

What we need to do to improve equality, diversity and inclusion in health research

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Inclusion problems: e.g. cognitive impairment

- A 2020 review found exclusions of people with cognitive impairment are seen in areas such as geriatrics, rehabilitation interventions after **hip fracture**, learning disabilities, peri-operative medicine, trauma and neurological research (<https://doi.org/10.1016/j.cct.2020.106054>).
- 'In this review [**of hip fracture**], 29 (82.9%) trials excluded potential participants based on cognitive impairment. This criterion does not seem appropriate as one in three patients with hip fracture have cognitive impairment.'



What to do: four steps

1. Think about who needs to be involved in the research.
2. Make sure your design allows the people in #1 to be involved.
3. Monitor and evaluate how you do.
4. Report your results in light of who was involved.

All of the above have a role for public contributors.



Step 1: who to involve?

Researchers have traditionally thought more about how many rather than *who* needs to be in our trials and other health research.

Instead, think about who are the people who could benefit from the results of your research? Who has something to gain?

You will need targets (more later..)



Step 1: who to involve?

Identifying who you need can be hard. We'd like data, and often those data are not to be found.



For ethnicity, there is some guidance from the STRIDE project at <https://www.trialforge.org/trial-diversity/how-to-decide-which-ethnic-groups-your-trial-needs/>



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Step 2: how to involve?

If you know that you need to involve e.g., people experiencing socioeconomic disadvantage, your design needs to reflect this.

If your design looks like the last one you did, the research is highly unlikely to be as diverse as it needs to be.



Step 2: how to involve?

There are tools to help e.g., the Equality Impact Toolkit (ARC East Midlands), or the NIHR INCLUDE Socioeconomic Disadvantage Framework.



There is very little robust evidence of strategies that improve involvement of historically under-served groups.

As a starter though, think about changes to improve:

Trust – Communication – Convenience



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Step 3: how are we doing?

Once you get going, you need to monitor how you are doing. This is why you need targets.

Monitoring means being prepared to take action, up to and including stopping recruitment of some people to allow recruitment of others.



Step 3: how are we doing?

Have a look at the ILANA trial protocol, a UK HIV trial (<https://bmjopen.bmj.com/content/13/7/e070666.long>) .

'Sites were selected based on research experience and on willingness to agree to a proactive recruitment strategy **with the application of caps**. Weekly reporting is distributed via a newsletter to all sites with a detailed breakdown of age, gender and ethnicity of participants recruited and **uses forecasting to monitor recruitment.**'



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Step 4: reporting

We all need to get better at reporting a) who should be in the research compared to b) who was in the research and **what are the implications of any differences.**



Step 4: reporting

This too is tricky. You could look at PRO EDI (<https://www.trialforge.org/trial-diversity/pro-edi/>)

This gives guidance on what information to collect re. diversity and how to interpret your results with regard to applicability.



Step 4: reporting (from PRO EDI)

Narrative statement	
Home fall-hazard reduction interventions may reduce the rate of falls	
Treatment effect size	GRADE assessment
RaR = 0.74 (95% CI = 0.61 to 0.91)	Low (-1 level: study limitations- six of 12 studies high RoB and four uncertain RoB; -1 level: inconsistency)
Populations to whom the GRADE assessment applies	Older people (especially women) in urban and high-income settings. The certainty of the evidence is likely to be lower for other populations.
From 12 studies (Campbell 2005; Chu 2017; Cockayne 2021a; Cumming 1999; Day 2002; Lannin 2007; Lin 2007; Lockwood 2019; Nikolaus 2003; Pighills 2011; Stark 2021; Stevens 2001).	

Result

To whom does the result apply?



Summary

1. Think about who needs to be involved in the research.
2. Make sure your design allows the people in #1 to be involved.
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