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NIHR ARC East of England:
Celebrating Research & Shaping Our Future Together

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Showcase:

Exploring and addressing inequalities in marginalised communities through research

Chaired by Dr Claire Thompson
Theme Lead, Prevention and Early Detection in Health and Social Care

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LOST MOTHERS

birth companions

UKRI Economic and Social Research Council

University of Hertfordshire

Mandatory Separation of Mothers from Newborns in UK Prisons: Findings from the Lost Mothers Project.

Dr Laura Abbott Associate Professor, University of Hertfordshire and Principal Investigator of The Lost Mothers Project;

Sam Lived experience team, Birth Companions and Lost Mother's team member;

Kate Chivers Head of Engagement at Birth Companions and Project partner for The Lost Mothers Project

What is The Lost Mother's project and Why is it needed?

'On the day she died, she was informed that she could no longer visit her baby but could express milk. She had no contact with prison psychiatric services in the postnatal period. The sudden change of plan by prison services, unavailability of equipment for expressing (a need which should have been anticipated) along with lack of psychiatric review, were likely to increase her sense of loss. In particular, no one asked her about thoughts of self-harm or suicide at a time that she herself had flagged up as being risky.' (Cantwell et al., MBRRACE-UK, 2018:56)

In 2022-2023, 194 pregnant women were in prison, with 44 giving birth. Additionally, 78 women sought placement in a prison Mother and Baby Unit, with 40 approvals and 15 refusals.

One woman died by suicide five days post birth. She had been separated from her baby who was on the SCBU. On the day she died, she was informed that she could no longer visit her baby or express breast milk.

The Lost Mothers Project aims to understand the experiences of health and social care professionals and prison officers caring for incarcerated women separated from their newborns, informing future policy and support initiatives.

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Dear

We want you to know that you are not alone in this challenging situation. We've walked a similar path and understand the difficulty you're facing. It's easier said than done, but we assure you, you can be strong through this. At times, you might feel isolated, but our source of strength was faith and a belief that things could change. Eventually, they did.

We have been out of a situation similar to yours, and life has transformed for the better. Some of us returned to studying and obtained qualifications in various areas. We have rebuilt relationships with friends, family, and children, and all of us find ourselves in a much happier place now. We share this with you to offer hope, knowing that tomorrow is another day, and this challenging period won't last forever.

On another note, we deeply appreciate your participation in the Lost Mothers project. Having been in your shoes, we understand the significance of your contribution, and want you to know how grateful we are for the invaluable help you're providing. Your involvement is vital to our research, and we wouldn't be where we are without you. As a team, we are immensely thankful for your support.

Remember, your current circumstances do not define your future. Things can change, and they can get better. If you ever need help or support, please know that you can reach out to us. Your release marks a continuation of your role in the project, and we consider you as much a part of it as we are.

Thank you sincerely for

Co-production and lived experience

"As a member of the lived experience team it has been amazing to be included in the entire research process, especially as someone who contributes a lot to projects. I feel like I've got the luxury from being here from the beginning."

Abbott *et al.*
Research Involvement and Engagement (2024) 10:53
https://doi.org/10.1186/s40900-024-00583-1

Research Involvement and Engagement

COMMENT Open Access

Co-production in the Lost Mothers Project: transforming criminal justice narratives through Lived experience engagement

Laura Abbott[1*†], Kate Chivers[2†] and Tuesdae Moncrieffe[3†]

Qualitative Methodology

One to one interviews

n = 66

Observation in 4 prisons

Thematic analysis

Midwives

n=16

Nurses and Health Visitors

n=7

Prison Officers

n=8

Social Workers

n=8

Women

n=27

Observation of Mother and baby boards

n=4

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LOST MOTHERS

Findings – Women

Health and care inequalities compounded by their incarceration. A uniquely painful experience for mothers in prison.

"I've never felt pain like it, and walking out of the hospital, getting handcuffed straightaway, because you're not handcuffed in the hospital, in the maternity department, but once you go onto the landings to walk away…it was like I was walking for miles and all I could think about is, that's it now, I've had to her behind".

"In the beginning, they had to give me sleeping tablets to get over this…and then they say you can see her once a month…I think my body just shuts down…It just doesn't want to be a mum; it just doesn't want to go through that pain again and again. I never want to hurt my own child. I never want to hurt anybody's child. How can you assume that I am this horrible person when you don't even know me? So, my mental health… it really broke down".

"They came and picked her up, and I've never felt the pain like that in my whole life. It was like something ripping off me… even the nurses cried… I think they got traumatised as well, some of them. It was just really hard, and then I come back to prison, and I just collapsed. I couldn't even walk".

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Findings Staff

LOST MOTHERS

Lack of joined up working practices from professionals. Disparate and variable levels of care and support.

"It changes how you view the world…to go through that process of removing a baby, a child, because of imprisonment, that significantly changes you. And if it doesn't, then to me, you shouldn't be in the job... The pain and desperation, absolutely gut-wrenching, soul-tearing experience for those women, is unbelievable. No amount of empathy in this world can allow you to even think, or feel one bit of what they must be going through... We have to hear it from women that have experienced it, to enable us then to say, this isn't right. This isn't what we should be doing."

Social Worker

"When you really know them really well, you can break those barriers down and talk about that loss with them and talk about them, whether they have contact or if they don't have contact, and how they're feeling. For some women - one woman told me, I'll keep having babies until they let me keep one. And she truly wasn't getting why she wasn't having any contact with her baby."

Midwife

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LOST MOTHERS

Findings Staff

"She was doing everything right, but then the courts decided no. So then you're supporting a mum that's literally grieving for a child, which is difficult, because she knows that she's lost him and the likelihood of her getting him back is going to be minimal. So she's grieving for that child that she's lost, even though he's still here, she's still grieving for him. It is difficult. It's difficult for them, and it's difficult for staff."

Prison Officer

"It depends on social services, so every social services is different. You might have one county that are really quick; other counties are really… Again, it might be that the background of the woman might be so complex, that it might just take time. There's so many checks that have to be done. Things just take time, unfortunately, but then when you're time-restricted with a pregnancy, it's really hard, isn't it?"

Health Visitor

What being part of Birth Companions and the Lost Mothers lived experience team means to me

"The lost mothers project is something very close to my heart. I am very grateful to be able to be a part of it and use my lived experience to make an impact with this project and have a voice to try and make change for all the other mothers that have been through the criminal justice system and the mothers that are currently in it."

A lived experience team member

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Thank you!

We extend our deepest appreciation to the mothers currently in prison who are participating in our research, as well as to individual prisons and their staff. We are especially grateful for the invaluable contributions of the Lived Experience Team of the Lost Mothers Project, whose firsthand insights and experiences have been integral to our work. Additionally, we appreciate the unwavering support from Birth Companions. Lastly, we would like to express our gratitude to the ESRC for their generous funding, which enables us to pursue this important research.

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The Impacts of Universal Free School Meal Schemes in England

Angus Holford **Birgitta Rabe**
Institute for Social and Economic Research
University of Essex

NIHR ARC East of England: Celebrating Research and Shaping our Future Together, 26th June 2024

School food provision, children's diets, and obesity

- Children consume around one-third of their daily energy during school hours.
- Free school food provision has the potential to improve children's diets
  - Directly, through children switching from packed lunches to school meals.
  - Indirectly, by enabling the cost of packed lunches or paid-for school meals to be spent on better food outside of school.

Our evaluation

- The impact of four local authorities' (LAs) Universal Primary Free School Meal Schemes (UFSM) on children's
  - Educational attainment
  - **Obesity and overweight**
  - Absences
  - Household finances.

Year-ending:	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Newham													
Islington													
Southwark													
Tower Hamlets													
Key													
Year 6 students currently receiving UFSM and have received for													
						1	2	3	4	5	6	7	years

Why could UFSM affect obesity?

- **School meal:** Should comply with School Food Standards, regulating nutritional or food content, and portion sizes (530kcal).
  - 61% kcal are still ultra-processed foods (Parnham et al., 2022)
- **Counterfactual: Packed lunch**
  - 1.1% meet all School Food Standards.
  - 27% have confectionary, savoury snack and sweetened drink
  - mean energy 624 kcal;
  - 11.8% meet calorie standard (Evans et al., 2010)
  - 81% kcal are ultra-processed foods (Parnham et al., 2022)

How many children changed what they eat?

- Meal options without Universal FSM (shares of children)

	Packed Lunch	School Meal
FSM-eligible	6%	36%
Not FSM-eligible	40%	18%

- Estimates based on Newham, Islington, Southwark, Tower Hamlets for 2007-2009

How many children changed what they eat?

- Meal options **with** Universal FSM (shares of children)

	Packed Lunch	**School Meal**
FSM-eligible	6% →5%	36%→37%
Not FSM-eligible	40%→8%	18%→50%

  - Estimates based on Newham, Islington, Southwark, Tower Hamlets for 2007-2009

- The policy **caused about 33% of children to switch** from taking a packed lunch to a school meal

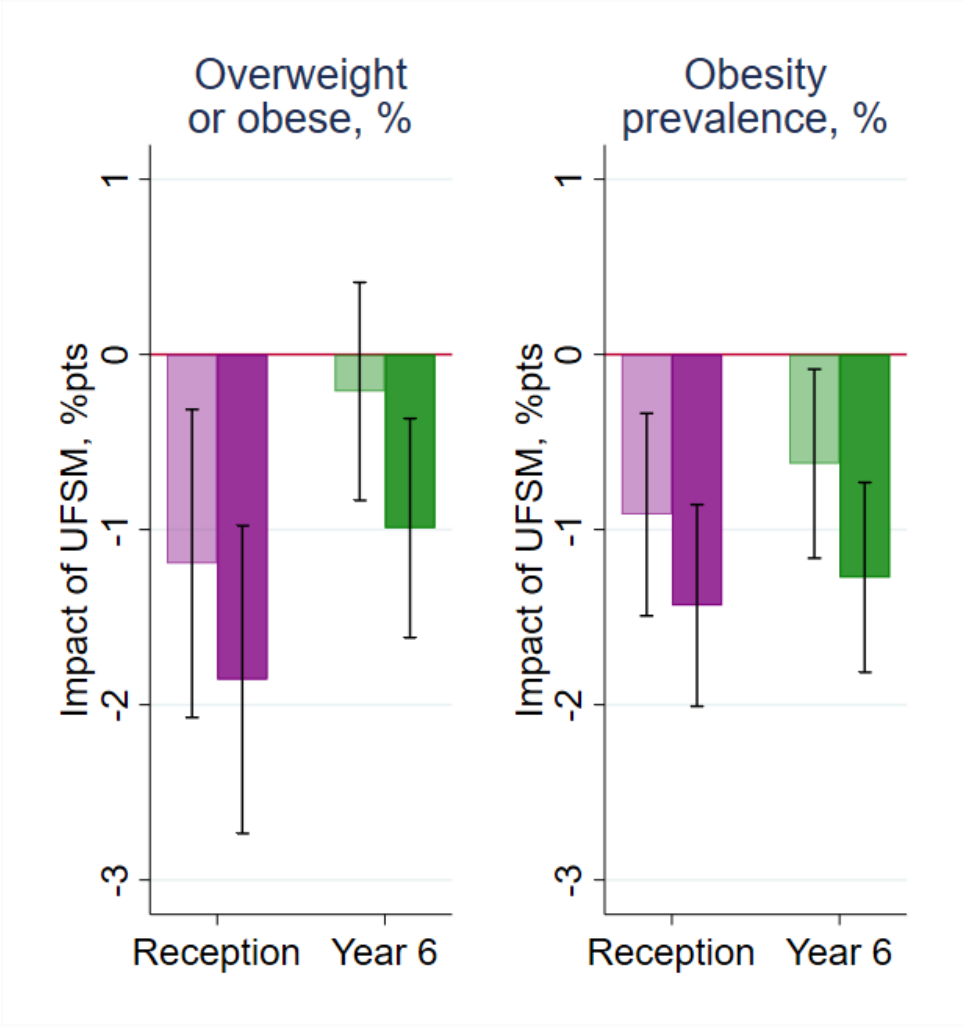
Our data: National Child Measurement Programme

- School-level data on overweight and obesity prevalence from trained nurse measurements of children's heights and weights.
- 2006/07-2018/19; and Reception and Year 6.
- We can track the same school over time.
- Limited additional information, to prevent us knowing the identity of the schools

Our method: ‘Difference-in-difference’

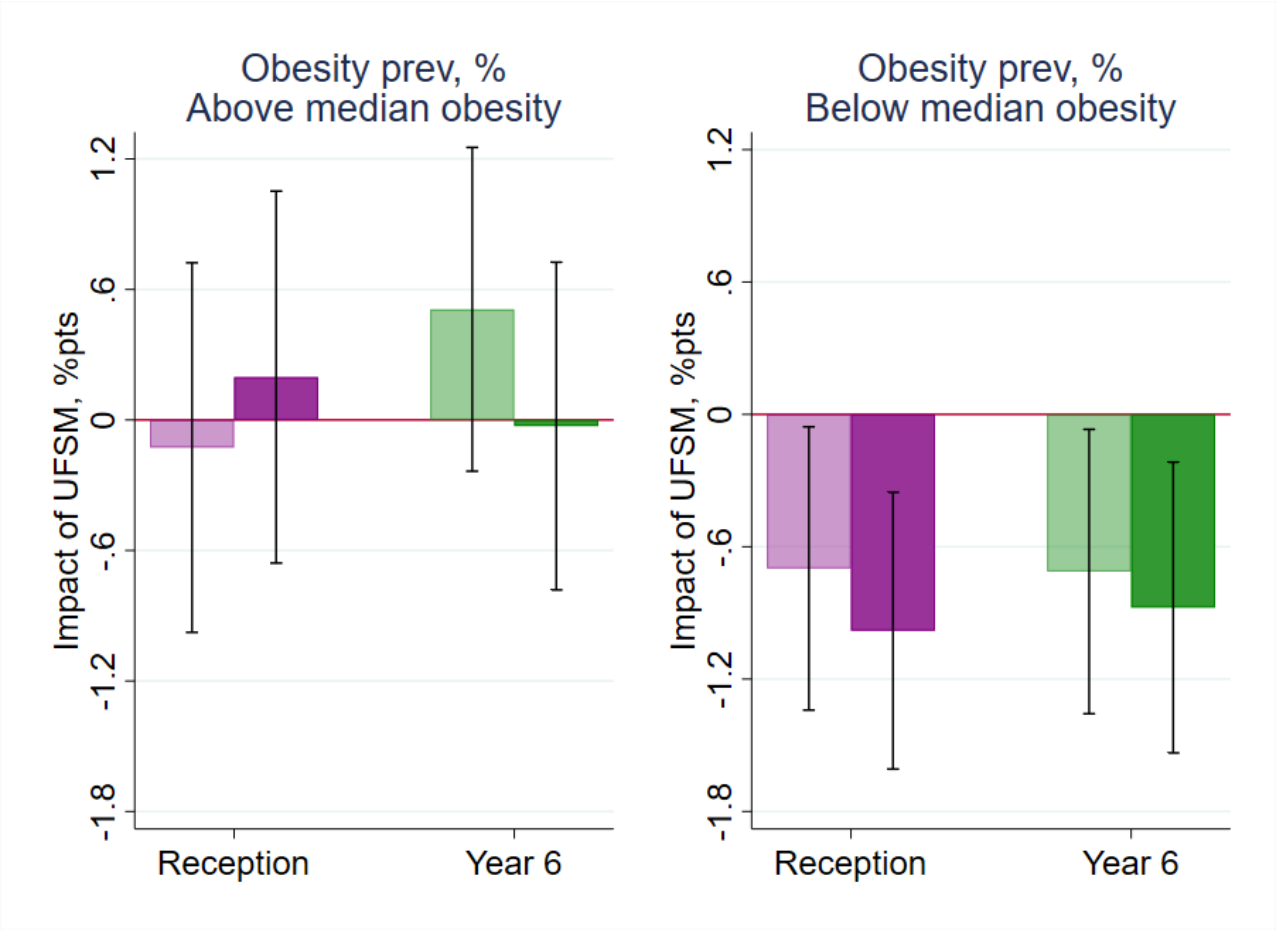
- Use the **change** in outcomes in LAs that never introduced UFSM as a guide to **what would have changed** in the LAs that did introduce UFSM.
  - We compare with ‘Rest of London’ and ‘Rest of England’,
  - These areas had **parallel trends** in outcomes in the lead-up period.

Results: Impacts on children's overweight and obesity



- **Reception**: reduces children's overweight and obesity.
  - 7-11% reduction in obesity.
- **Year 6**: reduces children's obesity by 2-5%.

Results: Impacts by pre-existing obesity



- Benefits do not extend to schools with the highest pre-existing obesity rates.
- Additional support will be needed in more challenging environments

Policy implications for Prevention, Improvement, Disparities

- Universal FSM reduces or delays the onset of obesity
  - Large effect size for a non-clinical / non-targeted intervention.
  - Direct evidence of impact of a policy that Local Authorities could spend their public health grant on.
- Expected to improve future productivity and reduce NHS costs.
- Families save time (to prepare lunches) and money
- Less effective in schools where obesity is already very entrenched, additional support needed or the policy would widen health inequalities.

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This work uses data provided by individuals and collected by the NHS as part of their care and support..

Specifically, the paper uses data from the National Child Measurement Programme, supplied by NHS England, also known as the Health and Social Care Information Centre, part of the Government Statistical Service.

his work also uses data from the Department for Education's National Pupil Database, carried out in the Secure Research Service, part of the Office for National Statistics (ONS). Statistical data from ONS is Crown Copyright, and copyright of the statistical results may not be assigned.

The use of the ONS statistical data in this work does not imply the endorsement of the ONS in relation to the interpretation or analysis of the statistical data. Research datasets may not exactly reproduce National Statistics aggregates.

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Engaging South Asian Women in breast cancer care

Professor Daksha Trivedi, Dr Claire Thompson, University of Hertfordshire

Collaborators: AWCG (Rohini Patel); Nasim Panjwani (Macmillan Trainer and facilitator), Jai Jayaraman (NHS Cancer Alliance East of England)

https://arc-eoe.nihr.ac.uk/research-implementation/research-themes/prevention-and-early-detection/engaging-south-asian-women

https://www.asianwomencancergroup.co.uk/

Outline

- Background
- Aims
- Methods
- Findings
- Reflections on Community engagement, Involvement & Participation

Breast Cancer and Ethnicity

- are less likely to attend breast screening compared to white women in the UK.
- present late for diagnosis resulting in poorer survival outcomes
- lower breast cancer awareness and knowledge of symptoms and risk factors than white women.
- report higher levels of depression, anxiety and poorer quality of life compared to white women.
- Understanding is limited by lack of consistent data from specific subgroups

T. Gathani, A. Chaudhry, L. Chagla et al., Ethnicity and breast cancer in the UK: Where are we now?, European Journal of Surgical Oncology, https://doi.org/10.1016/j.ejso.2021.08.025

Aims

- Understand the perspectives of Asian women around breast cancer and care

- Identify barriers and facilitators to accessing breast cancer care

- To co-produce the findings from the project and make recommendations for improving the experience of Asian women with breast cancer

What did we do?

Using community engagement:

- **Phase1:** A preliminary consultation with AWCG members who have breast cancer (listening events!)
- **Phase2:** Identify the barriers and facilitators to accessing appropriate breast cancer care for South Asian women (via 2 Focus Groups, total n=14)
- **Phase3:** A feedback consultation of the findings

How did we involve people?

- Working together with both AWCG and NHS Cancer Alliance- DT has strong links through her own cancer journey
- Trust, understanding, authenticity and shared learning of concerns rather than our own agendas

- Met with AWCG women to discuss their cancer journeys and level of support

- Informed the group of our findings through their local forum
- Kept in touch with the Chairperson, the NHS collaborator through the impact blogs and the process of publishing the findings

Findings and implications

Screening

Diagnosis

Treatment

Problems

- Information & Expectations
- Communication & dealing with HCPs
- Language and cultural issues

Problems

- Receiving the diagnosis
- Assumed knowledge
- Cultural barriers
- Time between diagnosis and treatment

Problems

Information and Trust

- Lack of communication about treatment
- Decision making process
- Use of language

Care & self-management

- Lack of holistic approach, advice or resource on management
- Post diagnostic/treatment care?

Implications

Suggested improvements and potential solutions

- Recruiting Asian women/support group as community champions with NHS support
- Access to support groups and better communication with GPs and health professionals- recognition of the role of AWCG
- *HNAT – holistic needs assessment tool, fragmented – should be used at diagnosis to better support families' needs*
- Culturally appropriate support, NHS screening and awareness campaigns
- Five-year post-discharge follow-up with GPs to check on self-management and wellbeing for Asian community
- More access to Macmillan nurses

Training workshops for clinicians and HPs to offer culturally tailored sensitive support to ensure that patients are involved in decisions despite cultural barriers

"It was helpful to take part in the project as it addressed our lived experience, our challenges, and more importantly we worked together to help identify potential solutions. It really was a 'listening event' in which our views mattered - AWCG member

"Meeting the needs of South Asian women in cancer care is paramount and working collaboratively with AWCG was a first important step in helping to inform NHS Cancer Services" Jai Jayaraman, NHS Cancer Services, East of England

" Working at grassroots level with women who I identified myself with, I was able to connect in a positive way and truly 'listen' to their voices"
Professor Daksha Trivedi, ARC EoE researcher

Thank you…

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Addressing inclusivity for older LGBT+ people in delivery of services

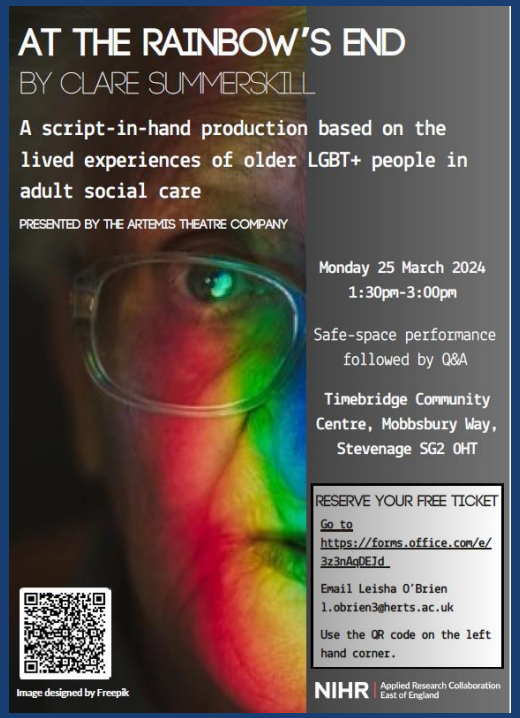
Kathryn Almack

Professor of Family Lives and Care – CRIPACC, University of Hertfordshire

Theme Lead, Ageing and Multi-morbidity, NIHR ARC East of England

- IncludeAge – Inclusive Communities with and for older LGBT+ people and people living with learning disabilities

- At the Rainbow's End



first performance in Stevenage funded by the ARC EoE Ageing and Multimorbidity theme

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Older LGBT+ people in Britain – some context

- Older LGBT+ people report poorer health (linked to minority stress)
- They are less likely than their heterosexual peers to have children/family to support them in old age; more likely to live alone.
- LGBT+ advocacy organisations can be important for developing older LGBT+ people's wellbeing – self-esteem & autonomy
- Ageing encompasses people's past, present & future – negotiating social roles
- Marginalisation among mid-older LGBT+ people can be experienced within LGBT+ spaces & communities as well as outside; intersectionality is important ('excluded because I'm a lesbian, or because I'm a woman?')
- Challenges with LGBT+ research – 'diversity' of samples and 'inclusion' of different voices

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IncludeAge (LGBT+ pathway)

- 60-80 life course interviews with LGBT+ people age 40+ in Britain
- Using an app ‘mapping tool’ – so participants can record day-to-day experiences of place and space
- Up to 20 social network analysis interviews with a sub-sample of LGBT+ participants
- Organisational interviews (with public agencies, voluntary and community representatives)

Involving Co-Researchers:

- 4 mid-older LGBT+ people
- Employed (by the University of Hertfordshire) not volunteers = commitment
- Provided with training and ongoing mentorship and group support
- Individual tailored support and handbooks
- Invited to join wider team meetings where we have discussions about progress and about ideas that are central to this project e.g. what does ‘inclusion’ or ‘community’ mean

Community-Based Participatory Research

- Promote and provide platform for voices of divers stakeholders
- Valuing experiential knowledge and resources

Experts by experiences are:

- Members of our Community Advisory Groups
- Co-researchers

Also working with:

- Sectoral stakeholders
- Other expert-by-experience stakeholders
- International Reference Groups

Regard :)

Dudley Voices for Choice

NDTi
National Development Team for Inclusion

sleeping GIANTS

OPENING DOORS

outsidethebox

INN
Intergenerational National Network

SCLD

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At the Rainbow's End

Written by Clare Summerskill and performed by the Artemis Theatre

- A short play (script in hand performance) with Q&A
- A verbatim script based on **real-life testimonies** from older LGBT+ people:
  - An original member of the Gay Liberation Front in the 1970s, who in later life is now campaigning for better provision in care homes after his partner suffered homophobic abuse and violence in a care home
  - An older disabled trans man who has experienced transphobic comments from carers in his home
  - A lesbian couple who bought a property in a retirement community supported by a housing association but moved following sustained discrimination from other residents.

Aims:

- To raise awareness of specific needs and the legacy of discrimination that LGBT+ people live with and fear in care
- To evaluate as a training intervention for social care staff (and others)
- Accompanied by training materials

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Planning

- Asked the Stevenage Dementia Group what they thought about the play and the idea
- Community venue and community focused
- Accessible building, served by public transport and with parking

Target audience: care homes, home care, supported living/extra-care, self-employed Personal Assistants.

Barriers to attendance might include:

- Shifts around the clock
- flexibly/other commitments/juggling life & work
- not being paid to come

Thank you!

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Improving data on health inequalities: development of an evidence resource

Louise Lafortune

Sowmiya Moorthie, Sian Evans, Aalia Karamat, Emre Oguzman, Carol Brayne, Jonathan Goodman

ARC EoE Population Health and Data Science Cambridge Public Health
Norwich, 26th June 2024

Improving data on health inequalities

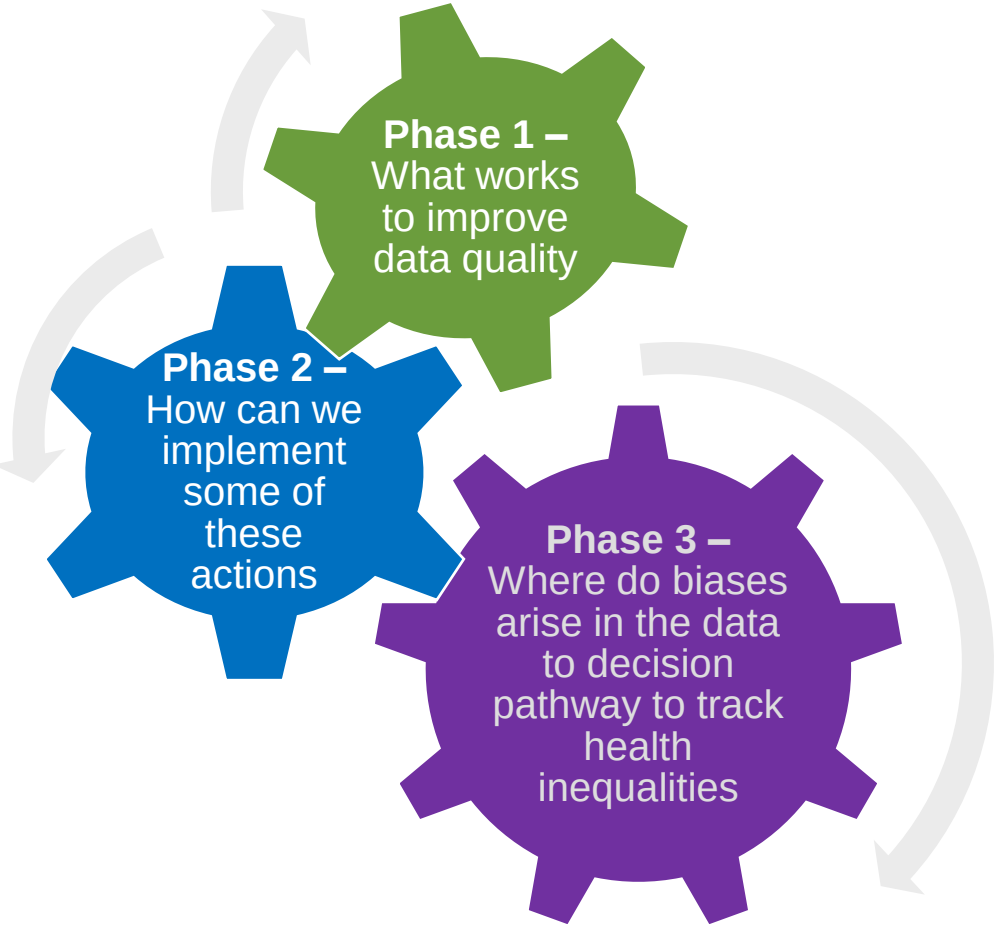
Why?

- Good quality data is needed to understand and address health inequalities
- Policy reports and practice partners across settings call for improvements to data quality

Key questions

- How can data quality be improved?
- What has been shown to work?
- How can we implement some of these actions?

Overview – 3 building blocks to develop a resource



Scoping review
- Summarised 57 reports

Interviews
- 16 health & care professionals

Scoping review
- Included 102 reports

Case studies & Resource

Data pathway & Best practices

Data to decision-making pathway

Cross-cutting factors

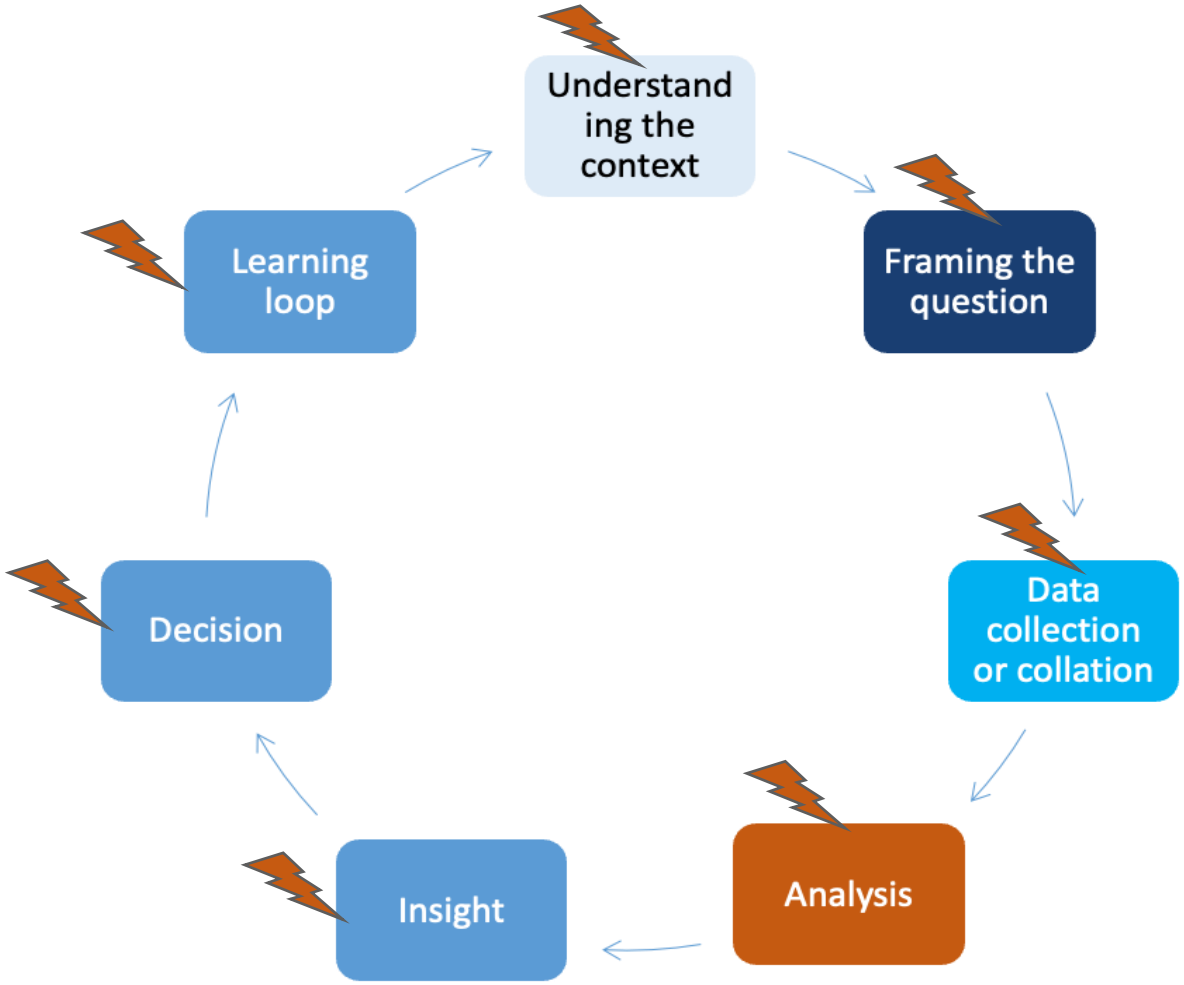
Social, economic & political factors

Conscious/unconscious bias

Systemic injustice and power hierarchies

Historic uses of categorisation

Knowledge and awareness of data generated inequalities



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Phase 1 – Scoping review

What works to improve data quality?

Why and how?

Aim

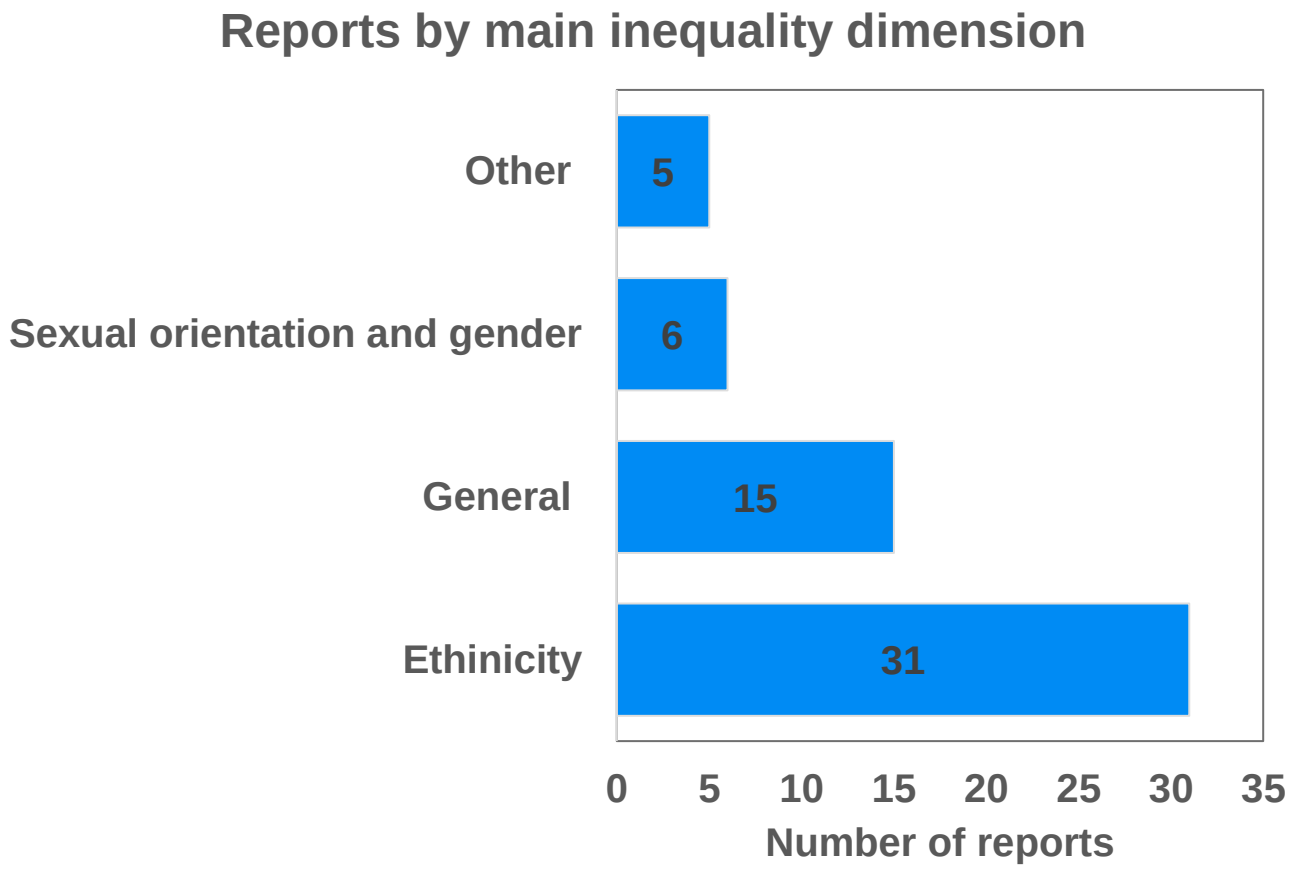
Summarise what we know of approaches taken to improve the quality of data used to identify and monitor health inequalities.

Method

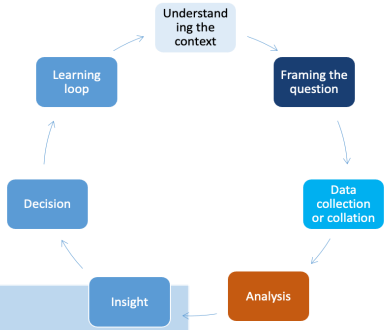
- Systematic literature search of peer review and grey literature
- Limited to publications after 2010
- Included any publications that described mechanisms to improve data quality
- Analysed “themes” that emerge
- Developed recommendations on what to do

Results

- 57 relevant studies & reports
- Mainly peer-reviewed publications
- Most from US or UK
- Grouped further into four themes



Results



Theme	Point in the data pathway	Actions
Distal factors	Upstream of data collection and analysis	Mandating data collection
		Legal safeguards to ensure non-discrimination
		Legislation incentivisation data collection
		Prioritisation in policy
Wider actions to enable improvements in data collection	Preparing for data collection	Achieving senior level buy-in in organisations involved in data collection
		Engagement activities with citizens, patients and communities
		Staff training programmes on purpose and mechanisms for data collection
		Developing guidance on how data can be used
		Demonstration of the value of data collection and analysis for organisations
Data collection instruments, systems and standardisation	Data collection	Using multidisciplinary groups to inform data collection instruments, systems and standardisation
		Creating standardised definitions and coding practices across organisations
		Improving granularity of data fields
		Developing standardised processes for collecting and recording data
		Developing audit processes to monitor data quality aspects
		Creating IT systems to facilitate data collection
Methodological approaches to improve data quality and accuracy	Data analysis	Linking with other data sources
		Use of proxy variables
		Imputation

Conclusion

- Variety of mechanisms available and can be utilised to improve data quality
- Work across different points of the data collection pathway
- A multi-level approach is needed
- Most studies identified were in relation to ethnicity data – put principles apply across other domains

International Journal of Environmental Research and Public Health

MDPI

Review

A Scoping Review of Approaches to Improving Quality of Data Relating to Health Inequalities

Sowmiya Moorthie [1,*], Vicki Peacey [2], Sian Evans [3], Veronica Phillips [4], Andrea Roman-Urrestarazu [1], Carol Brayne [1] and Louise Latortune [3]

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Abstract: Identifying and monitoring of health inequalities requires good-quality data. The aim of this work is to systematically review the evidence base on approaches taken within the healthcare context to improve the quality of data for the identification and monitoring of health inequalities and describe the evidence base on the effectiveness of such approaches or recommendations. Peer-reviewed scientific journal publications, as well as grey literature, were included in this review if they described approaches and/or made recommendations to improve data quality relating to the identification and monitoring of health inequalities. A thematic analysis was undertaken of included papers to identify themes, and a narrative synthesis approach was used to summarise findings. Fifty-seven papers were included describing a variety of approaches. These approaches were grouped under four themes: policy and legislation, wider actions that enable implementation of policies, data collection instruments and systems, and methodological approaches. Our findings indicate that a variety of mechanisms can be used to improve the quality of data on health inequalities at different stages (prior to, during, and after data collection). These findings can inform us of actions that can be taken by those working in local health and care services on approaches to improving the quality of data on health inequalities.

Keywords: health inequalities; health disparities; data quality; public health

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1. Introduction

Health inequalities are often defined as "differences in health across the population and between different groups" [1]. The study of health inequalities aims to better understand factors that contribute to unfair differences in the status of people's health to address them and achieve fairer and more inclusive health care. Inequalities in health can arise because of differences in the care that people receive and the opportunities they have to lead healthy lives, including differences in health status (e.g., life expectancy), quality and experience of care, and wider determinants of health [1].

Data analysis to improve understanding of health gaps is an important exercise that contributes to an aspiration for fair and inclusive health. Good data is vital for understanding inequality in health service provision and health outcomes, and necessary for informing and evaluating attempts to improve care or reduce inequality. In the United Kingdom, health inequalities are identified by analysing data across socio-economic factors, geography, and specific characteristics including those protected in law such as sex, ethnicity or disability, and socially excluded groups. However, the quality of data underpinning these analyses can be improved [2–4]. Good-quality data are data that are fit for the purpose; therefore, criteria on what constitutes "good" can vary. Dimensions such as

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Phase 2 – Interviews

How can we share what works and support the implementation of actions to improve data quality?

Why and how?

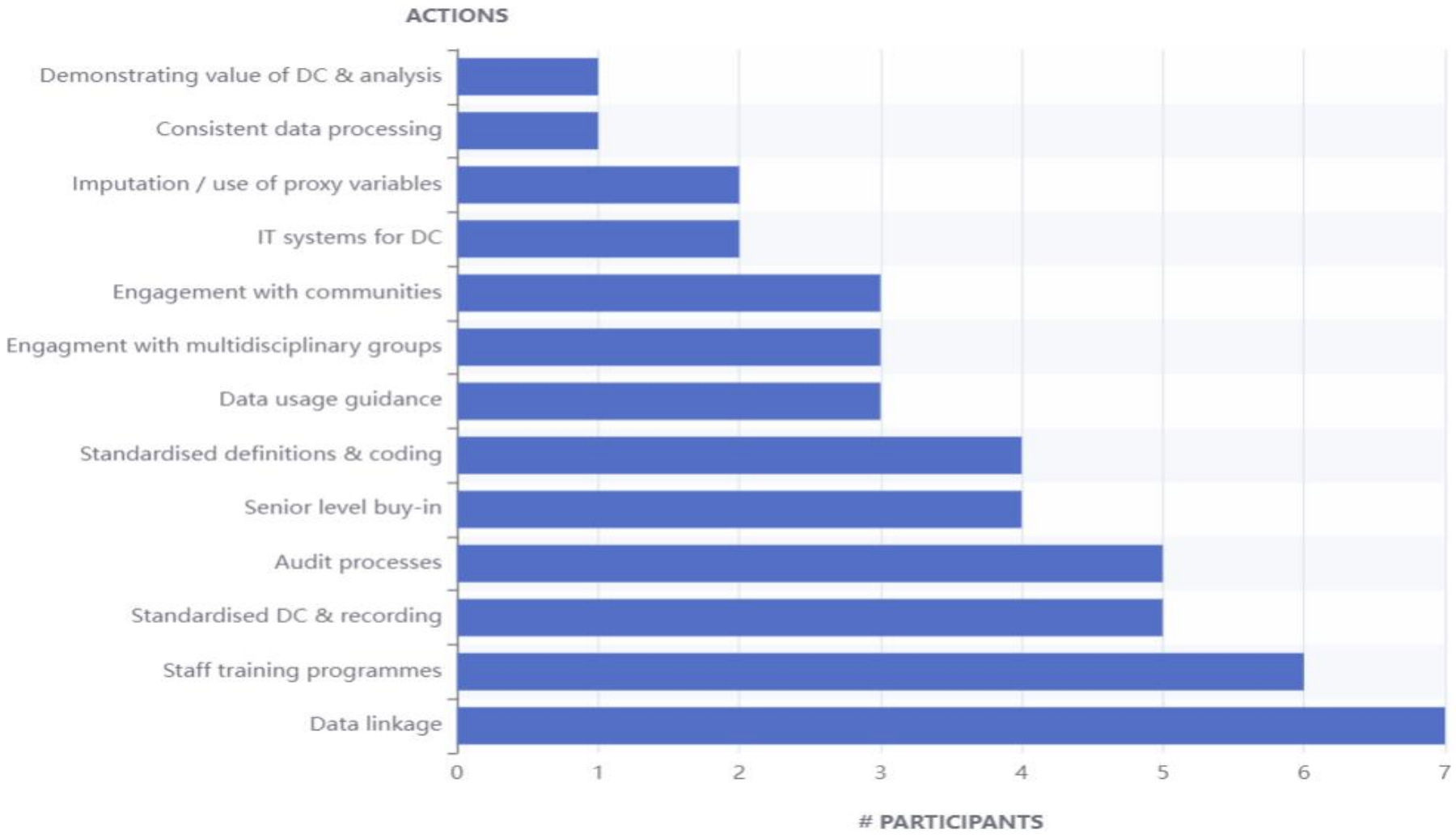
Aim

Identify the most effective ways to transition the identified actions into practice

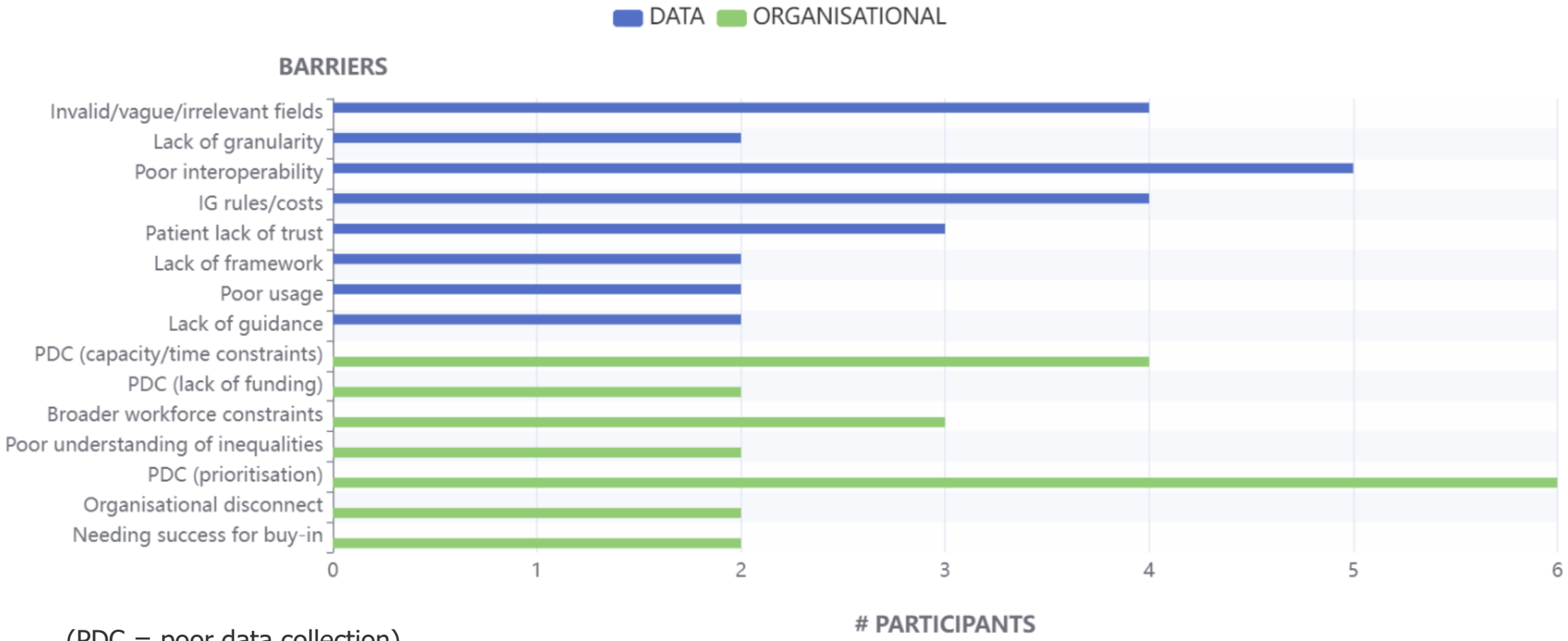
Process

- Interview and focus groups with professionals across health and social care, public health, and third sector organisations
  - Those involved in data capture, collation, analysis and use in decision-making in relation to health inequalities
- Gather views on the most useful resource(s) that could help implement the actions on mechanisms to improve data quality
- Use the above data to inform the development of a resource(s)

Results - Understanding of actions to improve data quality



Results - Barriers or issues



(PDC = poor data collection)

Results - Desired resources

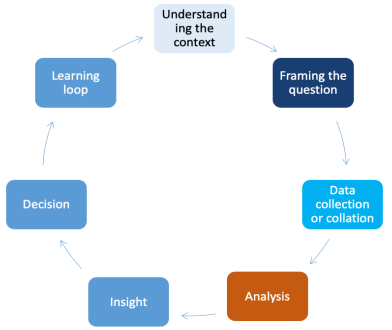
Category of resource	Suggestions
Knowledge sharing	• Sharing of strategies and mechanisms to improve data completion • What has been done in other parts of the country to improve data quality • Sharing of information governance structures • Best practice around ethnicity categorisation • National framework outlining consistent measures • Mechanisms for reporting and quality assurance around categories
Facilitating communication between groups	• Clear message on what the data is being used for • Description of how data process to address inequalities works • Enabling communication on the impact of data on health inequalities • Case studies and better understanding of analysis process and shortfalls in what can be done with existing data • Better understanding of health inequalities and role of data. • Demonstration of contribution of different stakeholder to health inequalities data pathway
Tools to aid data analysis	• Data catalogue • Best practice in terms of methodological approaches • Better interoperability • Mechanism to feedback to data sources/collectors on the gaps in data. • Sharing of information governance structures • Knowledge of tools that can be used e.g. Fingertips, or other tools for population health management. • Guidance or best practice on how to collect data

Conclusion

- Most professionals were aware of mechanisms that could be put in place to improve data quality and had implemented them to differing extents

- Several barriers impede efforts in implementing mechanisms, from logistical factors to system-level issues

- Different approaches are needed to both increase awareness of the variety of mechanisms that could be employed, and support their delivery:
  - Better understanding of health inequalities
  - **Better understanding of the data to impact pathway**
  - **Case studies of what worked**
  - Guidance on best practice in approaches to data collection and analysis



Thank you!

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