Considering Equality, Diversity and Inclusion within research projects

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Adapted to be shared online including notes and links.

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Safer Space Policy

**Ethos**

It is our responsibility to create spaces, both offline and online, that are welcoming and respectful to everyone. Adhering to these agreements is a collective responsibility and everyone is individually responsible for checking their own behaviour.

This policy aims to enable participants to enjoy, participate in and contribute to EDIS events. It exists to ensure that individuals do not feel harassed or uncomfortable in participating.

Participants who do not adhere to these rules will be asked to stop and expected to comply immediately. Participants may be removed from any meeting or communications at the discretion of the organisers/moderators if this behaviour continues. If you are being harassed/intimidated, notice that someone else is being harassed/intimidated, or have any other concerns, please contact the organisers/moderators immediately.
Safer Space Policy

EDIS explores concepts relating to equality, diversity and inclusion of individuals and underrepresented groups. This may include age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex or sexual orientation or any other aspect of diversity not included as a protected characteristic by the Equality Act 2010.

Addressing and promoting equality, diversity and inclusion in research provides the opportunity to make research better and more relevant to all members of society. This approach to seek diversity is not to use differences to further marginalise groups without/with less power or those who experience systemic exclusion. We must also be conscious to not conflate biological concepts (e.g. genetics) with social/cultural constructs and labels (e.g. race).

London, England | edisgroup.org | Joined April 2017

www.edisgroup.org

Mailing list:

Practical tools and guidance

Here you’ll find practical tools or guides that will help with planning, implementing, or evaluating projects and programmes to improve EDI in science and health research.

Our latest practical tools and guidance

- EDI Toolkit
- EDI Resource Bank – Initiatives
- National Institute for Health Research – INCLUDE Framework
- Anti-racism and Allyship in the Workplace & Brief Guide
- Diversity and Inclusion Survey (DIS) Quick Guide – 1
- The NuRI FOCUS DISCOVER Cookbook
- 14 Sep 2020
- Disability awareness and planning for accessibility
- A guide for everyone—planning, managing, and implementing strategies to ensure a feasible environment for people with a disability. How to plan an accessible and inclusive event and design appropriate strategies for accessibility with UK disability regulations.
- 22 Feb 2021
- EDI Resource Bank – Initiatives
- This database includes initiatives from Higher Education establishments (HEIs) to support and encourage equal opportunities and inclusion in the workforce. It includes current information on projects and schemes that are designed to improve EDI within organisations and institutions.
- 16 Apr 2020
- The INCLUDE Ethnicity Framework
- The INCLUDE Ethnicity Framework aims to help organisations think carefully about which ethnic groups should be included in their workforce policies. These guidelines suggest steps organisations can take to identify, measure, and improve the skills of their employees.
- 04 Feb 2020
- Inductive name change policy for publishers (question checklist)
- This guiding opinion, developed with support from SHERPA and the Law Society, allows publishers to define the steps they need to identify, investigate, and implement inductive name change policies. Please use the updated version 4 (published February 2021).
- 27 Aug 2020
- The INCLUDE Disability Framework
- This document provides a framework for organisations to determine the inclusivity of their workplace policies and procedures. It helps to identify and address barriers that may prevent employees with disabilities from accessing opportunities and roles.
- 14 May 2020
- National Standards for Public Involvement in Research
- These standards provide a framework for public involvement in research and ensure that involving the public is an integral part of the research process, from planning to dissemination.
Vision: For everyone to have equal opportunities and access to a successful career within Science or Health, its research and its outcomes.

Mission: EDIS will build a powerful, connected and coordinated movement to advance equality, diversity and inclusion in Science and Health research.

Desired impact: Equal and better science and health outcomes
Notes: Our theory of change has been developed to help guide our actions and with an understanding that systemic change is needed. The three themes outlined below interact in a complex system and no single action will improve EDI in all, but a collective multifaceted approach is required.

A lot of organisations, driven by clear needs from the diversity demographic data they collect, will initially or solely focus on who is doing research. However the perspective of EDIS is that this one part of the wider research system as a whole and who is involved in research, how it’s done and who benefits from it all feed into this complex system.
EDIS Member Aims

Inclusive research and experimental design
- Capacity building and training
- Research questions and priorities
- Health inequalities
- Patient and public involvement

Inclusive conferences and events
- Speaker selection
- Venue accessibility
- Best/good/emerging practice
- Experimentation
- Online accessibility

Notes:
The COVID-19 pandemic has shone a light on inequalities and barriers that already exist within research, and how to improve accessibility to events, work spaces and even data. What we learn from this pandemic could be how the actions and policies we put in place for emergency equitable assessments of research, careers, outputs can be used as a permanent fixture of the STEM sector. We have an opportunity get this right by reviewing what has and hasn’t been successful in this high stress crisis moment. You can read more in EDIS’s contribution to the APPG on Diversity in STEM – enquiry into equity in the STEM workforce.

COVID-19 has also been a clear example of how research needs to be inclusive and representative. Interventions and policies should involve the communities they are trying to help impact in order for them to succeed. Research gets taken up into healthcare, interventions and policies. As part of this, researchers might not always be in control of how their research is used or interpreted, so need to make sure they both research and present the full picture.
Promotes excellence in research, creativity in innovation, and improves social equalities (1)

Research funded by tax-payer monies should benefit everyone (2)

Research funded by the charity sector should aim to reduce inequalities (3)

It is recognised as good research practice although not applied consistently globally (4)
What do we mean by inclusive research design?

- An understanding and awareness of elements of ‘difference’ that can affect research outcomes
- A consideration for the impact research could have on people, society, healthcare, policy etc
- Differences could be biological or social/cultural
- You may be able to include analysis of these differences or have to note them as a caveat to your work

Sex, Gender and/or Diversity Analysis (Sex, Gender and/or Diversity Analysis)
Notes:

Research isn’t done in a vacuum.

Research is done by people in a complex system with real world influences and impacts.

It is easier to see when research hasn’t been inclusive through the impacts on people: racist soap dispensers or AI image tagging; sexist algorithms and translators, drugs removed after FDA approval due to harmful side effects seen in women; People with learning disabilities dying at higher rates from preventable diseases due to health inequalities in part driven by exclusion from health and social care intervention development; differential vaccine uptake amongst different communities; people with mobility impairments unable to get preventative health screenings such as mammograms; and international development schemes causing more long term harm than good to communities when equitable partnerships are not developed.
Non-inclusive research design

Simpler?
Costs less?

Inclusive research design

Improves reproducibility
Reduce research ‘waste’
Low hanging fruit
Reduces inequalities & improves applicability
Notes:

• Tools will often steer you in the right direction, but the will also identify knowledge gaps. This might mean you would look to engage an advisor, researcher or consultant who can represent a community, needs gap or similar to help you with that part of your research design.

• There are also elements of design you can implement to make your research process accessible to as many people as technically possible (‘Universal Design’ and ‘Design for All’ approaches).

• It is normally impossible to design accessibility for every individual with a single approach though – there can be conflicts in accessibility needs. However, do not rely on ‘lazy’ exclusion criteria e.g. all disabled people.

• You can develop more than one method or design configuration of the research process for where this might happen (‘Inclusive Design’ philosophy is a helpful approach).

• You can also consider equitable outcomes – and design research that focuses on accessibility/outcomes for an underserved group.
Tools: Designing for people

https://intersectionaldesign.com/

Intersectional Design Cards
These cards are designed to help teams explore, analyze, and invent inclusive design solutions.

Why?
- Navigate assumptions and biases
- Integrate intersectional thinking into your product
- Course correct
- Identify new markets and business opportunities
- Build an equitable, sustainable, and just society

How?
- To start a conversation
- To critique your product, process and/or organization
- To brainstorm ideas

https://cardsforhumanity.idean.com/
Tools: Checklists

These could be research call specific, or diversity characteristic specific. It’s about finding the right fit for your research

[UK Research and Innovation]
[Things to consider: incorporating gender equality into international development research and innovation]

- Understanding gender and gender equality
- Have you understood that your concepts of gender, norms, roles and values may vary across members of your project team, research and innovation participants and beneficiaries?
- Have you understood the different norms and values of gender depending on the context of your research and/or innovation?

- Equal opportunities and meaningful contributions
- Is there or is there a plan to work towards a gender balance in the project team at all levels? If not, why?
- Are there equal opportunities for persons of different gender in the recruitment of the project team?
- Are all members of the project team involved in the design and delivery of the research and/or innovation? By that we mean providing equality of opportunity for people of different genders and across intersecting axes of difference?

- Research and innovation content
- If the research and/or innovation involves human or human physiology, does the relevance of gender to the research question and/or innovation topic been addressed?
- Have you considered this impact on the welfare between people of different genders, and of the same gender? For example, changing roles and responsibilities in households, society, economy, politics, etc.?

- If the research and/or innovation involves human or human physiology, is there a gender balance? If not, why?
- If you have reviewed literature and other sources (such as experts/networks within local context) relating to gender differences in the research and/or innovation field?
- Have you considered how to disaggregate any data you collect by gender?

- Dissemination and impact of your research
- Have different audiences, outputs and impacts of the research and/or innovation been identified based on gender and gender differences?
- Have you considered how you will disseminate your research and/or innovation in a way that is gender-responsive? For example, the use of gender-sensitive language.

[Inclusive Research Practice Process for Autism Research]


Tools: Case studies

http://genderedinnovations.stanford.edu/case-studies-engineering.html
Tools: Toolkits

TOOLKIT FOR:
INCREASING PARTICIPATION OF BLACK ASIAN AND MINORITY ETHNIC (BAME) GROUPS IN HEALTH AND SOCIAL CARE RESEARCH

https://www.hiat.org.uk/

December 2018
NIHR CLAHRC North West Coast Health Inequalities Assessment Toolkit (HIAT)

“The toolkit has four sections:

1. helps you to clarify the inequalities associated with the health problem you want to tackle, and to identify the socio-economic causes of these inequalities.
2. helps you consider how you can plan your work to address some of the socio-economic causes of inequalities identified in section 1.
3. aims to make sure that you monitor or evaluate the effect of your activity on health inequalities and their socio-economic causes.
4. asks you to consider how your activity will have effects on the socio-economic causes of health inequalities that you are not directly considering.

Each section includes the following:
• An explanation of its purpose;
• Questions to help you carry out an assessment of your planned work;
• Questions to make sure you involve appropriate members of the public in all aspects of your work (this is required by our steering board);
• Resources such as readings, real HIAT assessments, films and activities providing more information about issues covered in the section.

In each section, the toolkit questions are applied to a hypothetical outline proposal to evaluate an intervention to increase the uptake of health checks. This example aims to show how using the toolkit could increase the potential for this intervention to reduce health inequalities.”
Notes:

Increasing participation of Black Asian and Minority Ethnic (BAME) groups in health and social care research

“This toolkit aims to capture such best practice and provide researchers with a framework on how to improve the participation of BAME groups in research.

The toolkit should help researchers develop more relevant research questions, consider engagement of BAME groups in a more structured way, and provide tips on better participation and dissemination of research findings.

The toolkit covers:

• Section 1: Consideration of the communities which your research needs to involve.
• Section 2: Undertaking effective patient and public involvement (PPI) in research
• Section 3: Conducting effective recruitment in BAME communities
• Section 4: Ensuring cultural competency in the conduct of your research
• Section 5: Providing effective feedback to research participants
• Section 6: Recognising the importance of recruiting BAME communities in research: preparing a grant application
• Top Tips”
Tools: Training

Notes:

Online Training Modules: Integrating Sex & Gender in Health Research (CIHR)

“Take these training course to learn how to:

• Distinguish between and define sex and gender in health research;
• Identify sex and gender differences in the mechanism, disease or treatment under study;
• Identify methods for integrating sex and gender variables in health research contexts; and
• Assess a research protocol or publication based on the integration or omission of sex and/or gender.”

https://cihr-irsc.gc.ca/e/49347.html
Being Inclusive in Public Involvement (PI) in Health Research:

Things to think about: for researchers and practitioners

“A diverse and inclusive public involvement community is essential if research is to be relevant to population needs and provides better health outcomes for all. We have been struck by the degree to which researchers and public contributors have encountered barriers when trying to work with different communities and populations. This suggests a system-wide issue that needs considered and careful attention.” (NIHR Going the Extra Mile 2015).

What are some of the things to think about to become more inclusive in public involvement in health research? How do we develop inclusive research communities?

This document has evolved from an original piece created by Bella Starling and is intended to be a helpful series of prompts for researchers, and for those whose job it is to support public involvement in health research (practitioners). This document was compiled from the INVOLVE Diversity and Inclusion Group’s collective experience as the evidence base is at an early stage. We hope that public contributors to research will find it useful too.

Things to think about

1. Check your power

Notes:

“The guidelines are a comprehensive procedure for reporting of sex and gender information in study design, data analyses, results and interpretation of findings.

The use of the guidelines by authors and reviewers, their adoption by editors as gatekeepers of science, and their respect by funders all contribute to integrating the assessment of sex and gender into manuscripts as an integral part of the editorial process.”

"The INCLUDE Ethnicity Framework aims to help trial teams think carefully about which ethnic groups should be included in their trial for its results to be widely applicable, and what challenges there may be to making this possible."

https://www.trialforge.org/trial-forge-centre/include/
Policies and progress
Wellcome - Diversity, equity and inclusion strategy: Inclusive research design and practice

“By 2031, all Wellcome-funded research will be inclusive in both design and practice, to help drive better science and more equitable health solutions.”

UKRI - Gender equality statement for international development research and innovation

“It is mandatory for all applications to UKRI Global Challenges Research Fund (GCRF) and Newton Fund funding opportunities to include a gender equality statement.” [Future work is planned.]

NIHR - Better healthcare through more inclusive research

Clinical Trials - no mandate but roadmap in place through INCLUDE.

“INCLUDE is an initiative from the UK’s National Institute of Health Research (NIHR) that aims to improve trial delivery for under-served groups. This will improve the applicability of the trial results and be in line with Principle 13 of the Declaration of Helsinki (‘Groups that are underrepresented in medical research should be provided appropriate access to participation in research.’)”

NIHR will start to monitor inclusion through shared outcomes framework (signed off in November) and key indicators currently being trialled.
Department for Health and Social Care (UK Gov) - Clinical research: Create a patient-centred, pro-innovation and digitally-enabled research environment

“Patient-centred research – to make access and participation in research as easy as possible for everyone across the UK, including rural, diverse and under-served populations.”


“Patients and service-users must also be routinely involved in the design of clinical research, to ensure outcomes match their needs and studies are designed with real participants and the realities of their daily lives in mind … This will result in fewer people finding themselves left out of research planning, help to bolster participation amongst under-served and diverse groups, and help tackle the health inequalities.”

Horizon Europe

The integration of the gender dimension into research and innovation content (i.e. sex and gender analysis) has become a requirement by default across the whole programme (more information ‘Gendered Innovations’).


ERC Work Programme 2021: “Principal Investigators should also determine the relevance of integrating sex and gender analysis into their research. Specific activities promoting equal opportunities or gender balance or covering the gender dimension of research funded by the ERC can be considered as eligible costs where these costs are necessary for the implementation of the action.”
Global Review of Sex, Gender, and/or Diversity Analysis in Research Policies of Major Public Granting Agencies

(currently in data analysis stage)


Publishers:
Author and Reviewer Guidelines for Evaluating Sex and Gender Analysis in Manuscripts:

ARRIVE guidelines include sex reporting: https://arriveguidelines.org/arrive-guidelines/experimental-animals

Sex and Gender Equity in Research: rationale for the SAGER guidelines and recommended use: https://researchintegrityjournal.biomedcentral.com/articles/10.1186/s41073-016-0007-6
Notes: There are two key trends for inclusive research design progress 1) embedding it in expected good research practice and 2) development of directive policies and practices. Both are necessary and need to be aligned for progress as behaviour change is dependent on a multifaceted approach. Directive policies must be supported with training and support; good research practice and awareness must be incentivised.
Addressing and promoting equality, diversity and inclusion in research provides the opportunity to make research better and more relevant to all members of society. This approach to seek diversity is not to use differences to further marginalise groups without/with less power or those who experience systemic exclusion.
Solutions: what can you do and what can you ask for?

Notes: What will enable inclusive research design and practice?

Researchers are best placed to describe the barriers they face to inclusive research design, and the support and enablers they need to overcome these. Reach out to let us know!

https://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-6-42

http://www.behaviourchangewheel.com/