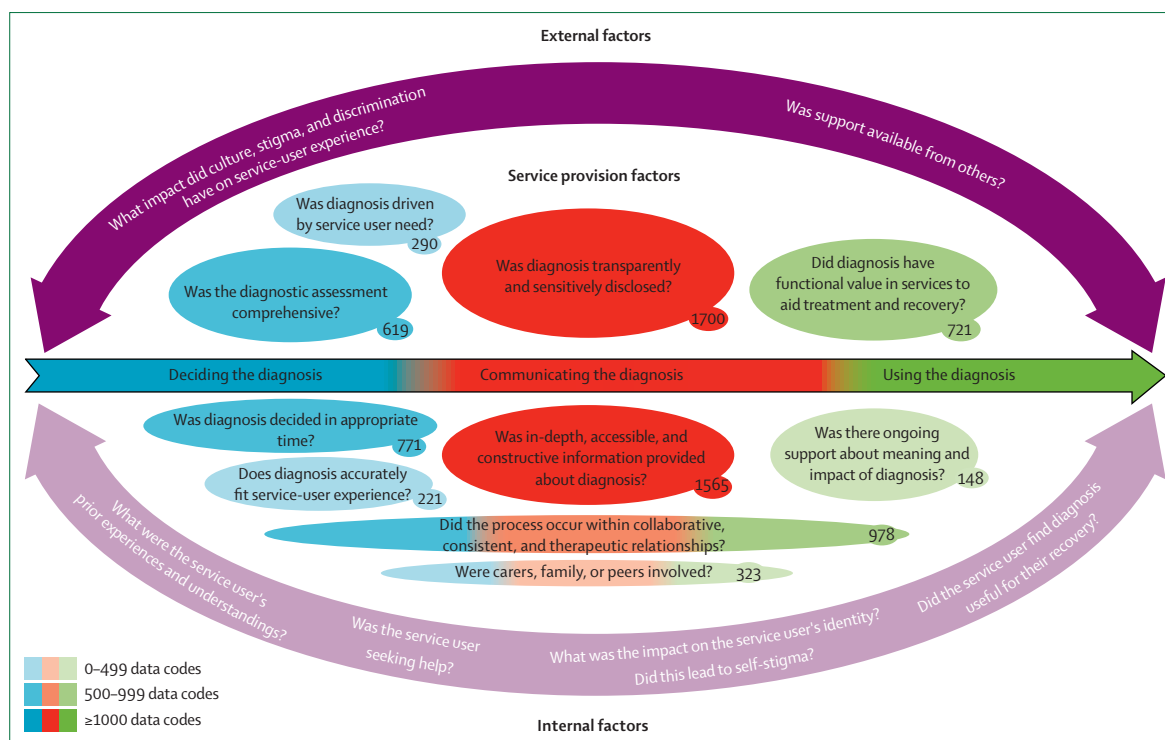
Figure 2: Model of considerations of factors influencing service-user experience of mental health diagnosis

inaccurate or incomplete symptom descriptors. Service users also expressed that to fully capture their experience, it was beneficial to consider comorbidities and the potential diagnosis of multiple conditions.

Time to diagnose

Clinicians expressed that diagnosis is complex; a comprehensive assessment takes time. They reported challenges across several areas, including differentiation of disorders with overlapping symptoms, determination of when symptoms were or were not considered clinically significant for diagnosis (eg, anxiety and low mood are normal to some extent, but there was uncertainty about deciding when they crossed the threshold into something diagnosable), and complications from symptom fluctuation. Nevertheless, service users often felt diagnosis was delayed, causing uncertainty, sense of rejection or abandonment, and delay in treatment. Service users more often reported a positive experience when diagnosis was felt to be efficient and timely.

Diagnostic accuracy and fit

Service users reported that diagnosis was most helpful when it aligned with their experience of symptoms, providing relief, validation, and a framework to interpret experiences. By contrast, misdiagnosis (being given one diagnosis then later being told another is more appropriate without a perceived change in presentation) caused distress, loss of confidence in services, and

inappropriate treatment. Service users and clinicians felt that it was unhelpful to over-pathologise and diagnose mild experiences that did not cause distress or dysfunction, or to under-diagnose or overlook a problem. Misdiagnosis could cause service users to reject their diagnosis or feel dismissed. When diagnosis was felt to be inaccurate, sometimes attributed to change in symptomatology over time, service users reported that it was helpful to remove or change the diagnosis accordingly; permanency of diagnostic labels was viewed negatively.

Service provision factors for communicating the diagnosis

Disclosure

This theme encompassed the most codes (figure 2). Disclosure was frequently described as a pivotal moment for service users. Clinicians described an internal struggle or dilemma, whereby they were unsure whether disclosure was beneficial. Most clinicians felt that service users had a right to know their diagnosis, while simultaneously fearing potential harm. Although sometimes experienced negatively, service users generally reported preference for disclosure, giving relief, validating their experiences, and providing greater self-understanding and empowerment. There were numerous negative accounts of having a diagnosis withheld that caused service users to feel isolated, confused, or insignificant. Service users felt particularly uninformed

Panel 1: Service provision factors

Drivers of diagnosis*

Quotations from participants:
- It seems as if consumers in the U.S. get stuck with and in their diagnosis due to insurance needs. (p 499)[44]
- … maybe I hesitate to diagnose a depression because of the long term treatment with antidepressant drugs… (p 56)[17]
- Makers of the DSM are in the pockets of "Big Pharma". (p 499)[44]
- I have a lot of difficulty throwing that diagnosis on somebody, because to be really honest with you, when somebody gets diagnosed with borderline personality disorder, it's a really negative diagnosis. (pp 69–70)[77]

Interpretation of study authors:
- … there is a tendency for [diagnosis] to be seen more as a label, and one associated with stigma in the community, which almost certainly contributes to reluctance to make a specific diagnosis. (p 376)[15]
- … Darlene wondered if her initial bipolar diagnosis of Bipolar II Disorder, later modified to Bipolar I, was given only to minimize her distress. (p 139)[50]

Comprehensiveness and quality of the diagnostic assessment*

Quotations from participants:
- So I said, "How can they diagnose me as bipolar if they don't even know who the hell I am, because I don't even know who the hell I am"? (p 189)[50]
- Psychiatrists take history of things in Axis 3… but it seems as if there is little interest in exploring how Axis 3 conditions influence the diagnosis of mental illness. (p 499)[44]

Interpretation of study authors:
- … GPs emphasize the necessity for a holistic approach to understanding the patient, including work, relationships and family contexts, in the process of making a diagnosis. (p 376)[15]
- Rebecca partly links her positive experience with getting the diagnosis with the process in which she got it. The doctor took time to examine her in great detail, not just subjecting her to standard tests or questionnaires. (p 27)[71]
- Assessments that seemed hurried, overly formal or impersonal, and clinicians who it was felt did not acknowledge their client's suffering, left participants feeling frustrated and unheard. (p 237)[25]

Time to diagnose*

Quotations from participants:
- For so many years I haven't, sort of like, had a label, I've sort of like floated. (p 260)[6]
- Sometimes I'm a bit hesitant to… say "Yes, you've got schizophrenia," because I'll be thinking, "What if it's drugs? What if it isn't a schizophreniform [disorder], have we really had enough time?" and things like that. (p 552)[16]
- It took us about 4 years to finally get a diagnosis for our daughter. It was not until we found a great psychiatrist in the private system, that we were given a clear diagnosis and the information and understanding of what our daughter was suffering from. (p 25)[65]

Interpretation of study authors:
- …delayed or inaccurate diagnoses frequently resulted in no intervention, less appropriate treatments being implemented, and/or repeated hospital admissions. (p S49)[52]

- One of the concerns of clinicians was a lack of diagnostic certainty, including the length of time needed to make a confident diagnosis, variables that confound a clear diagnosis, the symptom overlap between different diagnoses, and the fact that there are no confirmatory laboratory tests to buttress clinical opinion. (p 552)[16]
- GPs suggested that they used time as a tool… to increase certainty over the diagnosis… (p 6)[42]

Diagnostic accuracy and fit*

Quotations from participants:
- What a waste of life with being diagnosed the wrong things. (p 30)[64]
- … I don't like that there's a sheet that says what you must have if you have bipolar and I'm like "well that's not true because I don't have that, and I don't have that". (p 12)[27]
- It explained a lot of things and I felt an enormous sense of relief… (p 233)[62]

Interpretation of study authors:
- …participants expressed relief at receiving a "the right" diagnostic label as it offered an explanation for their distressing emotions and behaviours… (p 13)[63]
- The burden of illness was exacerbated by difficulties with obtaining an accurate diagnosis. (p S47)[52]

Disclosure†

Quotations from participants:
- I didn't understand why I was so sensitive… It was really a relief to find out that it wasn't something else or that it was just me… it was rather good to discover that I had an illness, even if it's not a very nice thing… it explained why I felt the way I did. (p 1227)[54]
- I knew what was wrong with me, and if I knew what was wrong with me I had a chance of possibly understanding it better and maybe work on it a bit more… (p 461)[66]
- Because some people just think borderline personality means difficult patient you know and I, that's not my opinion, but the thing is because of all that bad press of borderline um I don't bring that up right away. (p 87)[75]

Interpretation of study authors:
- Open diagnostic information sharing was often recommended by participants as it provided an understanding of the issues and symptoms, and facilitated access to treatment and support… (p 461)[66]
- It was a matter of concern that several people reported they had only discovered their diagnosis by accident, for example, on the back of a Disability Living Allowance form, on a hospital discharge certificate and, in one case unfortunately, on receiving a letter from their consultant asking if they would like to take part in this research… Apart from the shock of finding out such sensitive information in this way, the lack of any accompanying explanation left these individuals feeling anxious and upset. (pp 363–64)[7]

Provision of information†

Quotations from participants:
- It was quite nice to like for him to say I don't think it's bipolar, because – this reason, this reason, this one. But, I do think you are a little bit borderline because of this, this and this… He was like explaining it in a like a quite a simple way sort of thing instead of like "you're this and that's it". (p 237)[25]

(Continues on next page)

(Panel 1 continues from previous page)

- Not surprisingly then, as participants began to recognize the fleeting and arbitrary nature of the labels that the mental health system gave them, and how they lacked any meaning within the context of their own lives, they soon began to reject the labels altogether. (p 53)[5]
- I can't emphasise this enough… I would have accepted it more if they explained what schizophrenia was… (p 731)[3]

Interpretation of study authors:

- Individuals indicated that diagnostic conversations that were devoid of hope were extremely immobilizing and potentially dangerous… hope-focused discussions centered on recognition that individuals could live meaningful lives and be productive members of society. (p 462)[76]
- Where diagnosis was disclosed, sometimes the lack of information that accompanied that disclosure was one of the main causes of disempowerment. Lack of information meant participants often experienced diagnosis as "a prognosis of doom" about their future. (p 421)[4]

Functional value of diagnosis‡

Quotations from participants:

- Individuals indicated that diagnostic conversations that were devoid of hope were extremely immobilizing and potentially dangerous… hope-focused discussions centered on recognition that individuals could live meaningful lives and be productive members of society. (p 462)[66]
- Where diagnosis was disclosed, sometimes the lack of information that accompanied that disclosure was one of the main causes of disempowerment. Lack of information meant participants often experienced diagnosis as "a prognosis of doom" about their future. (p 421)[4]

Interpretation of study authors:

- In many situations, diagnoses serve to guide a plan of care and, thus, are viewed as useful. For these participants, however, the diagnosis… perpetuated a sense of being marginalized and potentially mistreated. (p 288)[69]
- Personality disorder was seen as having all the drawbacks of a mental illness diagnosis, especially in terms of stigma, but none of the benefits, particularly access to services. (p 365)[7]

Ongoing support‡

Quotations from participants:

- I was diagnosed with Bipolar II disorder. I had no idea that's what I had. I felt quite distressed afterwards and would have liked someone to talk to… (p 30)[41]

Interpretation of study authors:

- A number of patients expressed the need for post-assessment support, particularly when given a new and unexpected diagnosis… (p 30)[41]
- …it was seen as useful to offer more in-depth discussion and information at follow-up. (p 739)[10]

Collaborative and therapeutic relationships§

Quotations from participants:

- It's horrible having a label, having a label done to you. (p 233)[62]
- … overall, I think it is better to know and they talk to you about it [diagnosis], although it might take time to adjust to the thought of things, it's the "old nothing about me without me" idea. (p 463)[66]

Interpretation of study authors:

- Clinicians spoke of the importance of being as approachable as possible, attending to the patient's needs during the interview being a priority, and rapport being the basis of therapeutic interaction… (p 176)[70]
- Most participants said they preferred a multidisciplinary approach… (p 176)[70]
- Danielle described how any questions about the diagnosis were met with "No, this is definitely what you have. We are 100% sure". (pp 260–61)[6]

Involvement of family, carers, and peers§

Quotations from participants:

- They [Clinicians] were telling me stuff, but I'm so sick I can't take it on board. Your family, your carer, have to work together. They don't do that enough, they just treat the patient. (p 463)[66]

Interpretation of study authors:

- … the majority of family members reported that learning more about the illness and understanding its effects helped them to accept the diagnosis. (p 138)[37]
- A proportion of participants described family involvement as crucial as they supported the persons to navigate the system. (p 463)[66]

*Factors for deciding the diagnosis. †Factors for communicating the diagnosis. ‡Factors for using the diagnosis. §Factors across superordinate themes.

about changes to their diagnosis. Paradoxically, many clinicians reported reluctance to disclose due to fear of subjecting service users to stigma or damaging the therapeutic relationship, yet non-disclosure was more often associated with these outcomes.

Both service users and clinicians reported instances of disclosure using vague, less stigmatising, or euphemistic labels, compared with specific or so-called true diagnoses (eg, emotional dysregulation *vs* borderline personality disorder). Clinicians described using this practice to protect service users' best interests, yet service users reported uncertainty, reduced agency, and damaged therapeutic relationships as a result. Service users found it unhelpful when disclosure was unplanned, insensitive, or delayed. For example, discovering a diagnosis on health records, letters, or when it was inadvertently mentioned in care meetings caused distress. Whereas some clinicians were cautious of causing potential harm through premature disclosure, this cautious approach juxtaposed service-user reports that delays to disclosure were common and can have adverse consequences. Finally, service users found the process less damaging for identity when diagnosis was disclosed as a name for their experiences, rather than framed as an inherent trait, which could feel blaming or like a personal attack.

Provision of information

This theme had a pronounced influence on the experience of diagnosis and yielded the second greatest number of codes (figure 2). Many clinicians expressed concerns regarding lack of time and resources, and these concerns were also reflected by service users, who often reported being given little or no information when diagnosed. Nonetheless, receiving information about a

Stigma, discrimination, and culture

Quotations from participants:

- Schizophrenic is the worst diagnosis because I've heard it in the newspapers and on TV, that they are really mad schizophrenic people, they are very dangerous to society, they've got no control. So obviously I came under that category. (p 177)[38]
- I'd heard about people that had been diagnosed with personality disorder being the black sheep of the community. It made me feel I didn't belong anywhere. (p 55)[30]

Interpretation of study authors:

- Fears related to the stigma attached to mental illness and the diagnosis meant that individuals tried to hide their diagnosis or did not want to accept the fact that they have been identified as mentally ill. (p 444)[57]
- …clinicians commented that misconceptions and stigma relating to the diagnostic label still influenced a person's response to the diagnosis. (p 740)[10]
- …the effects of stigma resulting from a diagnosis can play a role in relapse and hinder the recovery process. (p 422)[4]

Support from others

Quotations from participants:

- He [father] wouldn't say the actual words… when I was diagnosed with being bipolar over the summer, my dad, there is no way that those words will ever come out of his mouth. And if I say something to him about it, he still doesn't believe it… Because of the way that I've seen them react to the diagnosis of bipolar, that totally gives me an idea of how people are going to react if I tell them about it. If it's my family that is reacting this way, how are people who I'm not even close to going to react? (p 147)[39]

Interpretation of study authors:

- … participants felt that they may have accepted the diagnosis sooner… if they had greater support from family and friends. (p 138)[37]
- Several participants reported receiving positive messages, motivation, and support from their families which helped them come to terms with their diagnoses. (p 144)[39]

preferred. Nonetheless, sole reliance on self-research without face-to-face discussion with a clinician was damaging, leading people to feel dismissed or unclear about their diagnosis. Service users reported feeling hopeless when told that their condition was permanent or untreatable. Rather, being offered realistic messages of hope yielded a more constructive experience. Service users discussed the use of biomedical approaches to explain the diagnosis or its cause. Some found this approach helpful because it reduced self-blame, although others criticised it for being inconsistent with their pre-existing psychosocial explanations. In addition, service users often felt that too much jargon was used, preferring accessible information, as long as it was not experienced as too simplistic, uninformative, or patronising.

Service provision factors for using the diagnosis
Functional value of diagnosis

Service users experienced diagnosis more positively when it was offered as a tool for recovery, leading to appropriate treatment. It was considered most helpful when used to guide care in consideration with service-user preference and other factors (eg, previous treatment experiences); relying solely on diagnosis was considered to be negligent. Similarly, service users believed that diagnosis should not be a prerequisite to accessing services. Others felt that their diagnosis was meaningless for recovery, or even removed support and evoked prejudice from providers. Diagnosis without functional value was experienced as disempowering and frustrating, leading to hopelessness and distrust of services. Service users expected treatment to follow diagnosis and were taken aback when this was not provided. Clinicians reported reluctance to record diagnoses due to potential harm (eg, stigma), despite potentially affecting continuity of care.

Ongoing support

Both service users and clinicians emphasised concern about consequences of diagnosis, including effects on relationships, finances, and identity. Service users reported follow-up appointments as helpful, to revisit the diagnosis and address its consequences, particularly stigma. Collaborative discussion was favoured, as service users reported occasions when clinicians made erroneous predictions about the consequences of diagnosis.

Service provision factors across superordinate themes
Collaborative and therapeutic relationships

Across all stages of the diagnostic process, service users felt respected when clinicians were empathetic, caring, and attuned to individual needs. Collaboration was preferred, although such practice was infrequently reported. Many service users described their diagnosing clinician as an authoritarian expert, causing them to

diagnosis was empowering and normalising for service users. Understanding symptoms provided validation and often helped people to come to terms with their diagnosis, despite sometimes causing fear initially. Service users and clinicians reported that diagnostic manuals could be a useful tool to learn about the diagnosis and its associated symptoms, although this approach was sometimes experienced as impersonal, and language could be interpreted as derogatory or confusing. Service users also found it helpful to receive information about likely causes of symptoms and the reasoning behind diagnostic decision making. However, many service users felt that aetiology went unexplored, and therefore that diagnoses were without basis, causing confusion, shock, and sometimes rejection of the diagnosis. Furthermore, service users expressed that diagnosis created fear and uncertainty about the future, with insufficient information and discussion regarding prognosis.

When and how information was accessed affected service-user experience. Delay could be experienced as neglectful, whereas having excessive information too soon was overwhelming. Resources such as leaflets, books, and web pages were helpful, and sometimes

feel uninvolved and unheard, and potentially to reject the diagnosis. Service users found diagnostic decision making more positive and credible when their expertise and opinions were valued alongside clinical knowledge. Nonetheless, sometimes this involvement caused service users to feel overwhelmed and clinicians to feel strained with regard to time and resources. Consistent therapeutic relationships were favoured by service users and clinicians alike, as they eased personal discussion and rapport. Quality of relationships between clinicians within and across services was also important. Service users valued a multidisciplinary approach that supported a holistic diagnosis, although some clinicians reported futile team dynamics as a limiting factor.

Involvement of carers, family, and peers

Where appropriate, carer or family involvement helped service users to navigate services and to come to terms with their diagnosis. Additionally, peer support groups reduced isolation, normalised the diagnosis, and facilitated acceptance and coping. Although carers and family sometimes found diagnosis a relief, it could also be distressing and confusing. Carers and family often reported lack of involvement and support from clinicians, including poor provision of information and limited opportunity for discussion, which could have negative, indirect influences on service-user experience.

External factors
Stigma, discrimination, and culture

This theme accumulated the largest number of codes among non-service-related factors. Service users found the diagnostic process damaging when it resulted in stigma. Many reported negative social side-effects of diagnosis, including hostility, exclusion, and marginalisation by others. Some felt that they were no longer seen as a person, but as a diagnosis to be feared or avoided. Fear of stigma alone could create anxiety about being diagnosed and cause isolation. When a service user's culture considered a diagnosis as normal or socially acceptable, the process was considered less frightening and easier to accept than when a diagnosis was associated with cultural discourses of abnormality, defectiveness, or craziness.

Support from others

Some service users reported that adjustment to a diagnosis was easier with support and encouragement from carers, family, and friends, as it reduced fear and isolation. At times, diagnosis led to the development of new social networks and a sense of peer connectedness, which normalised the experience. This theme differs from the involvement of carers, family, and peers theme, as it applies to the broader context outside service provision that is associated with adjusting to a diagnosis.

Panel 3: Internal factors

Service users' previous experiences and help seeking
Quotations from participants:
- It is good to put a name on somethings, because I knew there was something wrong there must be a reason as to why I am like I am. (p 233)[62]
- I believe the time is ripe for it; it has been long enough now that I've been letting this prey on my mind. I just needed this prod. Now it's time to clear my mind. (p 441)[84]

Interpretation of study authors:
- Their predominant reaction was to associate bipolar disorder with "crazy" and out-of-control or unpredictable behaviour…They remembered all of the worst conditions of their relatives with psychiatric and other cognitive disabilities and assumed their lives would follow the same trajectory. (p 250)[50]

Service-user identity and recovery
Quotations from participants:
- Having a name to put to that gave me something to attack. It gave me something to work with … a tangible framework of something I could manage. (p 15)[63]
- You're not human, once you have got that disorder you're not a human anymore, that goes your name goes. (p 233)[62]
- … it's made me very insecure about my worth as a person, who I am, because I used to be so capable and now I'm a nothing, a nobody. It's taken everything away from me. (p 11)[27]
- It was the beginning of being able to sort out a lifetime of feelings, events… my entire life. It was the chance for a new beginning. (p 66)[55]

Interpretation of study authors:
- Our results show that the common nominator among our informants is process—people are always in process as their relationship to a categorization like a depression diagnosis is never static, but always in motion. (p 30)[71]
- While participants expressed relief at receiving a "the right" diagnostic label… there was fear associated with "being" the label and what this meant for their relationships and sense of self. (p 13)[63]
- The diagnosis impacted the sense of self and identity of all of the participants. They all said words to the effect of "it IS me," rather than, "this is something I have and will have to deal with". (p 176)[50]

Internal factors
Service users' previous experiences and help seeking

Many service users had preconceptions of diagnoses, developed from previous experiences. If these were negative (eg, associated with poor outcome through negative familial experiences of mental health conditions), the diagnostic process could be particularly anxiety provoking. Many also developed theories about the cause of their symptoms. If these did not correspond with explanations offered by services (eg, believing symptoms were physical rather than psychological), the experience was conflicted. More broadly, if service users felt nothing was wrong or did not want a diagnosis, the process could cause anger and frustration. Individuals who were seeking help or diagnosis were more likely to experience relief and validation.

Service-user identity and recovery

Diagnosis was distressing when it was perceived as undermining individual identity, causing feelings of shame or loss when individuals felt like they were just a

diagnosis, a "freak",[5] or worthless. Conversely, service users less frequently found that diagnosis protected or positively defined their identity. Furthermore, when useful for recovery, service users experienced the process as meaningful and empowering, bringing attention to their difficulties and giving them "something to grasp",[7] as well as providing direction for positive change. Substantial individual variation was seen within this theme as the service user processed the diagnosis over time, a journey influenced by service provision and external factors.

Subgroup analysis

We considered similarities and differences between stakeholders in the overall analysis. An overarching finding was that, despite uncertainty, clinicians aimed to provide the best care, yet the care provided was sometimes found to be unhelpful or harmful by service users. There are few papers on carer or family views for comparison, although a common theme among this group was feeling excluded from the process.

Analyses revealed substantial similarity between diagnoses, albeit with some variation. Issues of non-disclosure and poor provision of information were commonly reported for psychotic and personality disorder diagnoses. These diagnoses were most associated with negative effects on identity and hope for recovery. Personality disorder diagnoses were also found to have least functional value and most likely to cause removal of services, reportedly being perceived as "not a mental illness"[33] or "difficult",[7] with connotations of blame. Correspondingly, personality disorders were most associated with institutionalised stigma within mental health services, whereas the other diagnoses were mainly associated with social stigmatisation. Depression diagnoses were most commonly experienced as validating and difficult to diagnose due to manifestations of physical symptoms, and were most often understood within a medical model. Inadequate involvement of family and carers was most frequently reported for psychotic diagnoses.

We found that themes were highly consistent between service types, although some differences were noted between primary and secondary care. Limited confidence and hesitancy about diagnostic decision making were commonly reported by clinicians in primary care settings. They discussed difficulty with diagnosing physical manifestations of mental health conditions, short consultations, and limited resources. The medical model was frequently associated with primary care settings, and team, family, or carer involvement was mostly mentioned in secondary and specialist settings. We found issues with assessment, disclosure, information provision, value of diagnosis for treatment and recovery, stigma, and identity were similar across time. Service-user self-research (eg, on the internet), access to peer support, and development of a sense of connectedness with others who have mental health diagnoses were mostly reported in studies undertaken within the past 10 years. Use of a medical model was discussed less over time, and the impact of cultural differences in presentation on diagnostic decision making was increasingly reported. In cross-national comparisons, we found issues with diagnoses being driven by billing and insurance unique to studies in Australia and the USA. Themes regarding political and financial influences on diagnostic decision making were most prevalent in US research. Stigma was frequently discussed in studies focused on cultural minorities. When including only the top-quality rated studies (highest 20% of scores) in the analysis, themes identified in the model were unchanged.

Discussion

Understanding the factors influencing service-user experience of diagnosis was limited by research focused on specific diagnoses, settings, or stages of the diagnostic process. Our synthesis identifies that how diagnoses are decided, communicated, and used by services is important. Disclosure, information provision, collaboration, timing, and functional value for recovery were among the most prominent themes. External and internal factors were found to further influence service-user experience throughout the diagnostic process.

Findings are represented in a model to inform service provision and clinical decision making (figure 2). To increase practical utility, we present themes as considerations for clinicians as they work with individuals through their diagnostic journey. These themes could be drawn upon in the implementation of diagnostic manuals, including the forthcoming release of ICD-11.[13] Although these manuals provide clinical descriptors that can guide diagnostic decisions, they do not inform clinicians about how to communicate or use the diagnosis. Our model aims to complement diagnostic manuals, providing guidance for communication and potentially alleviating uncertainty previously reported by clinicians. Our review also sought to inform service users, carers, and family; access to our model could support them to navigate the diagnostic experience and be actively involved.

We suggest that the model forms the basis of initial and ongoing diagnostic discussions between clinicians and service users. It encourages a holistic approach, including consideration of internal and external factors directly and in interaction with service factors. Of note, all stakeholders reported that diagnosis could be experienced as labelling, which had consequences for stigma and discrimination. This finding aligns with the theory that stigma exists when people distinguish and give labels to human differences that are associated with negative stereotypes.[91] Our subgroup analyses found that stigma was consistently reported over time, suggesting that it is an ongoing issue. Discussing and

providing support about stigma during the diagnostic encounter is a development that service users reported to find helpful.

Our Review advances previous research by collating and comparing experiences of service users, clinicians, and carers or family. Triangulation of perspectives in this area is a new approach and allows a more complex understanding of diagnostic practice. Findings suggest an element of unfounded paternalism. Many clinicians felt hesitant to decide and disclose a diagnosis, due to uncertainty or concern about causing harm, yet service users reported negative consequences from having a diagnosis withheld. Results also reveal discordant understandings and expectations of diagnosis between stakeholders. For example, clinicians emphasised difficulty and the need for time to make an accurate diagnosis, yet service users often felt diagnosis took too long. Highlighting variations in perspectives should encourage open and reciprocal discussions between service users and clinicians about preferences, expectations, and concerns regarding the diagnostic process. Such discussions might provide the foundation to make informed, transparent, and collaborative decisions regarding diagnostic practice, facilitating better outcomes for service users.

Comparison of diagnoses, service settings, time periods, countries, and cultures allowed us to identify considerations that might be more important in some contexts or groups than others. For example, stigma was frequently mentioned by research in cultural minorities, and negative effects of diagnosis on identity and hope were commonly discussed for personality disorder diagnoses. It is therefore important to be mindful of these differences and their potential associated influences. Our Review draws attention to other areas for reflection about clinical practice. Most prominent in the data were non-disclosure of psychotic and personality disorder diagnoses, as well as less recovery-orientated practice in diagnosing personality disorders. Also evident were financial influences on diagnosis in the USA and Australia. Furthermore, where access to information and service-user communities have increased, self-research and peer support might be more important to explore during diagnostic conversations. Increasing diversity within society means that cultural differences in social constructions of mental illness and presentation should also be considered. Clinicians identified particular difficulty with diagnosing in primary care settings, and using a team approach in multidisciplinary settings, highlighting potential areas for clinical training.

Our synthesis offers a way to integrate diagnosis with recovery approaches increasingly represented in international policy, emphasising hope, identity, and empowerment.[19] Recovery-focused models are traditionally thought to contrast with diagnosis, but many clinicians who value diagnoses are supportive of recovery approaches.[92] Our model could enable the diagnostic process to be implemented in a way that is concordant with recovery principles. It particularly supports collaboration, person-centred care, and service-user agency and empowerment, reflecting recommendations about service-user participation.[19]

Diagnosis has been criticised for being overly medicalised, offering little information about causation of psychiatric disorders and poor instruction for intervention.[93] A case-formulation approach has been considered a viable alternative to diagnosis.[93,94] Although the two practices are often considered to be dissimilar, our Review suggests that the experience of diagnosis might be improved by integrating some of the principles of psychological formulation.[93,94] This approach includes collaboratively developing a holistic understanding of a person's difficulties that addresses aetiology, and then using diagnosis as a tool to guide treatment and recovery. Further research could assess the benefit of the two processes becoming more affiliated within clinical services.

This systematic review offers a widely applicable understanding of the factors influencing service-user experience of diagnosis, capturing variation across contexts. Our model is evidence based; it has been developed through a co-produced process of rigorous synthesis. Although we presented overarching findings, it is important to recognise individual experiences of the diagnostic process; factors and practices might affect different people in different ways. For example, we identified the fact that provision of information was especially beneficial for individuals with negative preconceptions or limited understanding of their diagnosis. Similarly, clear disclosure was empowering to some but destructive for others. We therefore emphasise that there is not one right way to diagnose; rather, the data promote an approach that is sensitive to an individual's needs and preferences. A strength of our model is that it accounts for individuality by posing themes as questions for consideration, rather than providing a best-practice checklist. We propose that clinicians and service users have open discussions about the factors identified (eg, timing) to decide best practice for an individual. This approach aligns with growing evidence and guidance supporting shared decision making.[95] We also emphasise that diagnosis is not always wanted, necessary, or beneficial, irrespective of how the process is implemented; some service users, clinicians, and carers or family opposed the practice of diagnosis entirely. We recommend establishing service-user views on diagnosing early in consultation and proceeding according to individual preference, considering potential alternatives such as clinical formulation.

A limitation of this Review was lack of published research for some diagnoses, meaning that they were insufficiently represented in our synthesis. There was only one included study each for anxiety and eating disorders. It is possible that the factors that influence these diagnoses

differ from those identified in this Review, potentially making the model less appropriate for some groups. Rather, it might be most representative of the factors influencing psychotic, depressive, and personality disorders, which were the most common diagnoses explored in the literature. Similarly, most studies included were from the UK, the USA, and Australia. Although themes appeared to be similar, there were few data from other countries, potentially not capturing cultural variations and limiting transferability of our model. Furthermore, all countries included are upper-middle income to high income, and it is likely that service-user experience will differ in lower-income countries, where access to care and resources is limited. Although we incorporated research on multiple stakeholders, there were few studies including carers or family. These voices might therefore be under-represented. Future research would benefit from comparing findings with other contexts, such as child mental health services, and populations such as dual diagnosis. We recommend future testing of the acceptability, validity, and utility of this model with service users, clinicians, and carers or family.

Receiving a mental health diagnosis can hugely affect service users' lives, but research into how to best approach the diagnostic process has been limited. Our co-produced, evidence-based model can directly inform clinical training and practice, functioning as a reflective guide for clinicians. The model promotes a holistic understanding of individuals, which can empower service users, provide hope, and guide treatment. We emphasise that the model should be drawn on in collaboration with service users and that sensitivity to individual needs and preferences is important. The aim of our model as a foundation for open, transparent, and collaborative decisions regarding diagnostic practice is to facilitate improved experiences and outcomes for service users.

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