

Wellcome Engaged Research

Purpose, Power, Practice: A Primer for Engaged Research

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wellcome

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Introduction and Overview



Welcome to the Engaged Research Primer

This resource introduces the core ideas, practices, and values that underpin *engaged approaches to health research*: approaches that bring the people most affected by research into the process of shaping it. It offers key concepts and considerations about what engaged research is, why it matters, how to do it, who to include, and how to measure impact and success.



The Primer has been developed by a team of researchers and engagement experts through interviews, workshops, collaborative sense-making and user testing with researchers, engagement practitioners, community partners, and people with lived experience, all of whom brought valuable insights and expertise to this final product. Their quotes are referenced throughout this document.

You can find out more about how we did this work in the **Underpinnings** section.

Defining Engaged Research

Engaged research is an approach that involves working collaboratively with people who are affected by or have an interest in the research. It seeks to embed stakeholder perspectives across the research lifecycle from agenda setting, funding, and research design through to implementation, monitoring, and evaluation.

Engaged research approaches are grounded in relationship building and power sharing, and use inclusive, equitable practices that centre people's lived experience and values multiple ways of knowing. At its core, engaged research recognises that knowledge is co-created, and that involving diverse perspectives leads to research that is more relevant, ethical, and impactful.



Engagement vs Engaged Research

While engagement can describe specific activities or strategies, engaged research refers to how these are woven into the design, conduct, governance, and implementation of research. Not all engagement is engaged research but engaged research always involves thoughtful, meaningful engagement.

More than a Methodology

While often associated with specific methods, engaged research goes beyond methodology. Engaged approaches, when done well, make research more relevant, trusted and equitable.

Despite their enormous contributions to science, conventional research paradigms such as positivist and hypothesis-driven research models often risk overlooking the social, cultural, and ethical contexts that shape what questions are asked, whose knowledge is valued, and how findings are used.

Engaged research recognises that how we conduct research is inseparable from what we find, that knowledge produced without attention to justice can perpetuate harm. It requires us to rethink what counts as knowledge, who is recognised as an expert, how knowledge is created, who it belongs to, and what it is for.



Essential Elements of Engaged Research

Engaged research can be understood both as a methodological approach and as an ethos of collaboration and care to context. It draws on diverse traditions, from community-based participatory research to co-production, but is ultimately defined by a set of shared principles.

Because engaged research is adaptive, reflective, and context-specific, this Primer offers guidance, not prescription.

Core principles:

How research is done matters: who shapes it, whose voices are included, and what values guide it are as important as the results.

People directly affected by research are vital sources of knowledge and should help shape and make decisions.

Relationships must be reciprocal, respectful, and power-aware, embedding collaboration and reflection throughout the process.

The Primer Offering

This Primer offers an entry point for anyone wanting to begin or deepen their engaged health research practice. It strengthens understanding of key concepts in engaged research and supports their application in real-world research, guiding individuals and teams towards the skills, reflections, and relationships needed for stronger, more equitable research design and implementation. By fostering reflective and relational approaches, this Primer complements existing tools and provides links to additional resources to support ongoing learning.



Who is this Primer for?

This Primer is primarily designed for:

Individual researchers

Whether new to engaged research and looking for starting guidance, or experienced and seeking to deepen your approach, reflect on challenges, or strengthen your team's shared practice.



Collaborative research teams

Looking for shared tools, prompts, and resources to support co-design and relational ways of working.



Research support staff

Such as engagement professionals, project managers, ethics officers who are supporting others to design, deliver, or evaluate engaged approaches.



It may also be useful for **funders, policymakers, or research leaders** aiming to embed or assess engaged research within projects, institutions and systems, and for **community partners or lived experience experts** seeking clarity on roles, processes, and power dynamics.

Primer Pathways

This Primer is organised around four interconnected pathways that reflect key dimensions of engaged research practice.

You can start wherever feels most relevant. Each pathway offers ideas, prompts, and tools to help you reflect, plan, and act.

Finding your way – Primer navigation

Engaged research is not a one-size-fits-all process. Your starting point and priorities will be unique. Use these questions to help you decide which pathway to explore next: **WHY?, WITH WHOM?, HOW?,** or **SO WHAT?.**

Begin with 'Starting with Self'
The opening section that introduces reflective and relational practice, and helps you identify your motivations, assumptions, and context.

WHY?
Understanding the purpose and value of engaged research, especially in addressing inequities in health and science.

WITH WHOM?
Building equitable, trusting partnerships and attending to power dynamics.

HOW?
Translating principles into practice through inclusive methods, planning, and resourcing.

SO WHAT?
Making meaning, evaluating impact, and sustaining change.

Each pathway includes key concepts and considerations, reflective prompts and questions, and practical resources for further reading and action.

Feel free to choose your own path as you navigate to the sections most relevant to you. You may also want to return and review sections again as your understanding deepens or your project evolves.

Engaged Research as a Collective Action

While you can work through this Primer on your own, **engaged research is built through relationships**. Teams and partnerships will gain most by using it **together** as a scaffold for dialogue, reflection, and planning.

If you don't yet have collaborators or community partners, start there: enage with the **WITH WHOM?** pathway to reflect on who needs to be involved, whose perspectives are missing, and what relationships must be built before you begin.



Shared Learning Framework

Once a partnership or team is in place, use the Primer **as a shared learning framework**. Here are some suggestions for how you might do this:



Start your journey



Start with self and purpose

Each team member completes the **Starting with Self** reflections individually, then meets to discuss motivations, values, and positionalities.



Co-create working agreements

Together, articulate shared principles for equity, communication, decision-making, and care.



Move through the Pathways collectively

Dedicate a session to each, **WHY?**, **WITH WHOM?**, **HOW?** and **SO WHAT?**, using the discussion questions to plan concrete actions.



Document and revisit learning

Capture insights and decisions, return to them periodically, and note how relationships, roles, and understanding evolve.

Approached this way, the Primer becomes **a tool for building and sustaining the team itself, not just guiding the research.**

Starting with Self: Reflective and Relational Practice for Engaged Research



Introduction: Starting with Self

Engaged research begins with reflection. How we show up as researchers – our values, assumptions, and relationships – shapes every aspect of our work.

This section introduces the two interconnected concepts of **reflective** and **relational practice** and invites you to pause and reflect on why engagement work is important to you, who should be engaged, how engagement processes should unfold, and what the implications are for understanding and disseminating impact.

Use these reflections, individually or as a team, to orient your practice and decide which **Primer Pathway** to explore next.



Key Concepts: Reflective and Relational Practice

Engaged research is strengthened through ongoing reflective and relational practice.

Reflective practice involves examining your own position, privileges, and assumptions, and considering how they shape your practice.

Relational practice focuses on the quality of relationships and dynamics between people, recognising that relationships are not instrumental. They are essential to ethical and impactful work. It begins with knowing your own values and positionality, and extends to how you listen, how you share power, and how you respond to others in the research process.



Reflecting on Purpose, Equity and Risk

Ask yourself:



What motivates you to work in a more engaged or collaborative way in your research?

What assumptions do you bring to this work about who holds knowledge, what counts as evidence, or what success looks like?

What kinds of unfairness or exclusion do you see in your research field, community, or system and how do you hope your work might respond?

What role do you believe research can or should play in creating change, advancing justice, equity, or community wellbeing?

What feels exciting, uncomfortable, or uncertain about sharing power or making decisions together?

If these reflections are of particular interest to you, you may wish to explore them further in the **WHY?** pathway of this Primer.

Reflecting on Relationships, Values and Partnerships

Ask yourself:



Which people or groups usually shape what research is done and how? How would you like to see this change in your work?

Whose knowledge counts in your field or context and whose perspectives are undervalued or excluded? What is lost when those voices are missing and what becomes possible when they are included?

Which groups of people currently benefit from this area of research? Are there people who should benefit who are left out?

What responsibilities do you carry in shaping equitable and trusting relationships with partners and communities?

If these reflections are of particular interest to you, you can explore them further in the **WITH WHOM?** pathway of this Primer.

Reflecting on Context and Capacity

Ask yourself:



How does the environment around you - your organisation, discipline, or funding context - enable or constrain your ability to practice engaged research meaningfully?

What opportunities or constraints within these systems can you influence or work around?

What is your organisation's stance on equity, and how does that show up in research practice?

What knowledge, skills, or capacities exist in your team, and what might need to be strengthened to support engaged research?

If these reflections are of particular interest to you, you can explore them more in the **HOW?** pathway of this Primer.

Reflecting on Assessment and Dissemination

Ask yourself:



What do traditional definitions of success or impact leave out?

Whose perspectives are missing when research quality or outcomes are assessed, and whose voices should help define what matters?

What kinds of activities or processes could capture some of this learning reveal unexpected or hidden achievements?

Who usually benefits from ‘successful’ research, and who doesn’t? How might engaged approaches ensure that benefits of research are distributed more equitably?

If these reflections are of particular interest to you, you can explore them more in the **SO WHAT?** pathway of this Primer.

Engaged Research in Practice

The examples below offer grounded insights into how engaged research takes shape across different contexts. Together, they illustrate how principles of engaged research can take shape across different settings, disciplines and stages of the research lifecycle. They are not intended as templates, but as prompts for reflection and learning, offering insights into how power, relationships, and decision-making can be approached differently in research.

Co-creating a research study with Nairobi sex workers[1]

A global health study on HIV and gender-based violence co-produced with Nairobi sex workers (engaged as peer educators) to build trust, improve recruitment, and ensure community-relevant findings.

Shows how community partnership and lived experience can reshape research design with marginalised populations, advancing ethical and impactful engagement.

Embedding public voices into an organisation[2]

A national Public Advisory Group at Health Data Research UK integrated patient and public perspectives into governance, strategy and data science research decisions.

Demonstrates organisational-level engagement, showing how public voices can be embedded into institutional strategy and governance beyond single research projects.

Putting people with lived experience at the heart of research[3]

A large-scale genetic study of ME/CFS that embedded people with lived experience at the heart of research design, governance and delivery.

Shows how lived experience can meaningfully shape complex biomedical research, improving accessibility, trust and research quality.

Engaged Research in Practice

Co-producing research on physical activity with older people[4]

A research project on physical activity among older people that worked collaboratively with participants to shape research questions, methods and interpretation.

Shows how building trust and long-term relationships with participants can improve the relevance, ethics and quality of health research involving older populations.

Building networks for research engagement with marginalised communities[5]

A conference presentation summarising partnerships between voluntary sector and research institutions to develop a network for community engagement and involvement in research.

Demonstrates that long-term, funded support and capacity-building for equitable research approaches can overcome trust issues and provide opportunities for 'seldom listened to' communities to have their voices heard and acted upon.

Reflexivity and researcher learning in engaged health research[6]

An engaged research project on health and wellbeing reflecting on how collaboration with participants reshaped the researcher's assumptions, role and approach over time.

Highlights reflexivity as a core component of engaged health research, showing how learning, discomfort and adaptation are integral to meaningful collaboration.

Applying engaged research approaches in chemistry and environmental health[7]

A chemistry-led research project that used engagement to connect laboratory science with environmental concerns and human health impacts.

Shows how engaged research can inform problem framing and decision-making in technical fields, where the implications of research extend beyond the lab.

A community-led sandpit approach to inclusive health research[8]

A workshop that brought people from racially minoritised and marginalised groups together with health researchers to co-design research ideas and form new partnerships.

Shows how inclusive, structured, time-bound processes can be used to redistribute influence, surface community-defined research priorities, and support more equitable translational health research.

Community-led research on antimicrobial resistance[9]

Research teams engaged residents of Khayelitsha, South Africa to co-understand the impacts of antimicrobial resistance and to shape locally relevant interventions.

Illustrates how embedding community voices in evidence generation can fill gaps left by traditional data, connect lived experience to research priorities, and ground interventions in real-world contexts.

Engaged Research in Practice

Collaborating with Indigenous communities in climate and health research[10]

Research collaborations that work with Indigenous communities to integrate Indigenous knowledge and scientific approaches in addressing climate-related health challenges.

Demonstrates how recognising Indigenous knowledge as expertise can reshape research priorities, strengthen partnerships, and improve the relevance and impact of climate and health research.

Reflecting on collaboration with Indigenous communities in research[11]

A reflective podcast in which a scientist examines how working with Indigenous communities challenged their assumptions about knowledge, research practice and cultural authority.

Shows how reflexive learning, humility and relationship-building shape how researchers work with communities.

Rethinking research relationships with trans+ communities[12]

A critical essay examining how research with trans+ communities has caused harm, and arguing for trans+-led, accountable approaches to community-engaged research.

Challenges researchers to reflect on power, consent and authority in engaged research, and highlights why community leadership and trust are essential, not optional.

Co-producing autism research with autistic people[13]

A co-produced research project in autism that worked collaboratively with autistic people to shape research priorities, methods and decision-making.

Demonstrates how co-production can improve the accessibility, relevance and integrity of research by recognising lived experience as expertise throughout the research process.

Pathway – WHY?



Introducing WHY?: Purpose, Equity and Ethics

This pathway explores why engaged research matters for you, for your partners, and for the systems you work within.

Here, you'll explore key ideas such as epistemic justice and participatory practice, which challenge traditional notions of who creates knowledge, whose voices count, and what the research is for.

The pathway invites you to reconnect with your purpose, surface your assumptions, and consider how equity and ethics shape meaningful research.

Learning Intentions

This pathway will support you to:

Reconnect with your purpose as a researcher and reflect on how engaged approaches align with your values, practice, and context.

Explore the ethical and conceptual foundations that underpin engaged research.



Examine how conventional research structures and norms can reproduce or challenge inequity and exclusion.

Recognise the value that engaged research can bring to communities, institutions, and wider systems.

Where Are You Now? Reflecting on Purpose and Positionality

To understand your starting point, consider:



What motivates you to undertake engaged research? How does this connect to your values or lived experiences?

What assumptions, biases, or disciplinary norms have shaped your research so far, and how might they influence your approach to engaged research?

What feels exciting, uncomfortable, or uncertain about sharing power or making decisions collaboratively?

Motivations for Engaged Research

People are drawn to engaged research for many reasons. For some, it begins with frustration at traditional research approaches that generate benefit mainly for research institutions (and individual researchers) while excluding, or even harming, the people they study.



> There's a massive gap between enthusiastic grant reporting and headline writing about research findings, and their translation not just into the clinic but into practice and society. And so I became more interested in that gap, seeing what could be done, and what approaches might help.
>
> ***Academic Researcher, UK***

For others, it's a recognition that working with research communities, not doing research to (or on) them, creates more ethical, relevant, and impactful outcomes.



> You can't do research without working respectfully in mutually beneficial and reciprocal ways. If you've arrived at solutions together, you're triggering an action, and you're leaving people in a much better place than if you quietly wrote research up with your own recommendations. To what end? And who will benefit?
>
> ***Engagement Practitioner, South Africa***

Global Health and Colonial Legacies

Despite growing calls for equity in Global North–South partnerships, extractive practices, power asymmetries, and colonial legacies continue to shape how research is funded, led, and used.



Global health research often unfolds in contexts marked by deep historical and structural inequalities, where institutions in the Global North still control agendas, resources, and timelines. As a result, efforts towards 'equitable partnership' can be undermined by systems that still prioritise Northern institutions, languages, and timelines.

Engaged research asks us to confront these imbalances and work consciously to redistribute power, credit, and voice in our collaborations.

Ask yourself:

Whose systems of knowledge, ethics, and authority shape the research spaces you work within, and how might you begin to rebalance them?



Conceptual Foundations – Rethinking Knowledge and Power

Some key concepts help us reflect on power and inequality in research, especially in international and cross-cultural contexts:



Decolonising research means actively recognising and dismantling the colonial legacies that continue to shape research priorities, methods, and relationships. It asks us to question whose knowledge is privileged, whose interests are served, and how histories of extraction and exclusion continue to influence current practices. Decolonial research strives to rebalance, power and respect indigenous, local, and other marginalised knowledge systems as valid and vital.



Ask yourself:

Where do colonial or hierarchical assumptions still show up in the systems, methods, or partnerships that shape your work?

Epistemic justice is the commitment to valuing all people as knowers, and ensuring that knowledge systems outside dominant academic norms are respected. It aims to address the exclusion or dismissal of marginalised voices from research and decision-making.





Ask yourself:

Whose insights or experiences tend to be overlooked in your field, and what might change if they were recognised as equally valid forms of knowledge? How might your research challenge, rather than reproduce, the hierarchies of knowledge and power that shape your field?

Conceptual Foundations – Rethinking Participation and Care

Co-production is a partnership model in which researchers and community members collaborate as equals throughout the research process, from framing questions to interpreting findings. Co-production is often described as the gold standard of engaged research, yet it's challenging to achieve in practice because it requires genuine power-sharing, time, and trust.





Ask yourself:

Where in your research could decisions be shared more equally - and what conditions would make that possible?

Ethics of Care views ethical research as grounded in relationships, care, and mutual responsibility, not just in formal protocols or compliance. It draws attention to the emotional labour of research and the need to protect participants and researchers.





Ask yourself:

How do you attend to care, reciprocity, and emotional wellbeing in your collaborations?

Engagement as an Ethical Imperative

The 2024 Declaration of Helsinki now calls for community engagement and equitable partnerships in research. Academic publications and reward systems (such as national research assessment exercises) are also increasingly requiring researchers to undertake and report on engagement activities. But these requirements should not be the sole reason for taking this approach.

Engaged research rests on a simple but profound ethical principle: **research should be done *with* people, not *on* them**.

Engaged research reclaims research as a **shared, accountable, respectful,** and **responsive practice**, one that prioritises respect, reciprocity, and repair. It offers a way to rebuild trust, share power, and ensure that research genuinely serves the people it affects.

‘“Nothing about us without us” isn’t a slogan – it’s an ethical imperative.’

Engaged Research Funder, UK

Ethical Practice

The ethical foundations of engaged research include:

Recognising people as knowledge holders, not just data sources.



Ensuring research serves community needs, not only academic interests.

Confronting historical and systemic injustice and harm, including extractive and exclusionary research practices.

Prioritising relationships, transparency, and accountability.

Sharing purpose and power, from design through dissemination.



> You go to a community. You ask them to give you their time. They give you their time, you document all the answers, record them, etc. And although you said in your ethics application you'll go and give them a presentation, they never see you again. That is not ethical.
>
> ***Engaged Researcher, South Africa***

Ethics in engaged research are **relational and ongoing** - sustained through care, reciprocity, and follow-through. For practical guidance on embedding ethical reflection throughout your research, see the **HOW?** pathway.

Value of Engaged Research: Better Science

Engaged research isn't only ethically important; it also produces better science. When communities and stakeholders shape research from the start, studies become more relevant, robust, and impactful. Engaged approaches can lead to:

More relevant research questions, defined by those most affected, ensuring alignment with real-world needs.

Reduced risk of bias and harm, through ongoing reflection on power, positionality, and relationships.

Stronger design and delivery, shaped by diverse perspectives that surface blind spots and improve cultural relevance.



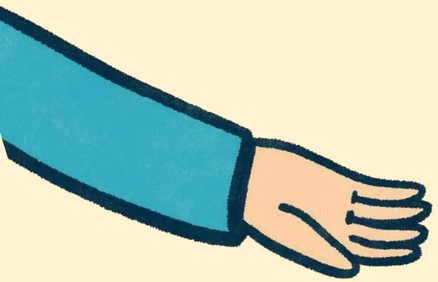
Ask yourself:

How might engaging others more deeply improve the quality, integrity, or usefulness of your own research?

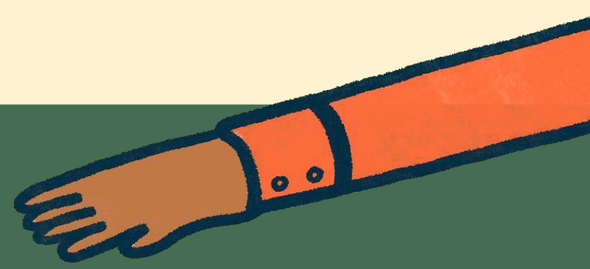


Value of Engaged Research: Strengthened Relationships

Engaged research strengthens relationships and creates the conditions for collaboration and trust. It leads to:

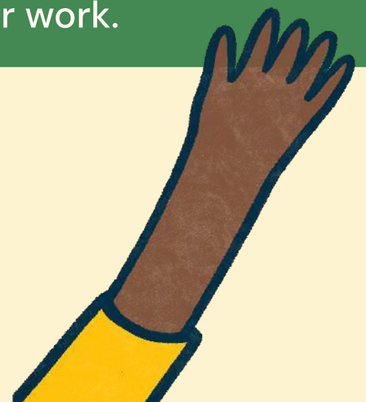


Mutual learning and capacity strengthening, as both academic and non-academic partners develop new skills, insights, and ways of working together.



Improved connections across sectors, as sustained engagement builds mutual respect, understanding, and long-term collaboration between researchers, communities, and practitioners.

Greater trust, uptake, and real-world benefits, because people are more likely to act on research they've shaped and see as meaningful to their lives or work.





Ask yourself:

How are you building and sustaining trust and reciprocity within your research relationships?

Value of Engaged Research: Change and Impact

Engaged research can create change that extends beyond academic outputs.

Direct benefits for people and communities, including improved health, greater confidence and capacity, increased health literacy, and strengthened social networks. These outcomes often emerge during the research process itself, not just after publication.

Institutional and systemic impact. Engaged approaches can influence institutional policies, reshape research practices, and open new pathways for community voices in decision-making processes.



> I did an improvement project... in partnership with a community organisation. We really co-produced a service... working with the communities themselves as outreach workers, and trained as facilitators. We had a situation where there was 100% registration and uptake of the service. And in terms of the retention, we had 99% retention.
>
> ***Funder, UK***



Ask yourself:

How might your research contribute to change - both within communities and in the systems that shape them?

What are Your Next Actions?

Reconnecting with your purpose is only the beginning.

Acting on it means aligning your motivations, ethics, and systems of work.



Remember:

There's no single right approach – only opportunities to stay reflective, intentional, and responsive as your practice evolves.

Based on this pathway, consider:

- What ideas or questions from this section feel most relevant to your current work or context?
- How will you make space for ongoing reflection on your motivations, values, and positionality?
- What actions could help ensure that engagement in your work remains both ethical and purposeful – not just procedural?
- What conversations might you initiate with collaborators, institutions, or funders about embedding engagement more deeply in research practice?
- How will you and your team stay accountable to the principles you've identified as important?

Resources

Exploring foundations and ethics

Understanding why engagement matters in health research begins with recognising that ethics and effectiveness are interlinked. Engaged approaches improve the **relevance, trust, and impact of science**[14] when grounded in shared purpose and accountability. **Public health**[15] and **social science**[16] perspectives emphasise that research should serve communities as well as institutions, ensuring that findings are accessible and meaningful.

Evidence shows these principles work in practice: systematic reviews of **community engagement in health research**[17] demonstrate clearer priorities, greater trust, and improved uptake of findings when communities shape study design. In global and public health, engagement has also been shown to **bridge the gap between research and implementation**[18], producing interventions better aligned with local needs.

Frameworks such as the **OCAP Principles**[19] highlight the importance of community ownership and data sovereignty, while guidance on **everyday ethics in community-based participatory research**[20] underscores reciprocity, transparency, and long-term accountability.

For researchers developing engaged health projects, these resources show that engagement is not only good ethics; it's good science.

Resources



Core concepts for rethinking knowledge and power

The following resources expand on the four core ideas introduced earlier in this pathway: decolonising research, epistemic justice, co-production, and ethics of care. They provide entry points for exploring how these principles can reshape health research.

Decolonising research, articulated powerfully by ***Linda Tuhiwai Smith***[21], calls on researchers to confront the legacies that shape health research systems and to centre accountability on indigenous and local knowledge. Practical frameworks show how rebalancing **authorship**[22], **leadership**[23], and **agenda-setting**[24] can make health research partnerships more equitable.

Epistemic justice, a concept developed by ***Miranda Fricker***[25], highlights the need to value diverse forms of knowledge and ensure that marginalised voices influence how evidence is produced and used. ***Bhakuni and Abimbola's***[26] work in global health shows how addressing epistemic injustice can strengthen the credibility and relevance of research.

Co-production offers a pathway for shared decision-making throughout the research process, guided by **ethical toolkits**[27] for power sharing that encourage transparency, equity, and reflexivity.

An **ethics of care perspective**[28] reframes research ethics as relational and continuous. In health research, applications of care ethics show how attentiveness, responsibility, and reciprocity help sustain humane and trustworthy partnerships.

Pathway – WITH WHOM?



Introduction to WITH WHOM?

Partnerships and collaboration are at the heart of engaged research. They shape not only what questions are asked but also how research is designed, conducted, and shared.

Engaged research builds more genuine, two-way relationships that recognise people as knowledge holders, rather than data sources. It enables sharing of power and decision-making where possible and evolves as relationships deepen over time.



> So our approach is working together in equal partnership for equal benefit. What's important is that it's underpinned by a set of core values that help us to kind of enact that.
>
> ***Engagement Practitioner, UK***

Engaged research creates ongoing dialogue that shapes every aspect of the research process, bringing together different forms of evidence and experience to create new knowledge and solutions that reflect societal needs and values.

What will You Learn in this Pathway?

This pathway will support you to:

Recognise that relationships are the foundation of engaged research, grounded in shared values, trust, and care.

Develop strategies for establishing, maintaining, and (where needed) ending partnerships in ethical and transparent ways.

Identify relevant partners and stakeholders for an engaged approach, and understand their contexts, assets, and needs.

Reflect on your own positionality and how it affects partnership dynamics.

Approach lived experience and collaboration through the lens of equity, recognising diverse forms of knowledge and expertise.

Anticipate the time, resources, and emotional labour needed for fostering meaningful partnerships in engaged research.



Where are You Now?

To understand your starting point, consider:



Who are your current partners in your research? Who might be missing from the conversation?

How might you approach new partners in ways that reflect shared purpose and respect?

What practices do you already use to build trust and establish relationships with research partners?

What personal skills and approaches help you to work effectively and equitably with others, and where might you need support or growth?

What is your current understanding of power and emotion in partnership work?

How do you plan to sustain, or appropriately end, partnerships when the research is over?

Identifying Partners

Who collaborates in an engaged approach will always be unique to the context and research at hand. Partners may include patients and carers with lived experience of a health condition, communities and organisations with specific expertise, or groups previously excluded from research. In early stage or discovery research, a broader public or people at risk of ill health may be most relevant.



> Who are the stakeholders? The stakeholders, in my opinion, should stretch between the public and contexts in which we live. Especially... when we come to some things like research priority setting. So who actually sets those priorities? To what extent can we decentralise priority setting?
>
> ***Academic Researcher, Ghana***

To understand your starting point, consider:

- Who cares about this research?
- Who has relevant knowledge or experience?
- Who might have the most immediate need or will be most affected by findings?
- Who has previously been excluded or, on the other side, has already been over-burdened by requests to engage?

Partnerships in Health Research – Starting Out

Once you have identified potential partners, consider how you might approach them and begin working together in ways that are equitable, transparent, and grounded in trust. It is a good idea to discuss, agree and document your shared values and ambitions, 'ground rules', and the practicalities of working together.

Build on existing connections and pre-existing institutional partnerships where possible.

Involve experienced engagement practitioners, within research institutions or community and cultural sectors, to help design inclusive approaches and facilitate early conversations.

Create new partnerships that centre equity and mutual respect.

Allow time and space for relationships to develop, through early 'getting to know you' conversations before research work kicks off.



Communicate inclusively and accessibly throughout the process.

Clarify practicalities together, including about anticipated tasks, timelines, and any constraints.

Be proactive in seeking out new partners where they are, rather than expecting them to come to you.

Authentic Partnerships: Power and Equity

Engaged research intentionally addresses power imbalances in health research. It goes beyond merely inviting different voices into established spaces where power remains concentrated.



> "It's not on the people with lived experience to fix your EDI problems, but the number of times I've seen teams be like, 'You know, we're doing some [EDI] training, and then we've got to make sure we've got a diverse group of people involved in the PPI'. It's power personified, sort of upholding... white supremacy.
>
> ***Engagement Practitioner, UK***

Equity in engaged research is supported by:



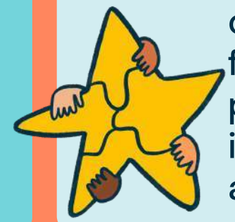
Reflecting on your own positionality and how it shapes decisions and interactions.



Embodying values important to relational approaches, such as respect, openness, and reciprocity.



Learning inclusive and equitable practices, such as anti-racist practice, trauma-informed practice or cultural humility.



Valuing all partners' contributions through fair recognition, payment, and access to institutional resources and expertise.

The Emotional Reality of Partnerships

Engaged research relationships involve emotional labour. It challenges traditional identities and hierarchies, and asks researchers to work with empathy, care, and self-awareness.

Partners outside academia may feel hesitant, over-researched already, or carry past experiences of exclusion. Partners within academia who already experience institutional marginalisation often bear the added burden of challenging the system while leading engaged research, often with limited structural support.



> It's hard stuff. So I think that's why the emotion it's really important to build in, because a lot of the things that you end up engaging with are painful. You're seeing people in difficult circumstances, whether it's through poverty, health challenges, social challenges, war trauma... You can't just go in and hear someone's pain and then run away and think it doesn't impact on you.
>
> ***Engagement Practitioner, UK***

Ask yourself:



- How can everyone involved feel safe and supported throughout the research process?
- Do any partners (e.g. young people) require considerations related to safeguarding, ethics, and care?
- What support systems should be in place (e.g. counselling or advisory services)?
- What could trigger emotional distress?
- How will confidentiality and consent be maintained?

Sustaining Equitable Partnerships

Sustaining relationships is key to mutual trust, but it can be difficult within short-term projects and constrained institutional structures. When engagement stops abruptly, feedback isn't shared, or the same people are re-engaged multiple times, it can cause frustration and ethical harm.

Aim to plan for sustainability and how to end a partnership from the start. Consider how you will:



'Close the loop' by routinely communicating to partners about how their input has informed and influenced research (See also **So What?**).

Celebrate shared achievements through a final partnership celebration event, a collaborative publication, or a creative output.





Approach institutional partners to identify legacy opportunities or pathways for ongoing collaboration.

Agree, at the outset, what an ethical and transparent conclusion to the partnership will look like.



What are Your Next Actions?

Building meaningful partnerships takes time, patience, and genuine commitment to sharing power and resources.



Remember

There are no perfect answers. It's about beginning to notice, question, and experiment so that your approach evolves over time.

Based on the content of this pathway, consider:

- How will you **identify** who to partner with in an engaged, collaborative approach?
- What **actions** will you take to understand partners' individual needs and preferences for working together?
- What will you **put in place** to document the engaged research partnership?
- How will you **plan and budget** for the time, care, and emotional labour required to establish, maintain, and end partnerships well?
- What **learning and development** will you undertake to work more equitably?
- What **actions will all partners take** to reflect on and address power and emotion in engaged approaches?

Resources

Finding the right partners begins with understanding who is most affected by particular health conditions, who experiences inequity and exclusion, and what local research priorities are. Exploring health statistics and reviewing academic literature can be helpful in **identifying potential types of partners** by understanding who is most affected by health conditions (**incidence and prevalence data**[29]), which populations experience health inequalities (in the **UK**[30] or **globally**[31]) and understanding who is currently excluded from health research. In England, **local public health profiles**[32], joint strategic needs assessments, and **constituency data dashboards**[33] can provide relevant information. Internationally, **country dashboards**[34] and research priorities setting processes (such as **this one**[35] in Africa) may be useful.

Tools like the **Inclusive Stakeholder Mapping Toolkit**[36] can support systematic and equitable partner identification. Guidance also exists for working with specific groups (e.g. **young people**[37], people with **learning disabilities**[38] and older people), and for inclusive communications (e.g. **NIHR**[39]).

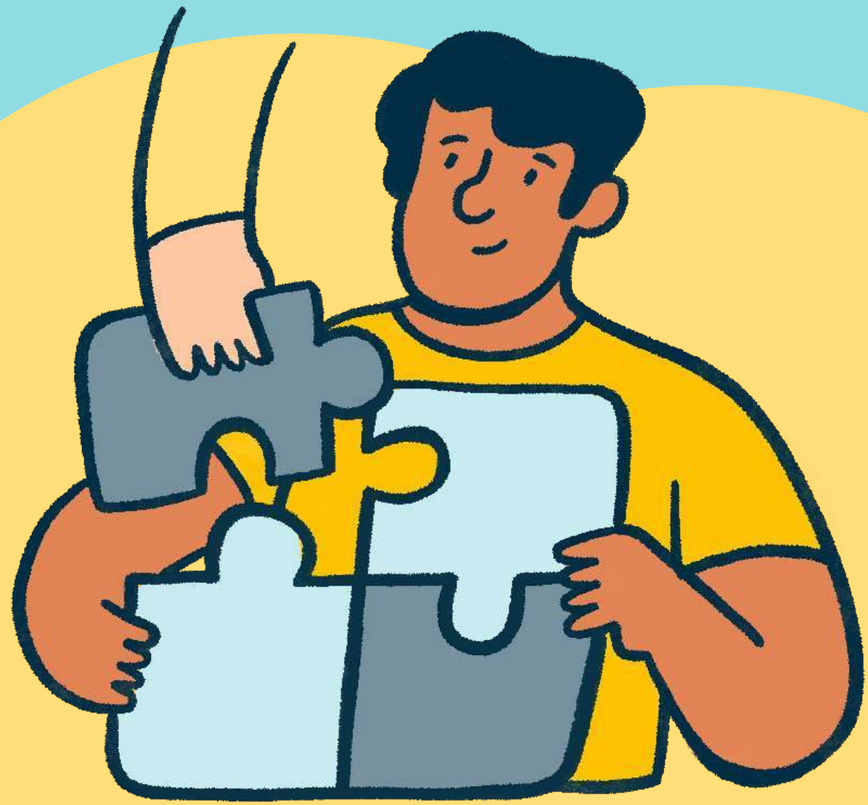
For deeper frameworks on partnership practice, explore this **guide on equitable research partnerships**[40], which contains practical guidance and case studies for setting up, maintaining and ending **authentic partnerships**. You can also explore **core competencies**[41] for equitable partnerships, and use templates for **collaboration agreements**[42].

Learning in cultural humility[43], trauma-informed practice and conflict resolution may be useful. For deeper thinking about power relationships, it is useful to understand **symbolic capital in public involvement**[44] and the **POWER framework**[45].

For a strategic and structural approach to working with minoritised partners, at an institutional and personal level the **NIHR Race Equality Framework**[46] is a useful starting point.

You may also want to read more about the emotional labour of **service users**[47] and **engagement practitioners**[48], including **how things can go wrong**[49].

Pathway – HOW?



Introducing HOW?

This pathway explores how to put engaged research into practice. It guides you towards deeply-seated engagement practices, acknowledges challenges and limitations, and offers practical ways to work reflectively and adaptively within real-world constraints. The pathway thus sets considerations for researchers to move towards the 'best possible' engaged research in your context, no matter what the circumstances.



Learning Intentions

This pathway will support you to:

Consider your current engaged research practice and methods.

Identify methods and ethical considerations for engaged research.

Understand different levels and forms of engagement across the research lifecycle.

Anticipate and navigate practical challenges, risks and institutional barriers.

Recognise the range of skills, resources and structures needed for engaged research practice.

Embed ethical principles and relational accountability in day-to-day research practice.

Apply engaged approaches across different stages of the research life cycle.



Where are You Now?

To understand your starting point, consider:



How embedded is an engaged research approach within your current practice? Is this, for example, part of specific methods, or integrated throughout your entire research process?

What transferable skills or experiences do you already bring to engaged approaches? Which skills do you need to further develop?

How does your institution recognise and support engaged research? Does it have any related strategic priorities, policies, or networks you can build on?

How will you build in time and resources to develop and sustain relationships with partners?

Engagement as an Approach and a Method

Engaged research is guided by an overarching ethos of collaboration, mutual learning, and shared decision-making. Every stage of a project can reflect this approach, but practical constraints - such as time, resources, institutional systems, or context - may limit the extent to which it can be fully realised.

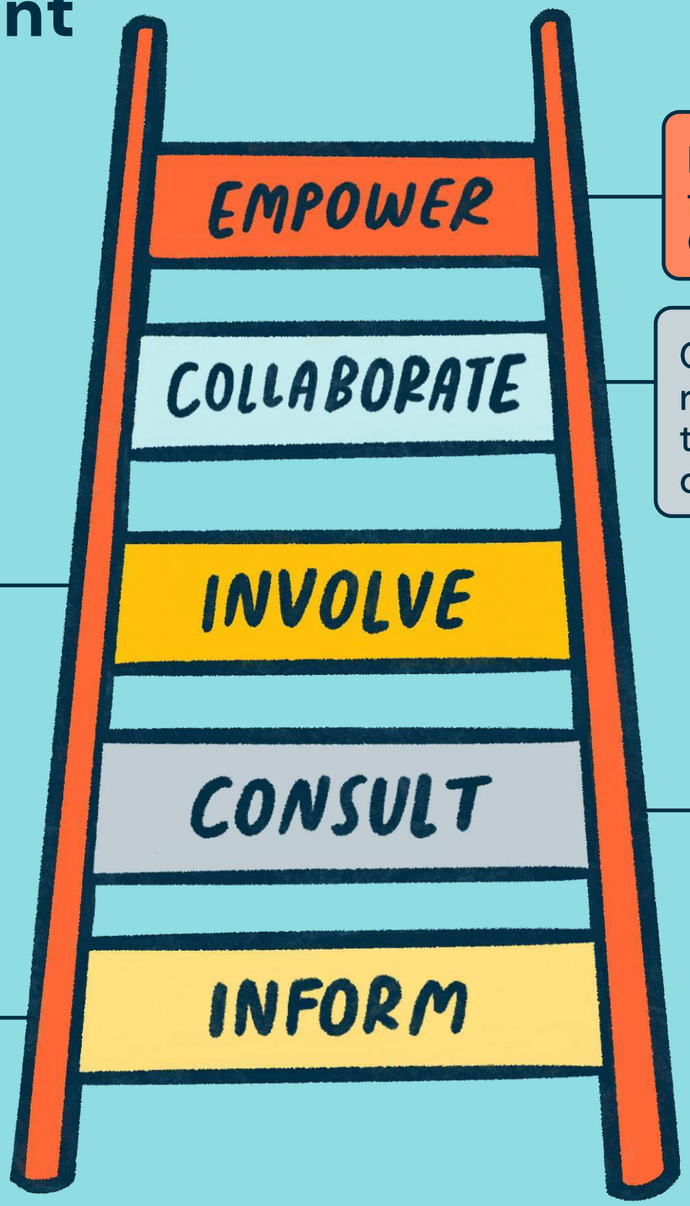
Embedding participatory methods such as co-applicant meetings, advisory or steering groups, or collaborative priority setting activities can represent meaningful steps toward this ethos. Even partial engagement strengthens the relevance, inclusivity, and impact of the research. (**See Pathway WHY?**).

Engaged research can take different forms and represent different levels of participation across the end-to-end research cycle, from informing and consulting to collaborating or sharing leadership.



Conceptual Framework: Levels of Participation and Engagement

Levels of engagement within engaged research can be understood along a spectrum. Best practice engaged research adopts shared decision-making and may also include activities within other levels.



Enable leadership and ownership from community partners, as in Community-Based Participatory Research.

Community members and academic researchers work as **equal partners** throughout the research process, jointly defining research questions and priorities.

Engaging partners in specific activities or decisions or for at least some portions of the project. Public and/or Patient Involvement or PPI often fits into this level.

Seeking feedback or perspectives about planned research.

Informing communities about research being undertaken.

Guiding Principles

The UK's National Institute for Health and Care Research **Guiding Principles for Community Engagement and Involvement**[50] sets out key principles for engaged research. These principles suggest that engaged research should be:

Appropriate & Relevant
Tailored to the local context, needs, and research aims.

Early & Ongoing
Involving communities and partners from the start and throughout the research process.

Understanding of Communities
Recognise diversity, lived experience, and context.

Inclusive & Equitable
Ensuring all relevant voices are heard and valued.

Transparent & Honest
Communicating clearly about processes, decisions, and expectations.

Sustained & Long-Term
Building lasting relationships, not one-off interactions.

Evaluative & Iterative
Continuously reflecting, learning, and adapting engagement practices.

These principles can serve as touchstones for planning or reflecting on your own engaged research practice.

Working to Purpose: Planning and Flexibility

The importance of careful planning for meaningful engaged research practice cannot be over-emphasised. It helps you anticipate challenges and respond to them when they do arise and allocate time and resources effectively.



> Building of capacities aligns with what roles people are supposed to play. What are you best placed to do as a community participant or community member? Sometimes you will require resources towards capacity building, so that people are ready for the research process and to participate... The other aspect of it is the fact that [engaged research] is geared towards actual change. So then there might be a need to invest in that.
>
> ***Engagement Practitioner, South Africa***

At the same time, engaged processes need to remain flexible, adaptive and responsive to context and changing circumstances. Building flexibility, in budget, timelines and approaches into your planning is, therefore, essential.

Reality of Engagement: Skills Needed

Working in an engaged way requires a mix of interpersonal, reflective, and facilitative skills that build trust and support collaboration. These include:



Knowledge and capacity in **trauma-informed**[53] approaches.



Cultural humility[54]



Clear and creative communication, including **inclusive language**[55] usage.



Inclusive facilitation[52]





Active listening[51]



Advocacy and influencing.



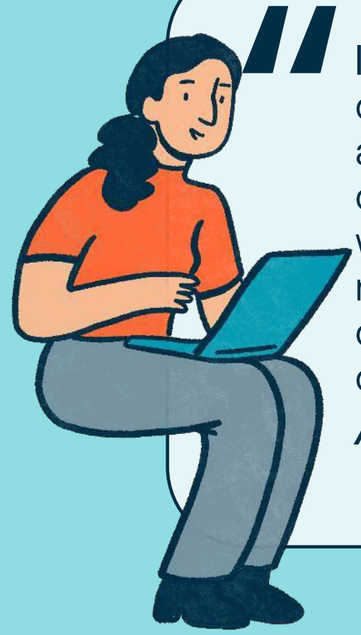
Ask yourself:

What assets and capacities already exist in your group that can support the level of engagement you want to take?

Which of these skills do you already hold, and which might need to be brought in or built with others?

Developing Skills

Engaged research skills are rarely part of formal academic training. This can leave researchers uncertain about how to collaborate effectively or fearful of causing harm through perpetuating power imbalances.



> I'm trained to read texts... I'm not trained to do anything to do with people – at best give a talk at a conference. There are some people coming from some disciplinary backgrounds where there's a huge amount that they either need to translate from other areas of expertise or kind of grow into in terms of in some cases quite basic skills.
>
> ***Academic Researcher, UK***

'Without deliberate facilitation strategies, the loudest voices in the room can dominate. We learned to use rotating chairs, structured turns to speak, and even small group breakouts to ensure everyone had a say..'

Funder, UK

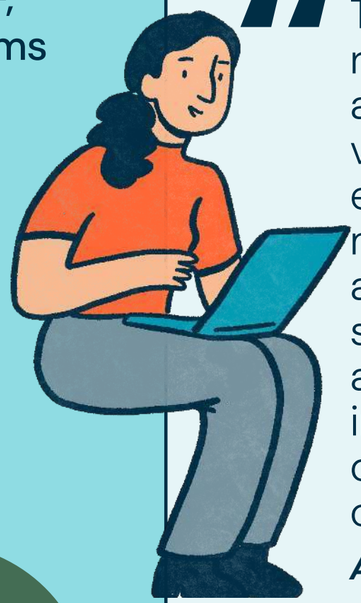
Skills required for engaged research can be learned, practised and improved over time. Continuous reflection, feedback, and peer learning help build confidence and competence in relational and participatory practice (see **Resources)**.

Reality of Engagement: Structural Needs and Challenges

Engaged research depends on **supportive structures**[56], which may be challenged by academic and funding norms and restrictions:

Relational approaches often require extra time for building and sustaining relationships and adaptive processes, yet research timelines are often set to funder, rather than community, needs.

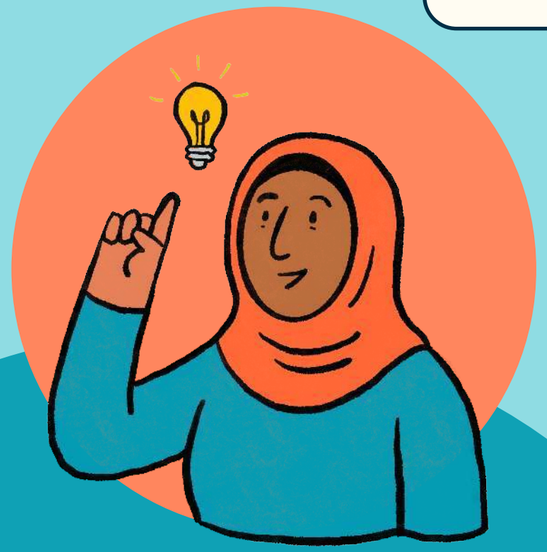
Equitable collaboration carries justifiable costs (such as partner remuneration, translation, or accessibility accommodations), which need to be built into funding applications equitably. Institutions require policies and processes to ensure payment in a timely manner.



> The thing I've been grappling with very intensely recently is the financial barriers and challenges that are faced with engaged research. So you have the value of fairly compensating people for their time, engaging in research, and for us that particularly means ensuring that people with lived experience are able to contribute their time and are properly supported. However, university financial structures are often really opaque. Even the researchers find it incredibly hard to understand what processes and options there are. It can often take a huge amount of time.
>
> ***Academic Researcher, UK***

Managing Structural Needs and Challenges

Ask yourself:



How will your funding plan support equitable collaboration? Will the budget cover partners' time, travel, subsistence, caring costs, translation, specialist equipment or software? How much should you contribute to the running costs for community organisations? How will payments to public partners be made?

How much additional time will you need to practice an engaged approach effectively, and how will you advocate for this with funders and institutions?

Who can provide advice and expertise on engaged research practice, policies and processes within your institution or beyond it?

Reality of Engagement: Relational Needs

Sustained collaboration in engaged research requires continuous attention to relationships and to how power, trust, and communication are shared. (See Pathways **WHY?** and **WITH WHOM?**).

Ensure partners feel heard and included, supported by inclusive facilitation, valuing lived experience, and setting clear expectations to address hierarchies.

Keep research processes flexible and responsive to partners' needs. This is supported by being clear about scope and constraints, early engagement, and collective problem solving.

Manage conflict or difficult conversations through clear expectations, regular reflections, and agreed ways of working.

Navigate different ideas across a collaborative team through equity in power and decision-making and clear terms of reference.



Planning to Manage Relationships

Ask yourself:



What **levels of participation** do you want to achieve in your research?

What are the team's **roles and responsibilities**, and how will these and the **ways of working together** be documented?

How will you ensure time to **build and sustain partnerships**, noting these relationships often need to be cultivated long before a project is funded? (See Pathway **WITH WHOM?**)

Setting your Research Methodology

In planning engaged research, it is important to distinguish between the overarching ethos of engaged research and the specific methods used to enact it.

To align with this ethos of engaged research, research questions and priorities should be set collaboratively, reflecting a commitment to shared decision-making, mutual learning, and inclusivity. Approaches may include co-applicant meetings, advisory groups, citizens' juries, focus groups, consensus-building exercises, appreciative inquiry, creative exploration, or collaborative priority setting.

Research methods and activities should also be chosen and designed to reflect this ethos, while also being shaped by the level of engagement sought, available resources, and contextual constraints. Further tried and tested **methods**[57] and this searchable **library of activities**[58] provide practical guidance to setting and implementing activities that support your overall engagement.

Planning your Research Methods and Activities

In planning your research methods and activities there are a number of key considerations.

Ask yourself:



What kinds of activities are aligned with your intended **level of participation**?

What relevant **skills and resources** do the team, including community partners, already have?

What activities and methods would **benefit** the different people and groups in the research?

Are there any forthcoming **opportunities**, such as community events or festivals that you could join? Linking to existing events can be particularly helpful for new relationships.

When, where and how would it be most **practical and convenient** for community partners to participate?

Considering Research Ethics

Formal ethics review processes designed for conventional research models can be rigid and lengthy, hindering meaningful collaboration, limiting flexibility and stifling innovations in engaged research. This often creates tensions between the procedural demands of ethics boards and the flexible, iterative nature of engaged research.





> It took me a year to convince [our university] ethics committee that we need to include race as a social determinant of health in our research in the work we're doing... what we realise in the process is the lack of guidance for research ethics committees.
>
> ***Academic Researcher, South Africa***

These tensions highlight the need for ethics frameworks that value lived experience and support co-designed approaches. Advocating for flexibility and responsiveness to emergent learning helps ensure that ethical review protects participants without constraining equitable collaboration.

Considering Research Ethics

Consider UK guidance that states public involvement in research does not require specific ethical approval, similar to collaborating with peers. However, working with people with lived experience of marginalisation or structural disadvantage within your engaged research approach can require additional formal ethical review.

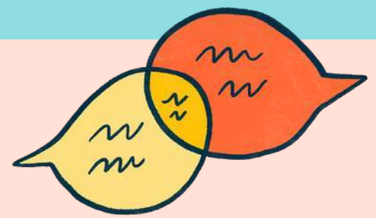
Ultimately, all engagement should, fundamentally, be guided by an ethic of care (see Pathway **WITH WHOM?, Emotional Labour**).



Care & Reciprocity

Prioritise wellbeing and mutual benefit for all partners, recognising emotional labour and shared responsibility.

Transparency & Consent



Communicate intentions, decisions, and constraints clearly. Ensure all partners understand how information and outputs will be used.

Accountability Through Relationship

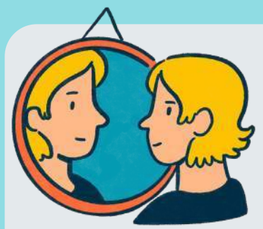


Build trust by keeping commitments, returning learning to partners, and ensuring that communities see the value of their contribution.

Equity & Inclusion

Continuously examine who is included, whose knowledge is valued, and who holds influence. Adjust processes to reduce inequity and enable participation.





Ongoing Reflection

Treat ethics as a living process. Reflect regularly on your own assumptions, the impact of decisions, and the quality of relationships.



Ask yourself:

How do your daily research practices demonstrate care, fairness, and shared accountability to those you work with?

What are Your Next Actions?

To understand your starting point, consider:

What assets and skills exist across your team and partners? What learning will you prioritise to support engaged research? What support might you seek from engagement experts and/or brokers?



Remember:

There isn't a perfect approach to engaged research. How you work will depend on your team and context.

How will you work with your team and community partners to co-develop research questions that reflect shared priorities?

How will you work together to plan and budget for an engaged approach that benefits everyone involved?

Will you need formal ethics approval for your engaged approach? How will you navigate this process?

What institutional barriers exist? What structural changes and institutional support will you need to embed an engaged approach in your work? How will you make this happen?

Resources

To think through your desired level of engagement, explore **different approaches**[59] and consider **this adaptation**[60] of Arnstein's ladder of participation. If you are limited in the engagement you can implement, carefully consider the **different stages of your research and where engagement might be most needed in your context**[61].

Skills involved in engaged research are transferable across sectors and there is a wealth of content available to suit different learning styles. Links for recommended and most relevant learning sources are embedded in the pages above. Consider working with a local **broker**[62] e.g. a public engagement or involvement practitioner from your institution, or an infrastructure organisation serving the communities you'd like to work with.

The **James Lind Alliance Guidebook**[63] and **Include project**[64] can support you to **collaboratively identify and prioritise research questions**, and **design inclusive research plans**. This complementary **paper**[65] provides recommendations from work in the Global South on **how to share power within priority-setting processes** and the conditions underpinning success.

Planning for engaged research **costs** can be supported by this **guidebook**[66] which considers assumptions, challenges and practical steps to support **equitable payments** to community partners, supplemented by best practice in defining **fair market value for charities in partnership work**[67], and comprehensive **payment guidance**[68] including a cost calculator.

Practical guidance on **ethical practice and review requirements** includes details of **how community partners should be involved in formal ethics review processes**[69], **guidance**[70] differentiating between research and engagement, and explorations of **how to navigate ethics**[71] in engaged research including useful case studies.

For the practicalities of implementing engaged research, use templates like this one for **terms of reference**[72], setting out ways of working together.

Pathway – SO WHAT?



Introducing SO WHAT?

In engaged research, documenting and sharing learning is key to demonstrating accountability, enabling continuous improvement, spreading knowledge, and recognising the contributions and voices of all partners. Yet many of the outcomes that matter most in engaged research, such as improved community well-being, local policy changes, or shifts in service delivery, fall outside traditional academic metrics of success and standard reward structures.

This pathway invites you to consider what counts as impact: what we measure, how we measure it, and how learning is shared. It supports you to generate learning insights from engaged research across multiple dimensions: the effectiveness of your engagement approaches, the extent to which power was genuinely shared, the accessibility of findings to those who contributed, and the ongoing influence on community wellbeing, policy change, and institutional practice.



> The need to engage journals and peer-reviewed publications... really changes the culture. We can learn from other areas that have changed, for example, how impact is measured. It took a very long time to get people away from measuring the journal impact factors as the core measure of impact and to make it a more ethical process for measuring that.
>
> ***Funder, UK***

Learning Intentions

This pathway will support you to:

Co-design evaluation strategies that reflect the values and goals of all research partners.

Communicate and report on engaged research in accessible and meaningful ways for diverse audiences.

Use a range of tools and approaches to assess both process and outcomes of engaged research.

Communicate and report on engaged research in accessible and meaningful ways for diverse audiences.

Recognise learning as a continuous and adaptive process, and use learning to guide improvements over time.



Where are You Now?

To understand your starting point, consider:



What might success look like in this research, and how might that differ across partners?

How do you currently assess the changes or benefits your work contributes to?

What are partners' learning requirements and information preferences, and how can evaluation address these?

What resources and capacity do you have for comprehensive evaluation? Who could help you? Do you require independent evaluation expertise?

How will you ensure all partners are appropriately recognised for their contributions?

What learning products and knowledge outputs will be most accessible and engaging for each audience?

What different reporting channels and dissemination routes can you or your partners use to communicate the difference engaged research has made?

Co-designing Evaluation

The **WHY?** pathway of this Primer highlights the value of undertaking engaged research in terms of ethics, relationships, and changes to individuals, communities and institutions. These values are not well captured by traditional assessment metrics, and what matters, and should be measured, will be specific to each context and may even vary between the different people involved.

Effective evaluation of engaged research must itself be participatory. Community partners may prioritise different outcomes than academic or policy audiences.

A **co-design approach** where all research partners are involved in defining what success looks like and how it should be measured ensures that evaluation reflects the diverse values, priorities, and perspectives of everyone involved.



Considerations for Co-design Success

Co-design works best when evaluation is approached as a shared, reflective process. Success can be increased if you:



Begin by starting with a shared process to understand what different stakeholders value and how they define meaningful change, avoiding assumptions about what is worth measuring.

Evaluation design can reproduce power imbalances if not carefully managed. Consider whose voices are centred, whose definitions of success are prioritised, and how different forms of knowledge are valued.

The process of collaboration is often as important as the final results, particularly for building trust and sustaining partnerships.

Practical Implementation Considerations: Evaluation Approaches

Evaluating engaged research often requires multiple methods that can capture both the processes of collaboration and the outcomes achieved. Common approaches include:

Most Significant Change technique - to capture unexpected outcomes.

Partnership quality assessments and relationship mapping - to understand dynamics and mutual accountability.

Stakeholder feedback sessions and follow-up forums - to reflect together on progress and learning.

Community benefit tracking and policy influence monitoring - to document tangible change.



Combining qualitative and participatory approaches with quantitative data can provide a more holistic picture of how engaged research creates value and impact.

Evaluation Implementation Challenges

Common challenges in implementing engaged research evaluation include balancing research rigour with community priorities, managing timeline pressures and relationship building needs, and navigating budget constraints while ensuring fair compensation for partners.

Embedding regular reflection within research design, and ongoing evaluation of research activities, helps identify when adaptations are needed and ensures continuous learning throughout the process.



> What's the point [of evaluation and reflective practices] if you're not going to make changes? The whole point of it is that we're iteratively developing the way that we're working together, so we're not waiting until the end to go 'Oh, look! This was great, and that was awful!' Because then you can, as a group, look at what's come out, and you can try and unpick it together and think about ways to make changes, because that's what's really important.
>
> ***Engagement Practitioner, UK***

Centring Engaged Practices in Research Evaluation

Partners should be involved in deciding how evaluation findings are presented, who the audiences are, and what messages are most important to convey. All communication outputs should, therefore, be co-produced.

Reflection on the engagement process itself – what worked well, what was challenging, what was learned, and how the approach influenced the findings – is equally important. Documenting this learning not only strengthens practice but also contributes to the growing evidence base for engaged research.

Sharing both process and outcomes demonstrates transparency, accountability, and care: core principles of engaged research.



Accessible Communication and Reporting

Engaged researchers have a responsibility to communicate findings in ways that are meaningful and accessible to all partners involved. Academic communication can exclude non-specialist audiences and risks being exclusionary. Community forums, clear and jargon-free open access reports, and digital outreach platforms can be used to ensure that the insights generated return to the people who helped produce them.

Accessibility ensures that knowledge returns to the communities who helped create it, and that the learning can continue.



> One of the things that we're finding really interesting about this project is we're asking people to produce and disseminate their research findings in ways that will be useful and intelligible to the world... and there's some really good bits of art coming out of this research project. People are presenting their research findings in artistic form so that might be sculpture, it might be actual paintings... And that I think is really interesting when you try to make things intelligible and understandable to the rest of the world.
>
> ***Activist and Community Researcher, UK***

Accessible Communication and Reporting

While embracing diverse communication approaches, academic publication remains important for building the evidence base and influencing research practice. However, navigating institutional expectations while maintaining the integrity of engaged approaches, particularly the principles of equitable collaboration, can be challenging.

Managing these tensions can be supported by:

Clearly articulating your engaged research approach and what difference it has made. This includes being explicit about methods, relationships, power dynamics, and the changes or benefits arising from your work, while addressing concerns about rigour and validity.

Using recognised reporting frameworks. Several frameworks exist to support systematic reporting of engagement including **GRIPP2 checklists** for patient and public involvement, participatory research reporting guidelines and community-based participatory research frameworks.

Contributions and Attributions

All partners should be appropriately recognised for their contributions in any product or dissemination process, including academic publications. Recognition can take many forms: co-authorship, acknowledgement statements, or other forms of attribution that respect different preferences and circumstances.

In academic contexts, implementing co-authorship should be routine practice. This includes:



Developing systems to support community partners in academic writing.



Providing training and mentorship to build skills and confidence in communication.



Recognising different contributions – conceptual, relational, logistical, or creative – while reflecting honestly on both successes and challenges in engagement.

What are Your Next Actions?

Evaluating and sharing the impact of engaged research requires planning, participation, and ongoing commitment to all partners. Based on the content of this pathway, consider:

How will you and your partners collectively define what success looks like in this research?

What evaluation approaches will be appropriate and meaningful for the diverse partners and audiences involved in your work?

How will you ensure evaluation itself is participatory, with partners involved in deciding what gets measured and how findings are interpreted?

How will you document and share learning about the engagement process itself: what worked well, what was challenging, and how this influenced your findings?

What accessible communication formats and channels will you use to return learning to the communities who helped create it?

How will you recognise and attribute contributions appropriately, including through co-authorship, acknowledgements, or other forms that respect partners' preferences?

What actions will you take to sustain relationships and support long-term changes beyond the formal end of your project?

What institutional or systemic advocacy might you undertake to support better recognition and reward structures for engaged research?



Remember

Evaluation and impact are ongoing practices, not one-time events. They require the same care, reflexivity, and shared power that characterise all aspects of engaged research.

Resources

Several toolkits offer frameworks for assessing and evaluating engaged research approaches, including the **Public Involvement in Research Impact Toolkit**[73] and the **International School on Research Impact Assessment resources**[74]. For those working specifically on engaged research in medicine development, **multi-stakeholder frameworks with metrics**[75] can provide structured approaches to evaluation.

Effective evaluation of engaged research benefits from taking an engaged (i.e. participatory) approach. Resources for co-designing evaluation strategies help ensure that what gets measured reflects the diverse values and priorities of all partners. **Guidance on measuring what matters for engagement**[76] can support this process, alongside **reflective learning resources**[77] and **step-by-step toolkits for implementing and evaluating co-design**[78]. **Critical perspectives on what we measure in public involvement**[79] – and whether we should reconsider our approaches – can help challenge assumptions about evaluation.

When it comes to communicating findings and reporting on engaged research, **guidance on monitoring, evaluation and learning for policy engagement**[80] offers approaches and questions for different contexts. The **High Impact Research Training Toolkit**[81] provides practical support for accessible communication.

For academic publications, the **GRIPP2 reporting checklists**[82] support systematic reporting of patient and public involvement, whilst the **UK Research Integrity Office**[83] offers guidance on authorship and appropriate recognition of contributions.

If you're starting out with evaluation, foundational resources like **Evaluation 101**[84] can provide grounding in basic principles. **Visual methods for evaluating public engagement**[85] offer alternative approaches to capturing and communicating what has been learned.

Underpinnings: Methods, Glossary, Bibliography and Acknowledgements



Our Approach in Developing this Primer

With the aim of modelling engaged research practices throughout this project, we used a hybrid mixed-method approach:

- **Structured review of resources and needs** – We intentionally centred embedded and experiential knowledge by speaking directly with researchers, engagement professionals, and community partners, while also drawing on existing tools and frameworks in peer-reviewed (including the Wellcome-commissioned "**Engaged Research for Health**" guide) and grey literature (reports, resources and guidance from various organisations such as government, the third sector, academia and industry).
- **Stakeholder interviews** – We conducted 15 semi-structured interviews with academic researchers, engagement specialists, funders, and researchers with lived experience. We used purposive sampling to ensure a diversity of perspectives, including by discipline, geography, and background.
- **Collaborative sense-making** – We held 2 facilitated sense-making workshops with 16 stakeholders to validate emerging findings, explore tensions, and surface critical gaps.
- **Thematic analysis** – We conducted a two-stage analysis process which combined deductive coding using a draft competency framework co-developed through the research process, with inductive coding to capture emergent insights and overlooked priorities.
- **User testing** – Eleven user testers and our Advisory Board reviewed a near final text-only version of the Primer. The user tester group comprised researchers with diversity across seniority of roles, institutions, and subject specialty including a majority working within discovery research. User testers answered a structured questionnaire with quantitative rating-scale questions and qualitative open-response prompts. All feedback was addressed.

Key Principles

Throughout the process of developing the Primer, we prioritised a number of key principles:

- **Reflective and relational practice** – Ensuring contributors felt heard, respected, and central to shaping the outcomes.
- **Ethical engagement** – Adhering to trauma-informed and inclusive research ethics, especially when working with contributors with lived experience.
- **Equity and inclusion** – Actively considering power dynamics in knowledge production and representation.

The result is a Primer that reflects not just what engaged research is, but how it is practiced – including the challenges, complexities, and care it requires.



Glossary

Term	Definition
Accessibility	Approaches that ensure all people, including those with disabilities, low literacy, limited digital access or language barriers, can participate fully in research activities. This matters in engaged research because involvement requires intentional design that removes structural barriers to participation.
Active listening	A communication approach involving full attention, withholding judgement, and responding with care. It matters in engaged research because trust, understanding, and strong relationships depend on listening deeply to community perspectives.
Adaptive practice	A flexible way of working in which researchers adjust plans, decisions, and methods based on new insights and partner feedback. This matters for engaged research because collaboration is dynamic and contexts often shift.
Advisory group	A group of community partners, stakeholders, or experts who provide guidance and oversight throughout a research project. Advisory groups matter because they embed shared decision-making and diverse expertise in the research process.
After-action review	A structured reflection process used after an activity or project phase to identify what worked, what didn't, and what should change. It matters because it supports collaborative learning and strengthens future practice.
Allyship	Actions taken by those in positions of privilege to actively support and stand alongside people facing marginalisation. This matters in engaged research because equitable partnerships require conscious efforts to address power imbalances.
Anti-racist	An approach that identifies, challenges, and works to transform practices and structures that reproduce racial inequities. It matters in engaged research because research has historically contributed to racial harm and must work actively against it.
Appreciative enquiry	A strengths-based approach that focuses on what is working well and builds on existing assets. This matters because it avoids deficit framing and supports empowering, collaborative relationships.
Assumptions	Beliefs or expectations researchers hold, often unconsciously, about communities, knowledge, or processes. Naming assumptions matters because unexamined beliefs can reinforce bias and undermine equitable collaboration.
Attribution	Recognising and crediting the contributions of all partners, academic and non-academic, to the design, conduct, and outcomes of research. It matters because fair and transparent attribution builds trust, accountability, and equity within research partnerships.
Bias	Unconscious or conscious preferences that influence how people interpret information, interact with others, or make decisions. Addressing bias is essential in engaged research to ensure fairness and respect for diverse knowledge.
Capacity strengthening	Expanding the skills, resources, systems, and confidence needed for partners to participate effectively in research. This matters because equitable engagement practice supports all partners to contribute fully.
Co-authorship	The practice of including partners who made intellectual contributions in research publications. It matters in engaged research because it recognises shared expertise and challenges extractive authorship norms.
Co-design	A collaborative process where people with lived experience work as equal partners to shape research questions, methods, or interventions. This matters because it produces research grounded in community needs and priorities.

Glossary

Term	Definition
Co-production	An approach in which researchers and partners share power and decision-making throughout the entire research process. It matters because it challenges extractive traditions and builds more just, relevant research.
Collaborative research	Research designed and carried out jointly with partners who share responsibility and decision-making. This matters because collaboration enriches research quality and ethical practice.
Colonial legacies	Historical patterns of exploitation, extraction, and inequality that continue to shape research systems. Understanding these legacies matters because engaged research seeks to avoid reproducing harm.
Coloniality	Ongoing systems of power that privilege Western knowledge and marginalise other ways of knowing. It matters because engaged research aims to respect and centre diverse knowledge systems and ways of knowing.
Community	A group of people connected by identity, experience, geography, culture, interest, or practice who may be affected by or involved in research. Defining community broadly matters because inclusive framing supports ethical representation and participation.
Community benefit	Positive outcomes, tangible or intangible, that research generates for communities involved or affected. This matters because engaged research prioritises reciprocity and value for communities.
Community partners	Individuals or organisations from communities who collaborate as equal contributors in research. They matter because their lived experience and contextual knowledge enhance relevance, ethics, and impact.
Community-Based Participatory Research (CBPR)	A collaborative research approach where community members act as equal partners throughout all stages of a project. This matters because CBPR offers long-standing models for shared power and community-driven inquiry.
Consultation	An engagement approach where researchers seek community or stakeholder input on specific questions or decisions. It matters because it is useful for targeted feedback, but must not replace deeper collaboration.
Context-specific research	Research designed to reflect the cultural, social, historical, and political realities of the setting where it occurs. This matters because context shapes relevance, ethics, and applicability.
Contribution analysis	An evaluation approach that examines whether and how an initiative contributed to observed outcomes. It matters in engaged research because impact is often collective and cannot be isolated easily.
Conventional research paradigms	Traditional ways of conducting research that prioritise objectivity, detachment, and researcher control. Understanding these paradigms matters because engaged research intentionally challenges many of their assumptions.
Cultural humility	A practice of ongoing self-reflection, learning, and openness to cultural difference. This matters because equitable engagement requires confronting privilege and positionality.

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Term	Definition
Decolonising research	The active effort to recognise and dismantle colonial structures in research by questioning whose knowledge is valued, whose interests are served, and how power operates. This matters in engaged research because it challenges extractive traditions and centres knowledge systems and priorities defined by communities.
Deliberative approaches	Methods that support structured dialogue, collective reasoning, and informed decision-making among diverse participants. These approaches matter because they help communities and researchers share power, negotiate differences, and make decisions collaboratively.
Developmental evaluation	An evaluation approach designed to support innovation in complex, evolving contexts by providing real-time learning and adaptation. This matters in engaged research because collaborative work often unfolds unpredictably and requires ongoing, iterative learning.
Dissemination	The process of sharing research findings in accessible, meaningful ways with the audiences who can use them. This matters because engaged research prioritises communication that is inclusive, relevant, and supports real-world change.
Emotional labour	The work of managing emotions, both one's own and others', to support respectful, caring, and productive relationships. This matters in engaged research because partnership work often involves navigating difficult stories, power imbalances, and interpersonal dynamics.
Engaged research	Research that meaningfully involves people with relevant lived experience, communities, or stakeholders in shaping decisions throughout the research lifecycle. It matters because this approach enhances relevance, ethics, and the real-world value of research.
Engagement	Any activity where researchers involve people who are affected by, knowledgeable about, or interested in the research. This matters because engagement creates opportunities for dialogue, influence, and shared understanding, even when full partnership is not possible.
Epistemic exclusion	The marginalisation or dismissal of certain people or groups as legitimate knowers, often due to systemic biases. It matters in engaged research because exclusion has historically undermined the contributions of communities and people with lived experience.
Epistemic justice	The commitment to valuing all people as legitimate knowers and recognising the validity of diverse knowledge systems. This matters because engaged research depends on fair recognition of lived, cultural, and community expertise.
Equitable partnership	A way of working where responsibilities, benefits, risks, and decision-making power are distributed fairly, not necessarily equally, based on context and strengths. This matters because meaningful engagement requires relationships grounded in fairness and mutual respect.
Equity (in research)	The practice of designing and conducting research in ways that actively address systemic inequalities and ensure fair access, participation, and benefit. This matters because engagement without equity can reinforce harm and exclusion.
Ethics of care	An ethical approach that emphasises relationships, responsibility, and attentiveness to the needs of others rather than compliance alone. It matters because engaged research depends on trust, reciprocity, and care.
Evaluation	The systematic assessment of a project's processes, outcomes, and impact to understand what happened and why. This matters because engaged research aims for learning, accountability, and evidence of meaningful change.
Experience-based design	An approach that centres user or community experience in designing services, interventions, or research processes. It matters because lived experience insight helps ensure that solutions are relevant and grounded in real-world needs.

Glossary

Term	Definition
Extractive research	Research that takes knowledge, stories, or data from communities without providing benefit, involvement, or accountability in return. It matters because engaged research aims to reverse these harmful patterns by prioritising reciprocity and shared decision-making.
Feedback loops	Processes that allow partners to share reflections, concerns, or new insights throughout a project and see how their input shapes decisions. This matters because feedback loops build trust, improve transparency, and strengthen collaboration.
Gatekeeping (in research)	Practices or structures that control who is allowed to participate, contribute, or lead within research processes, often limiting access for marginalised groups. This matters in engaged research because gatekeeping reinforces inequity and restricts meaningful participation.
Global North/South	Terms used to describe geopolitical and economic divides between high-income, industrialised countries (North) and low- and middle-income countries (South). This matters because engaged research must recognise and challenge the power imbalances shaped by these histories.
Human-centred design	An approach that places people with relevant lived experience at the centre of problem-solving and design processes. It matters because engaged research depends on designing with (not for) communities.
Humility	An orientation of openness, willingness to learn, and acknowledgment of one's own limitations. It matters because equitable collaboration requires recognising that expertise is shared and contextual.
Impact assessment	The process of identifying and understanding the effects of a research project on individuals, communities, or systems. It matters because engaged research prioritises real-world change over academic outputs alone.
Inclusion	The intentional practice of ensuring diverse people, perspectives, and experiences can meaningfully participate in research. It matters because without inclusion, engagement can reproduce inequity.
Inclusive facilitation	Techniques that create safe and equitable spaces where all participants can contribute. This matters because facilitation shapes whose voices are heard and how power is shared.
Indicators	Signs, measures, or markers used to track progress, outcomes, or change. Indicators matter in engaged research because they help assess impact in ways that reflect community priorities.
Institutional hierarchies	The formal and informal structures within institutions that determine who holds power, influence, and decision-making authority. This matters because these hierarchies often shape whose knowledge is valued in research.
Iterative process	A way of working that involves continuous cycles of testing, reflection, and adaptation. This matters in engaged research because relationship-based work evolves over time.
Knowledge holders	People who bring valuable lived, cultural, experiential, or professional knowledge to a research process. This matters because engaged research recognises knowledge beyond academia.
Knowledge production	The creation of knowledge through research, practice, and lived experience. It matters because engaged research challenges narrow definitions of what counts as legitimate knowledge.

Glossary

Term	Definition
Knowledge systems	The structures, traditions, and practices through which communities create, share, and validate knowledge. Understanding knowledge systems matters because engaged research seeks to respect and integrate diverse ways of knowing.
Knowledge translation	The process of moving research evidence into policy, practice, and action in accessible ways. It matters because engaged research aims to ensure findings are relevant and usable.
Lived experience	Direct personal experience of a condition, issue, or context that provides insight not accessible through theory alone. It matters because lived experience is essential for grounding research in real-world realities.
Marginalised background	Describes individuals or groups who face systemic barriers to power, resources, or representation. This matters because engaged research must avoid perpetuating harm against marginalised communities.
Mixed methods	Research that integrates both qualitative and quantitative approaches. It matters because engaged research often requires multiple ways of understanding complex social issues.
Most significant change	A participatory evaluation technique that captures stories of unexpected or significant change from stakeholders' perspectives. It matters because it centres community-defined outcomes.
Mutual benefit	An approach where all partners gain value from the research process. It matters because engaged research is grounded in reciprocity and fairness.
Narrative approaches	Methods that use stories, personal accounts, or collective narratives to explore experiences and meaning. They matter because storytelling is a powerful way for communities to shape research.
Outcome harvesting	An evaluation method that identifies and analyses contributions to outcomes after they have occurred. It matters because engaged research often produces complex, non-linear change.
Over-researched communities	Groups that have been repeatedly involved in research without receiving benefits or seeing change. This matters because engaged research seeks to avoid extractive patterns.
Parachute research	Research conducted by outsiders with little involvement of local communities, often leading to extractive relationships. It matters because engaged research aims to dismantle this harmful pattern.
Participatory evaluation	An approach where partners collaboratively design and conduct the evaluation. It matters because it shares power and strengthens relevance and accountability.
Participatory methods	Approaches that involve participants actively in shaping or generating knowledge. They matter because they shift research from 'on' to 'with' people.
Patient and Public Involvement (PPI)	Partnerships in which patients and public contributors shape research decisions, processes, and outputs. This matters because it embeds lived experience into health research.

Glossary

Term	Definition
Peer researcher	A person with relevant lived experience who contributes to or leads research activities. Peer researchers matter because they bridge academic and community perspectives.
Positionality	Awareness of how one's social identity, background, and experiences shape one's perspectives and relationships in research. It matters because power and bias influence every stage of engagement.
Positivist	A traditional research paradigm that prioritises objectivity, measurement, and detachment. Understanding it matters because engaged research often challenges positivist assumptions.
Power dynamics	The ways power operates within relationships, organisations, and systems. Understanding power dynamics matters because engaged research requires addressing imbalances openly.
Power sharing	Practices that intentionally give partners influence and decision-making authority. This matters because equitable engagement requires redistributing power.
Priority-setting partnerships	Collaborations where researchers and communities jointly identify the most important questions or areas for action. They matter because they ensure research addresses what communities value most.
Privilege	Unearned advantages based on social identity or positioning. Recognising privilege matters because it shapes how people interact, participate, and are heard in research.
Procedural ethics	The formal ethics review processes required before research begins. It matters because engaged research must go beyond compliance toward relational ethics.
Process evaluation	An evaluation approach that examines how a project was implemented. It matters because understanding process supports learning and improvement.
Psychological safety	A climate in which people feel safe to express ideas, ask questions, and raise concerns without fear of harm or judgement. It matters because trust and openness are essential for co-creation.
Realist evaluation	An approach that explores what works, for whom, in what circumstances, and why. It matters because engaged research operates in complex, context-specific environments.
Reciprocal relationships	Partnerships in which all parties contribute and benefit. It matters because reciprocity is a foundation of ethical engagement.
Reciprocity	The practice of ensuring benefits to both researchers and communities. It matters because engaged research rejects extractive approaches.
Reflexivity	The practice of continually examining how one's own identity, assumptions, power, and decisions influence research. It matters because reflexivity strengthens ethical practice and collaboration.
Reflective practice	A structured process of examining one's actions, decisions, and learning, to improve future practice. It matters because engaged research requires ongoing learning.

Glossary



Term	Definition
Relational practice	Ways of working that prioritise trust, care, communication, and strong relationships. It matters because successful engagement is built on relationships, not transactions.
Research ethics	Principles that guide responsible conduct of research, including consent, harm reduction, and fairness. This matters because engaged research raises unique relational and power-related ethical questions.
Research governance	The systems, structures, and processes that ensure research is well-managed, ethical, and compliant. It matters because strong governance supports accountability and trust in partnerships.
Research impact	The positive influence research has on policy, practice, communities, or understanding. It matters because engaged research prioritises meaningful real-world outcomes.
Research integrity	Commitment to honesty, transparency, and responsible conduct in research. It matters because trust is essential to engagement.
Research lifecycle	All stages of a research project, from idea to dissemination. It matters because engaged research encourages involvement across the whole lifecycle.
Research partners	Individuals or organisations who collaborate actively in the research process. They matter because partnership is central to engaged research.
Risk register	A tool for identifying, tracking, and mitigating potential risks throughout a project. It matters because collaborative projects often involve shared responsibilities and uncertainties.
Safeguarding	Policies and practices that protect people from harm, exploitation, or abuse during research activities. This matters in engaged research because partners may face heightened risks, particularly when sharing personal experiences.
Self-awareness	Understanding one's own emotions, values, strengths, and limitations and how these affect interactions. It matters because engaged research relies on mindful, ethical relationships.
Self-examination	The intentional process of exploring one's identity, privilege, and position in relation to others. It matters because it helps researchers understand how they influence research dynamics.
Sense-making	A collaborative process of interpreting information, experiences, or data to identify meaning and implications. It matters because engaged research values shared understanding between partners.
Social value	The positive social, cultural, or community-based benefits that arise from research. It matters because engaged research aims to create value beyond academic outputs.
Stakeholder	A person, group, or organisation affected by or involved in the research process or its outcomes. Stakeholders matter because diverse perspectives strengthen research relevance.
Stakeholder engagement	Approaches that involve stakeholders in shaping decisions, priorities, or activities in research. It matters because partnership improves quality and accountability.

Glossary

Term	Definition
Structural barriers	Systemic obstacles (such as policies, norms, or resource constraints) that limit people's ability to participate or benefit. They matter because engaged research seeks to remove or mitigate these barriers.
Structural racism	Systemic patterns of discrimination embedded within institutions and social structures that privilege some racial groups over others. This matters because research often reproduces these inequities unless addressed intentionally.
Sustainability	The ability to maintain relationships, benefits, and impacts beyond the life of a project. It matters because long-term change requires ongoing commitment.
Systemic inequalities	Deep-rooted disparities shaped by social, economic, or political systems. They matter because engaged research seeks to address inequities rather than reinforce them.
Theory of change	A description or visual map that explains how activities lead to outcomes and long-term impact. It matters because engaged research benefits from shared understanding of how change will occur.
Tokenistic involvement	Superficial or symbolic engagement that gives the appearance of inclusion without real influence. It matters because tokenism can harm trust and reinforce inequity.
Trauma-informed practice	Approaches that recognise the potential impacts of trauma and prioritise safety, choice, and empowerment. It matters because research discussions may trigger difficult memories or emotions.
Triggering content	Material or discussion topics that may evoke distress or trauma. Recognising this matters because engaged research must prioritise emotional safety.
Validity	The extent to which findings accurately represent what they aim to measure or understand. This matters in engaged research because validity improves when multiple perspectives inform the research.
Visual methods	Approaches that use images, diagrams, or creative visual tools to generate or communicate insights. They matter because they can make research more accessible and engaging.
Ways of knowing	Diverse forms of understanding and interpreting the world, including cultural, experiential, and community-based knowledge. It matters because engaged research values multiple knowledge systems rather than privileging academic ones.

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