

# BMJ Open Researching the hard-to-reach: a scoping review protocol of digital health research in hidden, marginal and excluded populations

Rachel Victoria Belt <sup>1</sup>, Kazem Rahimi <sup>1</sup>, Samuel Cai <sup>2</sup>

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<sup>1</sup>Nuffield Department of Women's & Reproductive Health, University of Oxford, Oxford, UK  
<sup>2</sup>Centre for Environmental Health and Sustainability, Department of Health Sciences, University of Leicester, Leicester, UK

## Correspondence to

Rachel Victoria Belt;  
[rachel.belt@wrh.ox.ac.uk](mailto:rachel.belt@wrh.ox.ac.uk)

## ABSTRACT

**Introduction** There is a significant growth in the use of digital technology and methods in health-related research, further driven by the COVID-19 pandemic. This has offered a potential to apply digital health research in hidden, marginalised and excluded populations who are traditionally not easily reached due to economic, societal and legal barriers. To better inform future digital health studies of these vulnerable populations, we proposed a scoping review to comprehensively map published evidence and guidelines on the applications and challenges of digital health research methods to hard-to-reach communities.

**Methods and analysis** This review will follow the Arksey and O' Malley methodological framework for scoping reviews. The framework for the review will employ updated methods developed by the Joanna Briggs Institute including the Preferred Reporting Items for Systematic reviews and Meta-Analysis Scoping Review checklist. PubMed, the Cochrane Library, PsycINFO, Google Scholar and Greenfile are the identified databases for peer-reviewed quantitative and qualitative studies in-scope of the review. Grey literature focused on guidance and best practice in digital health research, and hard-to-reach populations will also be searched following published protocols. The review will focus on literature published between 1 February 2012 and 1 February 2022. Two reviewers are engaged in the review. After screening the title and abstract to determine the eligibility of each article, a thorough full-text review of eligible articles will be conducted using a data extraction framework. Key extracted information will be mapped in tabular and visualised summaries to categorise the breadth of literature and identify key digital methods, including their limitations and potential, for use in hard-to-reach populations.

**Ethics and dissemination** This scoping review does not require ethical approval. The results of the scoping review will consist of peer-reviewed publications, presentations and knowledge mobilisation activities including a lay summary posted via social media channels and production of a policy brief.

## INTRODUCTION

Globally, health equity is not consistently or systematically applied within or across

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This review will be the first which considers the intersection of digital health research and marginalised, hidden or excluded populations without a narrow focus on a platform or specific population.
- ⇒ The rapid expansion in the use of digital health research risks further exacerbation of the digital divide among populations. This review will provide timely information on targeted strategies to promote and improve inclusivity of hard-to-reach populations in digital health research.
- ⇒ The inclusion criteria for this scoping review is set to be broad, including any digital research on both the environmental and social determinants of health in hard-to-reach populations. This allows a thorough review of existing digital methods used across different sectors and disciplines that may have a wide applicability to hard-to-reach population research.
- ⇒ The synthesis of data will be limited to a mapping of methods and categorisation and less on the strength of each study due to the variance across the different fields of study and specialisations.
- ⇒ The search is limited in publications in English language only.

populations and subpopulations. Marginalised, hidden and underserved populations are subject to barriers which affect the achievement of equitable health and social welfare outcomes. Populations residing in informal settlements, for example, face many socioeconomic, environmental and legal barriers that prohibit their access to health service. For example, they may lack formal government recognition; therefore, their health status and needs are not tracked sufficiently by official systems. This poor data presents a formidable challenge for both researchers and policymakers to redress health inequities among these populations.<sup>1</sup>

Digital research, defined as 'the use of online and digital technologies to collect and analyse research data', was increasing pre-pandemic.<sup>2</sup> COVID-19 has driven a digital

transformation in healthcare, with increases in access to telehealth, the use of big data for monitoring the pandemic and the deployment of health communications via social media and other digital platforms.<sup>3–5</sup> The use of online surveys, mobile devices and social media are examples of digital modalities used in digital research and to study the impact and spread of COVID-19.<sup>3,6,7</sup> The speed and breadth of COVID-19 research was impressive, yet commentaries like those of Jung *et al* raise concerns regarding the adherence to research quality and standards in terms of study design, data quality and analytical methods.<sup>8</sup> The latest guidance in the area of digital health such as the WHO Digital Health Guidelines and the Digital Health Equity Framework are opportunities to assess the quality of digital research.<sup>9,10</sup>

An improved understanding of the health for hard-to-reach populations is required to achieve the Sustainable Development Goals and to end the COVID-19 pandemic, which has displayed health and social disparities existing within and between countries.<sup>11–13</sup> For this scoping review, hard-to-reach populations are defined as populations who are underserved by health and social services and/or face barriers in achieving equitable health and well-being due to socioeconomic determinants of health, discrimination, location, disability or exposure to climate and environmental factors. Without further review of research methods at the intersection of hard-to-reach populations and digital research, and clarity on barriers to research inclusion, there is a risk that these populations will be further excluded, and health disparities, partly due to the increasing digital divide, will be exacerbated.<sup>14,15</sup>

Application of digital research methods represents an opportunity to improve health equity and the inclusion of traditionally hard-to-reach, underserved and marginalised populations in research to inform programme design and policy. Previous reviews have documented strategies to improve research with socially disadvantaged groups and reviewed specific digital platforms such as social media and the use of specific health research technologies. However, none have systematically documented the methods for applying digital research methods to a hard-to-reach population.<sup>3,16–24</sup>

This review will build on the previous reviews including by Bonevski and Shaghghi,<sup>22,23</sup> which systematically documented barriers and strategies for research with socially disadvantaged and vulnerable groups. Our scoping review has considered their findings in the design, but we will narrow the review to studies in which research was conducted, digitally. O’Conner,<sup>16</sup> Helena,<sup>17</sup> Adjekum,<sup>19</sup> Giustini,<sup>18</sup> Whitaker<sup>25</sup> and Edo-Osagie<sup>21</sup> published scoping, literature or systematic reviews, or frameworks and analysis of digital health interventions, social media in public health and digital health app development standards. However, these reviews are broader than the scopes in our proposed review, in which we will focus on the methods’ application to hard-to-reach populations and the specific barriers or concerns when researching the hard-to-reach.<sup>16–19,21,25</sup> A retrospective

analysis of National Institute of Health funded digital health research by Nebeker documented the increased application of social media platforms in the study of hard-to-reach populations. The analysis concluded that guidance to researchers is insufficient in evaluating key concerns around the use of social media in research.<sup>26</sup>

The objective of this scoping review is to identify appropriate digital research methods to improve health research inclusivity, documenting both strategies and limitations of digital research methods with hard-to-reach populations. This review is important to ensure that the growth in digital methods does not leave behind populations of concern due to design limitations. The timing of this review is critical due to the risks of the COVID-19 pandemic on already vulnerable populations and the need to reach and include the most vulnerable and marginalised in research across health and social disciplines to improve health equity.

## METHODS AND ANALYSIS

A scoping review was chosen due to the broad nature of the subject. In line with the methods developed by Arksey and O’Malley, this review will follow the framework for conducting a scoping study; stage 1: identifying the research question, stage 2: identifying relevant studies, stage 3: study selection, stage 4: charting the data and stage 5: collating, summarising and reporting the results.<sup>27</sup> Detail on each stage is provided.

### Stage 1: identifying the research question

The key research questions outlined in [box 1](#) provide focus to the aim of the review to improve understanding of how digital research methods are applied to hard-to-reach populations including identification of methods, potential challenges and ethical concerns. To inform the search for marginalised, excluded and hidden populations which may not be defined by a term, a list of populations of interest have been included in data extraction framework in online supplemental annex A.

### Stage 2: identifying relevant studies

The search strategy aims to be comprehensive in its inclusion of studies across different socioeconomic and environmental determinants of health among hard-to-reach

#### Box 1 Research questions

1. How are digital health research methods applied to marginalised, excluded and hidden populations?

The secondary research questions focus on the strengths and limitations of the identified methods which include:

1. What are digital research methods commonly applied to include or target hard-to-reach populations?
2. What are challenges in recruitment, retention and response rate in digitally designed studies for hard-to-reach populations?
3. What were identified areas of ethical, safety and anonymity concerns in using digital research platforms for hard-to-reach populations?

**Table 1** Databases and sources

Database/source	Focus	Article limit per search term combination
Published literature		
PubMed	Health and medical research	None
Cochrane Library	Relevant systematic reviews on digital health	None
PsycINFO	Mental health and social research	None
Google Scholar	All search terms	200
Greenfile	Impact of climate change on health	None
Grey literature		
Key technical agencies (WHO, UNICEF, etc)	Hard-to-reach/marginalisation population specific research guidance—digital and non-digital	50
Campbell Collaboration	Social sciences	50

populations. The example evidence map is available in online supplemental annex B. The selection of health, social science, mental health and climate/environmental research databases will be employed in this review.<sup>28</sup> The database, description and article limit can be found in [table 1](#).

While we primarily focus on peer-reviewed studies for this scoping review, we will also search grey literature, technical reports and policy briefs produced by key agencies following a novel approach as set out by Enticott *et al* (eg, the WHO, UNICEF and the Campbell Collaboration).<sup>29</sup> These reports, guidance and sector best practice will complement our primary evidence mapping based on individual studies to ensure the most complete view of evidence is achieved. The search strategy is available in the online supplemental file.

A population, concept and context framework for this review is illustrated in [table 2](#).<sup>30</sup> Various search terms will be included, namely common hard-to-reach populations, socioeconomic and environmental determinants of health, and names of various digital platforms and methods. These are in line with the draft data extraction framework. Completed search terms will be documented and shared in the final publication.

### Stage 3: study selection

The review has established wide inclusion criteria. The geographical scope of this research is global, but studies are limited to those published in English. Inclusion and exclusion criteria can be found in [table 3](#). Rayyan and Endnote will be used to store all search results. The first reviewer will screen all titles and abstracts against the criteria. The second reviewer will screen 10% of these to

validate the screening process for inclusion and exclusion criteria. The first reviewer will then import the full text of all included documents for detailed analysis.

### Stage 4: charting the data

The data charting will occur using a google form collecting the recommended general information about the study according to the guidance for scoping reviews and expanding data collection through a data extraction framework into key study characteristics, including type of digital study, methodology and limitations. The data extraction framework, available in online supplemental annex C, will be tested by both reviewers for accuracy and applicability and applied consistently across all included studies. The first reviewer (RVB) will extract all data, and the second reviewer (SC) will review 10% of the articles to check for alignment. If misalignment is identified, the second reviewer will provide a full review of the literature. The grey literature search will be performed by the first reviewer.

### Stage 5: collating, summarising and reporting the results

The data collected in the charting exercise will be analysed by both reviewers. The digital methods deployed will be documented with particular focus to how the method enabled inclusivity of the hard-to-reach population and followed ethical guidance for research. The limitations of the studies will be analysed with a focus on research strength, ethics, replicability, community engagement and feasibility. Quality of the reviewed studies will be assessed using checklists informed from Joanna Briggs Institute (<https://jbi.global/critical-appraisal-tools>) for different types of studies. Additional analysis will include the identification of key research gaps and future research priorities at the intersection of digital health research and marginalised populations.

### PATIENT AND PUBLIC INVOLVEMENT

No patient involved.

**Table 2** Population, concept and context (PCC) framework

PCC	Definition	Example
Population	Hard-to-reach	Homeless
Concept	Digital research methods	Online survey
Context	Health and social research	Mental health



**Table 3** Inclusion and exclusion criteria

Theme	Inclusion criteria	Exclusion criteria
Geographic	All	None
Time	1 February 2012 to 1 February 2022	Before 2012
Language	English	All other languages
Populations	Populations of interests documented as keywords in the search strategy and the data extraction framework (available in online supplemental annex C)	Digital health studies which are not focused on hard-to-reach/marginalised populations
Type of literature	Published, peer-reviewed literature Grey literature including technical reports and policy briefs that are endorsed by key agencies	Literature which is not peer-reviewed Unpublished literature which is not considered sector guidance including presentations, webinars and case studies
Digital application	Digital research approaches including digital data collection, use of apps to collect data, digital surveys, use of social media and other strategies, including using machine-learning analytical techniques	Digital interventions such as remote consultations, digital health communications, social media health campaigns Digital information systems which are not part of a research design method will be excluded

## ETHICS AND DISSEMINATION

This scoping review does not require ethical approval as it reviews already available publications. The results of the scoping review will consist of peer-reviewed publications, presentations and knowledge mobilisation activities including a lay summary posted via social media channels and production of a policy brief.

**Twitter** Rachel Victoria Belt @rvbhaiti

**Contributors** RVB: conceived the initial idea, designed the review and drafted the manuscript. KR and SC: provided inputs to the study protocol and revised manuscript. All authors approved the manuscript for submission.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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## ORCID iDs

Rachel Victoria Belt <http://orcid.org/0000-0002-0078-1236>

Kazem Rahimi <http://orcid.org/0000-0002-4807-4610>

Samuel Cai <http://orcid.org/0000-0003-1601-2199>

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Supplementary Files for “Researching the hard-to-reach: a scoping review protocol of digital health research in hidden, marginal, and excluded populations”

## A. Documented search strategy

### Contents

- I. Summary of search methods and approach
- II. Pubmed
- III. Cochrane Review
- IV. Pysch Info
- V. Greenfile
- VI. Google Scholar
- VII. Grey literature

### I. Summary of search methods and approach

- Screening for inclusion of published literature performed by first reviewer from February 1<sup>st</sup> to March 1<sup>st</sup> 2022
- Screening for inclusion planned by second reviewer in August 2022
- Data extraction from the first review occurred in parallel following the testing of the data extraction framework by both reviewers.

### Summary of search strategy method:

Database/Source	Focus	Article limit per search term combination
<i>Published literature</i>		
PubMed	Health and medical research	None
Cochrane Library	Relevant systematic reviews on digital health	None
PsycINFO	Mental health and social research	None
Google Scholar	All search terms	200
Greenfile	Impact of climate change on health	None
<i>Grey literature</i>		
Websites of key technical agencies (World Health Organization, UNICEF)	Hard-to-reach/marginalization population specific research guidance – digital and non-digital	50
Campbell Collaboration	Social Science	None

### II. PubMed [Search performed February 1 2022]

#### Concept 1: Digital

**Keywords:** "Digital health research"[TIAB] OR "Digital Survey\*"[TIAB] OR "Digital Epidemiology"[TIAB] OR "Online survey\*"[TIAB] OR "Mobile technology"[TIAB] OR "Health application\*"[TIAB] OR "Health app"[TIAB] OR "Interactive Voice Response" [TIAB] OR "SMS" [TIAB] OR "Whatsapp"

[TIAB] OR "Facebook"[TIAB] OR "Twitter"[TIAB] OR "smartphone\*"[TIAB] OR "Auto-photography"[TIAB] OR "Video"[TIAB] OR "Photography"[TIAB] OR "Smartwatch\*"[TIAB]

MH: "Digital Technology\*"[MH] OR "Cell phone"[MH] OR "Mobile Applications"[MH] OR "Social Media"[MH] OR "Digital Technology"[MH] OR "Wearable electronic devices"[MH]

**AND**

### Concept 2: Hard-to-Reach Populations

**Keywords:** "Hard-to-reach"[TIAB] OR "Marginalized"[TIAB] OR "Refugee\*"[TIAB] OR "Migrant\*"[TIAB] OR "Vulnerable"[TIAB] OR "Internally Displaced Person\*"[TIAB] OR "Slum Resident\*"[TIAB] OR "Slumdweller\*"[TIAB] OR "Homeless"[TIAB] OR "Housing insecure"[TIAB] OR "Illiterate"[TIAB] OR "Disability"[TIAB] OR "Remote-Rural"[TIAB] OR "Nomadic"[TIAB] OR "Indigenous"[TIAB] OR "Immigrant\*"[TIAB] OR "Prisoner\*"[TIAB] OR "Low-income"[TIAB] OR "LGTBQ"[TIAB] OR "Injecting drug-users"[TIAB]

MH: "Health Disparity, Minority and Vulnerable Populations"[MH] OR "Homeless Persons"[MH] OR "Opioid-Related Disorders"[MH] OR "Refugees"[MH] OR "Prisoners"[MH] OR "Poverty Areas"[MH] OR "Transients and Migrants"[MH] OR "Health Services for Transgender Persons"[MH] OR "Vulnerable Populations"[MH] OR "Social Vulnerability"[MH] OR "Intellectual Disability"[MH] OR "Disabled Persons"[MH] OR "Social Discrimination"[MH] OR "Persons with Mental Disabilities"[MH]

**AND**

### Concept 3: Health and social-determinants of health

**Keywords:** "Health"[TIAB] OR "Nutritional Status"[TIAB] OR "Nutrition"[TIAB] OR "Mental Health"[TIAB] OR "Unemployment"[TIAB] OR "Food insecure"[TIAB] OR "Discrimination"[TIAB] OR "Conflict"[TIAB] OR "Natural Disaster"[TIAB] OR "Flooding"[TIAB] OR "Pollution"[TIAB]

MH: "Health"[MH] OR "Social Determinants of Health"[MH] OR "Environmental Pollution"[MH] OR "Natural Disasters"[MH]

### **Documented Search Strategy**

<b>Final Search</b> – 4,966, limit to 10 years – 4,499. Search performed Feb 1, 2022	(("Digital health research"[TIAB] OR "Digital Survey*"[TIAB] OR "Digital Epidemiology" [TIAB] OR "Online survey*"[TIAB] OR "Mobile technology"[TIAB] OR "Health application*"[TIAB] OR "Health app"[TIAB] OR "Interactive Voice Response" [TIAB] OR "SMS" [TIAB] OR "Whatsapp" [TIAB] OR "Facebook"[TIAB] OR "Twitter"[TIAB] OR "smartphone*"[TIAB] OR "Auto-photography"[TIAB] OR "Video"[TIAB] OR "Photography"[TIAB] OR "Smartwatch*"[TIAB] OR "Digital Technology*"[MH] OR "Cell phone"[MH] OR "Mobile Applications"[MH] OR "Social Media"[MH] OR "Digital Technology"[MH] OR "Wearable electronic devices"[MH]) AND ("Hard-to-reach"[TIAB] OR "Marginalized"[TIAB] OR "Refugee*"[TIAB] OR "Migrant*"[TIAB] OR "Vulnerable"[TIAB] OR "Internally Displaced Person*"[TIAB] OR "Slum Resident*"[TIAB] OR
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	"Slumdweller*" [TIAB] OR "Homeless" [TIAB] OR "Housing insecure" [TIAB] OR "Illiterate" [TIAB] OR "Disability" [TIAB] OR "Remote-Rural" [TIAB] OR "Nomadic" [TIAB] OR "Indigenous" [TIAB] OR "Immigrant*" [TIAB] OR "Prisoner*" [TIAB] OR "Low-income" [TIAB] OR "LGBTQ" [TIAB] OR "Injecting drug-users" [TIAB] OR "Health Disparity, Minority and Vulnerable Populations" [MH] OR "Homeless Persons" [MH] OR "Opioid-Related Disorders" [MH] OR "Refugees" [MH] OR "Prisoners" [MH] OR "Poverty Areas" [MH] OR "Transients and Migrants" [MH] OR "Health Services for Transgender Persons" [MH] OR "Vulnerable Populations" [MH] OR "Social Vulnerability" [MH] OR "Intellectual Disability" [MH] OR "Disabled Persons" [MH] OR "Social Discrimination" [MH] OR "Persons with Mental Disabilities" [MH])) AND ("Health" [TIAB] OR "Nutritional Status" [TIAB] OR "Nutrition" [TIAB] OR "Mental Health" [TIAB] OR "Unemployment" [TIAB] OR "Food insecure" [TIAB] OR "Discrimination" [TIAB] OR "Conflict" [TIAB] OR "Natural Disaster" [TIAB] OR "Flooding" [TIAB] OR "Pollution" [TIAB] OR "Health" [MH] OR "Social Determinants of Health" [MH] OR "Environmental Pollution" [MH] OR "Natural Disasters" [MH])
1 February 2022	<ul style="list-style-type: none"> <li>• Pubmed search exported to endnote</li> <li>• Endnote export to RIS file</li> <li>• 4,499 references uploaded to Rayyan</li> </ul>

### III. Cochrane Reviews – Search performed 1 March 2022

Due to the broad reach of the complimentary databases in this review, only Cochrane Reviews were included.

Search Term for Title and Abstract.	Total Cochrane Reviews
"Digital Health"	61
"Digital Technology"	30
"Hard-to-Reach"	3
A total of 91 Cochrane reviews were added to Rayyan.	

### IV. PSYCH Info – search performed 20 February 2022

According to the methodology, there was no article limit, although only articles from 2012 were included.

Search Terms combinations	Total articles
(Digital) OR (Mobile technology)	86,159
(Vulnerable) OR (Hard-to-Reach)	89,864

(Health) OR (Climate)	1,963,823
<b>Final Search Strategy:</b> “Digital or Mobile technology AND vulnerable or hard-to- reach AND health or climate”	2,307

#### V. Google Scholar – Search performed on 28 February 2022

According to the methodology, 200 articles were the limit given the potential for duplication with other databases. Only articles from 2012 were included.

Search Terms combinations	Total articles
Vulnerable “digital health”	200

#### VI. Greenfile – Search performed on 20 February 2022

Search Terms combinations	Total articles
“vulnerable populations or groups or people” AND “digital technology or web technology or software technology or virtual technology”	17

#### Duplications

Following the compilation of all database results, 401 duplicates were identified by Endnote and Rayyan.

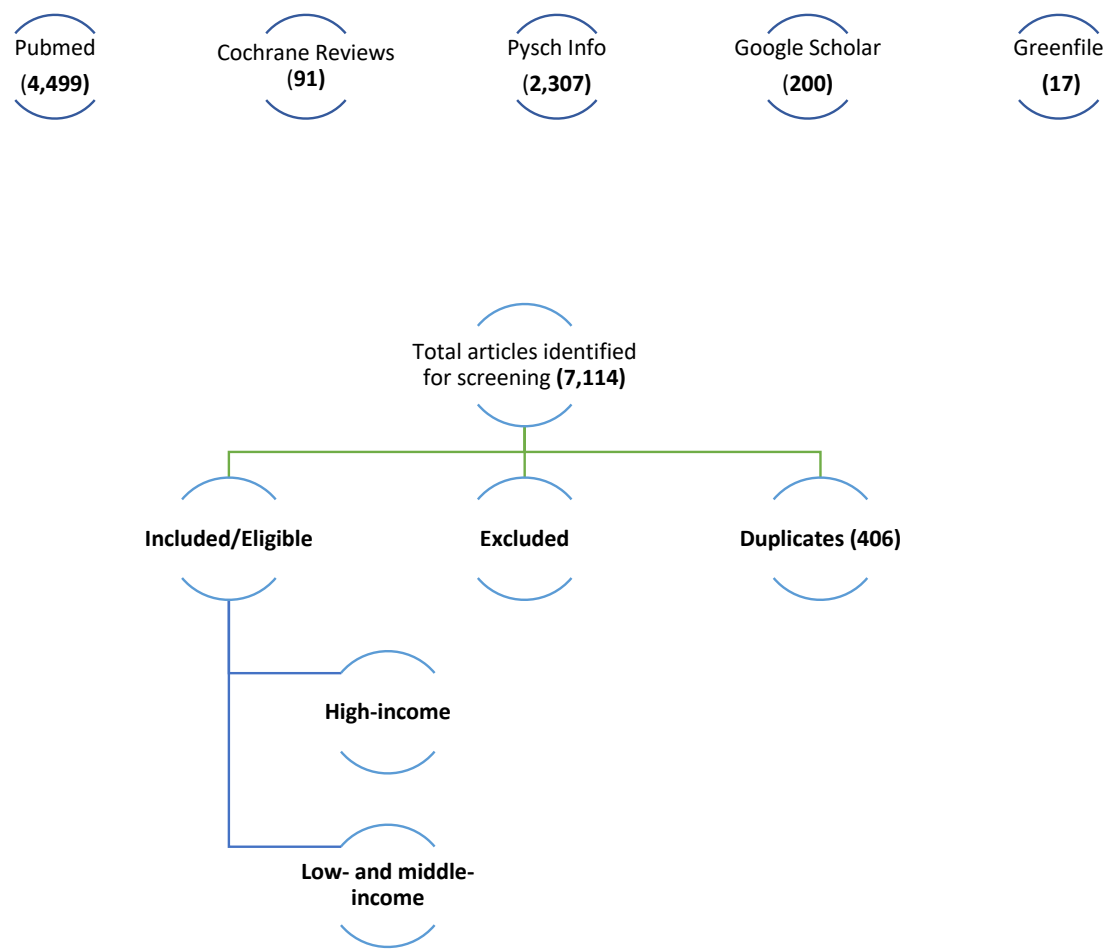
#### VII. Grey Literature

A grey literature search will focus on guidelines, reviews and commentaries related to the progress of standard setting and best practice for digital research inclusion. The review will include sector Guidance issued from the following institutions: the World Health Organisation, UNICEF and the Campbell Collaboration. References of key studies included in the review will also be considered. The articles identified in the grey literature search will be used to inform the data extraction framework and the analysis. This work is ongoing as of July 2022, informed by the feedback of the reviewers.

Planned search strategy for grey literature:

Search Terms	Database or Website	Document Limit
“Digital Health”, “Digital Technology”, “Hard-to-Reach”	Cochrane Collaboration	50
“Digital Health”, “Digital Technology”, “Hard-to-Reach”	The World Health Organisation, UNICEF	50
“Digital Health”, “Digital Technology”, “Hard-to-Reach” + “Guidance”	Google	50

B. Summary of inclusion and exclusion for published literature



An evidence map was developed to plan the review following guidance of a systematic review by Miake-Lye.(26)

### C. Data Extraction Framework

This framework has been adapted from the Chapter 11.3.7.3. of the data extraction guidance from JBI.<sup>(25)</sup> This is a draft will be adapted and iterated to a final version in line with the iterative process permitted in the Arksey and O' Malley methodological framework and will be documented in the final publication.<sup>(27)</sup>

Theme	Fields of data collection/categorization
Article source and authorship	Authors Title Journal/Source Year of publication Country High-income country Middle-income country Low-income country
Populations of interest (more than one selection, permitted)	Refugee Migrant Internally Displaced Person Informal Settlement Resident Homeless Low-literacy Disability including physical, developmental, behavioral or emotional and sensory-impaired disorders Remote-rural Nomadic LGBTQ+ Low-income Minority Youth * Elderly* Other _____ *These two populations are not included alone but with a secondary population. However, due to the presence of a large number of studies related to these populations they have been included for the analysis,
Type of digital research and digital platform (more than one selection, permitted)	Big Data (Machine learning, AI) Digital Survey Digital Epidemiology Online Survey Interactive Voice Response SMS WhatsApp Facebook Survey Twitter App (application, bespoke) Smartphone Auto-photography Video

	Photography Wearable Other ____
Research study focus	Health COVID-19 (y/n) Nutritional status Mental Health Social-determinants of health;(28) <ul style="list-style-type: none"> <li>• Income and social protection</li> <li>• Education</li> <li>• Unemployment and job insecurity</li> <li>• Working life conditions</li> <li>• Food insecurity</li> <li>• Housing, basic amenities and the environment</li> <li>• Early childhood development</li> <li>• Social inclusion and nondiscrimination</li> <li>• Structural conflict</li> <li>• Access to affordable health services of decent quality</li> </ul> Physical environmental determinants of health (air-quality, pollution) Climate-related factors such as flooding and heat
Research category	Qualitative Quantitative
Methods and limitations	Recruitment (multiple selections allowed) <ul style="list-style-type: none"> <li>• Social Media</li> <li>• In-person</li> <li>• snowball sampling</li> <li>• respondent-driven sampling (RDS)</li> <li>• indigenous field-worker sampling (IFWS)</li> <li>• facility-based sampling (FBS)</li> <li>• targeted sampling (TS)</li> <li>• time-location (space) sampling (TLS)</li> <li>• conventional cluster sampling (CCS)</li> <li>• capture re-capture sampling (CR) (19)</li> <li>• Other</li> </ul> Response rate Use of incentives Anonymity Ethics Presence of community engagement
Quality	Considerations for a rapid quality review of included studies will be developed based on checklists from Joanna Briggs Institute (JBI) ( <a href="https://jbi.global/critical-appraisal-tools">https://jbi.global/critical-appraisal-tools</a> )