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Innovations to Support Symptomatic Cancer Diagnostic Pathways for People with a Learning Disability: A Scoping Review V.1

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Abstract

People with a learning disability experience profound health inequalities; reasons for this are multifactorial and intersectional. There is substantial evidence that people with a learning disability are also experiencing poor outcomes specifically related to cancer, figures from 2022 showed that cancer was the second most common cause of death and accounted for 15.7% of avoidable deaths. Research to date has focussed on interventions to improve access to cancer screening rather than symptomatic detection for people with a learning disability, however only 6% of cancers are detected via screening. This review aims to systematically scope innovations that could support symptomatic cancer diagnostic pathways for adults with a learning disability in primary, secondary care, and community settings, published since 2014. We will focus on research which reports innovations that aim to improve symptomatic cancer diagnosis, as well as learning from research where cancer is relevant but not the main focus.

This scoping review will follow a six-stage methodological framework proposed by Arksey and O'Malley:
(1) identifying the research question; (2) searching for relevant studies; (3) selecting studies; (4) charting the data; (5) collating, summarising and reporting the results; and (6) consulting with stakeholders to inform or validate study findings.

To the best of our knowledge this is the first study of its kind to provide an overview of published literature in this area. We will build an openly available database of the findings, which can be updated over time to serve as a useful source of information for researchers working in this field. A manuscript providing a narrative synthesis of the findings will be submitted for publication, with an accompanying accessible summary to disseminate our findings to researchers, clinicians, people with a learning disability and their families and carers.

Background / Study rationale

1 There are estimated to be between 107 - 200 million people living with a learning disability worldwide [1] [2], representing 1-3% of the global population [3]. However, this is likely to be a significant underestimation, with those undiagnosed often referred to as the 'hidden majority' [4]. The term 'learning disability' covers varying degrees of intellectual impairment and diverse support needs but is defined by a lifelong reduced intellectual ability and difficulty with everyday activities [5].

Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (2006) [6] recognises that persons with disabilities have the right to the enjoyment of the highest attainable standards of health without discrimination on the basis of disability. The convention also states that "parties must provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate," as well as "providing persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons."

However, people with a learning disability (PwLD) experience profound health inequalities [5] [7] [8] [9] [10] [11]; the patient-related reasons for this are multifactorial and intersectional, including severity of communication impairments, levels of regular contact with healthcare professionals, variation in caregiver support, and other social determinants of health [12, 13]. Healthcare systems also affect outcomes for PwLD, for reasons including lack of access, ableism and discrimination, negative staff attitudes, lack of awareness or poor understanding of LD needs, and diagnostic overshadowing (the misattribution of symptoms of one illness to an already diagnosed comorbidity, leading to compromised patient care/outcomes) [14-18].

In the UK, improving healthcare access and cancer outcomes for people with a learning disability are key goals of the NHS Long Term Plan [9], with ambitions to reach 75% uptake of annual health checks and 75% of cancers diagnosed at stages I-II, and similar policies in the devolved nations [19, 20]. People with a learning disability are a priority group in NHS England's recent Core20PLUS5 approach to tackling healthcare inequalities [21]. The Health and Social Care Act 2022 [22] also introduced new Learning Disability Improvement Standards following recommendations from the Learning Disability Mortality Review Programme, a landmark commissioned review to improve the standard and quality of care [23] [24]. While integrated Care Systems (ICSs) are now responsible for undertaking reviews of health and social care received by people with a learning disability, who have died [25].

There is substantial evidence that people with a learning disability are also experiencing poor outcomes specifically related to cancer. The LeDeR programme, funded by NHS England and NHS Improvement, reports annually on deaths of people with a learning disability in England. Figures from 2022 showed that cancer was the second most common cause of death and accounted for 15.7% of avoidable deaths [26]. Ethnographic and survey studies have shown that access to healthcare is often dependent on support from social care and advocates, which can lead to delays [27] [28]. Carers have been shown to have some knowledge regarding cancer but are not clear on how to support symptomatic detection of cancer for people with a learning disability [29, 30].

The World Health Organisation recognises interventions as ‘an act performed for, with, or on behalf of a person to improve, maintain, promote or modify health, functioning or health conditions’ [31]. Among people with a learning disability, research to date has focussed on interventions to improve access to cancer screening rather than symptomatic detection, for example, screening liaison nurses, and accessible visits for patients to familiarise themselves with surroundings [32] [33] [34]. Still, only 6% of cancers are detected through screening in the UK [20]. Reviews exploring barriers and facilitators to cancer screening [35] and educational interventions to improve awareness and understanding of cancer screening have been published [36], as well as a review exploring cancer risk-factor and symptom awareness among people with a learning disability, carers and HCP’s [27].

Over three quarters of cancers are diagnosed symptomatically following consultation in primary care [37]. People with a learning disability experience inequalities in primary care due to lack of healthcare provider training and knowledge/awareness, poor communication, and unrecognised morbidity [28]. Opposing barriers and facilitators were identified in a review focussed on accessing and utilising primary care for people with a learning disability, including, training and awareness; fear and embarrassment, involvement in healthcare and decision making and time [38]. Further evidence has supported the misalignment between primary care and needs, including challenges with prioritising people with a learning disability because coding systems are inadequate, and lack of personalisation to support navigating the system (including online booking systems) [39] [40].

However, there has been limited research beyond primary health care, for example, in secondary care or community settings. A systematic review of the global barriers to equitable healthcare access for people with disabilities synthesised the interventions in place to address these barriers and promote inclusion [41]. Their methods involved searching two databases and selecting a random 20% sample of eligible articles to review. Of the 182 papers included, there were 5 papers focused on learning disability and 9 with mixed disability populations. For those focused-on interventions, just 7% of the included papers focused on learning disability. Examples of interventions

included training therapists to work with learning disability in improving access to psychological therapies [42], as well as self-advocacy training for people with a learning disability [43]. However, this was not an exhaustive appraisal of innovations that could support adults with a learning disability in equitable healthcare access and there has been no research to date focused on innovations that may expedite symptomatic cancer diagnostic pathways.

Aims and Objectives

2 This review aims to systematically scope innovations that could support symptomatic cancer diagnostic pathways for adults with a learning disability in primary, secondary care, and community
settings, published since 2014. We will focus on research which reports innovations that aim to improve symptomatic cancer diagnosis, as well as learning from research where cancer is relevant but not the main focus (e.g. innovations to support access to primary care or virtual health care for people with a learning disability). Further, our PPI group highlighted the need to include research about support or caring roles in help-seeking, and to cover both primary and secondary care, where innovations have potential relevance to symptomatic cancer diagnosis.

Protocol Design

3 With the expansion of evidence-based healthcare as a field, and the accompanying increase in availability of primary research, novel methods of conducting reviews have occurred. The scoping review, sometimes referred to as a mapping or scoping study, is one such example of knowledge synthesis. According to the seminal framework developed by Arksey and O'Malley, it is generally accepted that a scoping review addresses a broader topic than that of a systematic review, making it particularly suitable for advancing understanding in a relatively new or under-researched area. The aim of a scoping review is to rapidly map key concepts and detail the main sources and types of evidence available for a subject. While research question/s, may be less defined, the review should be no less systematic in its approach to searching, extracting, and reporting data, with the process transparent, well-documented and replicable, thus increasing the reliability and validity of the findings. As scoping reviews anticipate wide-ranging and diverse publication types on a given area, quality and risk of bias are not typically assessed. Rather, the available literature is compiled, indexed, and narratively synthesised to map the breadth of knowledge in the area.

Stage 1: Identifying the Research Question

4 The review question was developed and categorised using the Population–Concept-Context (PCC) mnemonic recommended by the Joanna Briggs Institute (JBI): What innovations have been developed that could support symptomatic cancer diagnostic

pathways for adults with a learning disability in primary, secondary care, and community settings? The 'population' in this question is adults with a learning disability. The 'concept' is innovations to support the symptomatic cancer diagnostic pathway, and the 'context' is broad in terms of primary or secondary care, or community, including internationally published studies since 2014.

5 Conducting a scoping review is often an iterative process, requiring reflexivity as familiarity with the literature progresses. As such, the research question, and sub-questions, below, are open to revisions and may be revisited and revised throughout the review:

5.1 What innovations have been developed with the aim to improve symptomatic cancer diagnostic pathways for adults with a learning disability?

5.2 What innovations have been developed with the aim to improve access to healthcare for adults with a learning disability, that may also improve symptomatic cancer diagnostic pathways?

5.3 Where are innovations based (country/location)?

5.4 Which cancer types do innovations support?

5.5 What settings are innovations delivered in (primary care, secondary care, or the community)?

5.6 Are the innovations focused on a particular subgroup of people with a learning disability e.g. mild/moderate/severe and profound disability?

5.7 What theory or frameworks underpin the innovations?

5.8 Have people with a learning disability been involved in the design of the innovations?

5.9 What stage of development is reported: development/implementation/evaluation?

5.10 What outcomes are proposed/employed to determine efficacy of the innovations?

Stage 2: Identifying Relevant Studies

6 Databases: Scientific databases will be searched for peer-reviewed literature. The databases chosen for this review are Medline, CINAHL, PsycINFO, and Embase. Through Medline we will access peer-reviewed publications in the field of medicine and life sciences. Similarly, Embase is a comprehensive biomedical database, with many records available across both, however Embase contains over 7,000,000 records which cannot be accessed via Medline. PsycINFO is the largest index of psychological science, through which we will access more than 5,000,000 interdisciplinary bibliographic records across the spectrum of behavioural and social sciences. CINAHL indexes the top nursing and allied health literature available, including nursing journals and publications from the National League for Nursing and the American Nurses Association.

7 As this is an under-researched area, the search strategy will be developed to include broad terms and Medical Subject Headings (MeSH) to capture all literature. The keywords that will be used for building the search strategy are outlined in Table 1 below.

Stage 3: Study Selection

8 Comprehensive searches of the 4 databases selected will be carried out by the lead researcher. Endnote reference management software will be used to extract search results. Initial papers will be screened, and duplicates removed. Web searching, forwards and backwards searching of reference lists will be carried out, with any additional publications added to the database. Results will be merged and exported to Rayyan software for collation, selection, and extraction. One researcher will screen all titles and abstracts according to the inclusion/exclusion criteria. Two other researchers will screen a proportion of titles and abstracts (20%) and be blinded to decisions of other researchers. Inter-rater agreement scores will be calculated and papers deemed not relevant removed. Full text for remaining papers will be sought and their contents matched to inclusion criteria, with final decisions for inclusion/exclusion made. Two reviewers will agree final selection, with a third reviewer arbitrating any discrepancies. The selection process will be documented using a PRISMA flow chart.

9 Inclusion criteria:

9.1 Empirical (qualitative, quantitative, mixed methods) article

9.2 Peer-reviewed article

9.3 Published on or after 1st January 2014

9.4 Published in English

9.5 Report the development, delivery or evaluation of an innovation to improve access to healthcare for adults with learning disabilities

9.6 Report innovations with potential relevance to cancer investigations (though need not be part of the cancer pathway) up to the point of diagnosis (not exclusively focused on aspects of the healthcare pathway beyond diagnosis e.g., treatment or end of life care)

9.7 NOTE: We define innovation to include novel products, interventions, services, processes, or methodologies.

9.8 EXAMPLES OF INNOVATIONS:

9.9 Systems level innovations that support recognising and reporting of learning disability related needs

9.10 Systems level innovations that support access to healthcare for people with a learning disability

9.11 Innovations to empower individuals with a learning disability at an individual or community level to access healthcare

9.12 Innovations that adapt healthcare consultations to meet learning disability related needs

10 Exclusion criteria:

10.1 Not learning disability focused

10.2 Not adult

10.3 Do not report empirical research (e.g. editorials or reviews)

10.4 Published in languages other than English, due to limited resources for translation

10.5 Published before 2014

10.6 Report innovations not specifically developed to support equitable access to healthcare for people with a learning disability

10.7 Report innovations criteria designed specifically for health conditions other than cancer (e.g., dementia, pregnancy)

10.8 Report innovations exclusively focused on aspects of the healthcare pathway beyond diagnosis e.g., treatment or end of life care

Stage 4: Charting the Data

11 Data relating to the research questions will be extracted from all articles included in the scoping review, including quantitative data regarding effectiveness of interventions and participant quotes regarding acceptability (See Appendix 1 for full details). The data extracted will be summarised in a table developed and piloted by the research team. An example of the data extraction form is provided in Appendix 1. The team will follow an iterative process whereby the data charting will be reviewed, refined, and continually updated. Disagreements will be resolved by discussion with the research team. Prisma flow chart will be updated and extended throughout the process to document any further exclusions. Quality appraisal of the included studies will be completed using the Mixed Method Appraisal Tool (MMAT).

Stage 5: Synthesising and Reporting Results

12 The aim of the scoping review is to map and aggregate available evidence reporting the development, delivery, or evaluation of interventions to support symptomatic cancer diagnostic pathways for adults with a learning disability, as opposed to critical analysis of the quality of individual studies. Data will be presented graphically in tabular form. Data extracted will be accompanied by a narrative report, relating the included articles to the research aims and questions.

Stage 6: Consultation and Patient and Public Involvement

13 A diverse patient and public involvement and engagement (PPIE) group has been established as part of a larger multistage research programme. Our partners have co-designed the PPIE strategy to ensure there is a robust and transparent process in place to capture and incorporate patient and public involvement throughout the research. For this scoping review, PPIE representatives (people with a learning disability and/or their representatives) will share their concerns and priorities regarding primary/secondary healthcare access, early diagnosis, and experience of cancer care. Their involvement will inform and shape each stage of this review, which will be reported using the GRIPP2 checklist. PPIE group members will be offered a variety of opportunities to suit their needs, this could include in-person engagement or providing input via email and/or virtual meetings.

Ethics and dissemination

14 Ethical approval is not required. Findings from this scoping review will inform subsequent work
packages of an NIHR funded project focused on understanding and addressing inequalities in cancer diagnostic outcomes for people with a learning disability. The review has
been registered on Protocols.io dx.doi.org/10.17504/protocols.io.6qpvrqjqzlmk/v1. To the best of our knowledge this is the first study of its kind to provide an overview of published literature in this area. We will build an openly available database of the findings, which can be updated over time to serve as a useful source of information for researchers working in this field. A manuscript providing a narrative synthesis of the findings will be submitted for publication, with an accompanying accessible summary to disseminate our findings to researchers, clinicians, people with a learning disability and their families and carers. By mapping the trends in publications over the period 2014-2025, areas with the highest/lowest volumes of publications will be identified. It is the hope that this database and the accompanying scoping
review can be used as a multidisciplinary resource where knowledge is indexed, evidenced, and synthesised, while priorities for research in this area are clearly established.

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