Research inclusion as a condition of funding

Emma Hadfield-Hudson, NIHR Research Inclusion Manager

Dr Nicola Hopkins, NIHR Research Inclusion Manager

Dr Rebecca Barnes, Senior Research Advisor & EDI Workstream Lead, NIHR Research Support Service (RSS)

Dr Christopher Newby, Senior Researcher Advisor, NIHR Research Support Service (RSS)

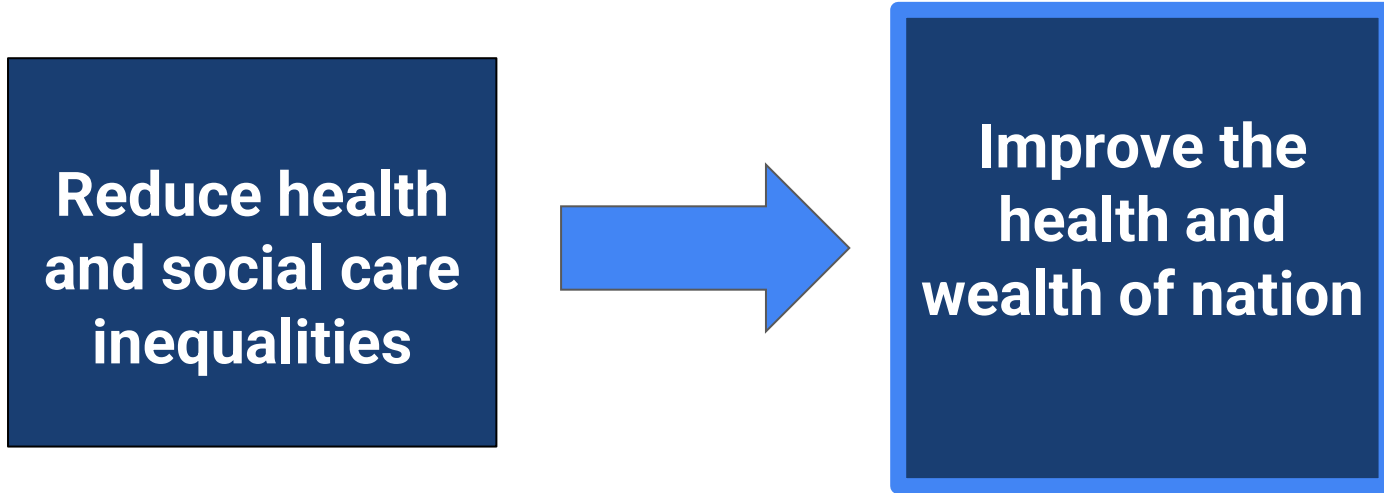Watch the recording of the session

Session aims

To understand:

- why NIHR are making the changes

- changes to the NIHR funding and award management processes

- what inclusive research entails

- where to seek further information and guidance

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The case for inclusive research

NIHR's mission

Reduce health and social care inequalities → Improve the health and wealth of nation

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Research is not currently serving those most in need

Participants aren't those who need research most (Bower et al, 2020)
- Participants in heart failure research: 20 years younger than patients
- Participants in diabetes research are not ethnically diverse

This results in problems, including:

- benefits and side effects of research may not translate to real-world populations or settings
- new treatments, services or initiatives may not be deliverable or applicable to all groups
- important findings specific to different populations may be overlooked
- health inequalities are maintained or increased

Why?
Research is not designed and conducted inclusively

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Example: Racial bias in pulse oximetry

1970s — **Pulse oximeter developed**

Pulse oximeter technology was originally developed and tested in non racially diverse populations

2019 — **Widespread use**

Applications have expanded to include a huge range of clinical and at home applications, and are used heavily in diagnostics and determining treatments

2020 — **Racial bias in pulse oximetry measurement**

Black patients were almost 3 times more likely to have undetected low oxygen levels than white patients (Sjoding et al, 2020)

2024 — **Racial bias confirmed**

Systematic review confirms pulse oximetry can overestimate oxygen levels in people with darker skin tones.
The clinical relevance of this bias remains unclear

Why are NIHR introducing inclusion as a condition of funding?

Design research inclusively → Reduce health and social care inequalities → Improve the health and wealth of nation

Inclusive research improves:

Scientific rigour
Using a diverse sample increases the accuracy, translatability and reproducibility of research

Patient safety & health outcomes
Treatments, services and initiatives may be ineffective or harmful if differences between groups are not defined

Economic Impact
Less research waste and improved practice and health outcomes translate into positive economic impacts at individual and population levels

Human rights and ethics
There is a moral imperative to ensure that NIHR's research benefits all people in society and fulfills everyone's right to health and social care

Legal justification
Research that is not inclusive can constitute discrimination under the Equality Act 2010

Adapted from MESSAGE Project

Overview of NIHR changes

Inclusive research as a condition of funding - timeline

2024/25	2025/26	2026/27
Roll out to all domestic programme awards	Global Health approach	Full roll out to all Infrastructure awards
Infrastructure pilot	Explicit requirements re sex and gender	Finalise ethnicity approach
	Engage with the sector re accounting for ethnicity	

Summary of new process requirements

There are **2 KEY** features of the strategic change:

1. That inclusive research design becomes an explicit condition of funding

2. That applicants are required to specifically cost for these inclusive design components

Applies to **Domestic awards, all programmes (from late Nov 2024***)*

The following processes will be impacted and have been amended accordingly:

Standard Application Form	Applicant guidance	Reviewer & committee forms/criteria	Monitoring	Publications
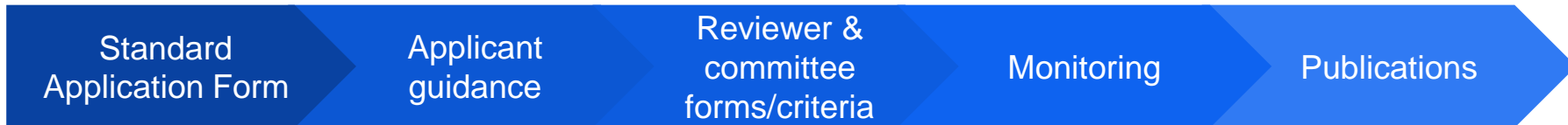
Standard Application Form (SAF)

Personal / career development awards:

Applicants **<u>must</u>** describe inclusion training needs relevant to their award in **the training plan**

- consider inclusion within the training plan (programme specific)
- training costs included

Applicants should describe inclusion training, skills, knowledge and experience in narrative CVs

Standard Application Form (SAF)

Awards with a research component:

Applicants **must** describe inclusive design across the research lifecycle in **the research plan**

Outline application (Stage 1)
- the Research Plan must address inclusion in the background, target sample and exclusions
- costings included in the overall cost figure

Full application (Stage 2)
- the detailed research plan must address inclusion in the whole research lifecycle
- costing included in the Application Budget - Research Inclusion costing line

What do we mean by inclusive design across the research lifecycle?

Critical review of each step in the research design process through an inclusion lens
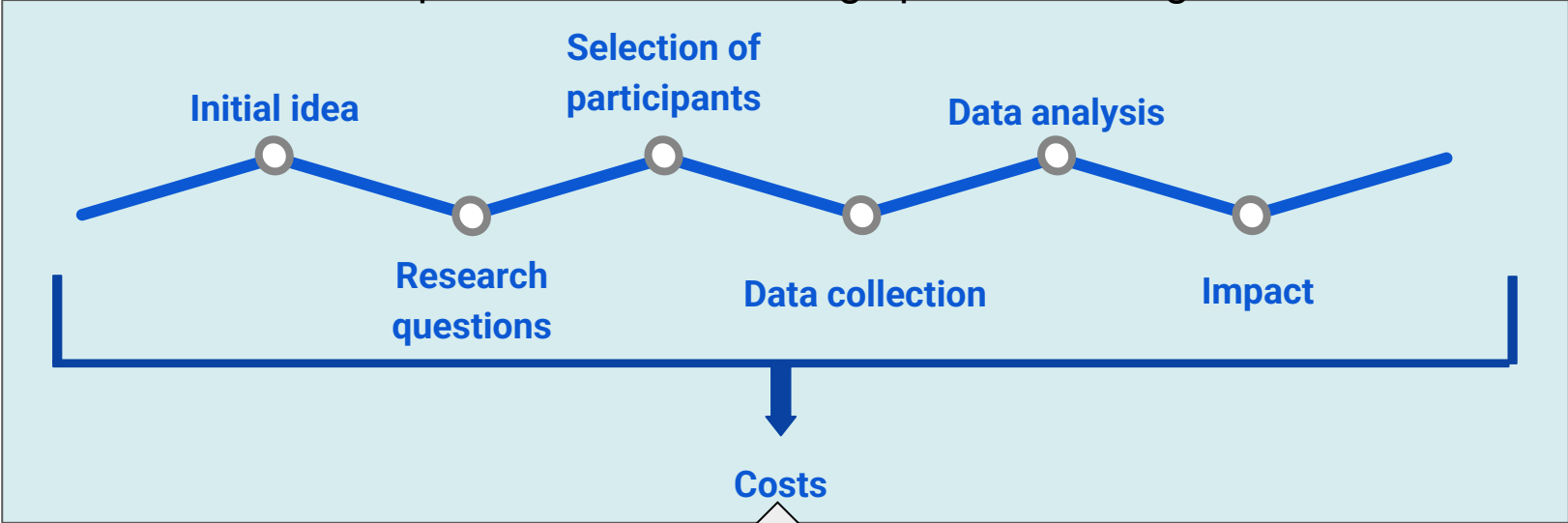
Applicant guidance

- Brief guidance included in the application at stages 1 and 2

- Full details of how to meet the requirements will be available via a dedicated web page (not live yet)

- Further support available via the NIHR Research Support Service (RSS)

Reviewers & committees

- **Reviewers and committee members**

  - New criteria

  - Training

  - Feedback

Monitoring

- To ensure compliance, post award, researchers will report on inclusion elements during the progress reporting mechanism

NIHR will:

- review the progress of research projects against their plan
- review any issues and their impact
- take a continuous learning approach and respond accordingly

Publications

- NIHR journals library have publication guidance for authors on inclusion and what to include
- Peer reviewer forms will also be reviewed and updated

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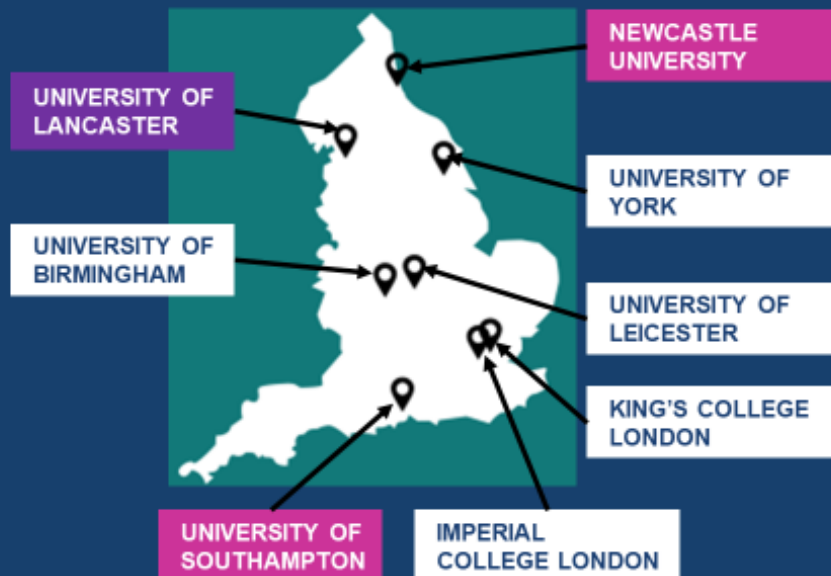
10 steps to inclusion across the research lifecycle

1) Substantiate your research inclusion statements

- Good intentions are not enough – how can you assure the funding committee that your proposals are realistic?

- What makes you confident that you can recruit from a particular under-served group (e.g. share your team's experience and skills)?

- Is your research team skilled enough to carry out research inclusion?

- *How* will your approach be inclusive?

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2) Ensure that you know which inequalities are relevant to your field

- Do prevalence, detection, prognosis, priorities, outcomes, service accessibility, use and experiences vary between groups?

- Whose outcomes, experiences and/or perspectives are absent in previous research?

- How is awareness of health or care inequalities driving your research question(s)?

3) Include areas under-served by research in your study

- Justify your choice of site(s)
- Where is the problem greatest but the research activity most sparse?
  - Use tools such as the CRN Research Targeting Tool or NHS Digital Adult Social Care Outcomes Framework. Regional Research Delivery Networks (RRDNs) can also offer support with this.
- Allow more time for the set-up of less research-ready sites

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4) Justify your research sample

- Are your exclusion criteria justifiable?

- Will you need specific services, skills or devices to make sure people are included?

- How will you capture the EDI characteristics of your sample?

5) Specify which demographic data you will collect and how you plan to use it

- People are usually willing to provide this data – if they understand why and how it'll be used

- Caution around terminology – draw on diverse PPI and resources such as EDIS' DAISY guidance

- For quantitative studies, consider including subgroup analyses

- For qualitative studies, use demographic data to contextualise the analysis, code for diversity dimensions – caution with anonymity

6) Budget for inclusion!

- Clearly specify all costs for inclusive research, and justify them

- Our RDS EDI Toolkit gives examples of the cost and time implications of genuinely inclusive research

- Re-calibrating understandings of value for money

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7) Consider how methodological innovation could overcome exclusionary aspects of conventional methods

- Participatory and creative methods e.g. art-based methods, photovoice
- Training peer/community researchers
- Community-based recruitment
- Remote or community-based monitoring for trials

8) Demonstrate how your research is shaped by diverse and inclusive patient and public involvement and engagement (PPI)

- Work with members of the public and communities to embed research inclusion at each stage of your project

- Consider the diversity of your PPI

- Identify potential barriers to meaningful involvement, and take steps to address these

How to incorporate Equality, Diversity and Inclusion (EDI) in Patient and Public Involvement (PPI)

Being inclusive in public involvement in health and care research
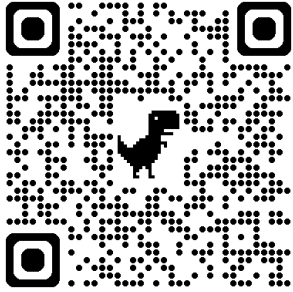
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9) Plan inclusive and impactful approaches to knowledge mobilisation

- Knowledge mobilisation and impact plans are essential and should include diverse groups from the outset

- Key messages from your research need to be useful, impactful, and accessible to relevant people, networks and communities

- A pathway to impact should be included, and could include health and social care inequalities

10) Use the resources available to help you

RDS EDI Toolkit

- [Contact the RSS](#) for further support

Historical Context and Structural Inequality	Data Collection
Public Involvement	Data Analysis and Presentation
Research Team	Dissemination, Implementation and Impact
Selection of Participants, Sites and Samples	Budgeting for Inclusion

https://www.rssleicesterresources.org.uk/edi-toolkit
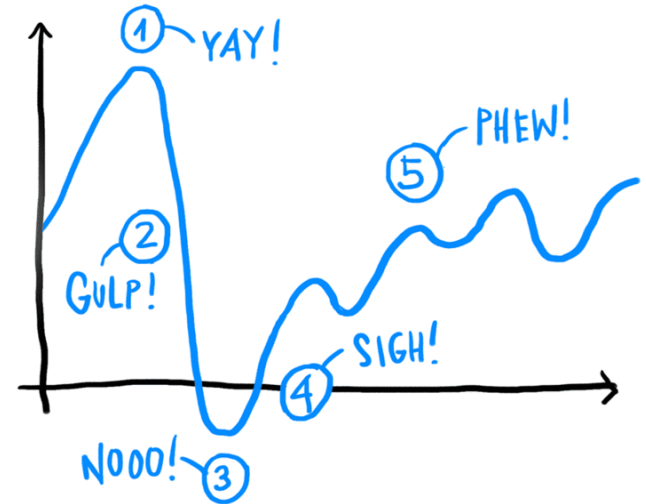
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Final points

How much detail do I put in my application?

- There will be a learning curve

- Differentiation between application stages

- Impossible to cover all groups and all inclusion issues

- There will always be compromises in design eg costs, time, feasibility etc

- Design choices should be justified and appropriate for the target population

- Proportional approach

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Where to access further resources and support

NIHR Research Support Service (RSS)

www.nihr.ac.uk/support-and-services/research-support-service

EDI Toolkit

www.rssleicesterresources.org.uk/edi-toolkit

NIHR Learn: NIHR Research Inclusion Toolkits Hub

https://learn.nihr.ac.uk/

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Thank you for attending