

# INPLASY

**Cancer and Deaf people who use sign language: what are the experiences and perspectives of Deaf patients, carers, and service providers through the process of identifying, treating and living with cancer? A scoping review protocol**

INPLASY2024110067

doi: 10.37766/inplasy2024.11.0067

Received: 15 November 2024

Published: 15 November 2024

Redpath-Healy, M; Rogers, K; Young, A.

## Corresponding author:

Molly Redpath-Healy

molly.redpath-healy@manchester.ac.uk

## Author Affiliation:

The University of Manchester.

## ADMINISTRATIVE INFORMATION

**Support** - n/a.

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

**Conflicts of interest** - None declared.

**INPLASY registration number:** INPLASY2024110067

**Amendments** - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 15 November 2024 and was last updated on 15 November 2024.

## INTRODUCTION

**Review question / Objective** This scoping review aims to answer the following question: What are the experiences and perspectives of cancer among Deaf people, carers and service providers in relation to Deaf sign language users? By Mapping existing literature, such as qualitative studies and firsthand accounts this review aims to identify the volume and variety of research conducted regarding the potential barriers and effective coping strategies faced by Deaf people, carers and service providers, thereby identifying gaps in support and areas for future intervention.

**Rationale** The use of the capitalised 'D' in the word Deaf within this review categorises any individual who uses sign language (e.g. British Sign Language (BSL) or American Sign Language (ASL) and so on). This scoping review will concern experiences and perspectives of Deaf patients, carers who are Deaf or carers of individuals who

are Deaf, and service providers. These experiences and perspectives will be related to cancer across three components: (i) the processes of identifying cancer (from recognition of symptoms up to diagnosis of cancer); (ii) the process of treating cancer; (iii) living with cancer. Preliminary searches of PROSPERO, JBI Evidence Synthesis, Cochrane and Campbell have identified no existing review regarding this topic, despite there being known concerns about the inequalities in many other health outcomes for Deaf people (Rogers et al, 2024). This inequality has also been found in relation to Deaf people and cancer, specifically that Deaf people were diagnosed at more advanced stages of colorectal and prostate cancer and are more likely to be diagnosed with larger breast cancer tumours (Druel et al, 2018). Cancer is responsible for almost one in six deaths worldwide, meaning cancer is a leading cause of death (WHO, 2022). WHO (2024) have predicted that the global cancer burden is projected to increase to over 35 million new cancer cases in 2050, compared to the 20 million cases in 2022.

This 77% increase by 2025 reflects the longevity of the issue at hand. It is imperative to explore the perspectives of Deaf patients, carers and service providers in relation to cancer journeys in order to identify what interventions need to be implemented. These interventions need to be identified and implemented urgently due to the imminent projected increase of cancer morbidity worldwide. In doing this it has the potential to reduce the total cost of cancer care within the UK, which is currently around £7 billion annually (Health Data Research UK, 2024). The objective of this scoping review is to assess the extent of the literature within the field of Deaf sign language users and cancer.

**Condition being studied** Cancer.

## METHODS

**Search strategy** The search strategy will aim to locate both published and unpublished studies. A three-step search strategy will be utilized in this review. First an initial limited search of MEDLINE (PubMed), PsychInfo, ProQuest Social Science, ProQuest Sociology, Project Muse, Web of Science, EthOs and CINAHL (EBSCO) will be undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles will be used to develop a full search strategy for report the name of the relevant databases/information sources. The search strategy, including all identified keywords and index terms, will be adapted for each included database and/or information source. The reference list of all included sources of evidence will be screened for additional studies. In addition to primary databases, key journals including Lancet Global Health and JDSDE will also be searched. Grey literature such as policy, practice and guidelines documents, and theses will be searched for. The search strategy will include the following headings or keywords: 1) descriptors of deaf terms (Deaf, sign language users); 2) descriptors of cancer of all types (Cancer, Leukemia, Lymphoma, Sarcoma, Melanoma, Myeloma, Mesothelioma, Glioma, Neuroblastoma, Retinoblastoma, Wilms' Tumor, Carcinoid Tumor, Basal Cell Nevus Syndrome, Papilloma); 3) descriptors of perspective and experience terms (e.g. opinion). The literature search will be conducted with the use of free-text words, truncation (e.g. deaf\* will generate the words: deaf and deafness), and use of Boolean operators such as AND and OR. Studies published in written English, British Sign Language (BSL), American Sign Language (ASL), International Sign Language (IS), Irish Sign

Language (ISL) French and German will be included, due to the fluency of all authors. Papers included will be publishing between 1966 – 2024 inclusive. The main reason behind why 1966 is the starting point is due to this is when the World Health Organization (WHO) established the WHO cancer programme. This can be seen as the early beginnings of modern cancer control efforts. If there are any exceptional articles found during this scoping review that are published outside of this date range, they will be included. It is anticipated that there will be few studies obtained involving deaf sign language users', carers or service providers' perceptions and experiences of cancer therefore, the data will be narratively synthesised following a thematic structure generated by evidence in the studies.

**Participant or population** Studies involving Deaf adults who use sign language as their primary method of communication. Carers for individuals who are Deaf sign language users, or Carers who themselves are Deaf sign language users. Service providers who in some capacity may interact with an individual who has been diagnosed with cancer such as GP staff, Cancer support service workers and hospital staff. There will be no confinements on gender, sexuality, ethnicity, disability, culture of country of origin. We define Deaf sign language users as individuals with all types and degrees of deafness, but they must use sign language as their preferred form of communication. This does not encompass sign systems such as Makaton not visual versions of the spoken word such as Sign Supported English. Instead it will wholly focus on signed.

**Intervention** n/a.

**Comparator** n/a.

**Study designs to be included** This scoping review will consider any sources of data pertaining to Deaf people who use sign language that focuses on experiences or perspectives. It will also include sources where there might be data on experiences of patients, carers, or service providers in relation to Deaf people and cancer.

**Eligibility criteria** Inclusion criteria are:

1. Items focusing on either or all of the following in relation to Deaf people: noticing and identifying symptoms of cancer, the process of being diagnosed with cancer, the process of cancer treatment, and life post-cancer diagnosis.
2. Primary research including scholarly journal publications, book chapters, books and similar including pre-prints.

3. Secondary data analysis of one or more primary sources including those derived from data sets that might include sign language users.

4. Evidence based meta-analyses and meta-syntheses

5. Grey literature including government reports, policy documents, legislation, professional guidance, information sources for Deaf people in relation to cancer.

6. Items published between 1966-2024. This is when the WHO cancer programme was established, in essence when cancer was seen as a global issue to be addressed. Where a item of note is published outside of this time frame that has been important in the field, exceptions will be made.

Exclusion criteria are:

1. Falls outside the inclusion criteria
2. Any studies that do not provide separable data for Deaf sign language users or have a focus on the topic of Deaf sign language users will not be included in this review.
3. Any articles that do not involve the cancer experiences or perspectives on identifying cancer symptoms, diagnosing cancer or managing/ treating cancer will not be included in this review.
4. Articles that solely focus on cancer morbidity and mortality rates.

**Information sources** Searches of the following databases will be used to gather relevant literature: MEDLINE (PubMed), PsychInfo, ProQuest Social Science, ProQuest Sociology, Project Muse, Web of Science, EthOs and CINAHL(EBSCO).

**Main outcome(s)** This scoping review aims to answer the following question: What are the experiences and perspectives of cancer among Deaf people, carers and service providers in relation to Deaf sign language users?

By mapping existing literature, such as qualitative studies and firsthand accounts, the review aims to identify the volume and variety of research conducted regarding the potential barriers and effective coping strategies faced by Deaf people, carers and service providers, thereby identifying gaps in support and areas for future intervention.

**Data management** Studies from all database searches (including additional sources such as dissertations and grey literature database) will be exported into EndNote. EndNote will screen for duplicates via titles. Manual screening for duplicates will also be done. Throughout the data screening and selection procedure, a bespoke Microsoft Excel template will be used to record the following: number of articles retrieved, number of duplicates found, number of articles excluded,

reasons for exclusions, year of publication, characteristics, location, research design, methods, analytical approach, participants' characteristics, setting, and studies involving secondary data. For grey literature, descriptive data will be added. This will include reasons for inclusion, relevant content, year of publication/ release and location.

**Quality assessment / Risk of bias analysis** The studies (not including grey literature) will be assessed using the Crowe Critical Appraisal Tool (CCAT) (Crowe & Campbell, 2011). The CCAT has been validated for both qualitative and quantitative study designs (Crow, Sheppard & Campbell, 2011).

**Strategy of data synthesis** The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (Peters et al., 2020). Following the search, all identified citations will be collated and uploaded into EndNote and duplicates removed. Following this, the titles and abstracts will then be screened by two reviewers for assessment against the inclusion criteria for the review with a yes/no/maybe conclusion for each study. Conflicting conclusions between the two reviewers will be resolved either through discussion or through a third reviewer. The sources categorised as either yes or maybe will be retrieved in full and their citation details imported into EndNote. The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Again, any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, or with an additional reviewer. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review.

**Subgroup analysis** n/a.

**Sensitivity analysis** n/a.

**Language restriction** Publications in written in English, French, German, and British Sign Language, American Sign Language, Irish Sign Language, and International Sign will be included in this scoping review.

**Country(ies) involved** United Kingdom.

**Keywords** Deaf; Sign Language; Cancer; Carers; Service providers.

**Dissemination plans** The scoping review findings will be published in a peer reviewed academic

---

journal and in conference presentations in English and BSL.

### **Contributions of each author**

Author 1 - Molly Redpath-Healy - Molly Redpath-Healy developed the scoping review plan and will be involved in every stage of the review protocol. This means that Molly Redpath-Healy will execute the literature searches, study selection, data extraction, reporting the results and preparing the manuscript for publication.

Email: [molly.redpath-healy@manchester.ac.uk](mailto:molly.redpath-healy@manchester.ac.uk)

Author 2 - Katherine Rogers - Katherine Rogers reviewed the protocol and will be involved in both the first stage and second stage screen as either a second screener or mediator.

Email: [katherine.rogers@manchester.ac.uk](mailto:katherine.rogers@manchester.ac.uk)

Author 3 - Alys Young - Alys Young reviewed the protocol and will be involved in both the first stage and second stage screen as either a second screener or mediator.

Email: [alys.young@manchester.ac.uk](mailto:alys.young@manchester.ac.uk)