

STUDY PROTOCOL

# **Exploring how health inequalities are conceptualised** REVISED and measured in patient experience surveys in acute care: a protocol for a scoping review

[version 2; peer review: 1 approved, 2 approved with reservations]

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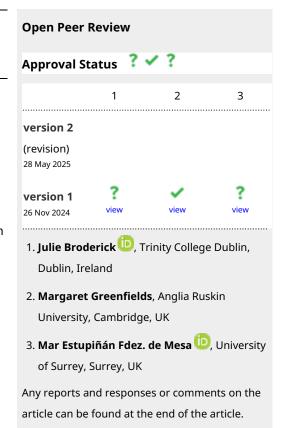
## **Abstract**

#### Introduction

Measuring patient experience has become standard practice in many countries. However, despite the widespread awareness of the impact of health inequalities on various aspects of health, including patient experience, a comprehensive examination of whether and how health inequalities are measured in patient experience surveys has yet to be completed. The ways in which these surveys conceptualise health inequalities may have important implications for how information about inequalities in patient experience is reported and used to allocate resources and plan quality improvement in health services.

## Objective

The objective of this scoping review is to map measured and overlooked health inequalities in patient experience surveys in acute care and explore what factors potentially explain current conceptualisations and measurement practices of these health inequalities. Inclusion criteria: Papers and survey programmes that contain survey materials relating to adult patient experience



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measurement in any acute care context will be included. No limits will be placed the personal characteristics of people who completes the survey.

#### **Inclusion criteria**

Papers and survey programmes that contain survey materials relating to adult patient experience measurement in any acute care context will be included. No limits will be placed the personal characteristics of people who completes the survey.

#### Methods

A search strategy was developed with an information specialist. The database search will be limited to after September 2021. Reviews, opinion pieces, letters, editorials, conference proceedings and other such sources will be excluded as a publication source. Grey literature searches will be completed, and relevant experts will also be contacted to identify any patient experience surveys not captured through database or grey literature searches. Non-English papers will be included only if resources allow. Two independent reviewers will complete title and abstract, and full-text screening. Additional reviewers will resolve any conflicts. A data extraction form developed by the review team is being used. The extracted data will be analysed using Critical Discourse Analysis, a qualitative method used to examine how power, dominance and inequality are enacted in text.

### **Keywords**

health disparity, health inequity, patient-centred care, qualitative research

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## **REVISED** Amendments from Version 1

In response to peer reviewer feedback, a number of changes have been made to the original manuscript. Minor changes were made to the wording of the abstract and introduction. Additional information was included in the introduction describing what patient experience surveys are and how they are distributed. Objective two and research question two were clarified further. Eligibility criteria were amended to only include primary studies, including secondary data analyses, and the language texts are written in were limited to English as mitigation steps where the volume of literature becomes unmanageable. The approach to the grey literature search was clarified further. Clarification was provided on the patient and public involvement contributors' prior experience with health inequalities. Further details were included on the authors' approach to reflexivity and positionality.

Any further responses from the reviewers can be found at the end of the article

### Introduction

#### Rationale

Despite the increase in research examining the impact of health inequalities on patient experience (Bone et al., 2014; Körner & Sizmur, 2013; Nuño-Solínis et al., 2021), there is still no consensus on how best to conceptualize and measure these inequalities in patient experience surveys. Patient experience has evolved as a concept over time (Wolf et al., 2014; Wolf et al., 2021). Over the past two centuries, it has been shaped by various innovations in medicine, patient advocacy and business management, eventually becoming a cornerstone of healthcare quality worldwide (Adams et al., 2024). Key evolutionary stages included the transition from the biomedical model of care, which placed priority on curing and managing disease, to a patient-centred model of care, which recognised the importance of the patient's experience of care in the healthcare system. Partnerships formed between medical professionals and patients to incorporate the patient voice into the decision-making process, summarised succinctly by the widely used slogan in patient advocacy circles, "nothing about me, without me" (Delbanco et al., 2001).

System changes in global politics then began to influence patient care, notably through the adoption of the New Public Management principles during the 1980s (Adams et al., 2024). These principles advocated for greater dependence on market forces to run public services, requiring a greater need for evaluation processes to differentiate between the quality of services provided by different healthcare facilities (Simonet, 2015). The experience economy emerged from these principles in the late 20th century, proposing that businesses who provide a better healthcare experience could charge more for this service in a competitive market (Pine & Gilmore, 1998). Despite the adoption of business management principles in healthcare throughout this period, there remained a focus on recognising the needs of the patients and how their experience can be improved through survey measures. Institutes such as Picker became experts in novel methodologies for measuring

patient experience, developing the first patient experience survey for the National Health Service in the United Kingdom (UK) in the early 21st century (Jenkinson et al., 2002). Since then, patient experience measurement has become standard practice in many countries across the world (Adams et al., 2024), seeking to further understand the various attributes of patient experience to support quality improvement initiatives in patient care. Patient experience programmes have been created by nation states across the world to integrate the patient experience into quality improvement initiatives in their healthcare systems (Canadian Institute for Health Information, 2024; Centers for Medicare & Medicaid Services, 2022; Patient Experience Library, 2022). Patient experience continues to evolve as a concept, with a recent concept analysis of patient experience identifying 20 attributes which define patient experience (Avlijas et al., 2023). Examples of these attributes include respect for patients, comfort and pain, professionalism and trust, and the hospital environment. The analysis drew on existing patient experience measurement tools and other literature that discussed patient experience more generally to define this concept. They define patient experience as, "...the combination of external and internal hospital processes, patient-centered attributes, patient-staff and staff-staff interactions during all episodes of care" (Avlijas et al., 2023, p. 20). Importantly, it differs from "patient satisfaction", in that it is concerned with what happened to a patient during their time in a health facility and how it happened, rather than the patient's personal expectations for the care provided to them (Bull, 2021). Dimensions of patient experience are generally measured via questionnaire surveys, sent to patients following their experiences of care (Ahmed et al., 2014). This data is then sent to the survey distributors where it is analysed and reported for use by various stakeholders, such as quality improvement teams in healthcare services. Various aspects of this process, such as the survey questions, how the survey is administered, the frequency with which data is collected, and how the data is analysed and reported, can differ across survey programmes with different rationales for such approaches provided.

Terms such as health inequality, health inequity and health disparity are concepts commonly used interchangeably in the literature with respect to how health outcomes differ according to how people or communities are positioned in society. Different geographical regions use these terms differently, which can cause confusion (McCartney et al., 2019). For example, in Europe, health inequality is used more commonly than health inequity to describe both terms. Arcaya and colleagues (2015) differentiate health inequality from health inequity in terms of social justice, where health inequity acknowledges the moral dimension of an inequality and the need to act on it - where inequality does not. They define health inequality as "any measurable aspect of health that varies across individuals or according to socially relevant groupings..." while health inequity or health disparity are defined as, "...a specific type of health inequality that denotes an unjust difference in health" (Arcaya et al., 2015, pp. 1-2). This "measurable aspect of health" can also apply to patient experience.

Examples of the effects of health inequalities and health inequities on patient experience have been explored across multiple contexts. A study examining the association between income disparities and patient-reported healthcare experience reported that, in a sample of 68,447 individuals in the USA who had a healthcare provider, lower income was repeatedly associated with poorer healthcare experiences compared to higher income (Okunrintemi et al., 2019). Results from a national survey in England reported that sexual minorities reported significantly worse patient experiences on four aspects of primary care (trust and confidence in doctor, doctor communication, nurse communication, and overall satisfaction) than heterosexual patients (Elliott et al., 2015). In a systematic review of 18 studies (n = 9,708 patients) examining racial, ethnic and socioeconomic differences in patient experience of clinician empathy, empathy scores were numerically lower for non-white patients compared to white patients (Roberts et al., 2021). Although none of these results from this review were statistically significant, the authors suggest that the empathy gap for low socioeconomic and non-white individuals may be widening over time, with further research required to test such disparities. When examining richer, qualitative reports of health inequalities in patient experience, a participatory study exploring discrimination and abuse in public healthcare towards indigenous people living in rural Guatemala provided evidence of numerous ways in which minority groups can be mistreated in healthcare (Cerón et al., 2016). Examples included the denial of access to care due to the systems' inability to communicate with patients in their own language, being yelled at during consultations, and patients being lied to and poorly informed about the procedures being done to them. The authors conclude by emphasising a need to further explore the structural determinants of such discrimination and abuse towards indigenous peoples.

Health inequalities are commonly measured using equity stratifiers, referring to dimensions of equality which represent perceived inequality in healthcare provision (Carroll et al., 2021). They are generally categorical in form, such as demographic indicators associated with social, cultural and economic capital, to enable the measurement of structural inequalities by analysing aggregate data across different groups of people (Carroll et al., 2021). The PROGRESS-PLUS acronym (place of residence, race, occupation, gender, religion, education, socioeconomic status and social capital; O'Neill et al., 2014) represents common sociodemographic indicators associated with health inequalities. The PLUS suffix describes additional indicators related to age, disability, sexual orientation, relationship factors and time-dependent stratifiers that may describe other vulnerable and socially excluded groups. In contrast to research on inequalities in health outcomes, the measurement of indicators associated with inequalities in patient experience has been relatively limited to date. Equity stratifiers enable analysis of potential differences between groups in relation to a particular topic, such as patient experience. For example, if data is collected about a patient's gender and ethnicity, along with their self-reported experience of hospital care, comparisons can be made between the experiences of people of different genders and ethnicities, generating more specific insights into potential inequalities experienced by these groups in

hospital. With the exception of age as a stratifier, there has only been a number of, sometimes ambiguous, results available on the relationship between other equity stratifiers and patient experience (Friedel *et al.*, 2023). Carroll and colleagues (2021) also noted the limited use of many PROGRESS-PLUS equity stratifiers across different health contexts, with different definitions frequently used. They call for agreed upon outcome measures of equity to allow for policy changes and interventions to be compared within and between populations.

Considering the lack of attention given to understanding health inequalities in patient experience measurement practices to date, this review aims to examine how health inequalities have been conceptualised and measured in patient experience surveys in an acute care setting and establish what factors may explain current conceptualisations and measurement practices of health inequalities in patient experience surveys. As the findings from patient experience surveys have important implications for quality improvement in patient care, mapping how these data are generated and discussing the implications of conceptualising patient experience survey items in different ways will help determine what more can be done to respond to health inequalities in patient experience. Acute care settings will be the focus of this review for two principal reasons. Firstly, the patient experience literature is large, with 153 patient experience measurement instruments identified for acute care settings in a recent concept analysis of patient experience (Avlijas et al., 2023). As we wish to examine in detail how health inequalities are conceptualised and measured in patient experience surveys in a limited timeframe, focusing only on acute care will enable a more thorough examination of the texts related to this process (e.g., guidance documents and technical reports of various surveys). Secondly, this review is part of a larger research project working with marginalised communities to make the National Inpatient Experience Survey in Ireland more accessible for, and increase participation in this survey among, marginalised groups. The National Inpatient Experience Survey collects data from patients who spend 24 hours or more receiving acute care in a public hospital in Ireland and are discharged during the survey period. The results of this review will directly inform later work completed on this project.

A scoping review methodology was chosen, as we aimed to identify and map existing evidence in the field and to clarify key concepts/definitions in the literature (Munn *et al.*, 2018). A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews and JBI Evidence Synthesis was conducted and no current or underway systematic reviews or scoping reviews on the topic were identified.

### Objectives

This scoping review proposes two objectives to examine how health inequalities have been conceptualised and measured in patient experience surveys in acute care settings internationally:

 Map which health inequalities have been conceptualised and measured, and which have been omitted or overlooked in patient experience surveys. Explore what factors potentially explain current conceptualisations and measurement practices of health inequalities in patient experience surveys and their implications

### Review questions

In correspondence with the review objectives, the following research questions will be answered by the scoping review:

- Which health inequalities have been conceptualised and measured in the patient experience literature, and which have been omitted or overlooked in patient experience surveys?
- What factors may explain current conceptualisations and measurement practices of health inequalities in patient experience surveys and their implications?

#### Methods

The proposed scoping review will be conducted in accordance with the updated Joanna Briggs Institute (JBI) methodology for scoping reviews (Peters et al., 2020). The review protocol is reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses Protocols (PRISMA-P) Checklist (Moher et al., 2015; Shamseer et al., 2015) with updates on best practice for reporting scoping review protocols also included (see the completed PRISMA-P checklist in the accompanying data repository available via the link in the "reporting guidelines" section below; Peters et al., 2022). The review is pre-registered on the Open Science Framework repository using the generalised registration form for systematic reviews (van den Akker et al., 2023).

## Eligibility criteria

#### Report characteristics

Primary studies, including secondary data analyses, will be included. Reviews, opinion pieces, letters, editorials, conference proceedings and other such sources will be excluded as a publication source. Only studies published in English will be included. However, where materials are identified on national survey programme websites that are not available in English, authors of these materials will be asked if it is feasible for them to translate their survey materials. Literature published after September 2021 will be included, with literature prior to this date accounted for through studies included as part of a previously published concept analysis of patient experience (Avlijas et al., 2023). This concept analysis completed a broad search of the patient experience literature up to September 2021, identifying materials we are interested in analysing as part of the current scoping review. Given the time-sensitive nature of this review, a targeted grey literature search will be conducted by consulting with experts on the research team on where relevant materials outside of the peer reviewed literature could be identified. Experts include researchers at Picker Europe and the Health Information and Quality Authority (HIQA) National Care Experience Programme which manages the patient experiences national surveys in Ireland.

#### **Population**

People who receive adult care in an acute health facility, or advocates for those people. By advocates we mean, a person who can offer advice, support or information to a health service user, or act on the behalf of the service user or their family, when dealing with a healthcare service. They can also represent the views of the service user when seeking information or making complaints where necessary (HSE, 2024a). Literature reporting experience surveys conducted in a healthcare setting that do not measure patient experience, such as healthcare staff experience only or measures of patient satisfaction only, will be excluded.

#### Concept

Materials that measure, or support the measurement of, patient experience will be examined in this review. Surveys and associated guidance and reporting documents will be examined. Attention will be given to identifying any adaptions made to preexisting surveys. Surveys routinely embedded in healthcare systems will be included. By routinely embedded, we mean surveys that are implemented and evaluated continuously over time (e.g., monthly, bi-annually, annually) as part of a healthcare system's evaluation and quality improvement processes. Surveys not embedded in healthcare systems will be excluded. These may include once-off surveys developed as part of small-scale studies that are not implemented in practice over time. These eligibility criteria will be applied due to the scope of the larger project this review is part of, which focuses on updating a national survey embedded in the Irish healthcare system. Literature that does not detail sufficient information about the patient experience survey will be excluded. This will be determined on a case-by-case basis with justifications for exclusion provided. Efforts will be made to retrieve survey materials from authors where there is insufficient published data.

In terms of examining various dimensions of health inequalities, as discussed in the introduction, we consider it important to be able to distinguish between health inequality and health inequity when examining how different groups conceptualise these terms in their surveys (i.e., whether justice or fairness are considered in their measurement of different dimensions of inequality). As such, both terms will be used in this review to distinguish between conceptualisations that only measure variability in health across groupings (health inequality) and those that also consider whether these variabilities are unfair or unjust (health inequity or health disparity).

#### Context

Any acute healthcare facility where patient experience is measured will be explored. By acute care we mean acute services that include all

"... promotive, preventive, curative, rehabilitative or palliative actions, whether oriented towards individuals or populations, whose primary purpose is to improve health and whose effectiveness largely depends on time-sensitive and, frequently, rapid intervention" (Hirshon *et al.*, 2013 p. 386).

Acute care includes a wide range of functions within the healthcare system including, "...emergency medicine, trauma care, pre-hospital emergency care, acute care surgery, critical care, urgent care and short-term inpatient stabilization" (Hirshon et al., 2013 p. 386). Literature reporting experience surveys that are administered outside of a patient or acute care context will be excluded. If the volume of included studies becomes unfeasible to synthesise, the context will be narrowed to account for the time constraints and resources of the review team. Inpatient experience surveys will be prioritised in this instance due to the objectives of the wider project to which this scoping review pertains. Inpatient care refers to care, "...requiring overnight stay in hospital as well as care provided through day case services" (HSE, 2024b). The wider project is discussed further in the "consultation with relevant stakeholders" section below.

## Information sources

Specific sources will include:

- Subject-specific online databases including MEDLINE via Ovid (Medical Literature Analysis and Retrieval System), CINAHL via EBSCOhost (Complete Cumulative Index to Nursing and Allied Health Literature), EMBASE via Elsevier and Psychological Information via EBSCOhost (PsycInfo).
- Forward and backward citation searches of included studies using the Citation Chaser tool (Haddaway, 2021).
   This will include Avlijas and colleagues' (2023) concept analysis of patient experience to capture relevant citations prior to the completion of this search.
- The "similar articles" function in PubMed will be used for included studies. This function uses its own algorithm that identifies articles that are similar to the original article.
- Expert stakeholder consultation. A contact list of international experts will be created by two authors (CF and LS) who work for the Health Information and Quality Authority (HIQA) an independent body created to ensure high-quality and safe care for individuals utilizing health and social care services in Ireland. CF and LS will be able to provide a comprehensive list of international experts through their networks at HIQA. Members of the project steering committee with relevant expertise (e.g., researchers at Picker Europe and HIQA) will also help identify grey literature on specialist websites.

#### Search strategy

Considerations were given to updating the search completed for the concept analysis of patient experience mentioned above (Avlijas *et al.*, 2023). However, as our review is only interested in a subset of the literature identified through this concept analysis, it was decided that developing a more specific search tailored to the review topic would be a more efficient use of time and resources.

Published and unpublished literature will be identified through the search strategy. A three-step approach was used to develop the search strategy for this review. First, an initial limited search of CINAHL Complete and PsycInfo was undertaken to identify articles on the topic. These databases were used in a previous review with a similar topic to this review (Beattie et al., 2015). Second, the text words and index terms from titles and abstracts of relevant articles identified through this initial search were used to develop a full search strategy for this review. Search terms related to patient experience were combined with terms related to surveys. Finally, the full search strategy was developed for CINAHL (see Table 1 in the "tables" section below). It will be adapted for each database where necessary. A more specific search was created as we are focused only on how health inequalities are conceptualised in patient experience surveys in acute care settings, rather than the concept of patient experience more generally. Search terms related to health inequality were not included in the search strategy to avoid overlooking relevant literature that does not explicitly refer to health inequality, or related terms, intext. An information specialist at HIQA with expertise in search strategy development in a health context was consulted to support the selection of the databases and search terms. The Peer Review of Electronic Search Strategies (PRESS) Evidence-Based Checklist for peer review was used to assess the search strategy (McGowan et al., 2016; see the completed PRESS checklist in the accompanying data repository available via the link in data availability section below). DH conducted the search in collaboration with the information specialist.

Table 1. Search strategy prepared for CINAHL in EBSCOhost.

#	Query		
S11	S4 AND S7 AND S10		
Concept 3: acute care			
S10	S8 OR S9		
S9	TI (Hospital* OR "Ambulatory care" OR "Secondary care" OR "Acute care" OR inpatient*) OR AB (Hospital* OR "Ambulatory care" OR "Secondary care" OR "Acute care" OR inpatient*)		
S8	(MH "Health Facilities+")		
Concept 2: Surveys or questionnaires			
S7	S5 OR S6		
S6	AB (patient* N3 (survey* OR questionnaire* OR measure* OR scale* OR assess* OR tool OR tools Ol instrument*)) OR TI (patient* N3 (survey* OR questionnaire* OR measure* OR scale* OR assess* OR tool OR tools Ol instrument*))		
S5	(MH "Surveys+") OR (MH "Questionnaires+")		
Concept 1: Patient experience			
S4	S1 OR S2 OR S3		
S3	TI patient* N1 experience* OR AB patient* N1 experience*		
S2	(MM "Patient Satisfaction")		
S1	(MH "Patient Centered Care")		

## Study records

#### Data management

All citations identified will be imported into the Zotero reference management software (Zotero, 2024).

## Study/Source of evidence selection

Citations will be imported to the proprietary screening software platform, Covidence (Covidence systematic review software, n.d.), from Zotero for de-duplication and screening. An alternative open-source screening platform can be found in the "software availability" section below. The inclusion and exclusion criteria will be applied, and pilot tested with a random sample of papers by two reviewers, with the criteria clarified if needed. Any changes will be reported in the final review paper. Two reviewers will independently screen the titles and abstracts against the criteria. Disagreements will be discussed between the authors and, if necessary, with additional reviewers until consensus is achieved. Potentially relevant sources will be retrieved in full, and their citation details imported into Covidence. Full text screening will take place for these citations by two independent reviewers. Disagreements will be resolved through discussion or by additional reviewers. Reasons for inclusion or exclusion at the full-text screening stage will be reported in the scoping review and presented in a PRISMA flow diagram (Page et al., 2021).

#### Data extraction

Data will be extracted from papers included in the scoping review by two independent reviewers using a data extraction tool developed by the reviewers in Covidence (see the data extraction protocol in the accompanying data repository available via the link in "data availability" section below). The tool was adapted from the data extraction template for scoping reviews published by JBI (Peters *et al.*, 2020). The data extraction tool will be piloted by two independent reviewers and amended where necessary prior to commencing data extraction. Any changes will be reported in the final review paper. Any disagreements will be discussed or resolved by additional reviewers. If required, authors of included papers will be contacted to request missing or supplementary data.

Specific attention will be given to how health inequalities are conceptualised and measured in included literature. Equity stratifiers will be used to support the organisation of survey items relevant to health inequalities. Any survey items measuring PROGRESS-PLUS equity stratifiers will be extracted and synthesised to explore similarities and differences in groups included, and survey item wording used. Identified dimensions of inequality in patient experience that cannot be categorised under any of the PROGRESS-PLUS equity stratifiers (e.g., a question about the experience of discrimination in healthcare setting) will also be extracted and synthesised.

## Data items

The data items that will be extracted from each study include: population, context (e.g., study setting), author/s, date, title, source type (journal, book, website, etc.), volume, issue, pages, country of publication, aims/objectives, number of

participants, study design, PROGRESS-PLUS equity stratifiers included in surveys or relevant survey materials (i.e., place of residence, race or ethnicity, occupation, gender or sex, religion, education, socioeconomic status, social capital, age, disability, sexual orientation, relationship factors, time-dependent stratifiers), data related to approaches to enhance the participation of minority or marginalised groups in patient experience surveys, other items included in survey, any rationale provided for conceptualisation and measurement of included survey items, and number of items in the survey.

## Data analysis and presentation

Extracted data will be presented in tables in the final report. Dimensions of inequality (e.g., PROGRESS-PLUS equity stratifiers) will be charted to highlight where these dimensions are included and excluded across included literature.

A critical discourse analysis (CDA) will then be conducted on the extracted data (Fairclough, 2023; Mullet, 2018) to examine how "...social power abuse, dominance, and inequality are enacted, reproduced, and resisted by text and talk in the social and political context" (Tannen et al., 2015, p. 352). Mullet's seven steps to CDA will be followed (see Table 2 in the "tables" section below). As the first objective of this review is to examine how health inequalities are conceptualised and measured in patient experience surveys, CDA will enable a thorough analysis of how certain conceptualisations of the different dimensions of health inequalities may limit a survey's, and by extension a patient's, ability to adequately capture experiences of inequality in a healthcare setting. As CDA aims to provide an explanation for how and why such inequalities may persist, it further responds to this review's second objective which aims to establish the potential factors that explain current conceptualisations and measurement practices of health inequalities in patient experience surveys identified during the analysis.

## Consultation with relevant stakeholders

JBI's guidance for knowledge user engagement in scoping reviews will be followed for this review (Pollock et al., 2022). This review is part of the first work package of a research project which aims to facilitate collaboration between people from marginalised communities and relevant stakeholders within the Irish health service to co-design strategies for (1) enhancing the sensitivity of the National Inpatient Experience Survey in Ireland to health inequalities, and (2) increasing participation in the survey by members of marginalised communities. There are several reasons why this project is focused on health inequalities in relation to the National Inpatient Experience survey, including the underrepresentation of marginalised groups such as the Traveller community in previous survey samples (HIQA, 2021), the limited number of equity stratifiers included in the survey (only sex, age and ethnic group included in the 2024 survey; HIQA, 2024), and the survey's, the limited number of equity stratifiers included in the survey, and the survey's limited accessibility, with participants requiring a fixed address to receive the survey which is only available in digital or hardcopy formats. On this

Table 2. Mullet's seven steps to critical discourse analysis (Mullet, 2018).

1	Select the discourse	Select a discourse related to injustice or inequality in society.	Discourses used in the development and reporting of patient experience surveys.
2	Locate and prepare data sources	Select data sources (texts) and prepare the data for analysis.	Systematic search of databases and grey literature identified through networks involved in managing patient experience surveys.
3	Explore the background of each text	Examine the social and historical context and producers of the texts.	Examine the social and historical context through which patient experience measurement has evolved and the producers of these texts.
4	Code texts and identify overarching themes	Identify the major themes and subthemes using choice of qualitative coding methods.	Draw upon interpretive repertoires relevant to health inequalities in patient experience and subject positions afforded to people who receive care in a health facility to be inductively coded following data familiarisation.
5	Analyse the external relations in the texts (interdiscursivity)	Examine social relations that control the production of the text; in addition, examine the reciprocal relations (how the texts affect social practices and structures). How do social practices inform the arguments in the text? How does the text in turn influence social practices?	Examine who is involved in the decision-making process regarding patient experience survey development (e.g., are patients reported to be involved at any stage) and what theory and empirical evidence informs the development of survey items (e.g., Marxian vs Weberian conceptions of social class).
6	Analyse the internal relations in the texts	Examine the language for indications of the aims of the texts (what the texts set out to accomplish), representations (e.g., representations of social context, events, and actors), and the speaker's positionality.	Interrogate the structure or layout of the text, linguistic devices used to make a point (e.g., metaphor, rhetoric, etc.).
7	Interpret the data	Interpret the meanings of the major themes, external relations, and internal relations identified in stages 4, 5, and 6.	Generate themes that represent the interplay between the discourse analysed, dominant social practices and structures, and interpretative repertoires to explain how health inequalities are conceptualised and measured in patient experience surveys.

review to date, research partners at HIQA (CF and LS) have reached out to their international networks engaged in patient experience measurement in acute care to request materials relevant to this scoping review (i.e., patient experience surveys delivered in acute care and their supporting documentation). Once an initial analysis of the extracted data has been complete, the research team will meet to discuss preliminary findings from the review. The findings will then be discussed with patient and public involvement (PPI) representatives from the local community who are part of the project. The findings from this review will inform a policy brief for HIQA and the national health service in Ireland which will be co-produced with the PPI advisory group. There are eight PPI contributors, five of which have prior experience as PPI contributors on other, unrelated research projects. Some PPI contributors have described direct experiences of health inequalities, but

it was not essential for PPI contributors to have this experience to join the group. Progress updates will also be provided to the project steering group who consist of researchers, representatives affiliated with the government health department and national health service in Ireland, and other community organisation representatives.

### Reflexivity

Reflexivity requires researchers to critically reflect on their role in generating knowledge throughout the research process, interrogating their own worldviews and what effects they might have on their interpretations of empirical data (Braun & Clarke, 2013; Finlay, 2002). The lead author (DH) will keep a reflexive diary to record critical reflections during each step of the review process. Allowing space and time to engage in reflexivity in this way enables the researcher to

continuously reflect on their research practice, particularly where there may not be others available to have these discussions at times (Nadin & Cassell, 2006). The review team consists of researchers, clinicians and community organisers with a broad range of experiences and commitment to health justice and equity. During this review, the team will engage in regular meetings to discuss progress as well as their engagement with each stage of the review. Kohl and McCutcheon (2015) describe this as kitchen table reflexivity - where research partners, through everyday talk, share their reactions to and reflections on working through the various review stages while challenging each other's assumptions about topics under discussion. This process repositions reflexivity and positionality from performance, where research partner characteristics are simply listed off in the manuscript, to practice, where it is recognised that reflexive practice is one that is enacted throughout the research process through critical engagement with the topic and other collaborators (Sibbald et al., 2025).

### **Discussion**

While there is recognition of the impact of health inequalities on various aspects of health, including their effects on patient experience (Bone et al., 2014; Körner & Sizmur, 2013; Nuño-Solínis et al., 2021), there is fragmented evidence on how health inequalities are considered when designing patient experience surveys. Examining how health inequalities are conceptualised and measured in this context, and establishing what the potential consequences of these conceptualisations are, will provide stakeholders involved in designing, implementing and responding to patient experience surveys with further insights into how health inequalities may be currently overlooked in these surveys. It will also offer a basis for determining what can be done to make patient experience surveys more sensitive to health inequalities that may arise in patient settings.

## **Study status**

At the time of this protocol submission, the systematic scoping review search was being conducted in each of the chosen databases.

## Data availability statement

Underlying data

No data are associated with this article.

#### Extended data

Open Science Framework Repository – Exploring how health inequalities are conceptualised and measured in patient experience surveys in acute care: a protocol for a scoping review. https://doi.org/10.17605/OSF.IO/FSEHK

This OSF project contains the following extended data:

- PRESS Evidence-Based Checklist for peer review.docx
- Data\_Extraction\_Protocol.docx

- Extractor\_instructions.docx
- Seven\_steps\_to\_critical\_discourse\_analysis.docx
- Screener\_instructions.docx

Data are available under the terms of the Creative Commons Attribution 4.0 International Public License.

## Reporting guidelines

Open Science Framework Repository – Exploring how health inequalities are conceptualised and measured in patient experience surveys in acute care: a protocol for a scoping review.

## https://doi.org/10.17605/OSF.IO/FSEHK

This OSF project contains the following underlying data cited in text:

• PRISMA-P-checklist\_with\_scoping\_review\_updates.docx

Data are available under the terms of the Creative Commons Attribution 4.0 International Public License.

## Software availability

The Rayyan open-source screening platform can be used to replicate the screening procedures described in this protocol.

Platform DOI: 10.1186/s13643-016-0384-4

### **Author contributions**

Healy – conceptualisation, methodology, writing – review & editing, writing – original draft, project administration

Gilmore - writing - review & editing, funding acquisition

King – writing – review & editing, funding acquisition

McSharry – conceptualisation, methodology, writing – review & editing, funding acquisition

Meade – conceptualisation, methodology, writing – review & editing, funding acquisition

Ní Shé – writing – review & editing, funding acquisition

Sweeney – conceptualisation, methodology, writing – review & editing

Foley – conceptualisation, methodology, writing – review & editing, funding acquisition

Noone – conceptualisation, methodology, writing – review & editing, funding acquisition

## Acknowledgements

We wish to thank Marie Carrigan of the Health Information and Quality Authority in Ireland for her contribution to developing the database search strategy for this scoping review.

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## **Open Peer Review**

## **Current Peer Review Status:**







## Version 1

Reviewer Report 07 March 2025

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## 🤾 💮 Mar Estupiñán Fdez. de Mesa 🗓

- <sup>1</sup> University of Surrey, Surrey, UK
- <sup>2</sup> University of Surrey, Surrey, UK

This study protocol aims to map out how inequalities in patient experience surveys is conceptualised and measured and the implications of these dimensions relating to examining differences among groups and informing quality improvement plans. The protocol is sounded and will cover a knowledge gap. However, the protocol will benefit from some revisions and further refinements. Below, I included some recommendations for authors' consideration.

### Recommendations:

Research question 1: How will authors determine what has been omitted and overlooked in the papers included in the scoping review? These points imply a deliberate / accidental failure to include something or failure to notice or consider something on the part of the authors of those papers. The protocol authors' are recommended to reconsider research question 1.

Since authors are interested in inequalities/inequities, they are recommended to check and include the PRISMA-EQUITY checklist for equity-focused reviews: https://www.prisma-statement.org/equity

For clarity and ease of read, authors are recommended to display key eligibility criteria using bullet points/listing key criteria. They are also recommended to include a list of exclusion criteria.

Regarding study design, authors are recommended to reconsider expanding the exclusion criteria. The aim of the research is to assess how inequalities are conceptualised and measured in patient experience surveys. Therefore, not only conference proceeding but also opinion articles, commentaries, editorials and their like do not seem relevant and may introduce subjective views from the respective authors. To this end, authors might want to reflect on limiting the inclusion criteria to patient satisfaction surveys, guidance and technical reports documenting how inequality-focused surveys were developed, methodological articles describing process to develop

inequality indicators to measure patient experience using surveys. This is in line with the criteria authors included under 'concept: Materials that measure, or support the measurement of, patient experience will be examined in this review.'

Authors are recommended to reconsider the inclusion criteria regarding language. At present, it is unclear what process they will use to ensure a robust and transparent mechanism to translate relevant documents, how many authors will be involved to validated the process, etc. Authors might want to consider including only papers in the English language if this is the main language spoken by all research team members.

Unless the authors' inclusion/exclusion criteria and search string is the same as that of Avlijas et al's paper, authors should consider expanding the search beyond 2021. Using different criteria and search string and searching publications from 2021 onwards means that authors may missed relevant documents.

Table 1. Search strategy only shows terms relating to surveys or questionnaires. However, under characteristics and concept, authors suggested that they will include technical reports, guidance, and the like. How do authors plan to retrieve these documents in a way that is robust, systematic, and transparent?

Reflexivity - since authors highlight the importance of equity and diversity, it would be useful to include a description of the team's demographic and not only the professional background (e.g., is the team ethnically and gender diverse?

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Yes

Are the datasets clearly presented in a useable and accessible format?

Yes

Competing Interests: No competing interests were disclosed.

**Reviewer Expertise:** Scoping reviews, mixed methods, patient care experience surveys, public health, policy, health systems and health services, equity/equality - inequity/inequality.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 06 March 2025

## HRB Open Research

## https://doi.org/10.21956/hrbopenres.15364.r44776

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## **Margaret Greenfields**

- <sup>1</sup> Anglia Ruskin University, Cambridge, UK
- <sup>2</sup> Anglia Ruskin University, Cambridge, UK

I was very pleased to have the opportunity to review this extremely thorough and well-written submission outlining the protocol for a scoping review focused on how health inequalities are conceptualised and measured in patient experience surveys routinely administered to adult patients receiving care in acute settings. In preparing the protocol the authors have undertaken a preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews and JBI Evidence Synthesis and have not identified any systematic or scoping reviews on the topic in question. In the designing for the scoping review the authors propose incorporating a very wide range of materials referring to patient experience surveys, excluding only conference proceedings and materials published after 2021. Somewhat ambitiously they also propose that materials not published in English should be included if feasible. Given the volume of materials which such an approach might generate mitigation steps to be taken should the volume of materials become unmanageable are incorporated into the design. The overall protocol as presented aligns to the updated Joanna Briggs Institute (JBI) methodology and reporting will utilise the PRISMA-P checklist. Importantly, materials will be interrogated to identify dimensions of inequality (identified through the use of PROGRESS-PLUS equity stratifiers) and subjected to critical discourse analysis so as to highlight inclusions and omissions (as well as strengths and weakness in phrasing of questions) in patient satisfaction surveys. The authors propose that these methods will enable in-depth analysis of how conceptualisations of health inequalities may limit the ability of the person completing the survey to adequately capture experiences of inequality in delivery and receipt of health care services.

## **Detailed Comments Review**

## 1. Is the rationale for, and objectives of, the study clearly described?

The authors have provided an extremely detailed and plausible rationale for undertaking this scoping review, highlighting the varying ways in the terms 'health inequality' and 'health inequity' are utilised in different geographic regions, and reporting on a number of large-scale international studies which have identified how lower socio-economic status, membership of particular ethnic or indigenous groups, or being a sexual minority are suggestive of worse patient experiences on a number of aspects of primary care, in particular those associated with trust in clinicians and communication. Additionally, abundant examples from smaller scale qualitative studies with marginalised or minoritised communities and individuals exist, which report on experiences of discrimination in healthcare when compared to majority or mainstream populations, and emphasise the necessity of undertaking additional research to understand how and why such disparities in patient experience occur.

In identifying that measurement of inequalities in patient experience surveys in Ireland has been

limited, and that use of PROGRESS-PLUS equity stratifiers varies by context, the review team argue that mapping how such data gathering is conceptualised and generated offers considerable scope for reducing health inequalities. The objectives of the study are very clearly defined and clearly aligned to their larger, overarching project on accessibility and engagement with the National Inpatient Experience Survey in Ireland which seeks to gather more insights from marginalised or under-represented minority groups.

## 2. Is the study design appropriate for the research question?

This is a highly ambitious (and important) scoping study focused on two research questions.

- a) Which health inequalities have been conceptualised and measured in the patient experience literature and which have been omitted or overlooked?
- b) What are the potential consequences of conceptualising and measuring health inequalities in different ways?

Whilst Question A can clearly be met by utilising the research design as specified, Question B is likely to be significantly harder to answer. Whilst the design element of the study which includes wide-ranging stakeholder consultation, knowledge exchange with international partners and the development of an action plan to engage with marginalised populations is to be applauded, the question pertaining to the consequences of conceptualising and measuring health inequalities 'differently', feels as though it is very open-ended and potentially unanswerable as framed. Whilst such activities may enhance the quality and quantity of data gathered "consequences" as a concept reaches significantly further and may for example engage with issues of training for clinicians with longitudinal impact which will require long-term monitoring. As such I would suggest that this protocol could perhaps be strengthened slightly by rephrasing the second research question to engage with a less wide-ranging term which focuses more on quality of data gathered and longer-term implications for capturing and improving patient experience.

Overall this is an exceptionally well designed and innovative protocol, although I do have a few qualms about the potential breadth of the data to be included in the review, particularly pertaining to the feasibility of the inclusion on materials in languages other than English (or other languages spoken fluently/understand well by the research team). Although reference is made to the opportunity to invite researchers to offer translated materials I do feel that this is perhaps a 'big ask' of international colleagues and may not generate many responses.

I would note too – that I am sure that if appropriate such materials will emerge within the review process - and there may be potential to explore data gathered by (for example) the European Fundamental Rights Agency who in their large-scale studies make repeated reference to health experiences of Roma, LGBT+, refugee and asylum seeking populations and frequently incorporate materials pertaining to the populations' use of both in-patient (for example maternity care) and receipt of out-patient primary care services. Whilst such FRA studies may not fully align to the protocol parameters it might be worthwhile for the reviewers to explore these further and consider if such materials are appropriate to include within the review given the large-scale multicountry nature of FRA research, focused on populations of interest to the team.

Overall (with the caveat above re the feasibility of responding to RQ2 as phrased and potential of incorporating international materials to be analysed) the design is robust and transparent. I have

a high level of confidence that as described the search strategy, data extraction and analysis will ensure reliability. Data management processes outlined in the protocol are appropriate.

## 3. Are sufficient details of the methods provided to allow replication by others?

Yes largely, more detail could be provided with regard to the stakeholder consultation process and engagement and how this will support responding to Question 2, but more details are likely to emerge around the precise shape of these engagement and consultation activities as the project develops further.

## 4. Are the datasets clearly presented in a useable and accessible format?

Not included although tables illustrate the search strategy for materials and the phased of critical discourse analysis to be undertaken. Data will be made available at the end of the project through the open source framework repository.

Is the rationale for, and objectives of, the study clearly described? Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others? Yes

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.

**Reviewer Expertise:** My area of expertise is predominantly in social/health policy pertaining to health inclusion of marginalised/minoritised populations. This includes a focus on best practice in community engagement and co-production to enhance health, My methodological specialism are in mixed-methods research and critical policy analysis, and I have experience in undertaking scoping reviews.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 24 February 2025

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## **?** Julie Broderick 🗓

- <sup>1</sup> Trinity College Dublin, Dublin, Ireland
- <sup>2</sup> Trinity College Dublin, Dublin, Ireland

This protocol is well written and is an important area to interrogate. The authors are to be commended.

Please address the following points to enhance the quality of this protocol.

### **Abstract**

End of introduction instead of 'we will analyse' - frame identify the purpose of the scoping review.

Inclusion criteria – could the word 'material' be reframed to refer to survey?

Methods – identify which scientific databased will be searched

"A data extraction form was developed" – rewrite in present tense.

## Introduction

Include more of a description about what patient surveys are in general– what do they normally ask about, how are they normally distributed and how often and at which points in the patient journey.

Para beginning with "Health inequalities are commonly measured..." could health stratifiers be explained including some examples.

## **Objectives**

Include an overall aim and rewrite objectives including 'patient surveys' – as reading them in isolation they are not clear in relation to this review. Also rewrite as " to explore ..." etc

## **Eligibility criteria**

"No limits will be placed on study design to ensure all relevant materials are identified" – I would advise to add in excluding reviews – as only primary studies should be included.

It seems unrealistic to include studies from any language – if so specific searches would need to be conducted and resources allocated – so I would question the value and consistently in approach of the current plan. For this reason, I would advise English language only.

Specific detail on how the grey literature will be searched is needed.

Clarify who will conduct the search.

Query amalgamating search from (Avlijas et al., 2023) - to me this seems unusual. The premise of the current survey would have to exactly map that of Avlijasso so search terms/engines exactly matched. Under the section "Search Strategy" it is acknowledged that the current review focusses on a subset of the review by Avlijasso. Therefore search terms would be different and engines listed would not appear to be matched. I suggest the authors run the full search or limit years

included in review and bring in Aviljas review in the discussion section.

Population - define age limit of adult

General point – these types of surveys embedded in practice are unlikely to be the subject of publications, therefore how will these be sourced?

In the section "Consultation with relevant Stakeholders" = "There are several reasons why this project is focused on health inequalities in relation to this survey, including the underrepresentation of marginalised groups such as the Traveller community in previous survey samples, the limited number of equity stratifiers included in the survey, and the survey's limited accessibility, with participants requiring a fixed address to receive the survey which is only available in digital or hardcopy formats. "Could references be included to back up some of these statements where possible?

"The findings will then be discussed with patient and public involvement (PPI) representatives from the local community who are part of the project" – clarify if members of the PPI group will have lived experience of health inequalities.

Is the rationale for, and objectives of, the study clearly described? Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Yes

Are the datasets clearly presented in a useable and accessible format?

Yes

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.