

Engaging with *hidden?* voices



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1 NO POVERTY



2 ZERO HUNGER



3 GOOD HEALTH AND WELL-BEING



4 QUALITY EDUCATION



5 GENDER EQUALITY



6 CLEAN WATER AND SANITATION



7 AFFORDABLE AND CLEAN ENERGY



8 DECENT WORK AND ECONOMIC GROWTH



9 INDUSTRY, INNOVATION AND INFRASTRUCTURE



10 REDUCED INEQUALITIES



11 SUSTAINABLE CITIES AND COMMUNITIES



12 RESPONSIBLE CONSUMPTION AND PRODUCTION



13 CLIMATE ACTION



14 LIFE BELOW WATER



15 LIFE ON LAND



16 PEACE, JUSTICE AND STRONG INSTITUTIONS



17 PARTNERSHIPS FOR THE GOALS



(United Nations 2015)

Structural barriers
in research

EQUALITY VERSUS EQUITY



In the first image, it is assumed that everyone will benefit from the same supports. They are being treated equally.



In the second image, individuals are given different supports to make it possible for them to have equal access to the game. They are being treated equitably.



In the third image, all three can see the game without any supports or accommodations because the cause of the inequity was addressed. The systemic barrier has been removed.

NIHR-INCLUDE
No single definition for an under-served group. Some key characteristics are:

Lower inclusion in research than one would expect from population estimates

High healthcare burden that is not matched by the volume of research designed for the group

Important differences in how a group responds to or engages with healthcare interventions compared to other groups, with research neglecting to address these factors



Demographic Factors

- Age extremes (e.g. under 18 and over 75)
- Women of childbearing age
- Different ethnic minority groups
- Male/female sex (depending on trial context)
- LGBTQ+ / sexual orientation
- Educational disadvantage

Groups by Health Status

- Mental health conditions
- People who lack capacity
- Cognitive impairment
- Learning disability
- People with addictions
- Pregnant women
- People with co-morbidities
- Physical disabilities
- Visually/ hearing impaired
- Too severely ill
- Smokers
- Obesity

Social and Economic Factors

- People in full time employment
- Socio-economically disadvantaged/ unemployed/ low income
- Military veterans
- People in alternative residential circumstances (e.g. migrants, asylum seekers, care homes, prison populations, traveller communities, the homeless and those of no fixed abode)
- People living in remote areas
- Religious minorities
- Carers
- Language barriers
- Digital exclusion/disadvantage
- People who do not attend regular medical appointments
- People in multiple excluded categories
- Socially marginalised people
- Stigmatised populations
- Looked after children

Groups by Disease Specific Factors

- Rare diseases and genetic disease sub-types
- People in cancer trials with brain metastases

Research Methodologies – what can we learn from other approaches?

There is a domination of western- centric frameworks in research and this can lead to ‘blaming individuals’ for their experiences rather than challenging the structural and cultural aspects (Gobena et al., in press) which reinforces negative stereotypes (Wilson et al., 2019).

We can learn from Indigenous methodologies considering

- culture
- language
- religious protocols
- worldviews
- relationality
- co-creation
- translation of findings into actions to promote social justice
- different ways of dissemination

Challenges

- Preparation and training of researchers follows a largely western centric approach, yet our research is often international and may not follow this
- Need to consider positionality and address power dynamics
 - especially in nurse led research and power and prestige associated with our role
- Participation Information forms
- Participant consent forms (especially regarding literacy)
- Ethical approval panels and frameworks
 - Overly cautious approach, focus on vulnerability/deficits rather than strengths which can deny citizenship and rights of participation
- Perspectives regarding appropriately reimbursing participants (esp. unfunded research linked to educational programmes)
- University processes for reimbursing participants (presumption that people have internet, even bank accounts), payment in advance or proxy payments (vouchers)

The invisibility of invisibility of certain groups in reviews

PROGRESS-Plus framework

Equity extension to PRISMA to help identify, extract and synthesize evidence on equity in reviews

But not part of the PRISMA guidance itself

PROGRESS

- **P**lace of residence
- **R**ace/ethnicity/language
- **O**ccupation
- **G**ender/Sex
- **R**eligion
- **E**ducation
- **S**ocio economic status
- **S**ocial Capital

PLUS

- personal characteristics associated with discrimination (e.g. age, disability)
- features of relationships (e.g. smoking parents, excluded from school)
- time-dependent relationships (e.g. leaving the hospital, respite care, other instances where a person may be temporarily at a disadvantage)



Where Now??

In our role as the largest health professional group and as advocates for the people we work we need to consider

- ✓ working with individuals and communities rather than researching on....
- ✓ importance of PPI at each stage of the research process
- ✓ challenging ethical procedures which can compound inequity
 - ✓ Template Participant information forms which are complex and unwieldy
 - ✓ Re-educate ethical panels and examine the diversity of these
- ✓ developing more creative research methodologies/research practices that are inclusive
- ✓ critical reflexivity
- ✓ need to address power dynamics
- ✓ the environment in which we undertake research
- ✓ how to develop more inclusive methods of dissemination

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