



FUNDAMENTALS OF INCLUSIVE RESEARCH



NCRM
NATIONAL
CENTRE FOR
RESEARCH
METHODS



**“WHILE WE SEEK TO
STANDARDISE AND SCALE
THERAPIES, WE MUST
RESPECT THE INDIVIDUALITY
OF HUMANITY.”**

AMY WEST, 2023

Groups of people, such as people from minoritised ethnicities, rural populations, and those experiencing socioeconomic disadvantage, generally experience poorer health outcomes than groups of people with more societal privilege.

In parallel, these groups have been historically under-represented in health research. This means that both patients and health and care professionals cannot be certain that the results of health research can be applied to the people who stand to benefit most. Without equitable research which is intentionally inclusive by design, health inequalities will continue.

This is a practical introductory guide to support researchers in the design and delivery of more inclusive research, created by a group of researchers that have been there, done that, and made mistakes that we would like to help you avoid.





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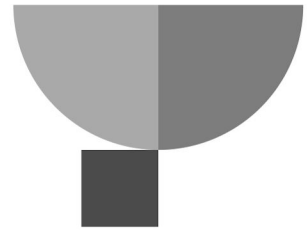
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QUICK CHECK: INCLUSIVE PRACTICE

PART 1 OF 2

Resources: Before you start (you can never start too early!)

- Have you looked for services and resources designed to support inclusivity that can be applied to your research project (e.g., organisational or funder research support service)?

- Do you or your colleagues have existing partnerships that have the potential for broader impact (e.g. contact(s) within a community organisation or advocacy group)?

The what: Getting to grips with your research

- Do you have an understanding of what a representative sample looks like in your research?

- Have you invited the views of different staff, patients, and/or members of the public to gain perspective on your research questions, design and outcomes?

- Have you explored different methods to enable a range of perspectives to be represented (e.g. forums, surveys, conversations within communities)?

- Does your research reflect the priorities of these perspectives?

The who: Building diverse perspectives into your research

- Does the research team (including patient and public partners) represent relevant and diverse academic disciplines, cultural backgrounds, and/or lived experiences?



QUICK CHECK: INCLUSIVE PRACTICE

PART 2 OF 2

The how: Designing your research

- Have you thought about how you would change your research if the recruitment of underserved populations to your research is poor? (e.g., eligibility criteria, recruitment strategy)
- Can you use this approach to begin with?
- Have you involved multiple staff, patients, and members of the public in conversations on the patient/public-facing materials you will use throughout your research (e.g. readability/accessibility, main messages received)?
- Have you targeted communication and imagery to the specific demographics that your research aims to impact (e.g. language, diverse imagery, mode of delivery, and colours that resonate with various age groups or ethnicities)?
- Can potential participants easily access additional information about your research if they would like to find out more?
- Have you made a plan for how you will investigate the effectiveness of the methods you are using to recruit participants with a focus on inclusivity?
- Can you use data that are already collected elsewhere?
- Have you involved multiple staff, patients, and members of the public in conversations on the data you are planning to collect, and how they will be collected?
- Have you involved multiple staff, patients, and members of the public in conversations on the research activities (including the activity itself, the length of the time, and where the participant needs to be) required for participation in your research?

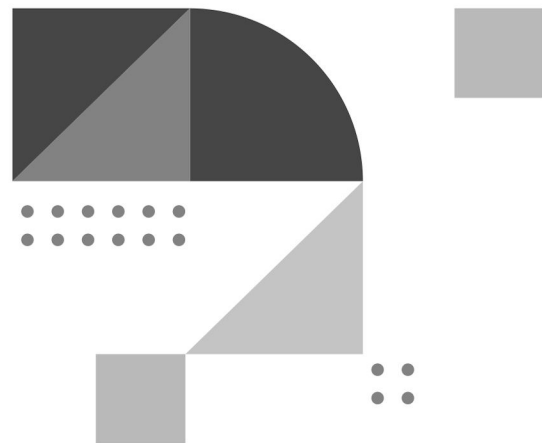


QUICK CHECK: COMMUNITY ENGAGEMENT

- Cultural Competence Training: Consider investing in cultural competence courses for yourself and your team to enhance your understanding of diverse cultural contexts and improve your ability to engage effectively with diverse communities
- Accessible Venue: Choose a venue that is accessible and convenient for the community, ensuring that physical barriers are minimized and logistical concerns are addressed.
- Open Language: Use clear and accessible language. Avoid jargon and start questions with 'what' 'how' and 'can you tell me about..', to promote discussion.
- Multiple Methods: Employ a variety of engagement methods to cater to different preferences and needs (e.g., online forums, surveys, focus groups)
- Relationship Building: Invest time and effort in building genuine relationships and trust with the community, as this lays the groundwork for future engagement.
- Communication Enhancement: When conducting workshops or events, utilize interactive and participatory methods to enhance communication and foster engagement among participants (e.g., storytelling, visual elicitation).
- Feedback and Iteration: Encourage ongoing dialogue and feedback with people to share the impact of the work done and to continuously improve your engagement strategies.

Link: [Cultural Competence Training](#)

Link: [Public Engagement, A Practical Guide \(Sense in Science\)](#)



ACCESS: VIDEO SCRIPT

PART 1 OF 2

Research that is easy to find, understand, and take part in is accessible. Accessible research is a critical but sometimes overlooked aspect that can impact the diversity of recruited participants.

Joining research studies can be a big deal for people. So, as researchers, we should try to make it as easy as possible for them by reducing the physical and mental work that people need to do to take part.

For instance, we could think about whether the data we need is already collected and available elsewhere, or if we can be more flexible with the timing of activities so people can work around other commitments. It's easy to forget how our decisions affect the people taking part.

A good way to start is by putting ourselves in their shoes and asking, "What would I need to join this study? What might make it difficult for me to take part?" Talking to just one person, like a patient or someone from the public, can give your research a whole new perspective. And talking to a variety of people—different ages, backgrounds, and ethnicities—can be even better. You can usually find guidance from research support services or the funder of your research on how to budget time and money for this.

We also need to make sure that potential participants understand why our research matters and what it means to them. Sometimes, the information we give out can be too complicated. Did you know that the average reading level in the UK is like that of a 9-year-old? So, keeping things simple and clear is key.

[Link: Top tips for writing a lay summary](#)

[Link: Colour contrast checker for easy viewing](#)

ACCESS: VIDEO SCRIPT

PART 2 OF 2

Some studies offer easy-to-read versions of information sheets, audio summaries, or short videos to help.

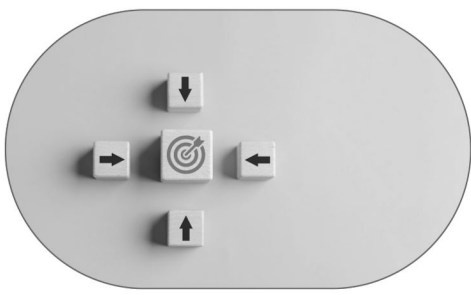
[Link: Introduction to Web Accessibility](#)

Specific to research involving humans, there are rules to what should be included in the information provided to people thinking about taking part in research but could you be putting people off taking part because of the way you're framing your research?

For example, discussion groups with Nigerians suggested invitations to cancer screening need to be reframed from a focus on the risk of death to another way of staying healthy. This is because many Nigerians believe and accept that their fate is in the hands of God, so focusing the information on the avoidance of death is more likely to make this population disengage.

When it comes to finding people to take part, we need to be creative. Think about where our target group go, what services they use, and who influences them. This could be online as well as in person.

Spreading the word about your research might mean reaching out through community events, radio ads, or social media campaigns. An excellent example of access is from the PRINCIPLE study, which worked with pharmacies across the UK to make communities that would not commonly engage with other healthcare services or media aware of their research. The team provided pharmacies with material to advertise in 7 different ways including stickers, text messages, email templates, and posters. They also developed information sheets in 10 different languages. Speak to your colleagues and explore your organization's services to find out if they can help get you started in making your research more accessible.



RELEVANCE: VIDEO SCRIPT

PART 1 OF 2

When we talk about relevance, it's all about asking ourselves: if someone saw your research materials, questions, and the data you're gathering, would they see it as something important and relevant to them?

Your research should help address real-world issues, but let's dive a bit deeper. There might be people in your target population who might have different needs and could benefit from a well-thought-out approach that encourages them to take part.

For example, to improve intervention adoption and outcomes in an osteoarthritis study, a team at the University of Leeds created a peer-support program with people experiencing socioeconomic disadvantage, so participants are supported by people who can relate to them and their situation.

[Link: Accessible Meeting and Event Checklist](#)

The more lenses you can look at your research through, whether that be different academic backgrounds, cultural experiences, or life stories, the more you can understand how your research is perceived by different people.

These conversations can shape your research proposal, refine study questions, and ensure you include outcomes that are most important to the communities you want to help. You might be surprised to find that research questions you believe are vitally important aren't the ones most important to those you wish to recruit.

RELEVANCE: VIDEO SCRIPT

PART 2 OF 2



Involving different people is about welcoming a critical friend, having genuine conversations, and learning from each other.

Link: [Community Engagement Choosing the Right Tools](#)

For example, The People's Trial invited members of the public to develop a research question, decide the eligibility criteria, data collection methods, and how to report the findings. The researchers were merely there to enact the major decisions made by the public. It's an extreme example, but it shows how involving the community can make research more relevant and impactful.

Relevance can be enhanced in various ways. For example, researchers on the INCLUDED project trained community partners to run focus groups so that participants could comfortably share their feelings about the collection of their ethnicity data with someone who shares their cultural background.

Receive price quotes from community partners before you submit for funding!



Thinklusive



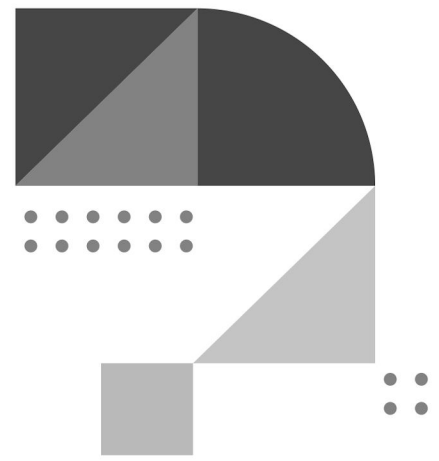
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Tailoring your research to communities within your target population can help ensure your work is embraced by groups that have previously been underserved.

For example, if you want certain people to engage with your work, use language, imagery, and colors that resonate with them. A simple exercise would be to search charities or organizations commonly associated with these groups and see if there is imagery you could mirror in your research advertisement. In doing this, your research could have a greater impact on the diversity of your target population.

TRUST: VIDEO SCRIPT

PART 1 OF 2



The historical backdrop of research, particularly within the medical sphere, has left some segments of the public apprehensive about engaging with research. Establishing trust is paramount if we are to achieve a more inclusive research environment.

[Link: Do No Harm Video](#)

There are a couple of avenues you can explore to build trust between people, you, and your research and to show them that you have their best interests in mind.

Recent interviews have suggested you could start by introducing yourself, who you work with, and why you're doing your research. This could be in a letter, video, or in person. We want to provide people with ways to see behind the curtain.

"A little letter of introduction. You know, my name is XYZ.

I've been studying at the University, you could help me an awful lot.. and my occupation is... or not even not even that, but something personal...you know, they were asking me personal questions.."

Participant quote from the EQUATE study

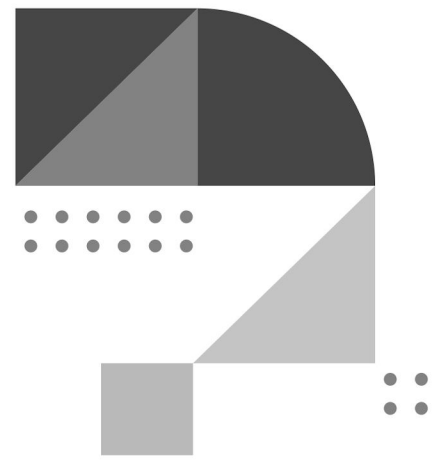
Educational resources can help demystify the research process and the meaning of technical terms which could reduce potential misunderstandings and alleviate apprehensions.

Consider the initiative undertaken by the Quintet team in Bristol, who crafted an educational video to broadly introduce clinical trials in five distinct languages and shared them on YouTube for anyone to use.

[Link: Educational Clinical Trial Videos](#)

TRUST: VIDEO SCRIPT

PART 2 OF 2



As research communities, creating and sharing these initiatives helps progress towards the shared goal of trust across diverse communities. Specifically, to help people feel safe, interviews with people who enrolled and declined invitations to different studies told us that providing avenues to validate the legitimacy of the research can go a long way towards building trust.

This can be achieved through a dedicated study web page, strategic partnerships with reputable organizations, and sharing experiences and quotes from past participants.

Keep in mind that trust is contingent upon various factors that may vary across different demographic groups so it's important to apply a couple of strategies in your work. Refrain from making presumptions and if you can, directly solicit the concerns of your target audience. You might discover that your place of work or other local areas have societies you can reach out to.

In the case of an IVF project in Aberdeen, the research team wanted to ensure South Asian women were well-represented, so they invited a group to discuss the research proposal. The group was concerned their involvement in the research would leak into South Asian Communities where there is a stigma surrounding the topic. To overcome this issue of trust, this group of women suggested having initial contact with researchers from any other ethnicity. This is an excellent example of the impact of building rapport and listening to the concerns of the target group.

Initiating discussion can start by reaching out to a community leader or joining online forums and inviting them to talk to you about any concerns they have.

Link: [Recommendations on collecting ethnicity data from the INCLUDED project](#)

RECOGNITION: VIDEO SCRIPT

PART 1 OF 2

In research, we understand the value of participants' time and information. But how can we express recognition for their efforts effectively? Factors such as personal preferences and the level of commitment required can influence how participants prefer to be acknowledged.

Across hundreds of interviews, people have told us that one of the biggest reasons they take part in research is to help other people. However, despite their altruistic motivations, participants may sometimes question the impact of their individual contributions.

Communication at critical junctures like the beginning of the research journey can help participants realize that they're more than just numbers and that we truly value them taking the time for our research. When communicating with participants—whether through personal interactions, invitations, or thank-you notes—think about wording that emphasizes the significance of their involvement.

Add depth by explaining how or why they've had an impact in the context of your research and the questions you're trying to answer.

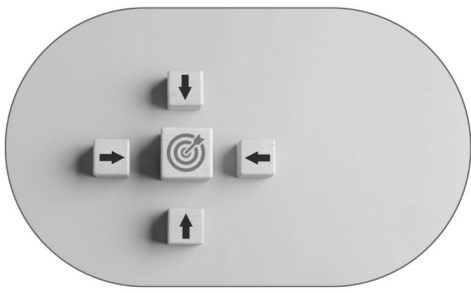
“Your contribution to this research is invaluable because...”

“Each participant plays a vital role in shaping...”

“Your insights and experiences are integral to helping...”

“Your involvement is making a meaningful difference in advancing the understanding of...which we hope will...”

“Without your participation, research that helps those in a similar position to you would not be possible”



RECOGNITION: VIDEO SCRIPT

PART 2 OF 2

Another key way to show ongoing recognition is by promptly addressing any queries and being open to feedback. This fosters an environment where participants feel valued and heard, which not only motivates their initial involvement but also encourages ongoing participation.

This approach can be particularly effective in longer-term studies, where maintaining participant engagement is vital.

Additionally, involving participants in decisions about how they'd like to be kept informed can further enhance their sense of involvement. Whether it's updates on research progress, summaries of data, key findings, or the impact of the research, providing choices ensures participants feel connected every step of the way.

It's important to acknowledge that there's no one-size-fits-all approach to recognition. Working with representatives of the target group can help identify meaningful incentives, which may include financial rewards, skill-building opportunities, acknowledgments, or access to something of interest in that group. Be flexible where you can. For example, a high street or food voucher that can be used at several places and which can be sent by post or online.

By implementing these strategies, we can show people that their individual contributions are recognized.



FUNDING APPLICATIONS

Funders and ethics committees are increasingly expecting researchers to tell them how they are going to embed inclusive practices in their research, and also how the findings will be relevant to those underserved, in your target population.

Alongside the recommendations in the videos, here are some prompts that can help you plan and respond to questions on this topic.

Question: How will you ensure equality, diversity and inclusion are embedded within your research design?

Based on [insert source information] a representative sample for this research is [insert representative statistics].

We have worked/will work with [insert community/ public engagement information] to tailor [research advert/design/dissemination] to optimise engagement with these populations.

Consider

Information on how you are maximising access and trust, also if and how you will monitor the characteristics of your sample and adjust your research plan accordingly.

Question: How will you ensure your research findings will be relevant to those people who are currently being underserved?

We have/will [insert work] to make sure that our research questions and intended outcomes are of interest and relevance to [insert underserved group].

If work has been completed

Specifically, the outcomes of this work were [insert outcomes and impact on research].



THIS IS JUST THE START

In the dynamic landscape of research, the ethos of inclusivity is undergoing an evolution. With a purposeful commitment to making our research findings applicable to different strata of the population, researchers are delving deeper into discovering the most effective methods for inclusive research practice.

The journey relies on meaningful interactions with people from varied backgrounds and experiences. There exists no one-size-fits-all formula; no simple A, B, C plan can guarantee success in this endeavour, but there are some fundamental principles you can follow to enhance your practice.

Aspiring researchers keen on embracing inclusivity are encouraged to allocate sufficient budgeting for both time and financial aspects, recognizing that the dividends of such investments extend far beyond conventional boundaries, enriching the fabric of research and society alike.



UNTIL NEXT TIME!

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