








BMJ Open Prevalence of mental, behavioural or neurodevelopmental disorders according to the International Classification of Diseases 11: a scoping review protocol

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To cite: Nafarieh K, Krüger S, Deutscher K, *et al.* Prevalence of mental, behavioural or neurodevelopmental disorders according to the International Classification of Diseases 11: a scoping review protocol. *BMJ Open* 2024;**14**:e081082. doi:10.1136/bmjopen-2023-081082

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<https://doi.org/10.1136/bmjopen-2023-081082>).

Received 18 October 2023
Accepted 15 April 2024



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ABSTRACT

Introduction Due to a change in diagnostic prerequisites and the inclusion of novel diagnostic entities, the implementation of the 11th revision of the International Classification of Diseases (ICD-11) will presumably change prevalence rates of specific mental, behavioural or neurodevelopmental disorders and result in an altered prevalence rate for this grouping overall. This scoping review aims to summarise the characteristics of primary studies examining the prevalence of mental, behavioural or neurodevelopmental disorders based on ICD-11 criteria. The knowledge attained through this review will primarily characterise the methodological approaches of this research field and additionally assist in deciding which psychiatric diagnoses are—given the current literature—most relevant for subsequent systematic reviews and meta-analyses intended to approximate the magnitude of prevalence rates while providing a first glimpse of the range of expected (differences in) prevalence rates in these conditions.

Methods and analysis MEDLINE, Embase, Web of Science and PsycINFO will be searched from 2011 to present without any language filters. This scoping review will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Review guidelines.

We will consider (a) cross-sectional and longitudinal studies (b) focusing on the prevalence rates of mental, behavioural or neurodevelopmental disorders (c) using ICD-11 criteria for inclusion. The omission of (a) case numbers and sample size, (b) study period and period of data collection or (c) diagnostic procedures on full-text level is considered an exclusion criterion.

This screening will be conducted by two reviewers independently from one another and a third reviewer will be consulted with disagreements. Data extraction and synthesis will focus on outlining methodological aspects.

Ethics and dissemination We intend to publish our review in a scientific journal. As the primary data are publicly available, we do not require research ethics approval.

INTRODUCTION

In 2019, mental health conditions were among the 10 primary contributors to disease burden worldwide—an increase in burden being observable since 1990.¹ The current Global Burden of Disease

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review will be the first to summarise the characteristics of the literature assessing prevalence rates of mental, behavioural or neurodevelopmental disorders (MBND) according to the 11th revision of the International Classification of Diseases (ICD-11). Additionally, it will identify research gaps and inform subsequent systematic reviews and meta-analyses on the prevalence of the mentioned disorders.
- ⇒ Our search strategy consists of four electronic databases targeting peer-reviewed literature as well as grey literature sources to reduce publication bias; it will be conducted with no language restrictions.
- ⇒ We will adhere to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines for the conduct of Scoping Reviews to ensure transparent reporting.
- ⇒ To the end of a timely review, this scoping review covers the vast majority but not the entirety of diagnostic entities located within the MBND chapter of ICD-11.

study estimates roughly 970 million cases of mental health disorders worldwide to be responsible for more than 125 million disability-adjusted life years and for 15% of all years lived with disability¹: numbers which highlight the relevance of mental health conditions as a global public health concern.

Reliable and standardised measurements of health issues—relying on proper categorisation of diseases and associated processes—are necessary to understand, prevent and treat diseases while guaranteeing efficient resource utilisation.²

Through several revisions,³ the International Classification of Diseases (ICD) has evolved from a limited catalogue of causes of death⁴ into the ‘essential infrastructure

for health information² and as such should serve the aforementioned functions.²

The product of its 10th revision process, the ICD-11, was accepted by the World Health Assembly of WHO in May 2019.² Notable differences in its mental, behavioural or neurodevelopmental disorders (MBND) chapter were described by Gaebel *et al* and are summarised as follows⁵:

1. *Altered subchapter structure*: with 21 subchapters, the MBND chapter encompasses almost twice as many as chapter V of the ICD-10.⁵ This change resulted from the removal of a rule limiting the number of subchapters to 10 at every level of the ICD-10.⁶ Cross-links within chapter VI refer to the new sleep-wake disorders and conditions related to sexual health chapters, and in an effort to emphasise the continuous nature of development, the subchapter on mental or behavioural disorders with onset during childhood and adolescence was disintegrated, locating the respective diagnoses elsewhere.^{5 7}
2. *New diagnostic entities*: the revision resulted in the elimination of diagnostic groupings and the introduction of new diagnostic entities such as body dysmorphic disorder, prolonged grief disorder and complex post-traumatic stress disorder (complex PTSD).⁵
3. *Changes regarding diagnostic criteria*: examples comprise a higher diagnostic threshold for PTSD⁵ and schizoaffective disorders⁶ and a new conceptualization of personality disorders, which removes the established category types classification of the ICD-10.^{5 6 8}

As observed in the context of other revision processes, changes in diagnostic criteria can lead to a change in prevalence rates of diagnoses.⁹ The introduction of a reduced diagnostic threshold for attention deficit hyperactivity disorder in older adolescents and adults by the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), for instance, led to an increase of 65% in reported prevalence rates within these populations.⁹ Considering this, the publication of the ICD-11 alpha browser in May 2011¹⁰ initiated a growing body of work pertaining to the prevalence rates of new diagnostic entities and the difference in prevalence rates of MBND assessed according to ICD-11 and ICD-10 criteria.^{11–13}

As accurate estimates of prevalence rates are of key importance for public health planning, healthcare resource allocation as well as identifying risk factors or health disparities, this scoping review seeks to provide an overview of primary studies which examine the prevalence of mental disorders based on ICD-11 criteria. It aims to analyse the methodologies used to determine prevalence rates, including data sources, sampling methods, diagnostic tools and population characteristics. As such it will also support the decision on which diagnoses are most suitable for subsequent systematic reviews and meta-analyses, which can

provide more accurate estimates on how the ICD-11 will impact prevalence rates of specific MBND and disorders of this grouping in general.

The purpose of this review is represented by its rationales

- Rationale 1: the rationale of this review is to outline how prevalence rates of MBND of ICD-11 have been assessed so far and thereby summarise the approaches of currently available primary studies.
 - Associated review questions are:
 - What are the sample characteristics of primary studies?
 - Where were the primary studies based?
 - What was the timeframe for data collection within primary studies?
 - Study period.
 - Year of data collection.
 - What are the study designs of primary studies?
 - What were research aims of the primary studies?
 - Which MBND are most frequently assessed?
 - How were diagnoses assessed?
 - What measurement tools were used?
 - How was data collected?
 - What prevalence was estimated for the diagnoses?
 - Additionally, research gaps will be identified:
 - Associated review questions are:
 - Which mental, behavioural or neurodevelopmental disorders are least frequently assessed within prevalence studies?
- Rationale 2: identify mental, behavioural or neurodevelopmental disorders most suitable for subsequent systematic reviews and meta-analyses: here we are interested in:
 - Disorders, where multiple (≥ 2) primary studies exist which assess the prevalence of the disorders listed below (table 1) according to ICD-11 criteria and ICD-10 criteria within one cohort.
 - Newly introduced disorders, where multiple (≥ 2) primary studies exist which assess the prevalence of the disorders listed below (table 1) according to ICD-11 criteria.

As is reflected within these rationales, the main outcome of our project is a summary of the study characteristics of a body of work. A scoping review lends itself to the most appropriate method of evidence synthesis.

A preliminary search of MEDLINE, Embase and PsycINFO for existing scoping and systematic reviews on the topic was performed on 6 October 2023. We did not identify reviews pertaining to a similar topic.

METHODS

This scoping review in its final form will be reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension tool for Scoping Reviews.¹⁴ This protocol has been developed in

Table 1 Relevant mental, behavioural or neurodevelopmental disorders adapted from the WHO ICD-11 browser

Neurodevelopmental disorders	<ul style="list-style-type: none"> ▶ Autism spectrum disorder ▶ Attention deficit hyperactivity disorder
Schizophrenia or other primary psychotic disorders	<ul style="list-style-type: none"> ▶ Schizophrenia ▶ Schizoaffective disorder ▶ Schizotypal disorder ▶ Acute and transient psychotic disorder ▶ Delusional disorder
Catatonia	<ul style="list-style-type: none"> ▶ Catatonia associated with another mental disorder ▶ Catatonia induced by substances or medications
Mood disorders	<ul style="list-style-type: none"> ▶ Bipolar disorders: <ul style="list-style-type: none"> – Bipolar type I disorder – Bipolar type II disorder – Cyclothymic disorder ▶ Depressive disorders: <ul style="list-style-type: none"> – Single episode depressive disorder – Recurrent depressive disorder – Dysthymic disorder – Mixed depressive and anxiety disorder
Anxiety or fear-related disorders	<ul style="list-style-type: none"> ▶ Generalised anxiety disorder ▶ Panic disorder ▶ Agoraphobia ▶ Specific phobia ▶ Social anxiety disorder ▶ Separation anxiety disorder ▶ Selective mutism
OCD and other related disorders	<ul style="list-style-type: none"> ▶ Obsessive-compulsive disorder ▶ Body dysmorphic disorder ▶ Olfactory reference disorder ▶ Hypochondriasis ▶ Hoarding disorder ▶ Body-focused repetitive behaviour disorders <ul style="list-style-type: none"> – Trichotillomania – Excoriation disorder
Disorders specifically associated with stress	<ul style="list-style-type: none"> ▶ Post-traumatic stress disorder ▶ Complex post-traumatic stress disorder ▶ Prolonged grief disorder
Dissociative disorders	<ul style="list-style-type: none"> ▶ Dissociative neurological symptom disorder ▶ Dissociative amnesia ▶ Trance disorder ▶ Possession trance disorder ▶ Dissociative identity disorder ▶ Partial dissociative identity disorder ▶ Depersonalisation-derealisation disorder
Feeding or eating disorders	<ul style="list-style-type: none"> ▶ Anorexia nervosa ▶ Bulimia nervosa ▶ Binge eating disorder ▶ Avoidant-restrictive food intake disorder ▶ Pica disorder ▶ Rumination-regurgitation disorder
Elimination disorders	<ul style="list-style-type: none"> ▶ Enuresis ▶ Encopresis

Continued

Table 1 Continued

Disorders of bodily distress or bodily experience	<ul style="list-style-type: none"> ▶ Body integrity dysphoria ▶ Bodily distress disorder
Disorders due to substance use or addictive behaviours	<ul style="list-style-type: none"> ▶ Disorders due to substance use: <ul style="list-style-type: none"> – Disorders due to use of alcohol – Disorders due to use of cannabis – Disorders due to use of synthetic cannabinoids – Disorders due to use of opioids – Disorders due to use of sedatives, hypnotics or anxiolytics – Disorders due to use of cocaine – Disorders due to use of stimulants including amphetamines, methamphetamine or methcathinone – Disorders due to use of synthetic cathinones – Disorders due to use of caffeine – Disorders due to use of hallucinogens – Disorders due to use of nicotine – Disorders due to use of volatile inhalants – Disorders due to use of MDMA (3,4-Methylenedioxyamphetamine) or related drugs, including MDA (3,4-Methylenedioxyamphetamine) – Disorders due to use of dissociative drugs including ketamine and phencyclidine (PCP) ▶ Disorders due to addictive behaviours <ul style="list-style-type: none"> – Gambling disorder – Gaming disorder
Impulse control disorders	<ul style="list-style-type: none"> ▶ Compulsive sexual behaviour disorder ▶ Intermittent explosive disorder
Disruptive behaviour or dissocial disorder	<ul style="list-style-type: none"> ▶ Conduct-dissocial disorder ▶ Oppositional defiant disorder
Personality disorders and related traits	<ul style="list-style-type: none"> ▶ Personality disorder ▶ Prominent personality traits or patterns
Paraphilic disorders	<ul style="list-style-type: none"> ▶ Exhibitionistic disorder ▶ Voyeuristic disorder ▶ Paedophilic disorder ▶ Coercive sexual sadism disorder ▶ Frotteuristic disorder
Factitious disorders	<ul style="list-style-type: none"> ▶ Factitious disorder imposed on self ▶ Factitious disorder imposed on another
Neurocognitive disorders	<ul style="list-style-type: none"> ▶ Dementia: <ul style="list-style-type: none"> – Dementia due to Alzheimer's disease – Dementia due to cerebrovascular disease – Frontotemporal dementia
Mental or behavioural disorders associated with pregnancy, childbirth and the puerperium	<ul style="list-style-type: none"> ▶ Mental or behavioural disorders associated with pregnancy, childbirth or the puerperium, without psychotic symptoms ▶ Mental or behavioural disorders associated with pregnancy, childbirth or the puerperium, with psychotic symptoms

Continued

Table 1 Continued

Gender incongruence (chapter 17: conditions related to sexual health)	<ul style="list-style-type: none"> ▶ Gender incongruence of adolescence or adulthood ▶ Gender incongruence of childhood
Sexual dysfunctions	<ul style="list-style-type: none"> ▶ Hypoactive sexual desire dysfunction ▶ Sexual arousal dysfunctions ▶ Orgasmic dysfunctions ▶ Ejaculatory dysfunctions: <ul style="list-style-type: none"> – Male early ejaculation – Male delayed ejaculation ▶ Sexual pain-penetration disorder
Premenstrual dysphoric disorder	<ul style="list-style-type: none"> ▶ Premenstrual dysphoric disorder

OCD, obsessive-compulsive disorder.

accordance with the JBI methodological guidelines.¹⁵ We will describe protocol modifications with their respective dates.

Eligibility criteria

We will include

1. Cross-sectional and longitudinal studies
2. assessing the prevalence of MBND listed (table 1)
3. as per ICD-11 criteria

In sight of the feasibility of our project, provision of insufficient data on full-text level of primary studies constitutes an exclusion criterion: we will exclude primary studies which fail to provide

1. Case numbers and sample size
2. Study period and period of data collection
3. Details of diagnostic procedures

Information sources

We will conduct a search for the peer-reviewed literature from 2011 to present in the following databases: MEDLINE, Embase, PsycINFO and Web of Science. No language restriction will be applied. Sources identified in other languages which require translation for the full-text screening will be translated by state-certified translators.

Search strategy

Our search strategy for the peer-reviewed databases will consist of a search string of the general pattern:

1. String element for retrieving articles on each of the specific diagnoses as listed in table 1
2. String element for retrieving diagnoses according to ICD-11 criteria
3. Search filter identifying cross-sectional and longitudinal studies

The MBND listed in table 1 will be searched for.

The reference list of all included studies will be searched for additional sources. Sources of grey literature will also be identified and searched.

The search strategy was developed in consultation with an information specialist. The search string will be modified for the grey literature sources. We will repeat the search before the final analysis. The exact search strategy for MEDLINE via

Ovid can be found in the online supplemental material. The planned start and end dates for this study are May 2024 and May 2026, respectively.

Data management and study selection process

After performing searches across the databases, the title and abstract of each article will be exported to EndNote. Any duplicates will be removed at this stage. The titles and abstracts of all articles will be reviewed by two reviewers (KN and SG) according to the inclusion/exclusion criteria. Disagreements at this screening stage will be resolved by consensus of a third reviewer (SF) and studies will be retrieved for full-text review, if not excluded at this stage. Similarly, the full-text review will be conducted by two reviewers and disagreements will be resolved by consulting a third reviewer.

Data extraction

Following the review of titles and abstracts, an Excel spreadsheet will be created for the full-text review where the reviewers will have to document (a) whether the article is to be included or excluded, (b) record the reason for exclusion for excluded sources and (c) extract key information from each included paper. Data will be extracted by two reviewers, and discrepancies will be solved by a third reviewer.

The data extraction form will be piloted on a sample of the included studies and possibly modified.

Inclusion of a primary source provided; we intend to contact authors for further information when necessary.

Concerning the data extraction—in alignment with the aims of this project—our current data extraction form contains the following items:

1. Bibliographic information
 - a. Last name of the first author
 - b. Year of publication
 - c. Peer-review status (peer reviewed: eg, yes, no as in pre-print)
 - d. Journal/source
2. Study location
3. Study period/year of data collection
4. Study design
5. Scope of the investigation/research aims
 - a. Investigating the prevalence
 - b. Investigating predictors
 - c. Investigating consequences
 - d. Investigating psychosocial correlates
6. Study sample
 - a. Study sample (as in sampling process)
 - b. Sample size
 - c. Age range of the study population
 - d. Sex/gender ratio
7. Psychiatric disorders assessed
8. Diagnostic tool
 - a. Measurement tools used
 - b. Method(s) of data collection
9. Prevalence of psychiatric disorders
10. Analysis performed

As these data points provide the basis for an appropriate description of the methodology of this body of work, we cannot distinguish between main and additional outcomes.

Due to the aim of our work (ie, to give an overview of prevalence data available and methodological approaches used to obtain these estimates), we will use the JBI prevalence critical appraisal tool (possibly with minor modifications) to assess the methodological limitations or risk of bias of the evidence of primary studies included.

Data synthesis

For all studies meeting the inclusion criteria of the scoping review, we will use a descriptive synthesis approach. Our summary will focus on the extracted data. The results will be presented as charts, maps or tables. We will choose those visualisation and summary approaches that best fit the extracted content.

Patient and public involvement

This project aims to analyse an existing body of research studies, and we include an expert of experience (peer-to-peer trainer) and a representative of relatives in our research group. The expert of experience (AJ) was involved in the development of this protocol and will be consulted during the process of data synthesis and the discussion of our results. The representatives of relatives will be consulted during the process of data synthesis and the discussion of our results.

Dissemination and ethics

Regarding the dissemination of our work, the scoping review will be provided to scientific journals for consideration for publication, and its results may be presented as conference posters and presentations. No ethics approval is required as the analysed data originates from publicly available material.

Contributors SG and KN conceptualised this scoping review. KN is the author of the first draft of this protocol. SF, AH, SG, SS, KD, SK and AJ critically reviewed the manuscript and provided amendments. The search strategy was developed by KN with input from information scientists, SG and SK. All authors read and approved the final manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, conduct, reporting or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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