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# Considering Equality, Diversity and Inclusion within research projects

Presented: 19<sup>th</sup> April 2021

Adapted to be shared online including notes and links.

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Wellcome

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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).



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Equality, Diversity & Inclusion in Science and Health. #EDIS2019 for symposium coverage. Subscribe here: [eepurl.com/di3XmX](http://eepurl.com/di3XmX) | Archive: [bit.ly/3nAGyZZ](http://bit.ly/3nAGyZZ)

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**edis** @edisgroup · Apr 1

📖 We'd like to share the following set of reports and research on barriers faced by Black, Asian and people from minority ethnic backgrounds within health, research, academia and society. #RacismIsReal 1/10

💬 1 🔄 54 ❤️ 52 📤 📄

[Show this thread](#)

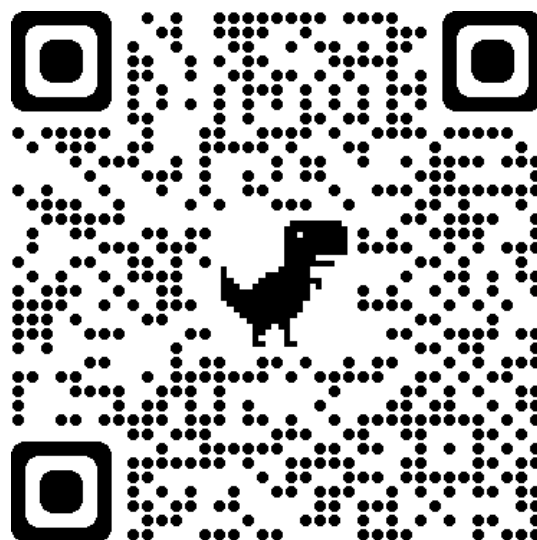
🔄 **You Retweeted**

**Inclusive Research Collective** @inclusiveRC · 7h

“We don't collect data from the patients' point of view”

[www.edisgroup.org](http://www.edisgroup.org)

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EDIS > Resources > Practical tools and guidance

## 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

1 2 Next Page >

<p>04 Feb 2021</p> <p><b>Inclusive name change policy for publishers (question checklist)</b></p> <p>This guiding questions checklist was created by EDIS and the trans community to prompt publishers on all of the steps they need to consider when creating and implementing inclusive name change policies. Please use this updated version 4 (Published February 2021).</p> <p>📄 PDF download (1mb)</p>	<p>22 Jan 2021</p> <p><b>EDI Resource Bank – Initiatives</b></p> <p>This database includes initiatives from Higher Education Institutions (HEIs) - guides and resources produced to improve EDI within organisations and institutions.</p> <p>📄 University of Nottingham</p>	<p>14 Sep 2020</p> <p><b>Disability awareness and planning for accessibility</b></p> <p>A guide for event planning covering: Disability awareness and planning for accessibility, the benefits of inclusiveness, how to plan an accessible and inclusive event, and a best practice checklist for accessibility to comply with UK Equality regulations.</p> <p>📄 Function Central</p>
<p>27 Aug 2020</p> <p><b>The INCLUDE Ethnicity Framework</b></p> <p>The INCLUDE Ethnicity Framework aims to help clinical 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. Having identified potential challenges, the trial team can then consider ways to reduce those challenges.</p> <p>📄 Trial Forge</p>	<p>14 Aug 2020</p> <p><b>Anti-racism and Allyship in the Workplace: A Brief Guide</b></p> <p>There is a new sense of urgency in the fight against racism. This guide outlines the steps individuals in the workplace can take towards becoming an effective ally.</p> <p>📄 Business in The Community (BTC)</p>	<p>01 Aug 2020</p> <p><b>National Institute for Health Research: INCLUDE Framework</b></p> <p>INCLUDE provides a suggested framework of questions to guide the deliberations of funders, researchers and delivery teams as they design and assess clinical research proposals. It gives examples of good practice and resources to guide teams seeking to engage with, and include under-served groups in clinical research.</p> <p>📄 NIHR</p>
<p>14 Jan 2020</p> <p><b>Diversity and Inclusion Survey (DAISY) question guidance v1</b></p> <p>This comprehensive guide from Wellcome, supported by EDIS, gives general recommendations when asking diversity questions. It includes suggestions for questions you could ask and why you might choose to ask them in certain ways.</p>	<p>14 Jan 2019</p> <p><b>The NumFOCUS DISCOVER Cookbook</b></p> <p>Diverse &amp; Inclusive Spaces and Conferences: Overall Vision and Essential Resources - This cookbook is intended as a resource for organizers of conferences and events to support and encourage diversity and inclusion at those events. Developed by the NumFOCUS Diversity &amp; Inclusion in</p>	<p>14 May 2019</p> <p><b>UK Standards for Public Involvement in Research</b></p> <p>The UK Standards for Public Involvement are designed to improve the quality and consistency of public involvement in research. This link takes you to the resources listed to support meeting the 'inclusive opportunities' standard.</p>

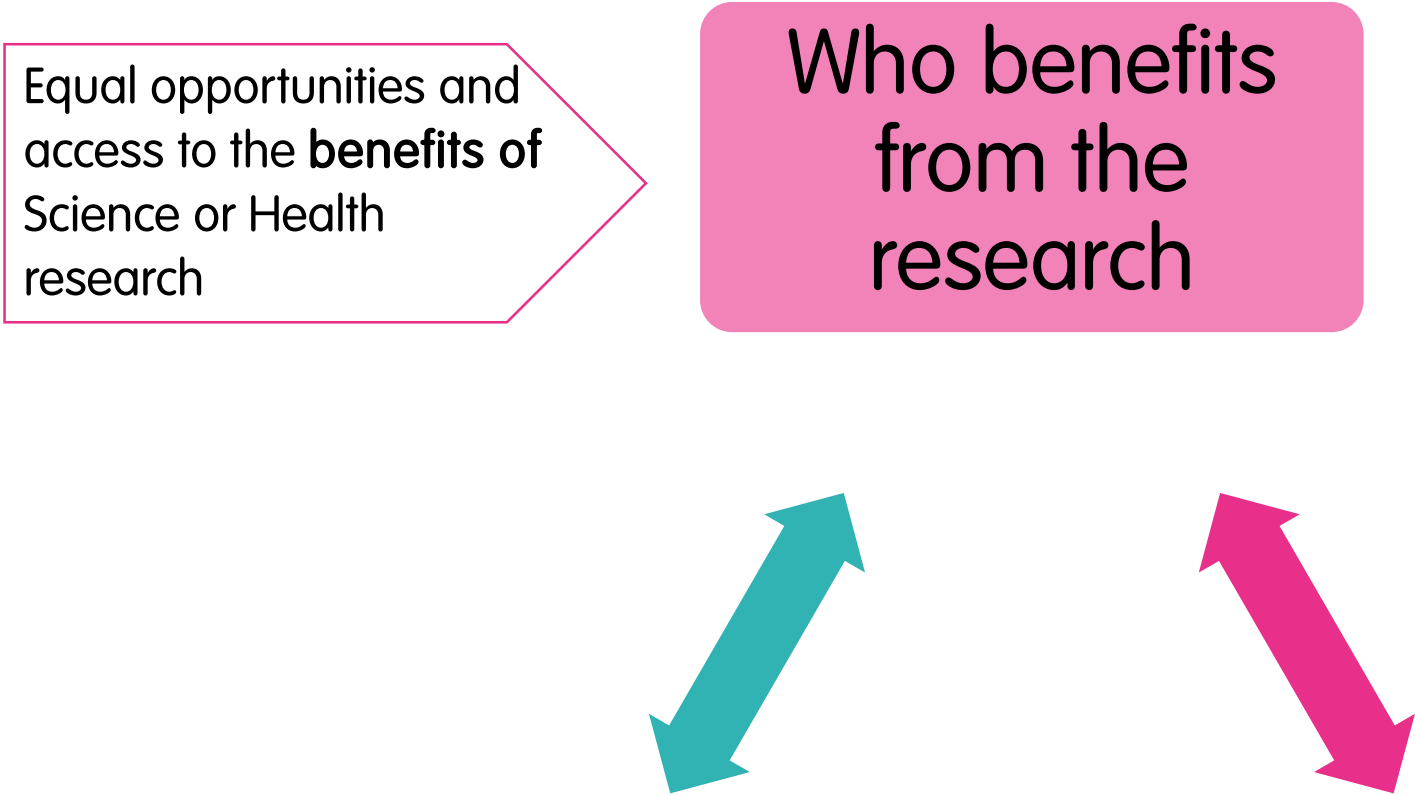
edisgroup.org | @edisgroup

# 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 **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](#).

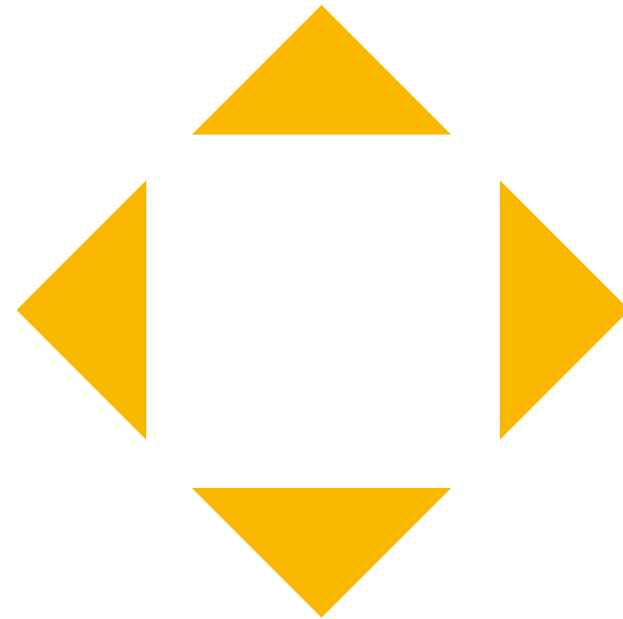
COVID-19 has also been a clear example of how research needs to be inclusive and representative. Interventions and policies should involve the communities they are trying to help impact in order for them to succeed. Research gets taken up into healthcare, interventions and policies. As part of this, 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?



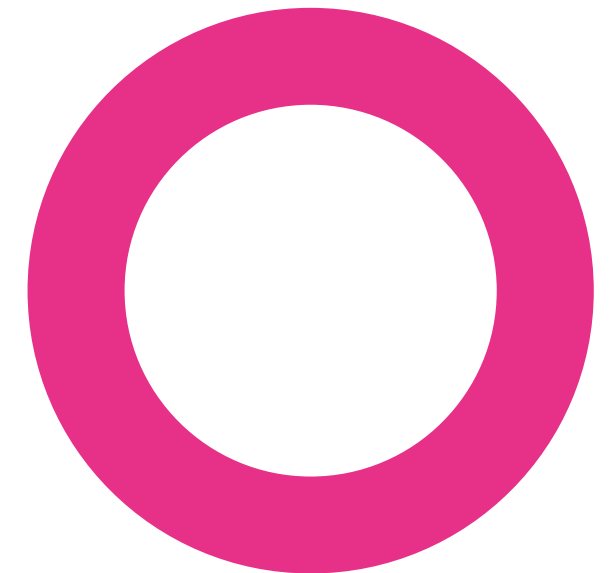
Promotes excellence in research, creativity in innovation, and improves social equalities [\(1\)](#)



Research funded by tax-payer monies should benefit everyone [\(2\)](#)

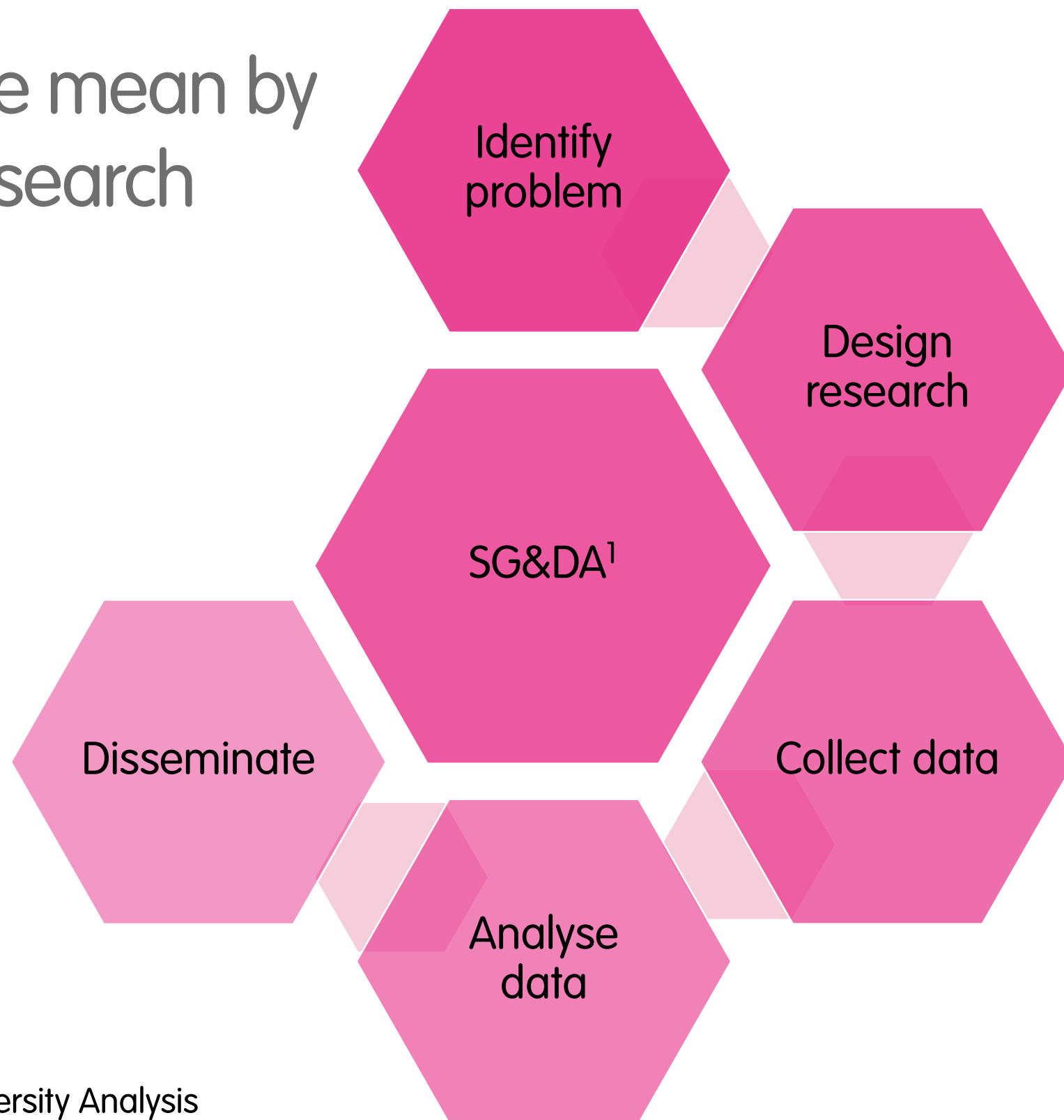


Research funded by the charity sector should aim to reduce inequalities [\(3\)](#)



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 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

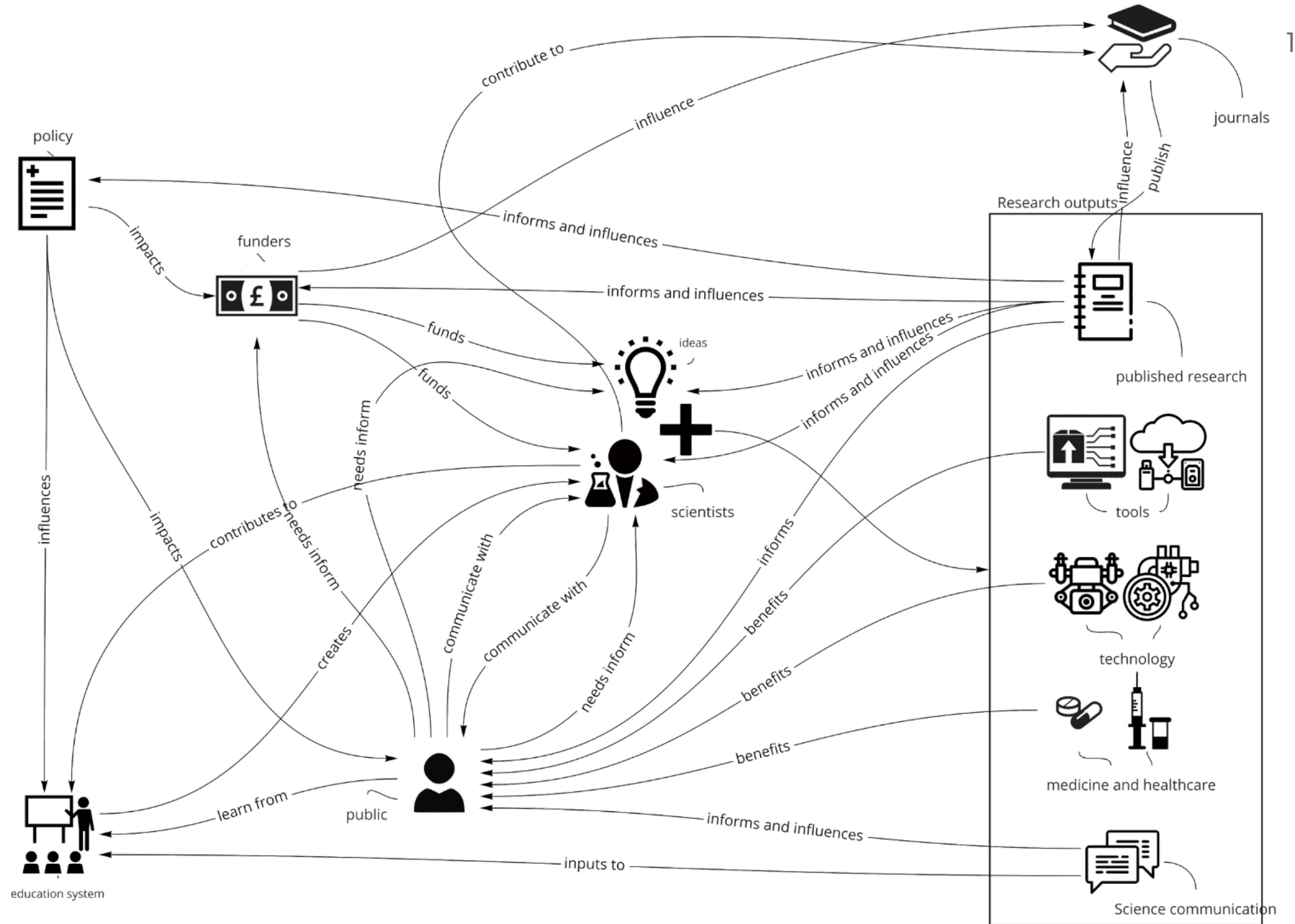
<sup>1</sup>Sex, Gender and/or Diversity Analysis

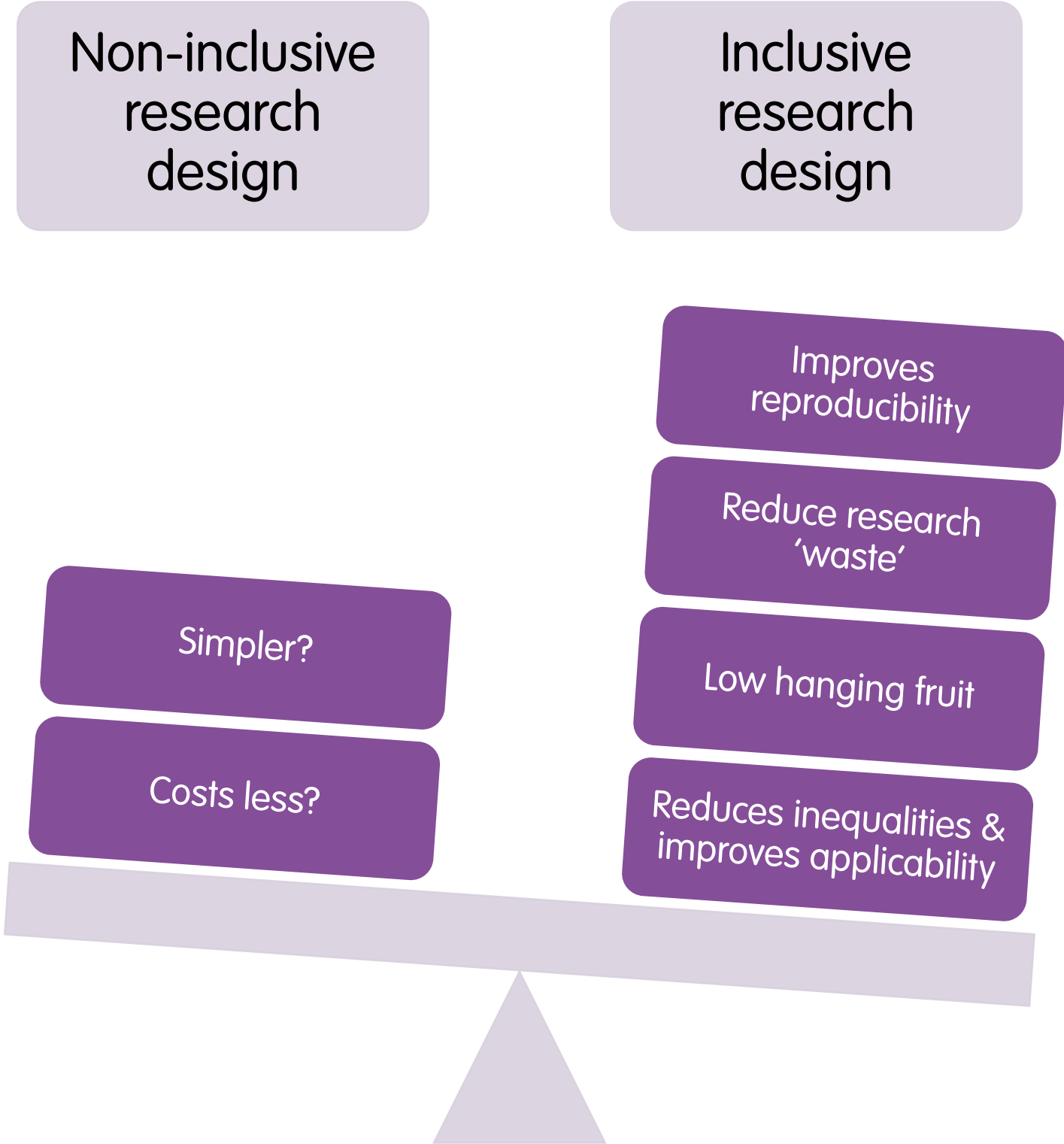
Notes:

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.





# Tools: Designing research for people

## Notes:

- Tools will often steer you in the right direction, but they 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/>



[Home](#) [About](#) [Digital Experience](#) [Resources](#) [Contact](#)

## Intersectional Design Cards

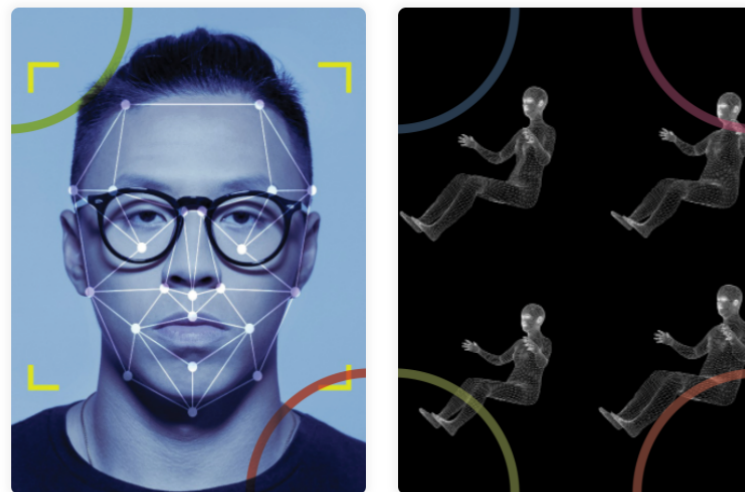
These cards are designed to help teams explore, analyze, and invent inclusive design solutions.

### 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

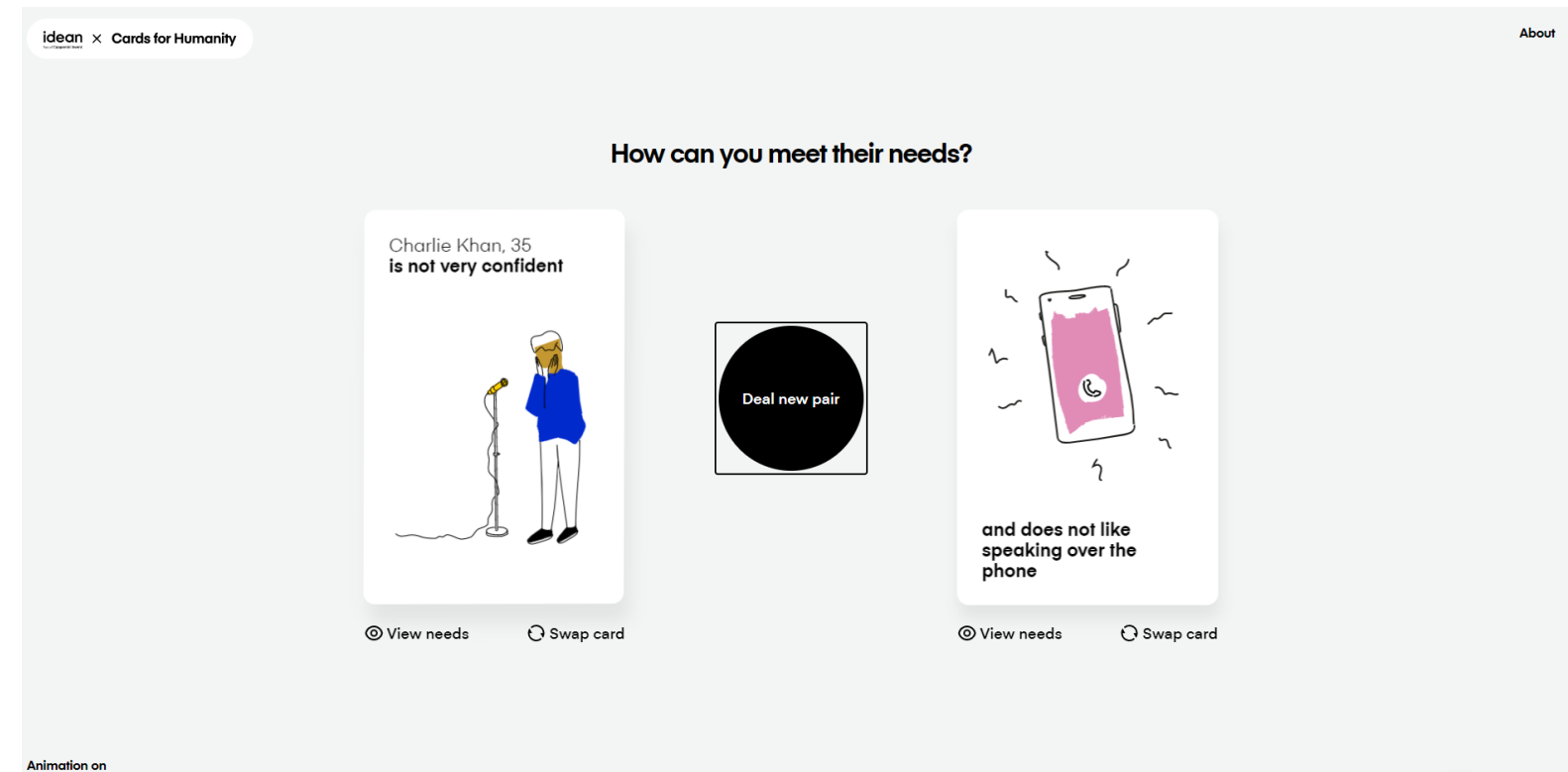
### HOW?

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

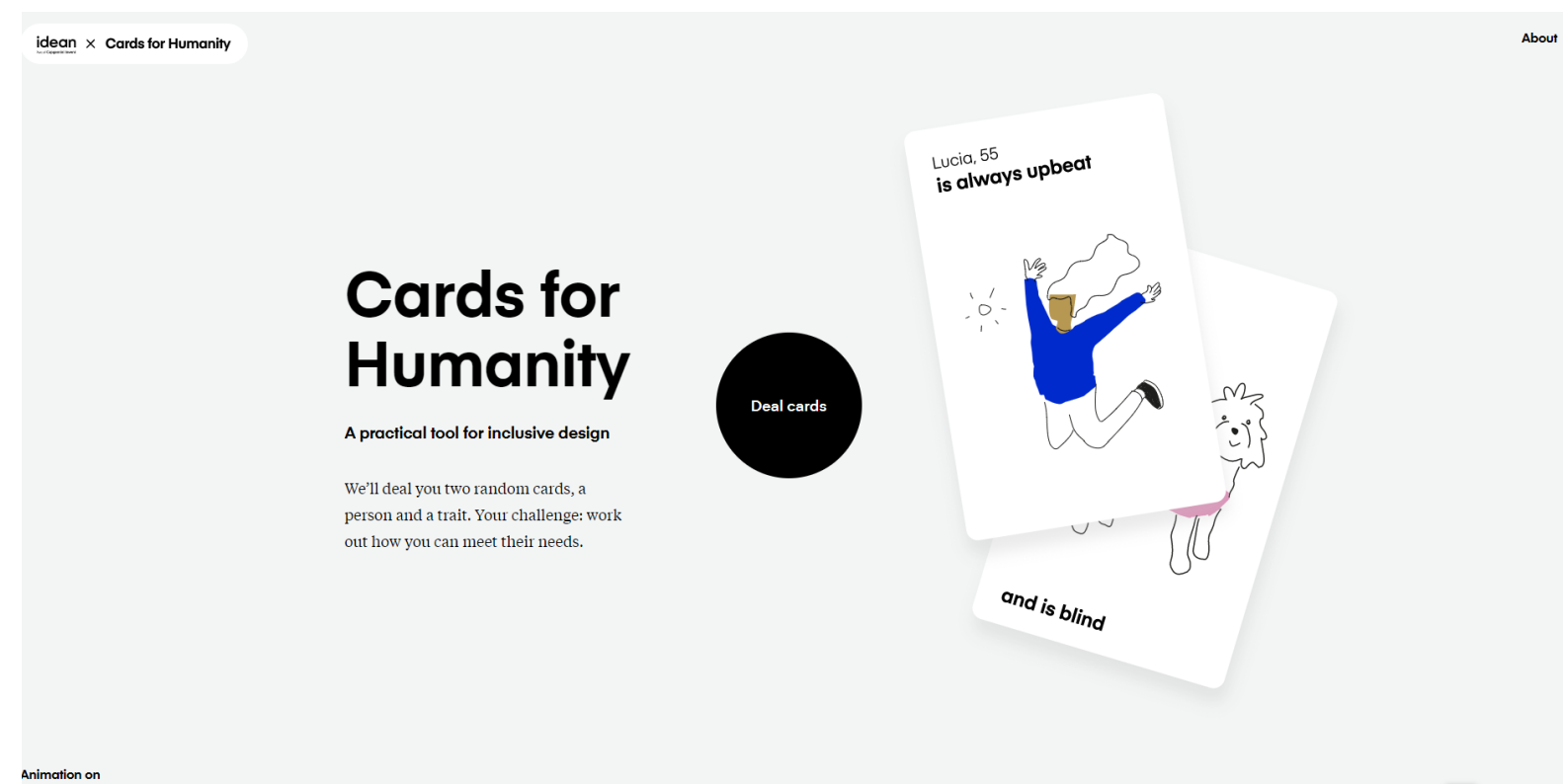


ENTER the digital experience

[edisgroup.org](http://edisgroup.org) | [@edisgroup](https://twitter.com/edisgroup)



<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 in a way that is 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 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>



Inclusive Research Practice Process for Autism Research



© Autism CRC 2016

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

# Tools: Case studies

The screenshot shows the website for Gendered Innovations, which focuses on science, health & medicine, engineering, and the environment. The main navigation bar includes links for Home, Contributors, Links, Translations, and Contact Us, along with a search bar. The left sidebar contains a menu with categories: What is Gendered Innovations?, SEX & GENDER ANALYSIS (with sub-items: General Methods, Specific Methods, Terms, Checklists), CASE STUDIES (with sub-items: Science, Health & Medicine, Engineering, Environment), INTERSECTIONAL DESIGN, POLICY RECOMMENDATIONS, and VIDEOS. Social media sharing options for Print, Tweet, and Facebook are also present.

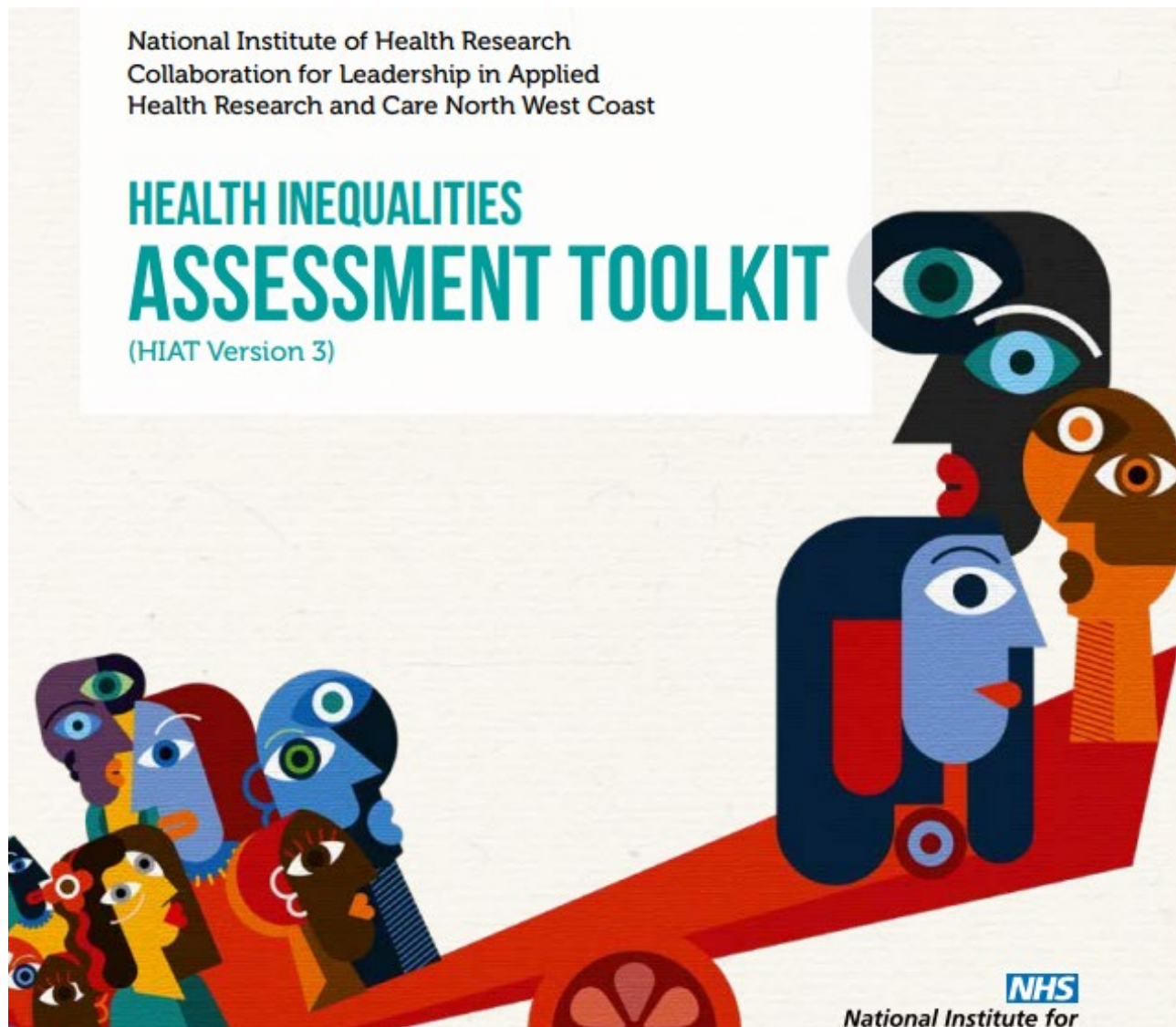
The main content area features a large header for "Engineering & Technology Case Studies" with the subtitle "Demonstrate Gender Methods In Design". Below this, a text block states: "This page provides practical examples of how sex and gender analysis leads to gendered innovations." This is followed by a 3x3 grid of case study thumbnails, each with a title and a representative image:

- Assistive Technologies for the Elderly**: Image of a hand holding a small robot.
- Extended Virtual Reality: Analyzing Gender**: Image of a person wearing a VR headset.
- Facial Recognition: Analyzing Gender & Intersectionality**: Image of a stylized face with circuit patterns.
- Gendering Social Robots: Analyzing Gender**: Image of a small white robot.
- Haptic Technology: Analyzing Gender**: Image of a hand interacting with a haptic device.
- HIV Microbicides: Rethinking Research Priorities and Outcomes**: Image of a colorful molecular structure.
- Inclusive Crash Test Dummies: Rethinking Standards & Reference Models**: Image of a crash test dummy.
- Human Thorax Model: Rethinking Standards and Reference Models**: Image of a 3D model of a human thorax.
- Machine Learning: Analyzing Gender**: Image of a glowing sphere with binary code.

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



# Tools: Toolkits



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



**TOOLKIT FOR:**

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

December 2018

<https://arc-em.nihr.ac.uk/clahracs-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.”

# 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”

The screenshot shows the Canadian Institutes of Health Research (CIHR) website. At the top, there is a navigation bar with the Government of Canada logo and the text 'Canada.ca | Services | Departments | Français'. Below this is the CIHR logo and a search bar. A secondary navigation bar contains links for 'Funding', 'Institutes', 'College of Reviewers', 'Initiatives', 'Collaboration', and 'Discoveries for life'. The main content area is titled 'Gender and Health' and features a sidebar with a table of contents including 'About us', 'Events', 'News', 'Learning', 'Training and Career Development', 'Publications', and 'Funding'. The main content area displays a banner for 'IGH LEARNING' and three online training modules: 'Course 1: Sex and Gender in Biomedical Research', 'Course 2: Sex and Gender in Primary Data Collection with Human Participants', and 'Course 3: Sex and Gender in the Analysis of Secondary Data from Human Participants'. Each course has a 'Start course' and 'More Information' button.

# 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



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



### 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/nih.ac.uk/pi-standards/resources-and-support#h.p\\_mW6c18EMITh](https://sites.google.com/nih.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.”

**HOW THEY HAPPENED**

The guidelines were developed by a panel of 13 experts representing nine countries through a series of teleconferences, conference presentations and a 2-day workshop. The panel conducted an internet survey of 716 journal editors, scientists and others in the international publishing community and a literature search on sex and gender policies in scientific publishing.

**HOW THEY WORK**

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

**AND WHO SHARES RESPONSIBILITY**

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.

**13 EXPERTS FROM 9 COUNTRIES**

**716 JOURNAL EDITORS, SCIENTISTS, AND PUBLISHERS SURVEYED**

**MEMBERSHIP OF THE GENDER POLICY COMMITTEE**

Co-Chairs	Members	Members	Members
Paola De Castro EASE Council Head of the Publishing Unit National Institute of Health - Italy Executive editor <i>Annali dell'Istituto Superiore di Sanità</i> paola.decastro@iss.it	Rachael Carol Medical Editor, Emendo Bioscience, UK rachael@emendo.co.uk	Joan Marsh Deputy Editor <i>The Lancet Psychiatry</i> , UK Joan.marsh@lancet.com	Petter Oscarson Technical Editor of <i>Oikos</i> , Managing Editor of <i>Hereditas</i> , Sweden oikos@oikosoffice.lu.se
Thomas Babor Editor-in-Chief, <i>Journal of Studies on Alcohol and Drugs</i> , USA babor@nso.uch.c.edu	Janine Clayton NIH Director for Research on Women's Health, USA Janine.Clayton@nih.gov	Ana Marusic Editor-in-Chief, <i>Journal of Global Health</i> , Croatia ana.marusic@mefst.hr	Ines Steffens Editor-in-Chief, Eurosurveillance, Sweden ines.steffens@ecdc.europa.eu
Shirin Heidari EASE Council/ Founding Chair Director and Editor, <i>Reproductive Health Matters</i> sheidari@rhjournal.org.uk	Mirjam Cumo Editorial Office Manager, <i>Frontiers</i> mirjam.cumo@frontiersin.org	Ravi Murugesan Science Editor and AuthorAID Consultant, India ravi@uwalumni.com	Cara Tannenbaum, MD, MSc Scientific Director Institute of Gender and Health Canadian Institutes of Health Research (CIHR) cara.tannenbaum@umontreal.ca
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	Jibril Handuleh For <i>African Journals</i> jibril.mahamed@gmail.com		

**CONTACT US**

If you are interested in the work of the EASE Gender Policy Committee or in joining it, or the presentation and adoption of the SAGER guidelines, please contact us through [secretary@ease.org.uk](mailto:secretary@ease.org.uk) and visit <http://www.ease.org.uk/about-us/organisation-and-administration/gender-policy-committee>.

SEPTEMBER 2016 • Content by GPC of EASE • Graphic Design: Marti Betz Design

**SAGER** Guidelines

SEX AND GENDER EQUITY IN RESEARCH

PREPARED BY  
THE GENDER POLICY COMMITTEE  
OF THE  
EUROPEAN ASSOCIATION  
OF SCIENCE EDITORS

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

# 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.”

**TRIAL FORCE**  
Ensuring your trial is designed for all who could benefit

**Key Questions.** The starting point for all trials is to think about who the trial is for. The trial team then needs to do everything possible to make their trial relevant to the people to whom the results are intended to apply (often patients) and those expected to apply them (often healthcare professionals). This means thinking carefully during trial planning and design about who should be involved as participants.

The four questions below are intended to prompt trial teams to think about who should be involved as participants, and how to facilitate their involvement as much as possible. These questions should always be considered by trial teams in partnership with patient and public partners, including individuals from, or representing, groups identified in Question 1.

**Note that:** • 'Intervention' means the treatment, initiative or service being evaluated. • 'Comparator' means the what the intervention is being compared to. • 'Effective' means the intervention provides important benefits for people with the disease or condition that is the focus of the trial.

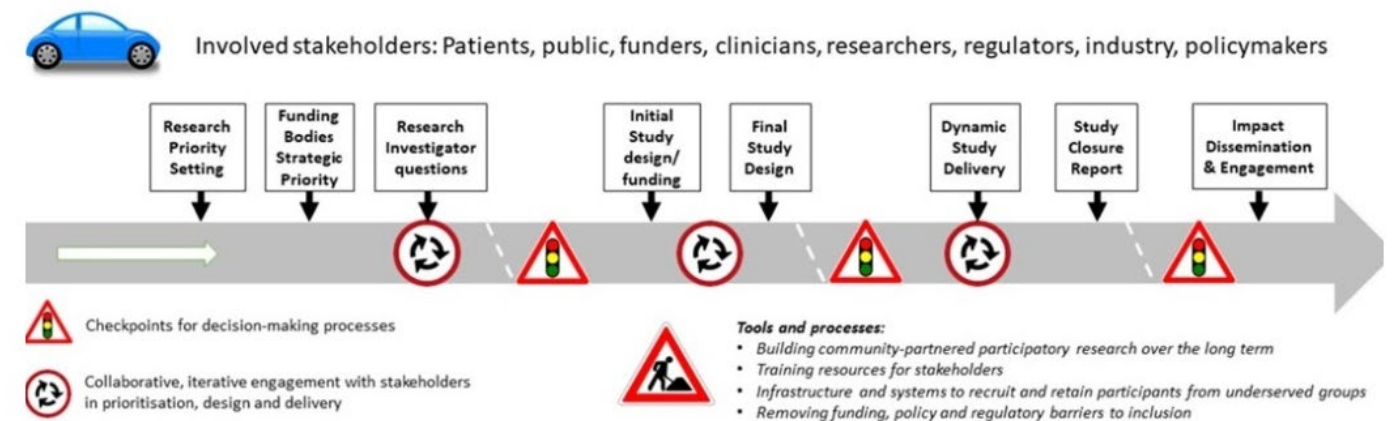
We recommend that trial teams use the worksheets to help them think through their answers to the four key questions.

- 1. Who should my trial results apply to?**  
Which groups in the community could benefit from the intervention if it was found effective, or benefit from not having it if it was found ineffective and/or harmful?
- 2. Are the groups identified in Question 1 likely to respond to the treatment in different ways?**  
How might the disease or cultural factors mean that some groups in the community respond to, or engage with, the treatment(s) being tested in different ways?
- 3. Will my trial intervention and/or comparator make it harder for any of the groups identified in Question 1 to engage with the intervention and/or comparator?**  
How might the intervention and/or comparator, including how they are provided, make it harder for some groups in the community to take part in the trial?
- 4. Will the way I have planned and designed my trial make it harder for any of the groups identified in Question 1 to consider taking part?**  
How might elements of trial design, such as eligibility criteria or the recruitment and consent process, make it harder for some groups in the community to take part?

THIS WORK IS PART OF THE LARGER NIHR INCLUDE PROJECT.  
• <https://sites.google.com/nihr.ac.uk/include/> • <https://doi.org/10.1186/s13063-020-04413-7>  
For more information download our worksheets at [www.trialforge.org](http://www.trialforge.org)

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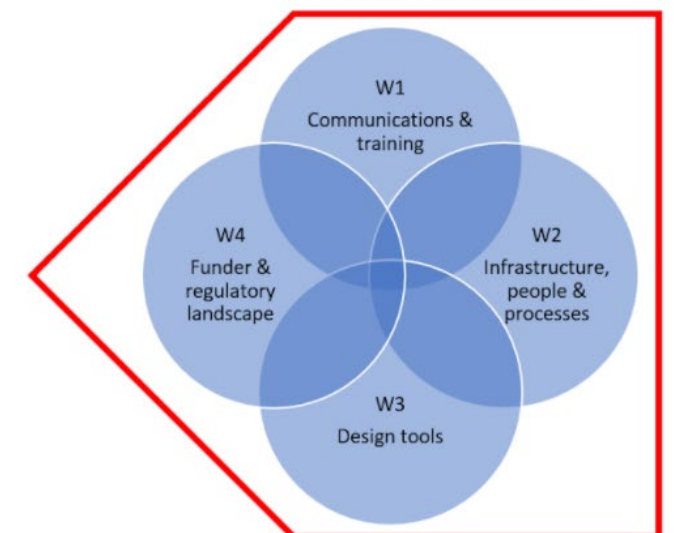
<https://www.trialforge.org/trial-forge-centre/include/>



## 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





### **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.

## 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](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



## 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?

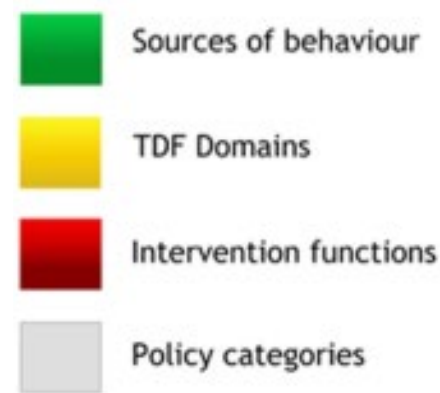
6. What barriers exist for participants to being included in research?

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.

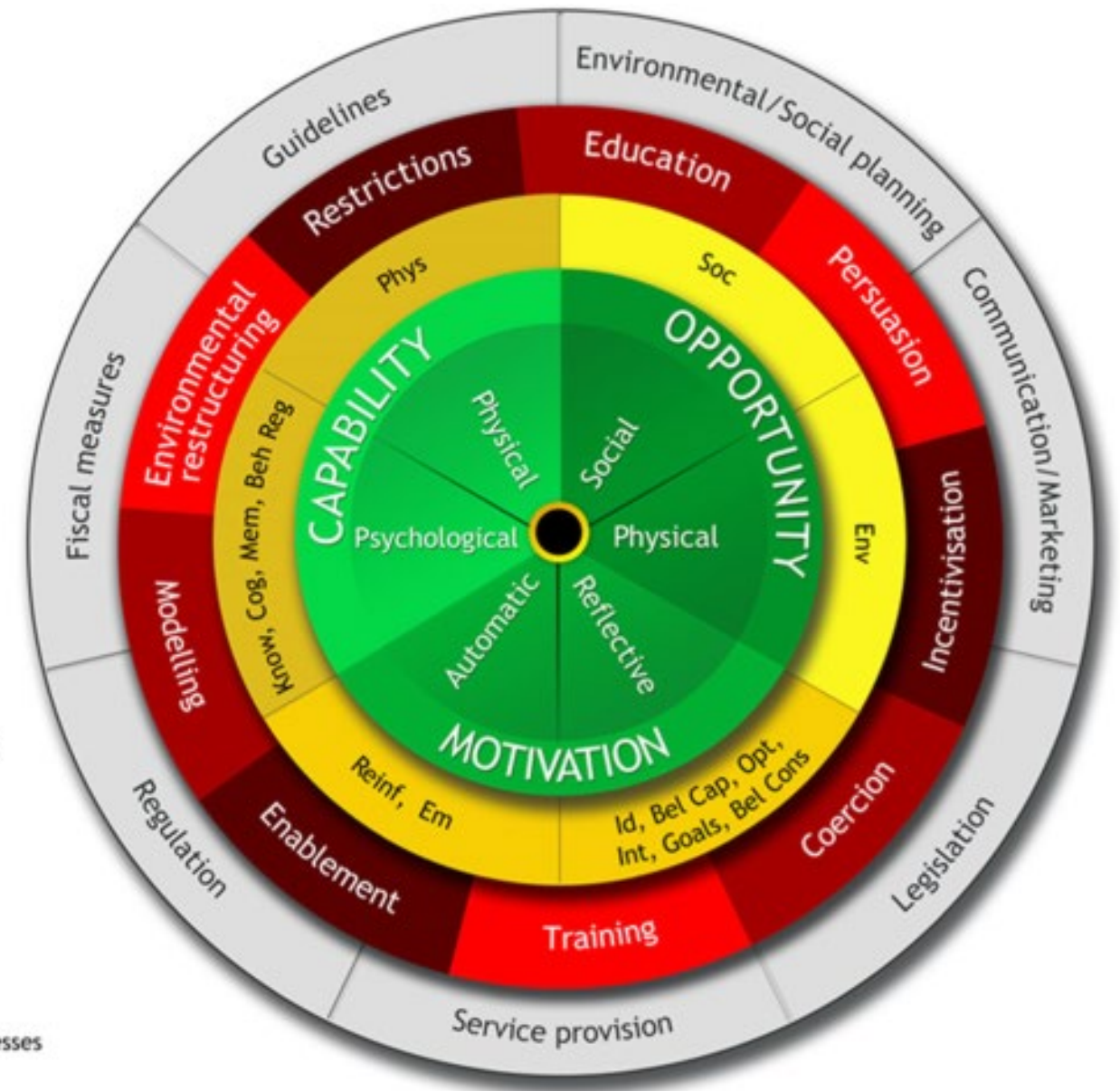
# Solutions: what can you do and what can you ask for?

**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/>