



The Centre for Ethnic Health Research

national centre for tackling health inequalities



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Equality Monitoring Data in Research



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Welcome!

Professor Marion Walker

Chair of the Equality, Diversity and Inclusion
(EDI) Committee



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Introductions

Julian Harrison

(Equality, Diversity and Inclusion Consultant)

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(Research Fellow)

Laura Gray

(Data2Health Theme Lead)



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Agenda for Today

- What is Equality Monitoring?
- Why should we collect Equality Monitoring Data?
- Our Learning and Experiences
- Facilitated Discussion / Question and Answer Session
- Thank You and Close



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Event hashtag

There is a hashtag for today's event:

#EqualityInResearchMatters



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What is Equality Monitoring?

- Equality data includes both quantitative and qualitative information
- The questions used relate to each of the protected characteristics identified in the Equality Act 2010
- They can go further though, recognising that disadvantage and discrimination can relate to other areas, e.g. social class, language, immigration status, geography
- Note that the ‘socio-economic status’ duty in the Equality Act is likely to come into force this year in England – it already exists in Wales and Scotland – therefore effectively increasing the number of protected characteristic identities to ten



What is Equality Monitoring?

- It is a means of accumulating knowledge across the protected characteristics
- Gathering data therefore becomes more consistent over time, particularly if collected with sufficient granularity
- Data collection has to have the potential to lead to action of some sort. It is not just about bringing knowledge up to date
- What to do with that knowledge should be at the core of your monitoring procedures, aims and practice



Why should we collect Equality Monitoring Data?

Does this look familiar?

"Could you please complete this form for us?"

"No. I know it's a pain, but if you could, we'd be grateful"

"We have to ask these questions as part of the project requirements"

"Do I have to do it?"

"What is used for?"



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Why should we collect Equality Monitoring Data?

Perhaps most fundamentally, it can highlight gaps – in participation and inclusion, in knowledge and focus, in research reach and findings. How do you know where, how and to what extent there are gaps unless you ask the right questions?

When we are thinking of equality and diversity, it helps to assess and understand inclusion, accessibility, different experiences, discrimination, unfair treatment and prejudice

But there are other reasons to collect...



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Why should we collect Equality Monitoring Data?

- It is a key part and mechanism of the Public Sector Equality Duty (PSED) of the Equality Act 2010
- It produces 'better' and more up-to-date information
- It helps to assess equality impact (particularly differential impact) – thereby an important part in Equality Impact Assessments
- It helps to identify specific and disproportionate patterns of inequality
- It can help identify positive, remedial and mitigating actions – sometimes in precise detail



Why should we collect Equality Monitoring Data?

- This can therefore have a positive impact on the quality as well as the inclusivity of research
- And therefore on issues relating to people's lives – not just in service delivery (more effective and relevant care, for example) but in elevating issues in the political context
- It makes the organisation more reputable/trusted in communities – particularly perhaps within minority groups



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Issues of Sensitivity

- Some areas/identities may be more sensitive than others for a variety of reasons
- Sensitivity is very much to do with context
- Think about how to ask questions in sensitive areas
- Remember: What may be sensitive to you, isn't necessarily sensitive to everyone. And vice versa, of course!
- People from 'minority' identities are potentially less likely to be 'sensitive' – and therefore feel sensitivity – about those identities



Our Learning and Experiences

- The more familiar people are with the process of data monitoring and collection, the greater the return rates. Researchers become more confident to ask the questions. Respondents become more aware of why completion is important
- The credibility of an organisation can increase, as can related issues of confidence and trust
- Providing assistance and guidance on how to understand and complete a form can have advantages
- Always include a 'Prefer Not to Say' option. Some areas may be more sensitive to individual people than others
- Tell people that the information they provide can have an impact on improving things



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Our Learning and Experiences

- Provide reassurance on data collecting, handling, storing and confidentiality issues (e.g. Data Protection Act 2018)
- Think carefully not just about questions, but about the options you provide.
- Use up-to-date demographic data as one way of guiding you here.
- If possible, go beyond the categories included in the Census 2021. Make things more up-to-date and relevant to your local demographics
- Ask relevant questions about language needs
- Be led by what the data tells you. Be aware of the dangers of confirmation bias
- Have a positive and pro-active outlook to equality monitoring and data collection.



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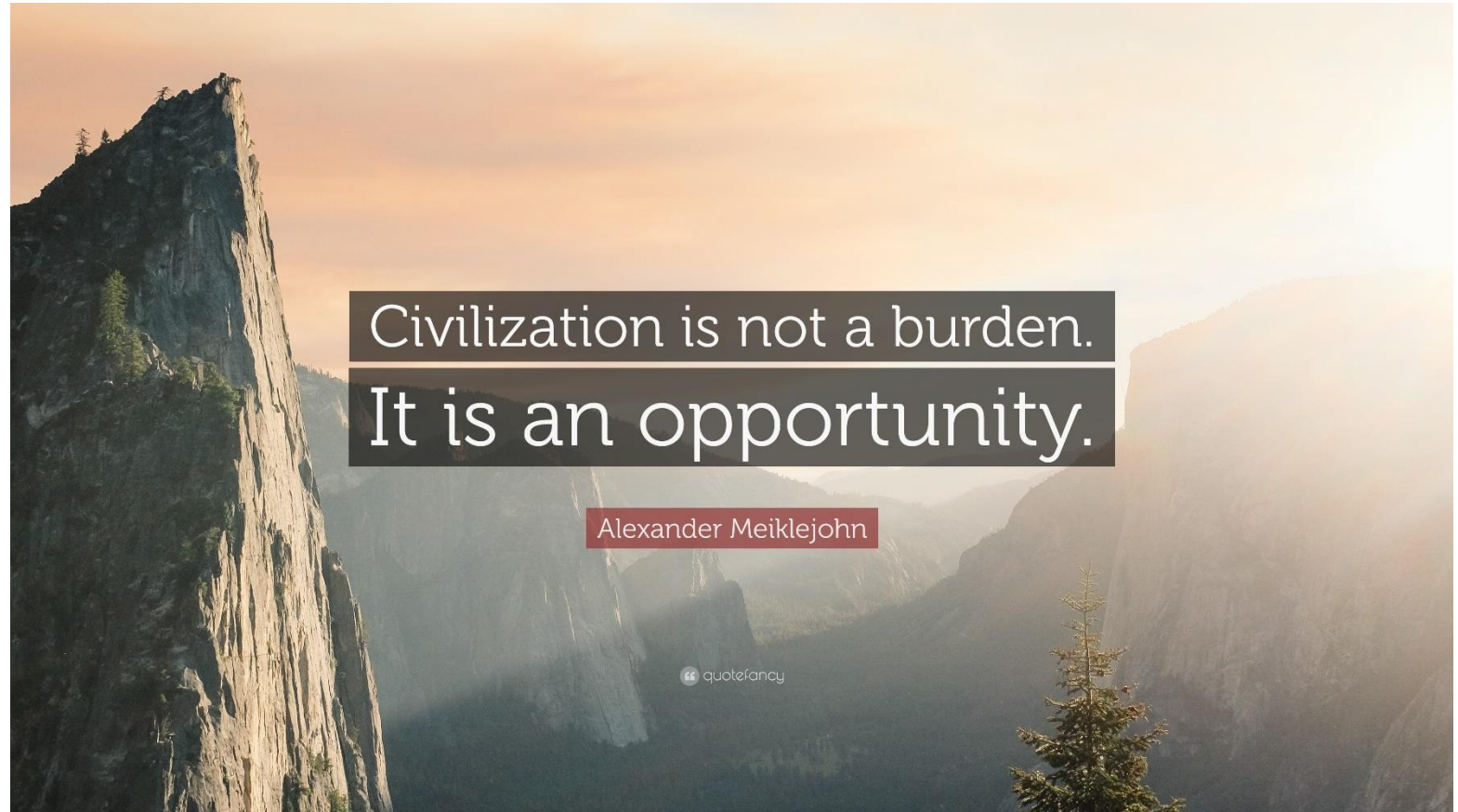
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A Change of Mindset

Data capture as
an 'opportunity',
not a 'burden'



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ARC EM Equality Monitoring

- Since 2019 ARC-EM has implemented an equality monitoring form.
- All ARC-EM funded studies are asked to collect data from their participants on:
 - age, gender, sexual orientation, pregnancy and maternity, marriage and civil partnership, religion and belief, refugees and asylum seekers, ethnicity, language, disability, caring responsibilities, geographic location.

Equality Monitoring Form

We recognise that the population of the East Midlands is diverse and changing. However the health and social care services we produce from our research may not always benefit everyone fairly. Minority communities are often overlooked at the research stage, leading to fundamental disparities in service. Completing this Form will help us to ensure that our work is fair. It will also help us meet the requirements of the Equality Act 2010.

While providing answers is voluntary, the more open and comprehensive you can be, the fuller the picture we create, thus benefiting the work we do to improve health services across the region. Your information will be anonymous, and kept confidential and private, though we may use the data from this Form for producing statistics, monitoring our work and planning our future research.

Age

- Under 16 16-19 20-29 30-44 45-59 60-74
 75 and over Prefer not to say

Gender

- Male Female Intersex Non-binary Prefer not to say

If you prefer to use your own term, please describe below

Do you identify as the same gender identity you were assigned to at birth?

- Yes No Prefer not to say

Sexual Orientation

What is your sexual orientation?

- Asexual Bi/bisexual
 Gay man Gay woman/lesbian
 Heterosexual/straight Pansexual
 Prefer not to say Prefer to self-describe (please describe below)



Feedback on Equality Monitoring

- Not all studies collected data on all 12 characteristics.
- This was related to inclusion criteria, participant choice, and suitability of questions to the population.
- For example, for one study the sponsor pushed back due to capacity of the population and issues with proxy completion.
- Most studies provided the data as summary descriptives.



Collecting the Data

- Some staff may lack the knowledge, confidence or cultural competence to collect equality monitoring data.
- There may be concerns from patients, service users and staff that data might be used to assess eligibility to receive public services.
- There is a need for standardised guidance and training.



Training

We shall be developing a new training module based around the issue of equality monitoring data in research, so WATCH THIS SPACE!



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Facilitated Discussion / Questions & Answers

Facilitated by the
Centre for Ethnic Health
Research Team



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Thank You and Close

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The National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) East Midlands is a partnership between Nottinghamshire Healthcare NHS Foundation Trust and the Universities of Nottingham and Leicester



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