This work is licensed under a Creative Commons Attribution 4.0 International License.

Considering Equality, Diversity and Inclusion within research projects

Presented: 19th April 2021

Adapted to be shared online including notes and links.

Dr Lilian Hunt - EDIS Programme Lead
Wellcome
l.hunt@edisgroup.org

Equality, Diversity and Inclusion in Science and Health

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).

The Academy of Medical Sciences

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

BIOCHEMICAL SOCIETY

Babraham Institute

Daphne Jackson Trust

Benevolent AI

gsk

AstraZeneca

The Physiological Society

University of BRISTOL
Elizabeth Blackwell Institute for Health Research

THE FRANCIS CRICK INSTITUTE

BRITISH PHARMACOLOGICAL SOCIETY

EMBL-EBI

sfam society for applied microbiology

Royal Society of Biology

wellcome sanger institute

WELLCOME GENOME CAMPUS
CONNECTING SCIENCE

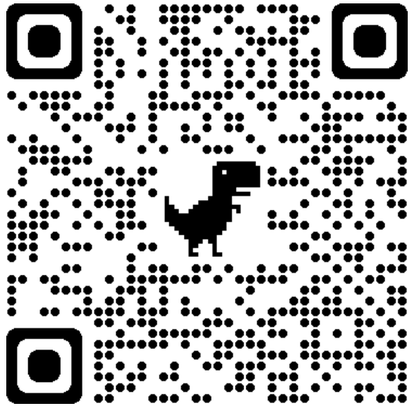
ELRIG UK

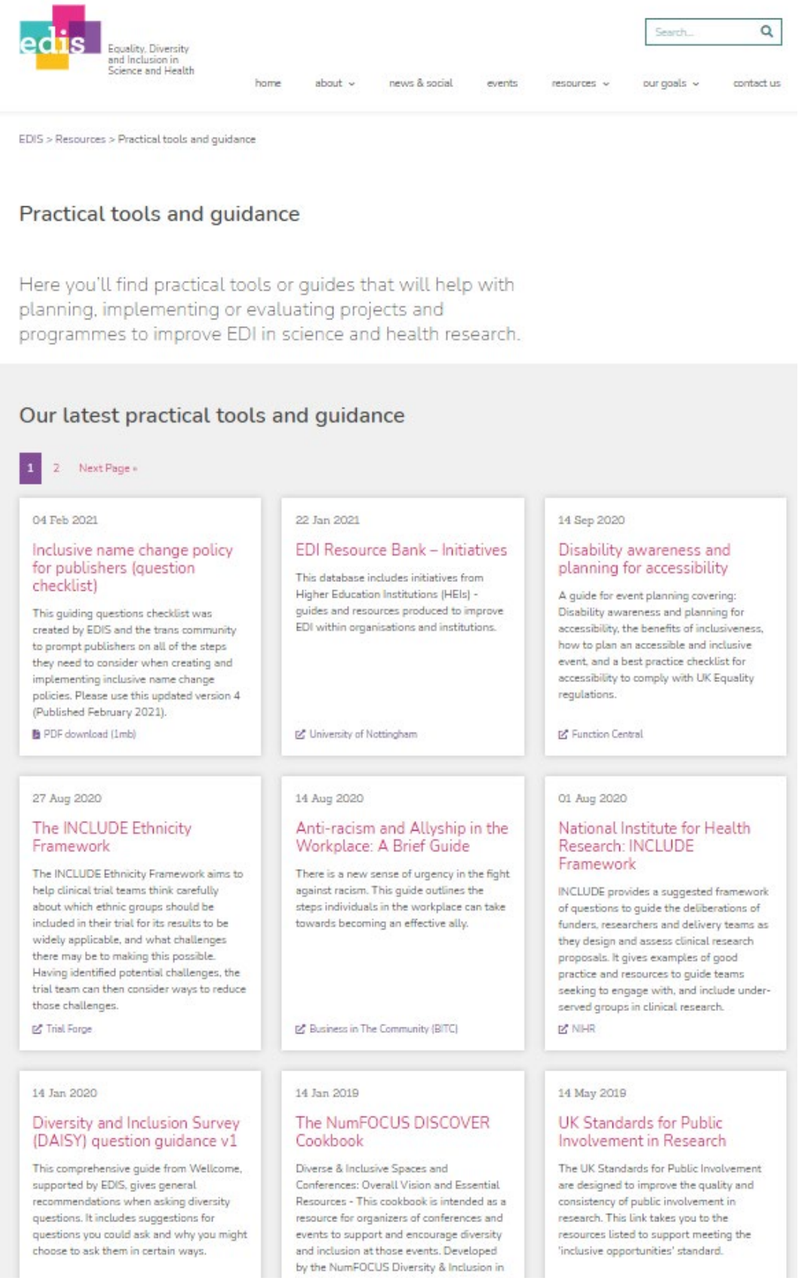
wellcome

edis
Equality, Diversity and Inclusion in Science and Health

www.edisgroup.org

Mailing list:





About Us

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

Equal opportunities and access to the **benefits of** Science or Health research

Who benefits from the research

Equal opportunities and access to **involvement in** Science or Health research

Who is involved in the research

Who is doing the research

Equal opportunities and access to a **successful career** within Science or Health

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

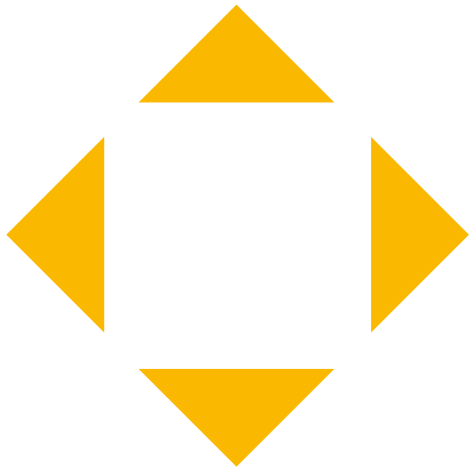
- Speaker selection
- Venue accessibility
- Best/good/emerging practice
- Experimentation
- Online accessibility

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.

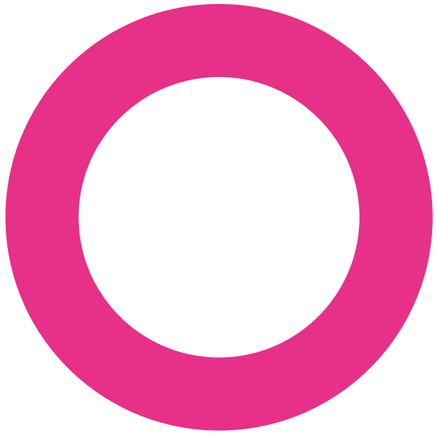
Considering Equality, Diversity and Inclusion in research projects: Why?

Promotes excellence in research, creativity in innovation, and improves social equalities (1)



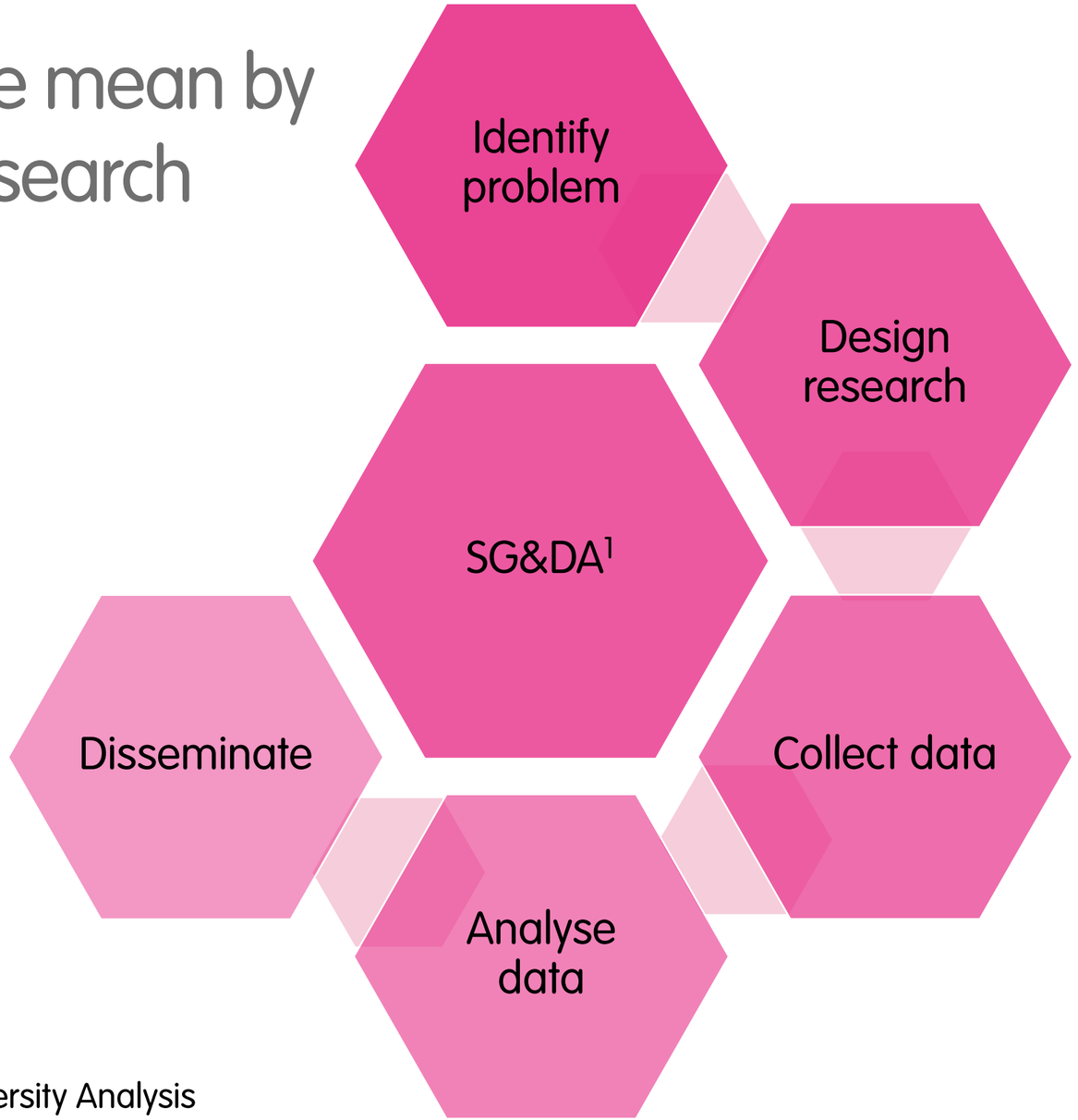
Research funded by tax-payer monies should benefit everyone (2)

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 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

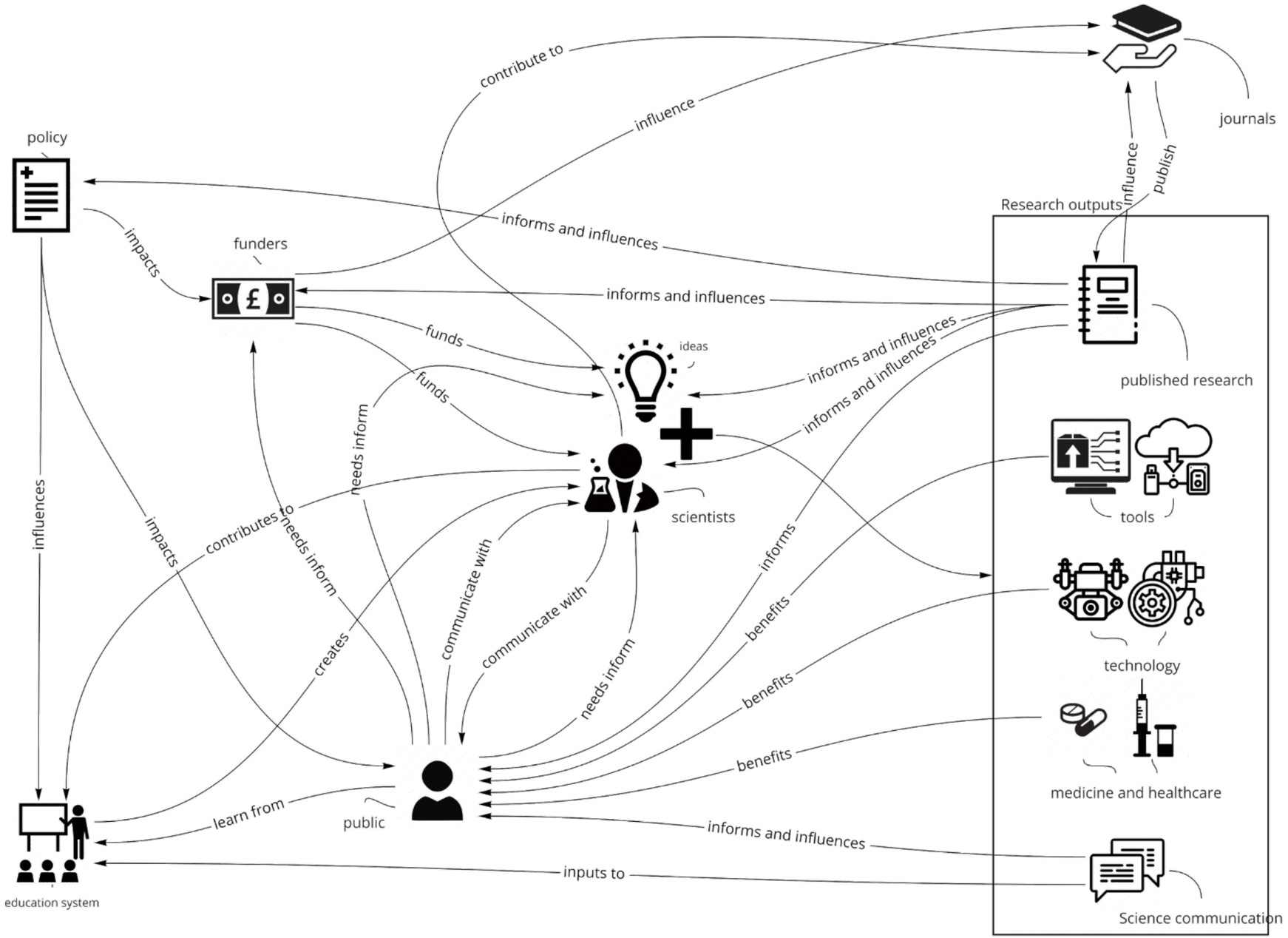
[1]Sex, Gender and/or Diversity Analysis

Notes:

Research isn't done in a vacuum.

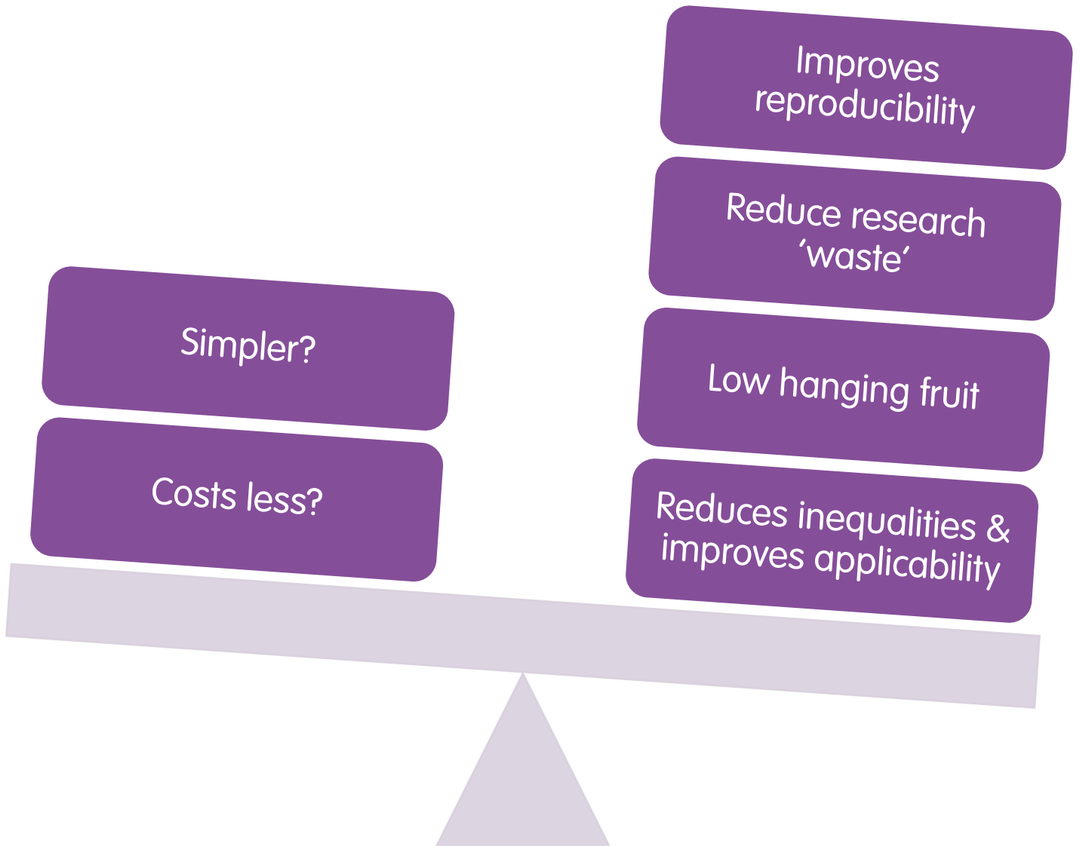
Research is done by people in a complex system with real world influences and impacts.

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

Inclusive research design

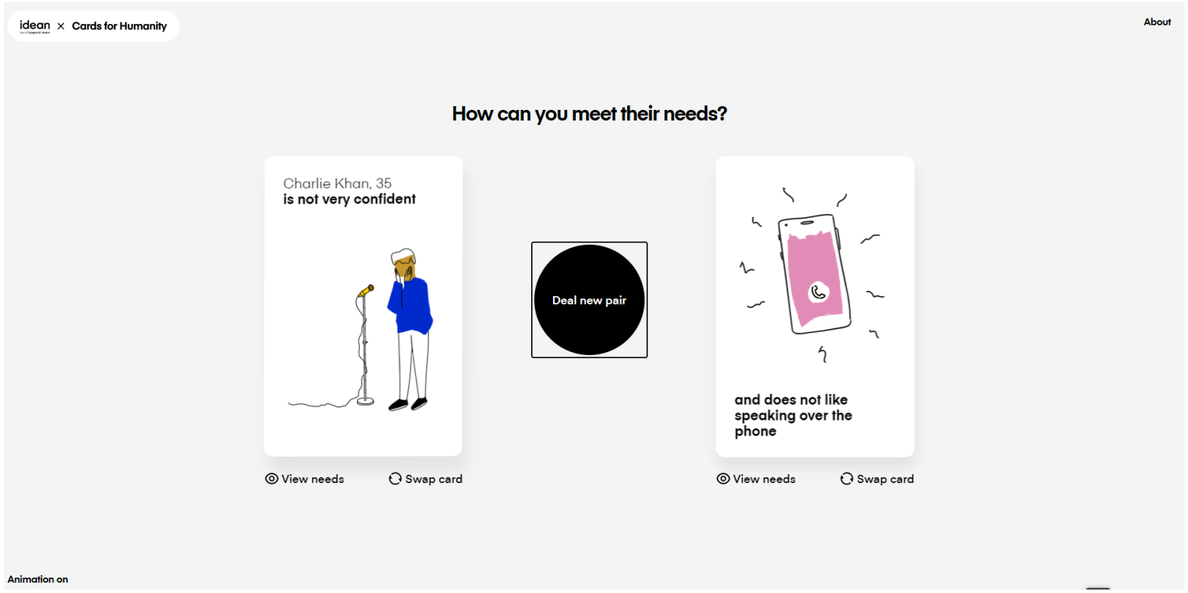


Tools: Designing research for people

Notes:

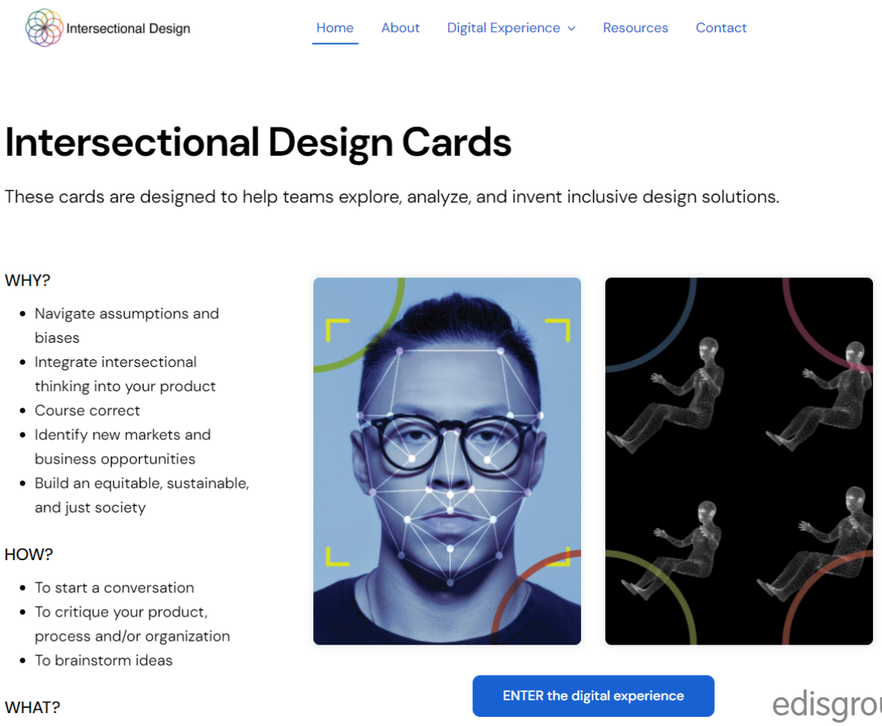
- Tools will often steer you in the right direction, but the will also identify knowledge gaps. This might mean you would look to engage an advisor, researcher or consultant who can represent a community, needs gap or similar to help you with that part of your research design.
- There are also elements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

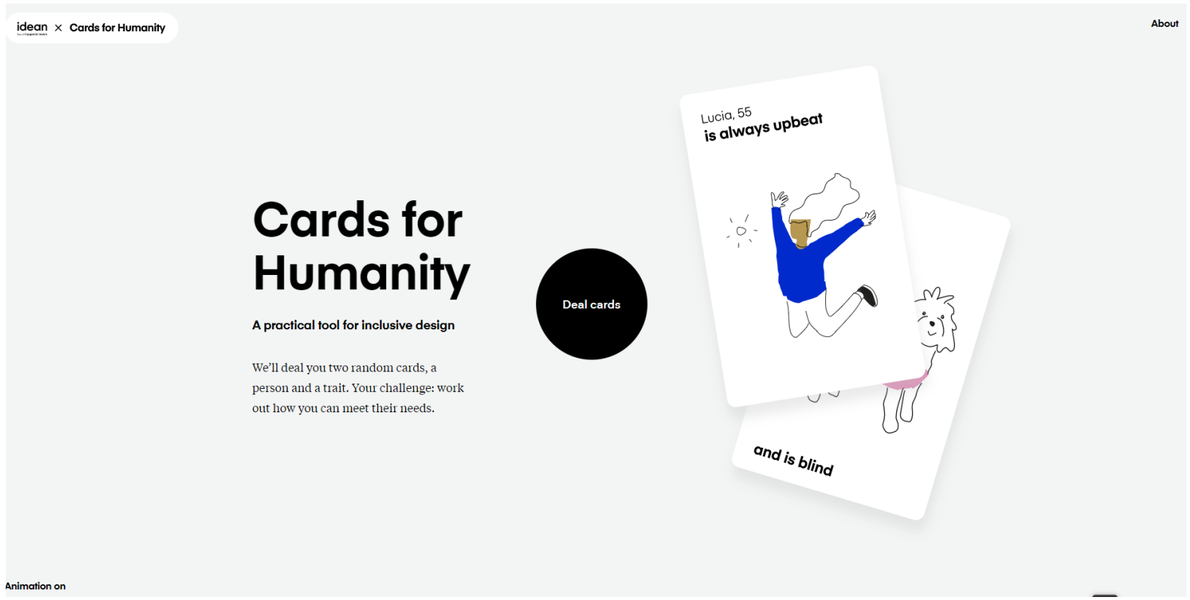
Tools: Designing for people



https://cardsforhumanity.idean.com/

https://intersectionaldesign.com/





Lilian Hunt, May 2021

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

GCRF Newton Fund

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 in a way that is providing equality of opportunity for people of different genders and across intersecting axes of difference[i]?

Research and innovation content

- ☐ If the research and/or innovation involves humans or human physiology, has the relevance of gender to the research question and/or innovation topic been analysed?
- ☐ Have you considered the impact on the relations 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 participants or human physiology, is there a gender balance? If not, why?
- ☐ Have you reviewed literature and other sources (such as expertise/networks within the 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 outcomes, 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-impartial language.

https://www.ukri.org/wp-content/uploads/2021/02/UKRI-250221-Things-to-consider-incorporating-gender-equality-into-international-research-and-innovation.pdf

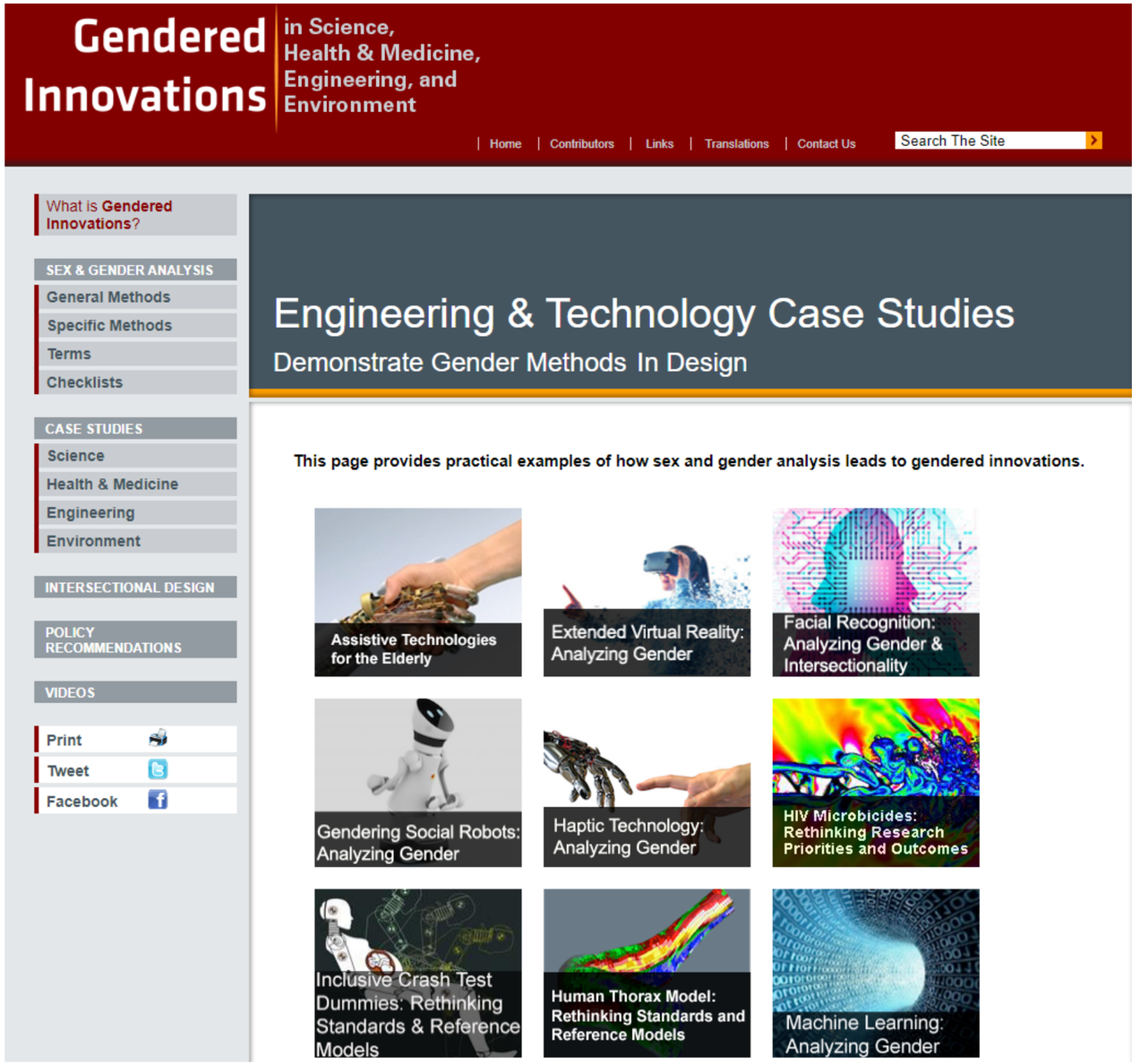
AutismCRC

Inclusive Research Practice Process for Autism Research

© Autism CRC 2016

https://www.autismcrc.com.au/knowledge-centre/resource/inclusive-research

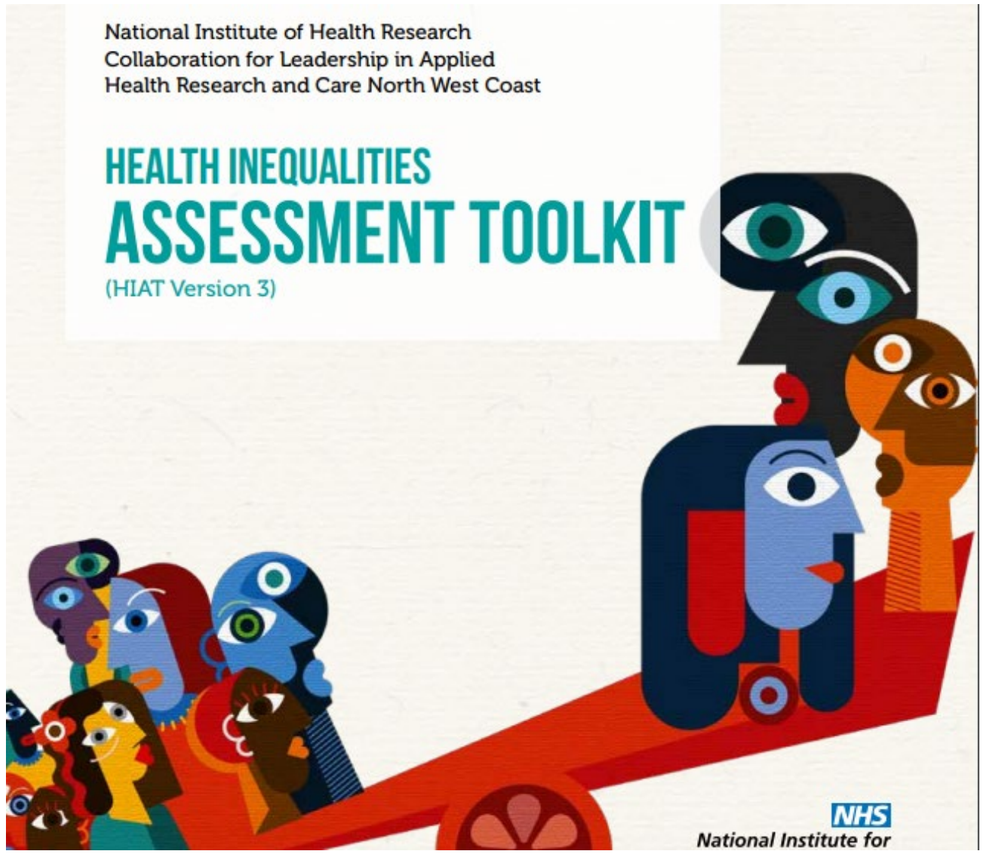
Tools: Case studies



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

Lilian Hunt, May 2021

Tools: Toolkits



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

TOOLKIT FOR:

INCREASING PARTICIPATION OF BLACK ASIAN AND MINORITY ETHNIC (BAME) GROUPS IN HEALTH AND SOCIA CARE RESEARCH

December 2018

https://arc-em.nihr.ac.uk/clahrcs-store/increasing-participation-black-asian-and-minority-ethnic-bame-groups-health-and-social

Tools: Toolkits

Notes:

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."

https://arc-em.nihr.ac.uk/clahrcs-store/increasing-participation-black-asian-and-minority-ethnic-bame-groups-health-and-social

Tools: Toolkits

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.

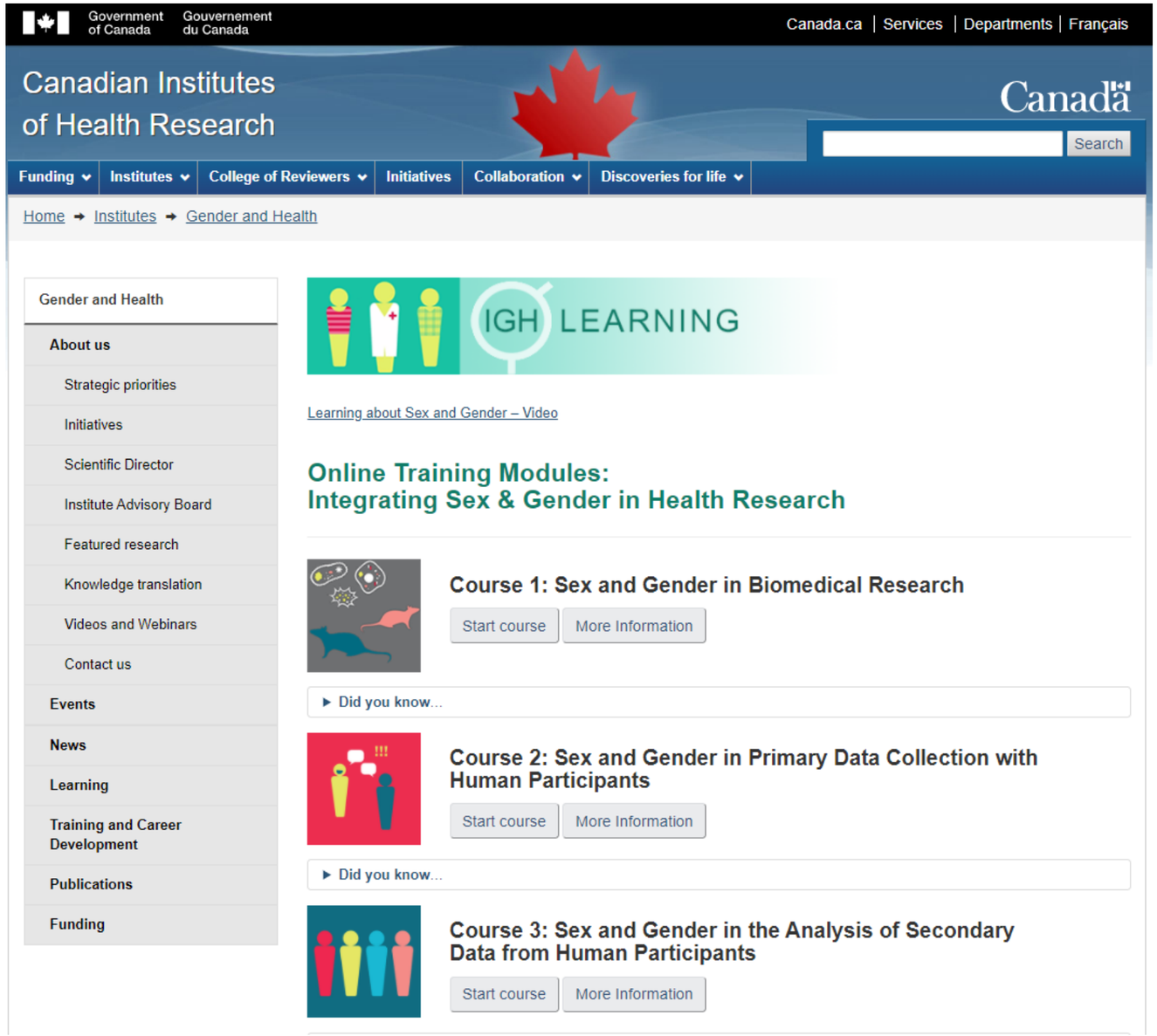
The toolkit covers:

- 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

Tools: Patient and Public Involvement tips

NIHR | INVOLVE

Public Programmes
People | Research | Dialogue
at Manchester University NHS Foundation Trust

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

https://edisgroup.org/being-inclusive-in-public-involvement-pi-in-health-research/

INVOLVE

NHS
National Institute for Health Research

Involving children and young people in research: top tips and essential key issues for researchers

"Never overlook comments from young people – they are unlikely to continue to contribute if you ignore their points" (young person)

Introduction

This is a short overview of the key issues on involving children and young people in NHS, public health and social care research. These have been developed by INVOLVE in response to requests from researchers for practical information on what they need to consider when involving children and young people in research.

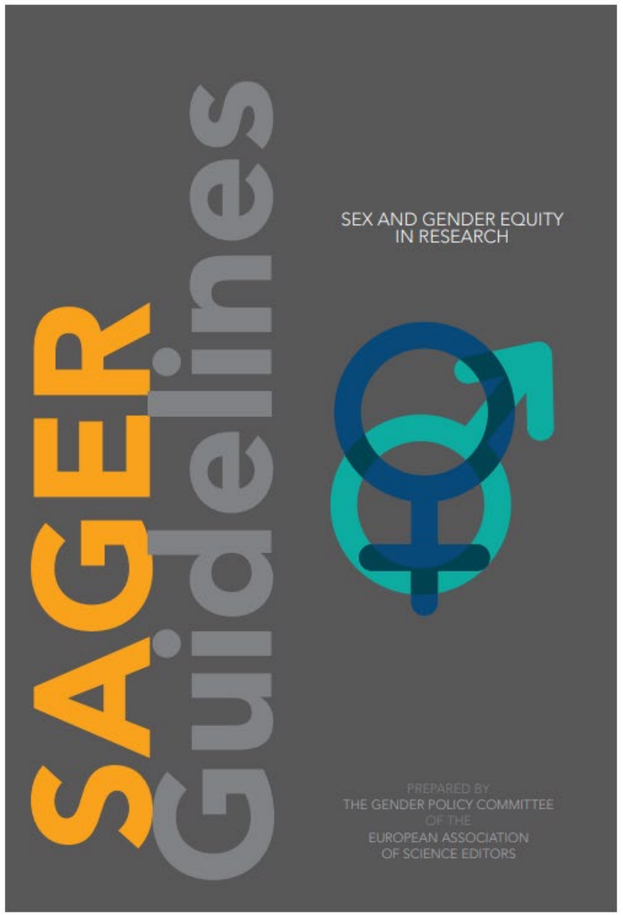
What is involvement in research? INVOLVE defines 'involvement' as research being carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them. This might include involving people in setting research priorities, design, carrying out the research, analysis, reporting and dissemination, rather than participating in research or in research education.

https://sites.google.com/nihr.ac.uk/pi-standards/resources-and-support#h.p_mW6c18EMITh

Tools: Publishing

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."



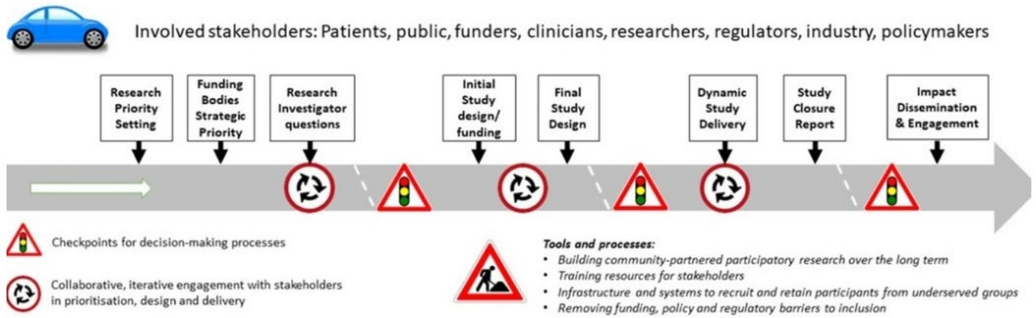
https://www.ease.org.uk/wp-content/uploads/2016/09/Sager.for-web.pdf

Lilian Hunt, May 2021

Tools: Frameworks (Clinical Research)

"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/



Core Objectives

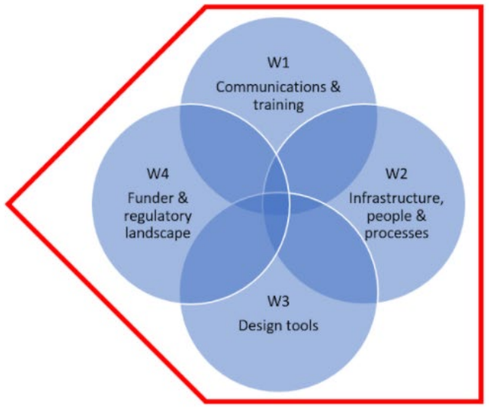
Develop *Community Partnered Participatory Research* building long-term relationships and opportunities for participation for underserved groups.

Develop tailored training resources to design & deliver trials for underserved groups.

Develop infrastructure & systems to reach, engage, recruit & retain underserved groups.

Work with funders, regulators and other stakeholders to remove barriers to including underserved groups in clinical trials.

Workstreams



NIHR INCLUDE: the framework, NIHR article and Trials Journal publication

Policies and progress

Notes

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."

https://wellcome.org/what-we-do/our-work/diversity-and-inclusion/strategy

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.]

https://www.ukri.org/about-us/policies-standards-and-data/good-research-resource-hub/equality-diversity-and-inclusion/

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.

Notes

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."

https://www.gov.uk/government/publications/the-future-of-uk-clinical-research-delivery/saving-and-improving-lives-the-future-of-uk-clinical-research-delivery

"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').

https://ec.europa.eu/info/sites/info/files/research_and_innovation/strategy_on_research_and_innovation/documents/ec_rtd_gender-equality-factsheet.pdf

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."

Notes

Gendered Innovations in Science, Health & Medicine, Engineering, and Environment

edis Equality, Diversity and Inclusion in Science and Health

SAGER Guidelines Sex and Gender Equity in Research

ARRIVE

Global Review of Sex, Gender, and/or Diversity Analysis in Research Policies of Major Public Granting Agencies

(currently in data analysis stage)

DOI 10.17605/OSF.IO/AGWY6 https://osf.io/hc29j/ in collaboration with Professor Londa Schiebinger of Gendered Innovations. Supported by an international advisory board of experts.

Publishers:

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

http://genderedinnovations.stanford.edu/sex-and-gender-analysis-policies-peer-reviewed-journals.html

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 have 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.

Prompt Questions

1. What could your research influence in society?

2. What elements of 'difference' could affect your research outcomes?

3. What elements of 'difference' could affect how your research is applied/received?

4. Who will your research benefit and who will it leave out?

5. Where to barriers exists to designing and practicing inclusive research?

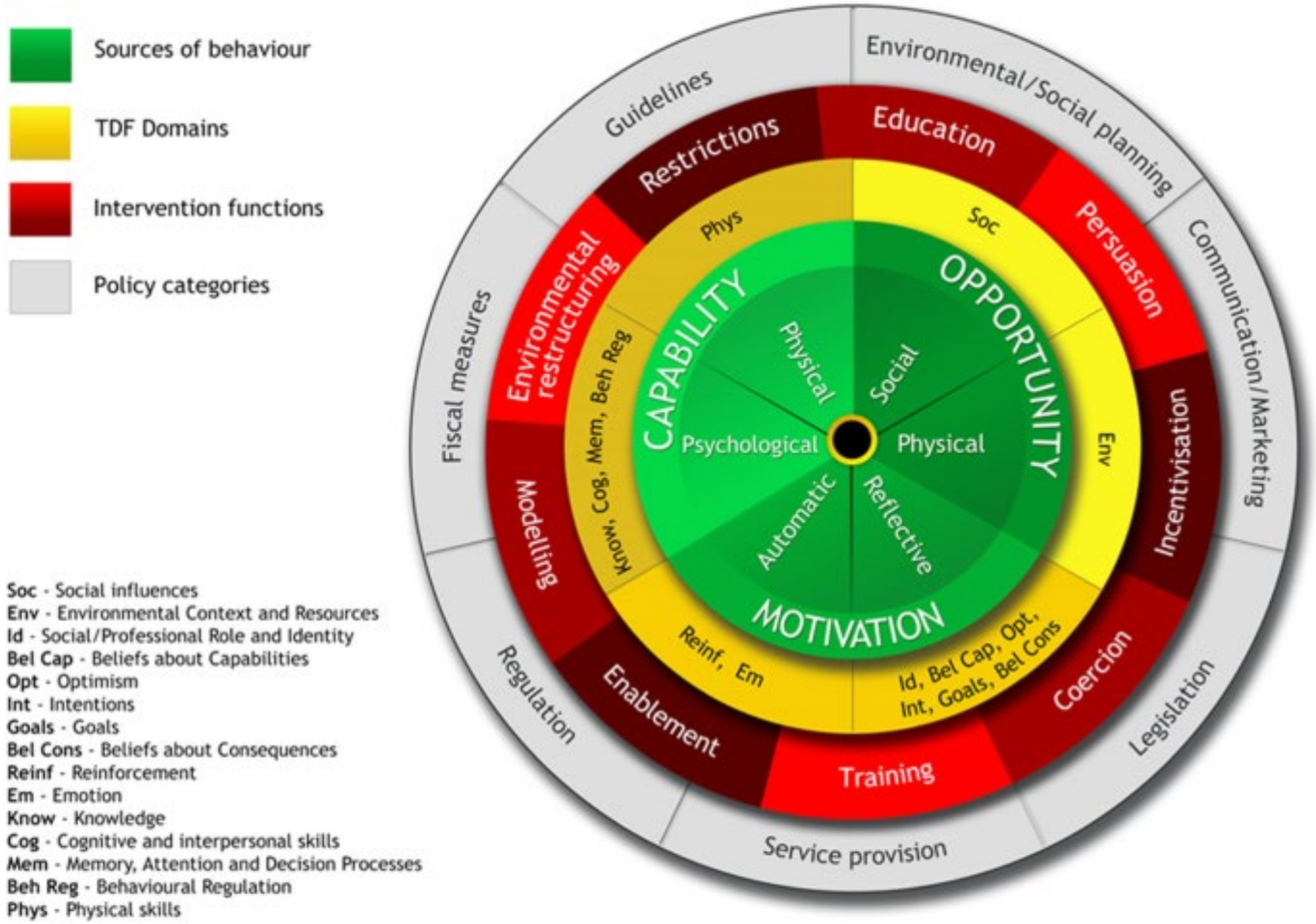
6. What barriers exist for participants to being included in research?

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!



Soc - Social influences
Env - Environmental Context and Resources
Id - Social/Professional Role and Identity
Bel Cap - Beliefs about Capabilities
Opt - Optimism
Int - Intentions
Goals - Goals
Bel Cons - Beliefs about Consequences
Reinf - Reinforcement
Em - Emotion
Know - Knowledge
Cog - Cognitive and interpersonal skills
Mem - Memory, Attention and Decision Processes
Beh Reg - Behavioural Regulation
Phys - Physical skills

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

http://www.behaviourchangewheel.com/