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University of Galway

National Care Experience Programme

HRB Health Research Board

No data about us without us: co-designing strategies for a more inclusive National Inpatient Experience Survey

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Project Team

Academic Partners

University of Aberdeen

RCSI University of Medicine and Health Sciences

UCD School of Nursing, Midwifery and Health Systems
UCD College of Health and Agricultural Sciences

Policy & Practice Partners

Picker

HSE

An Roinn Sláinte
Department of Health

PPI

Community Partners

Galway City Community Network
Líonra Pobail Chathair Na Gaillimhe

Patient Advocacy Service

AgeAction Age Equality

COPE Galway

LGBT Ireland
For Inclusion
For Equality
For Everyone

L.C.A.I. Long Covid Advocacy Ireland

NDA Údarás Náisiúnta Míchumais
National Disability Authority

Epilepsy Ireland

Applied Partners

National Care Experience Programme

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Project summary

Objective 1a: Exploring how health inequalities are conceptualised and measured in patient experience surveys in acute care: a scoping review

Objective 1b: Conceptualising health inequalities in patient experience: a critical discourse analysis of national patient experience survey programmes

Objective 2: Qualitative study to understand the experiences of marginalised communities in public acute healthcare in Ireland

Objective 3: A co-design workshop to develop strategies to make the National Inpatient Experience Survey more inclusive for marginalised communities

Objective 4: Involve members of the public in the research process throughout the project

Objective 5: Consult key stakeholders on knowledge translation activities

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Scoping review and critical discourse analysis

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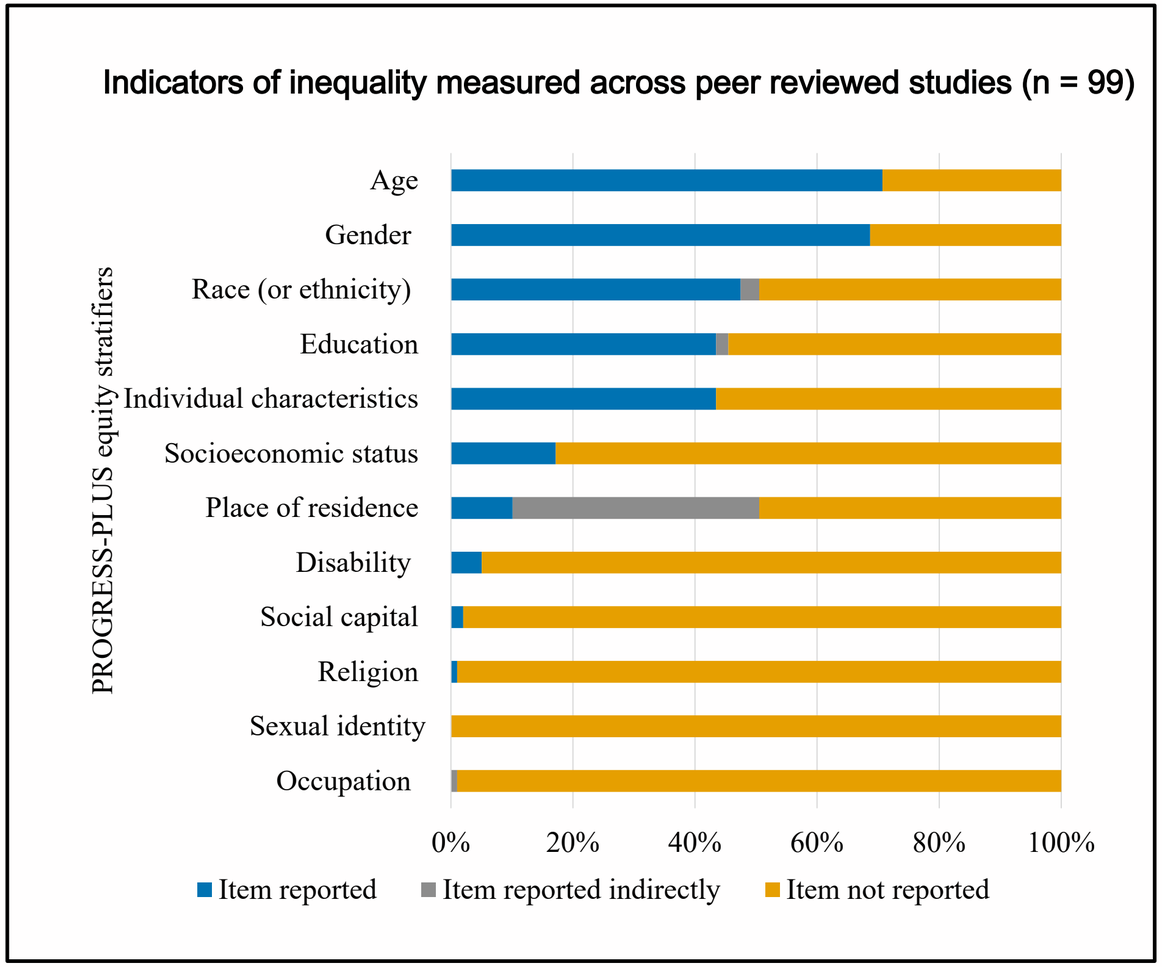
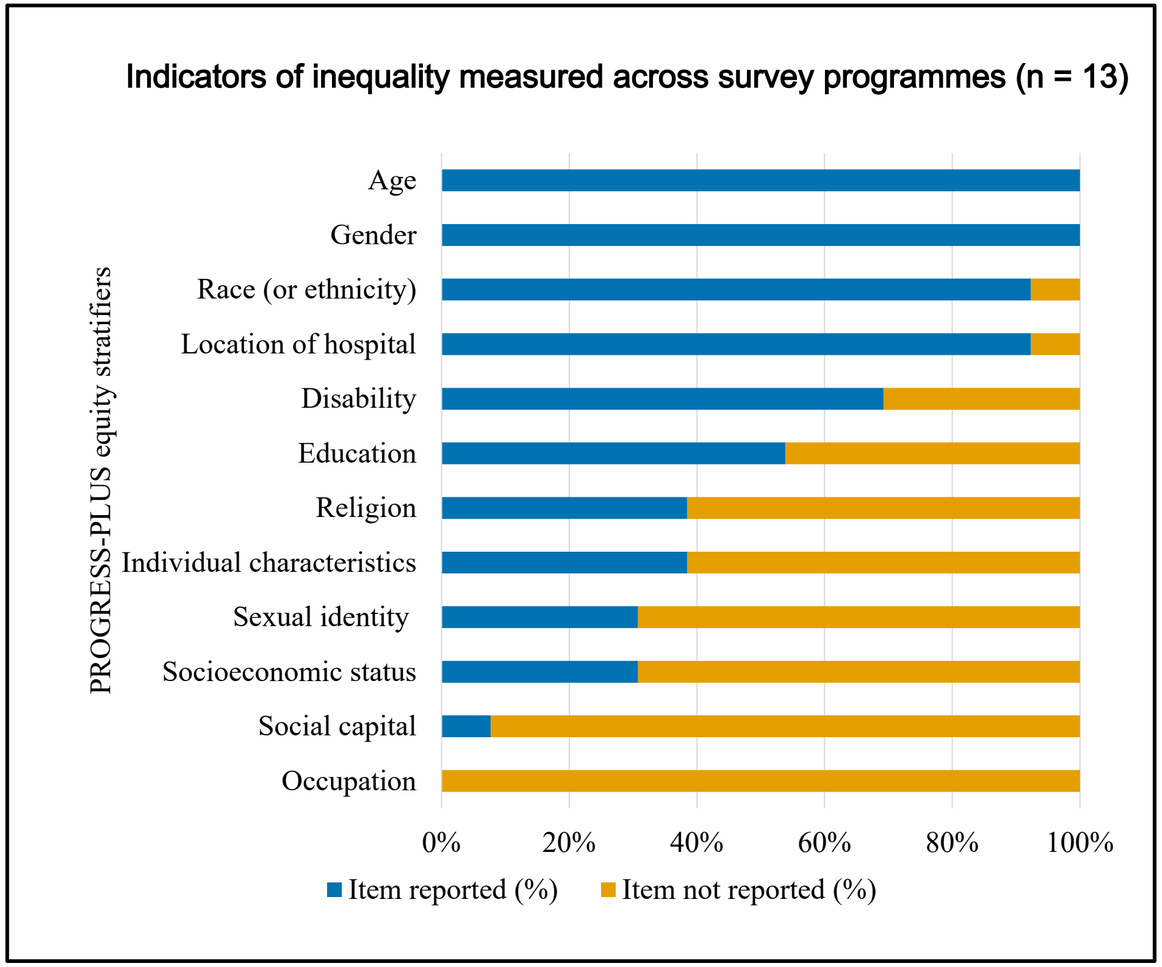
Indicators of inequality





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Aims and objectives related to health inequalities

- Of 99 studies examined, only 36 stated aims and objectives that were considered related to health inequalities.
  - Of these studies, only 6 actually included specific references to terms like health inequalities.

- Similar pattern in the national survey programmes. Of the 9 survey programmes examined, only one stated aims that we considered related to health inequalities.

- In general, we found that engagement with health inequalities theory was limited across both empirical studies and survey programme documentation.

CDA Findings

Theme 1

Alignment with New Public Management prioritises hospital performance and comparison, constraining engagement with issues of equality, equity and justice

Theme 2

"Interpret with caution": methodological constraints shape how health inequalities are conceptualised and measured in patient experience surveys

Theme 3

Health inequalities are peripheral and under-theorised when addressed in survey programme documentation

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Qualitative study

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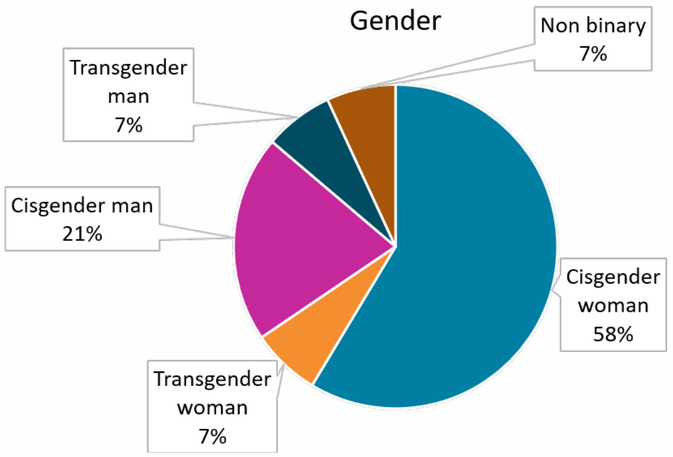
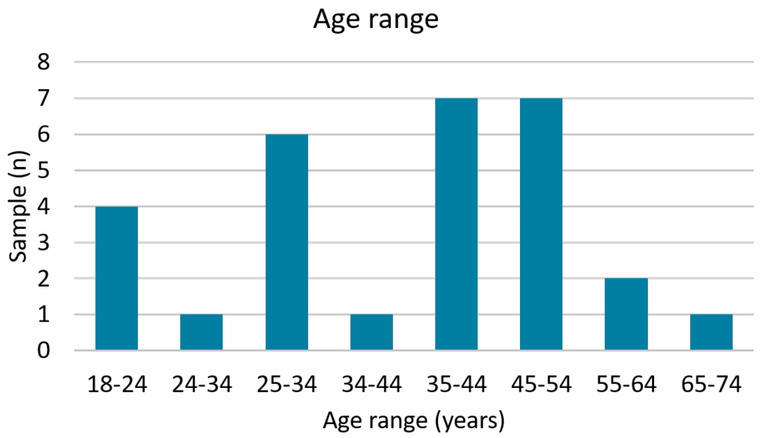
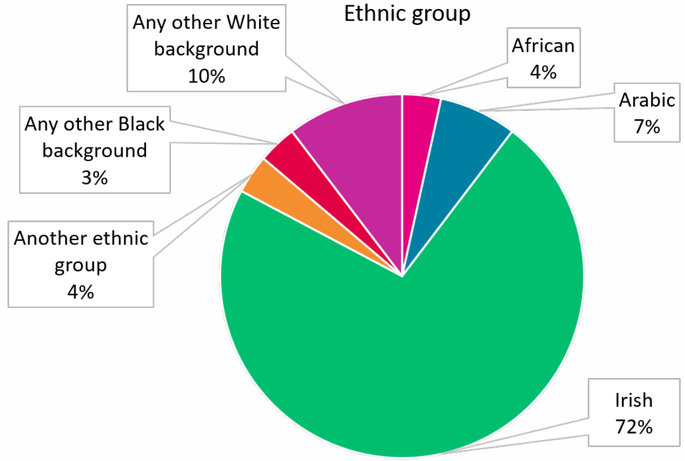
Subset of sample characteristics (n = 30)







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Preliminary findings

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A strained system straining marginalised patient care

"So once I go in [to the hospital] I have to go on a stretcher. I worry about pressure sores. Because you'll be left waiting on the stretcher for hours on end. With no proper air mattress and you end up getting a pressure area on your skin… ***You have to wait for people to do it for you***. And… in the end there's no staff to do that so you're stressed about that. You're stressed about the waiting. ***You've lost control of everything***."

(Participant 6)

Marginalised patient problems met with dismissal

"…I couldn't get anybody get me a bed pan, not that I could have used it, I needed a pad. And she [the nurse] said, "***You're a young woman, you should be helping yourself***." And yet ***if you understood what I did to help myself in order to survive at home and when you're in hospital***. And that's what you're being told. When actually you have nothing to give, you can't even create words, but you should help yourself."

(Participant 3)

Kindness, dignity and respect central to positive experiences of care

"She [the nurse] ***makes sure that she explains everything again*** that the consultants have said to you. She ***makes sure that she is there if you need any specific assistance***. She has been the only nurse ever to offer to help me use the toilet facilities… it just ***made me feel valued and it's difficult when your automatic response is, I am a pain to people*** and their daily life. So just – Yeah, the fact that her attitude to people's care is to see us as valued, rather than just something that she had to do for her job is the positive in that respect."

(Participant 16)

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Co-design workshop

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Co-designing strategies for a more inclusive NIES

- Participants (n = 25):
  - Healthcare sector
  - Academia
  - Community organisations
  - Marginalised people

- Full-day workshop generating:
  1. Questions to better understand marginalised inpatient care experiences.

  2. Ways to improve survey accessibility and participation

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Co-designing strategies for a more inclusive NIES

Questions to better understand marginalised inpatient care experiences

- Question on type of disability to be made specific and co-design with patient.
- More demographic details collected.
- Include more text box options.
- Open question on experience of discrimination.
- Inclusion of care giver/advocate experiences.
- Patient experience includes entire journey from pre-hospital to post-discharge care.

Ways to improve survey accessibility and participation

- Engagement with community organisations to reach marginalised people.
- Co-designing for accessibility.
- Assistance in completing the survey.
- Don’t just survey – include interviews and focus groups.
- Translation services in hospitals.
- Incentives to take part.
- See how survey results are used.
- Extend to A&E and day patients.

Final reflections

Evidence was generated to support the National Care Experience Programme to implement changes that will make the National Inpatient Experience Survey more inclusive for marginalised communities.

Main takeaways

More time must be spent theorising how best to conceptualise and measure health inequalities in patient experience surveys.

Improving survey uptake will require meaningful partnerships with marginalised communities.

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Thank you

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