INPLASY PROTOCOL

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Review Stage at time of this submission: The review has not yet started.

Conflicts of interest: None declared.

"What are Deaf sign language users' experiences as patients in healthcare services?": A scoping review protocol

Rogers, KD[1]; Lovell, K[2]; Bower, PJ[3]; Armitage, CJ[4].

Review question / Objective: A scoping review with specific reference to the context of Deaf populations, in relation to Deaf people's experience of health and mental health services, including the use of a questionnaire regarding their experience as a patient, is needed in order to assess and synthesise the current knowledge. As this is an exploratory type of review drawing on qualitative as well as quantitative work, the PICo approach Population, (Phenomena of) Interest and Context, will guide the question formulation. Following the identification of the gap in the existing systematic reviews and scoping searches concerning patient experience and Deaf people's experience of using healthcare services, the research question is as follows: "What are Deaf sign language users' experiences as patients in healthcare services?".

Information sources: The bibliographic databases that will be searched for this review will includes PsycINFO, PubMed, Web of Science, CINAHL, and Medline. Grey literature sources (e.g., policy, practice, and guideline documents), including contacting the relevant investigators working in the field of Deaf populations, will be searched for this review study. Forward citation sources, from the relevant reference lists, will also be searched to ensure the process is thorough.

INPLASY registration number: This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 19 January 2022 and was last updated on 19 January 2022 (registration number INPLASY202210102).

INTRODUCTION

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quantitative work, the PICo approach Population, (Phenomena of) Interest and Context, will guide the question formulation. Following the identification of the gap in the existing systematic reviews and scoping searches concerning patient experience and Deaf people's experience of using healthcare services, the research question is as follows: "What are Deaf sign language users' experiences as patients in healthcare services?".

Rationale: The rationale for a scoping review is to establish a better understanding of current knowledge with respect to Deaf people's experience of the health services, which would inform healthcare professionals and commissioners. This would in turn assist them in tackling the inequalities and issues faced by Deaf people. Searches from PROSPERO, the Cochrane Library and the NIHR Journals Library have identified that there are no existing, nor current, systematic reviews on the topic of Deaf people's experience of health services. This review will focus on the topic of patient experience in healthcare from a Deaf person's perspective, including scoping for patient experience questionnaires that may have the potential to be adapted for the Deaf population. The method for scoping review will follow Arksey and O'Malley's (2005) methodology framework for scoping studies. This includes five stages: (i) identifying the research question; (ii) identifying relevant studies; (iii) study selection; (iv) charting the data; and (v) collating, summarising and reporting the results.

Condition being studied: This protocol refers to Deaf people who are users of signed languages such as British Sign Language (BSL), with the focus on Deaf people's experience of health services. NHS Institute for Innovation and Improvement (2013) define the patient experience as "what the process of receiving care feels like for the patient, their family and carers". Valuing patient experience has become an important factor in seeking to improve healthcare and health outcomes (Chatterjee et al., 2015).

This benefit is not so clear when considering a population that has historically been excluded from research and who experience inequalities in health outcomes, such as Deaf populations (Rogers et al., 2017). The NICE guideline on "Patient experience in adult NHS services" (NICE, 2012) states that The Equality Act 2010 "provides an important legal framework which should improve the experience of all patients using NHS services" (p.5). However, that is not always the case with Deaf populations as they often face inequality in maximising health outcomes, in accessing healthcare, and in reaching satisfaction with the service. A scoping review with specific reference to the context of Deaf populations, in relation to Deaf people's experience of health and mental health services, including the use of the questionnaire relating to their experience as a patient, is needed in order to assess and synthesise the current knowledge.

METHODS

Search strategy: PsycINFO, PubMed, Web of Science, CINAHL, and Medline, as well as grey literature sources (e.g., policy, practice, and guideline documents), including contacting the relevant investigators working in the field of Deaf populations, will be searched for this review study. Forward citation sources, from the relevant reference lists, will be searched to ensure a thorough search is carried out. Examples of key words will include: deaf, sign language, patient experience, assessment, and questionnaire (please see table 1 for more details of search terms), as these will ensure that all possible relevant words will be covered in the search. Techniques for conducting the systematic literature search will include using free-text words, truncation (e.g. sign* language will produce the words: sign language, signed language), common phrases with double quotation marks (e.g. "hearing impair*" will produce the words for hearing impaired as well as hearing impairment), Boolean operators will also be used (i.e. OR and AND) to connect the key search words (see table 1). Three searches

of syntax (S1, S2, and S3) will then show how many hits have been produced, this will then become the fourth search (S4), which will combine the initial three searches, to produce all possible relevant results. The results from the fourth search (S4) will then be moved to EndNote, to begin the next step of the eligibility screening search, identifying what can be included within the review. Table 1.

Search terms will include: S1 (deaf* OR "hearing impair*" OR "hearing loss" OR "hard of hearing" OR "DHH" OR culturally Deaf) AND ("sign* language" OR signing)
S2 (patient*) AND (experience OR satisfaction OR cent* OR activation OR feedback OR perspective OR opinion)
S3 (health* setting OR healthcare OR health care OR health* service OR health* professionals OR health* personnel)
S4 (S1 AND S2 AND S3).

Participant or population: Any studies that involve Deaf signing individuals or populations, whether it be British Sign Language (BSL); American Sign Language (ASL), German Sign Language (Deutsche Gebärdensprache DGS), etc., will be included in the review. Any deaf populations who do not use sign language, or those who are predominantly spoken language users, will be excluded from the review.

Intervention: Any report of patient experience within healthcare settings as perceived by Deaf signing populations will be included in the review. Additionally, if there is report of using a measurement in sign language to measure patient experience, then it will also be included in the review. The setting will be in any healthcare setting. This includes a broad range of healthcare services, including health care prevention, actual treatment experiences, etc.

Comparator: Although not essential for this review, any study that includes comparators will be included.

Study designs to be included: All published studies of any design, as well as grey literature sources (e.g., policy, practice, and

guideline documents), including contacting the relevant investigators working in the field of Deaf populations, will be included in the review study. Any publications that are published in languages other than English or a Signed Language (e.g. published in Deaf Studies Digital Journal) will be excluded from the review.

Eligibility criteria: Any studies that involve Deaf signing individuals or populations will be included in the review. Any deaf populations who do not use sign language, or those who are predominantly spoken language users, will be excluded from the review as they will not be applicable to Deaf signing populations.

Information sources: The bibliographic databases that will be searched for this review will includes PsycINFO, PubMed, Web of Science, CINAHL, and Medline. Grey literature sources (e.g., policy, practice, and guideline documents), including contacting the relevant investigators working in the field of Deaf populations, will be searched for this review study. Forward citation sources, from the relevant reference lists, will also be searched to ensure the process is thorough.

Main outcome(s): The main outcomes will be any report of patient experience within healthcare settings as perceived by Deaf signing populations will be included in the review.

Data management: The selection of the studies to be included in the review will involve two stages: (i) screening of the title and abstract; and (ii) screening of full text articles/book chapters/professional writing/policy documents/government papers. The screening will begin with the results given from the inclusion and exclusion criteria, where the number of results that are produced in the initial search will be recorded. The references will be held, along with the relevant articles, in software such as EndNote library, Covidence, or Rayyan. The selection for the inclusion from screening the title and abstract (first stage) will be assessed by

two reviewers, included in the review. The second stage of the screening process involves reviewing the full text of the articles highlighted in the first stage. These will be reviewed by two reviewers, a third reviewer will resolve any disagreements between the first two. Decisions regarding whether to include or exclude various articles at either the first or second stage of screening will be recorded, including details highlighting the reason for exclusion. In addition, the second stage of screening which reviews article's full text will be recorded too. Reporting of the findings from the searches and the selection will follow the EQUATOR NETWORK guidelines for the PRISMA Extension for Scoping Reviews (PRISMA-ScR). The relevant data from each study will be extracted from the full-text articles (stage two of the screening), and the relevant data will be recorded in a Microsoft Excel document. The descriptive data (e.g. methods; participants' characteristics; setting; and interventions) and analytical data (i.e. outcome data) to be extracted will include, for example: author(s); year of publication; publication type; country where the study was carried out; study design; number of participants; age; gender; inclusion/exclusion criteria; intervention; and comparisons (if using the control group); outcome data/results (statistical data or results from qualitative data). Where there is missing data from the included studies in the review, the authors of the primary study will be contacted with a request to provide the missing data if possible. Detailed information regarding the descriptive data in each study, and the findings of each of the studies, will be presented in the data extraction table in MS excel.

Quality assessment / Risk of bias analysis: The assessment of the quality of the articles in the review will be obtained using the Crowe Critical Appraisal Tool (CCAT) alongside the CCAT user guide (https://conchra.com.au/2015/12/08/crowe-critical-appraisal-tool-v1-4/). The CCAT has eight categories (22 items in total) where one can appraise and score, these categories include: (i) Preliminaries; (ii) Introduction;

(iii) Design; (iv) Sampling; (v) Data collection; (vi) Ethical matters; (vii) Results; and (viii) Discussion. The CCAT was considered suitable for this review as it includes both quantitative and qualitative studies therefore suitable for various research designs, and the reliability and validity of CCAT have been examined and were found to be reliable (Crowe, Sheppard, & Campbell, 2011).

Strategy of data synthesis: It is anticipated that there will be a limited availability of studies involving Deaf signing populations on the topic of patient experience that meet the inclusion criteria for this review study. If this is the case, it is unlikely that this review will have sufficient data to carry out a meta-analysis (nor will it be able to transform the statistical data) nor sufficient articles to produce a qualitative meta-synthesis. Therefore, this review will use an aggregative approach and a narrative synthesis of the data will be presented. The preliminary synthesis will tabulate the results using the extracted data such as study design, quality of the study, comparison group (if used), whether or not the baseline information was collected at the start of the study, and key findings. A within study analysis of each study included in the review will be reported involving a description of the findings and a description of study quality. Then the cross-study synthesis will be carried out to describe the overall summary of the findings.

Subgroup analysis: As this is a scoping review, there is no plan for subgroup analysis.

Sensitivity analysis: As this is a scoping review, there is no plan for sensitivity analysis.

Language: Any publications that are published in languages other than English or a Signed Language will be excluded from the review.

Country(ies) involved: United Kingdom.

Keywords: Deaf populations; Deaf individuals; signed language; patient experience; patient satisfaction; healthcare; scoping review.

Dissemination plans: The scoping review findings will be published in peer-reviewed journals and/or presented at conferences.

Contributions of each author:
Author 1 - Katherine Rogers - KR develop the scoping review plan for this study and will be involved in every stage of the review protocol (e.g. carrying out the search strategy; study selection; data extraction; reporting the results; preparing the manuscript for publication; etc).
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Author 2 - Karina Lovell - KL supported the development and a reviewer for the scoping review and supporting the writing and contribution of the manuscript.
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