Creating a public interface with your research

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wellcome

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Creating a public interface with your research

This workbook outlines an approach to building a public interface with your research that enables people to engage with it on an ongoing basis. Creating an interface is a collaborative process, and in our experience, the foundations of this must be led by the lead researcher(s) rather than being delegated out. It centres on inviting a core group of individuals with a stake in your research to inform how the research is communicated, including the core way the research is described, framed and shared. Drawing on decades of practice at Sense about Science and in the research community, it includes a step-by-step process and examples of how this has been done by other researchers. It is relevant to a range of research, including:

- New research facilities
- Research programmes where data emerges in stages
- Data monitoring, for example in climate science and health research
- Multi-year projects or pilots that may result in larger-scale activities in the community
- Other research of high public interest.

Note that the use of 'engage' and 'engagement' in this document also encompasses research involvement. Further information on how these activities are defined can be found here.

Building lasting connections with your research

Scientific research is enriched by meaningful connections with the people, communities and organisations it relates to. These connections rely on building relationships with a range of people[1] who have a stake in your research, which can in turn build trust in your work.

[1] Public contributors, patients, parents and carers, healthcare professionals, practitioners, local residents, policymakers and others who have a stake in your research.

Those with high trust in scientists are three times as likely to know someone who works in science or medicine as those with low trust.[2]

There is also a desire for transparency among the public,[3] and forming a team with them from the beginning can provide a strong foundation for lasting connections and relationships with your research.

Just 10% of those with low trust in scientists in general say that scientists are open and transparent.[4]

Building lasting relationships with your research can be challenging. Researchers often find themselves balancing this alongside intensive research activity, publishing their work, securing funding and supporting their teams. Research leaders report that their engagement activities often suffer from a lack of incentives and recognition by their institutions, funders and the wider scientific research system. The combined weight of staff turnover, precarious short-term contracts and the time-consuming nature of public engagement – often outside of working hours – can make it challenging for researchers to embed engagement in their research practices.

Two-thirds of research staff are employed on fixed-term contracts, making it challenging to sustain relationships with the communities around them.[5]

[2] 49% of high-trusters know someone working in science, while only 25% and 16% of mid- and low-trusters respectively do. Survey question responded to by 2,817 UK adults with 'high trust' (7–10) in scientists in general, 206 with 'low trust' (0–3) and 1,107 'in the middle' (4–6), 8–11 May 2026 (The Policy Institute at King's College London and Sense about Science, *Trust in Scientists: The role of values and moral and political identities in the UK* (2026), https://www.kcl.ac.uk/research/trust-in-scientists-the-role-of-values-and-moral-and-political-identities-in-the-uk).

[3] The Policy Institute at King's College London and Sense about Science, *Trust in Scientists: The role of values and moral and political identities in the UK*.

[4] Perceptions of openness and transparency are vital across different types of scientists: for example, 73% of those with high trust in scientists in general say they are open and transparent, compared with just 28% of those in the middle and 10% of those with low trust. Survey question was responded to by 2,817 UK adults with 'high trust' (7–10) in scientists in general, 206 with 'low trust' (0–3) and 1,107 'in the middle' (4–6), 8–11 May 2026.

[5] University and College Union, 'Manifesto Launched as Data Shows over 6 in 10 University Research Staff Denied Permanent Jobs', February 2025, https://www.ucu.org.uk/article/13919/Manifesto-launched-as-data-shows-over-6-in-10-university-research-staff-denied-permanent-jobs/.

Why relationships matter

Relationships are rarely built through one-off activities. Without ongoing communication, members of the public may be left wondering what happened to their contributions and whether their input made a difference to the research. However, for the reasons outlined above, it may be difficult for you to sustain relationships with contributors indefinitely. Communicating clearly at the outset what contributors can expect, what commitments can be realistically sustained and how relationships will be maintained over time can help to manage expectations and avoid participants feeling let down or used. Be clear from the outset about when public engagement activities might need to be limited or end because of funding, staffing or other constraints. Keep people informed about what happens after engagement ends and show how their time, knowledge and contributions have influenced the research.

It is also important to ask people with a stake in your research how they would like to stay in touch and be kept informed about the work as it develops, and to make sure shared information is understandable and accessible to a wide range of people.

Creating an interface with your research can help to:

- **Avoid relationships feeling extractive** by creating a place that the public can return to on their terms, stay connected to your research, see any developments and understand how their contributions have shaped them. Don't just limit engagement to when you need something from participants or leave people wondering how their contributions were used.
- **Support the public to be involved longer term**, both in your research and in connecting to science more widely. A research interface can extend public connection to research across and beyond the lifetime of a research grant. It can help you reach a wider range of people and create opportunities for shareable and scalable forms of engagement, like building interested communities, developing networks of actively contributing participants, and centralising resources that can be reused and adapted over time.
- **Ensure transparency and openness**, which is particularly important in the light of fragile levels of trust among the public.[6] Sharing information about how research is conducted, who is involved and who funds it, as well as being open about uncertainties, limitations and challenges, can help build trust across different groups.
- **Create a more trusting basis** for considering how research could be expanded, applied or regulated.
- **Sustain interest and hope in the outcomes of your research**. Communicating how your research is progressing, and any developments or potential real-world applications, can help build interest in your research over time, rather than simply sharing outcomes at the end.
- **Avoid misinterpretation of your research**. Research data can sometimes be misunderstood or used to support misleading claims. Setting out the scope, methods, evidence and wider context in an accessible way can help to combat this.
- **'Bank what you've built'** by writing up engagements and creating a record of public involvement in your work.

[6] The Policy Institute at King's College London and Sense about Science, *Trust in Scientists: The role of values and moral and political identities in the UK*.

The following pages give an overview of the 'public-led, expert-fed' approach and key steps Sense about Science have taken to co-create public interfaces with research over the past two decades. Sense about Science's 'public-led, expert-fed' approach means engaging early and directly with the public, starting with where the public is in a discussion, and addressing people's questions and concerns directly.

Before you create this interface, you will likely have already:

Designed your approach to engaging people in your research, for example using Wellcome Engaged Research - Purpose, Power, Practice: A Primer for Engaged Research, NIHR's Guiding Principles for Community Engagement and Involvement for Global Health Research, and involving stakeholders in this process.

Begun building relationships with a range of stakeholders by arranging meetings, one-to-one discussions and workshops and setting up panels, for example when creating a funding proposal or carrying out a pilot or initial study.

Scoped out who has a stake in your research and how they view your research, for example by reviewing what is being said about your subject in news, media, public statements and on websites, social media, blogs and forums, and—where relevant—in advertising, policy documents or reports. This will help to give a picture of where people are starting from when they engage with the issue. There are many tools out there to help you explore this, including Sense about Science's Public engagement: a practical guide.

But have you also:

- Agreed what the purpose of the engagement is?
- Considered what's needed for people to engage in this process?
- Decided what principles you will follow?
- Considered how you can develop or tailor these with communities?

Wellcome's engaged research primer can help you work collaboratively with people who are affected by or have an interest in your research throughout the research life cycle.

Search: wellcomeopenresearch.org/documents/11-260

Five steps to follow

The core group of stakeholders refers to people who will help create the interface between your research and the wider world. It may include public contributors, patients, people locally who might be impacted by your work, parents and carers, healthcare professionals, practitioners, local residents, policymakers and others who have a stake in your research.

Actions research lead should take	Core group with a stake in your research
Step 1: Assemble your group	
	Core group agrees to help you create an interface with the research
Step 2: Ask how people want to find information about your research and manage expectations	
	Group shares insights and questions
Listen, reflect, and answer questions raised	
Step 3: Create a simple description of your research. Send to group and invite to a workshop or online discussion	
Activity 1 2 3 4	Group reviews description and gives feedback so it can be understood by their peers
Step 4: Create a mock interface	
Activity 5 6	
Revise interface based on feedback	
	Group advises how to layer information
Group reviews interface and tests it with their friends, family, and community	
	Revise interface based on feedback
Step 5: Launch your interface and take care of the relationships you've built in the process	
Activity 7	

Step 1: Assemble your group

Creating an interface with your research is a deeply collaborative process, and in our experience, the foundations of this must be led by the lead researcher(s) rather than being delegated out. This first step focuses on bringing together a core group of stakeholders who will help create the interface between your research and the wider world. This means they can:

- Influence how key ideas and the wider context are explained
- Identify concepts that need clarification
- Highlight what feels relevant, meaningful or confusing
- Ensure that any concerns or questions about your research are addressed honestly and upfront
- Help determine which questions and insights should be foregrounded and what order they should come in
- Influence the format, design and user journey.

This is different from producing a lay summary or plain English summary that sits alongside one research output. Instead, it is an opportunity for others to influence across a strand of research, the core way the research is described, framed and shared. Their perspectives become part of the interface itself. The core group should be thanked and compensated for their time.

Who to invite

You should assemble a group of people from different walks of life, including key stakeholders you will have mapped out prior to starting this process (for more information see: Public Engagement Guide and the Quality in Public Dialogue Framework. Their role will be to create the core language and framing through which the research is communicated. We find that **8–12 people** is the right size to have the type of conversations needed for this process. This group should be made up of people who are:

- Most interested in the topic or data, or are likely to use the interface
- Directly affected by the issues being researched or the data your interface will share
- Able to bring perspectives that differ from those typically represented in your area, including those who have lower levels of trust in science and/or who can connect you to these groups. For more information see the Trust in Scientists survey. You can identify trust groups that are under-represented in your research engagement by using our TrustMapper tool.

Resources for inviting public participants

Stakeholder mapping

- Bill & Melinda Gates Foundation | Inclusive stakeholder mapping[7]
- NCCPE | High quality engagement template[8]
- Government Analysis Function | Stakeholder mapping[9]
- Miro | The complete stakeholder mapping guide[10]

Compensating public partners:

- Guidance on payment for public partners[11]
- Payment guidance for researchers and professionals involving people in research[12]

Before moving on to the next step, ask yourself

Have I brought together a group of 8–12 people whose experiences and perspectives are genuinely different from my own, and am I prepared to let them shape how the research is described?

[7] Bill & Melinda Gates Foundation, *Inclusive Stakeholder Mapping*, Convening for System Level Impact Toolkit (2021), https://docs.gatesfoundation.org/documents/tool_inclusive_stakeholder_mapping.pdf.
[8] National Co-ordinating Centre for Public Engagement, 'High Quality Engagement Template', October 2023, https://www.publicengagement.ac.uk/resources/tools-and-frameworks/high-quality-engagement-template.
[9] Office for National Statistics, *Stakeholder Mapping* (Government Analysis Function, 2024), https://analysisfunction.civilservice.gov.uk/policy-store/stakeholder-mapping/.
[10] Mandy Bray, 'The Complete Stakeholder Mapping Guide', *Miro Blog*, 25 October 2023, https://miro.com/blog/stakeholder-mapping/.
[11] Medical Research Council, *Guidance on Payment for Public Partners* (UK Research and Innovation, 2026), https://www.ukri.org/publications/payment-for-public-partners/guidance-on-payment-for-public-partners/.
[12] National Institute for Health and Care Research, *Payment Guidance for Researchers and Professionals Involving People in Research* (2025), https://www.nihr.ac.uk/about-us/who-we-are/policies-and-guidelines/payment-guidance-researchers-and-professionals.

Step 2: Ask how people want to find information about your research

It is important to ask people who have a stake in your research where they want to find out about your work. People will differ in how they prefer to find, receive and engage with information and how much they trust different sources. Using data from the Trust in Scientists Survey, we explore this in our TrustLens tool. Asking the core group what works for them, and other people like them, can help ensure your research is easier to discover and interact with.

Suggested prompts for this discussion:

- If you wanted to find out about this research, where would you prefer to get that information from? E.g. on a website, on TikTok, on Substack or via email. Where would you like a description of the research to be accessible? What about your friends, family, colleagues, neighbours or people you volunteer with?
- How do you want to be kept informed of developments with the study? Is there any other information you want to know about?
- How often do you want us to update you?
- What format would work best for you? E.g. video, text, print, infographics.
- Funding for this research is due to end on *[month, year]* and we hope to have completed *[X]* by this point. We would like to discuss what will happen to the interface at this time. Do you have thoughts about this now that we can consider? Build in time for someone to take responsibility for following up on this point in ***Step 5: Launch your interface and take care of the relationships you've built in the process*** and only agree what is realistic. Manage expectations about what is possible or feasible to deliver.

This may also be a good time to discuss:

- What you are aiming to achieve by engaging communities in your research more widely.
  - Wellcome | Purpose, Power, Practice: A Primer for Engaged Research (pg. 28)[13]
  - Sense about Science | 'Why are you asking me?'
- The areas of your research plans that are up for discussion and the areas that are fixed.

[13] Wellcome, *Purpose, Power, Practice: A Primer for Engaged Research [Version 1; Not Peer Reviewed]* (2026), https://doi.org/10.21955/wellcomeopenres.1115436.1.

The group you have assembled may ask for in-person meetings and talks, social media posts, email updates, a website, an online hub or other avenues. Consider:

- **In-person support**
  - Involving a trusted member of the community who is supported to speak to people they are closer to than you.
- **Emails**
  - Making sure the people you engage with have an email address, so they can return to your team to ask questions, request updates and find opportunities to get involved in future activities. You should set a realistic commitment to responding to the queries you receive to help build relationships.
  - Sending email updates to people you've involved, including how you've addressed their thoughts, or to say goodbye at the end of the research period or if staff contracts end. This may sound like a small step, and you might not hear anything back from the people you contact, but committing to doing this can help people feel their contributions are recognised and valued.
  - Making sure to let people know when research findings are published. Research has shown that participants want to be informed, with more than two thirds of respondents rating receiving a study outcomes summary as very important in deciding to join a future study.[14]
  - Creating a graphic that summarises what you are trying to achieve and how people can get involved with an online form to collate interested people's questions.
- **Online**
  - Creating a blog or a simple, online holding page that is updated at key points along the research life cycle.
  - Creating an online hub or website that describes what your research aims to achieve, shares progress and findings, and provides ways for the public to contribute feedback or ideas.

The group may ask to be kept informed about your research in a format or frequency that isn't feasible for you. Be honest about what is achievable for you within the time, budget and other pressures you may have, and discuss and negotiate that with the group.

[14] Rhonda G. Kost *et al.*, 'What Research Participants Say about Their Research Experiences in Empowering the Participant Voice: Outcomes and Actionable Data', *Journal of Clinical and Translational Science* 9, no. 1 (2025): e43, https://doi.org/10.1017/cts.2025.3.

Step 3: Curate a description of your research

A simple description of your research can form the core part of your research interface, which will be reviewed and adapted by the group you have assembled. The description is intended to help people who are not in the room, or who haven't had direct conversations with the research team, to be able to understand and engage with the research.

This is about responding to what people want to know, not what to tell them. Sense about Science's 'public-led, expert-fed' approach means engaging early and directly with the public, starting with where the public is in a discussion, and addressing people's questions and concerns directly.

Start by **practising verbally explaining your research to different audiences**. This will help when you speak to stakeholders and ask them to contribute to your research, and to help create a lasting interface. It will avoid your research sounding too technical or difficult to engage with.

Activity 1: Practise explaining your research to different audiences

Imagine you are explaining your research to somebody who has not come across your research before. What steps would you take them through? What language or analogies might you use? What key terms might need explaining? How can you break the information down into bite-sized pieces?

Now repeat this for the following groups: a researcher in another field; a friend of a similar age; a 10-year-old child; a person of a very different age to you; a person who lives in another part of the country to you; a person who has no relationship to the research; a person who is hostile to your area of work; or other stakeholders of interest in your research. How does your description change?

Activity 2: Summarise in 3 minutes

Can you now distil this down into a three-minute description? You may want to cover:

- Who you/your research team are
- What problem your research addresses and why it's important to address it
- What your research is trying to find out and what you've done so far
- How your research may benefit the communities you're speaking to, alongside potential risks, safeguards and uncertainties
- Who is funding your research
- Impacts you hope to have.

Activity 3: Consider how your description might be viewed

Consider how this description will be viewed by people who may have different levels of trust in scientists.

- Are there signs of polarisation in this area of research? Our Trust in Scientists survey identified that there are five groups in the UK with distinct levels of trust in scientists, shaped by their experiences, values and identities.
- Are there any contested terms or concepts?
- Are you using government targets or policy ambitions as a rationale? How might this be viewed by people with differing views of government, authority and institutions?
- Does the research raise any social or ethical issues? How might these be handled?
- Will the research provide unequal benefits to different groups?

For example, communities may not always respond to national government targets (e.g. reaching net zero by 2050) as a convincing rationale for research and may prefer you to highlight local benefits.

You may not need to change anything in the description just yet, but this can help you prepare for discussions during the next steps.

Activity 4: Draft and organise your description, and share with your group

Now write the description down and think about the flow of concepts and length (we find that 1–4 pages is a good starting point). Share this description with the group you have assembled and ask them to review it in detail, line-by-line, and provide feedback on topics such as the below.

Example questions for your core group:

- **Questions they might have about the research**
  - How will this treatment be safety tested before it's offered in a trial?
  - How will the data collected be used to inform decisions?
- **Concerns or fears that they want to discuss**
  - Could my personal health information be accessed by people outside the research team?
  - Could the research negatively affect my livelihood or the local community?
- **Hopes and aspirations about the research**
  - Who might benefit from the research?
  - Could the research lead to earlier diagnoses?
  - Will the project increase awareness and understanding about this issue?
  - Over what time period?
- **If there is anything missing**
  - Have you provided information about potential risks, safeguards and uncertainties?
  - Is it clear who is funding the research?
  - Is it clear on how people can stay involved as the project develops?

You can then have a specific discussion about:

- Key terms, concepts and language used
- Sections, headings, length, order
- If anything is too detailed, repetitive or if there is more they want to know
- Views on what friends, family and other people they know may think about this description.

Guidance for running discussions and workshops with your group:

- NCCPE | Online Engagement: A guide to creating and running virtual events[15]
- NCCPE | Panels and user groups guide[16]
- Scottish Co-production Collective | The Co-production Guide (pages 26–30)[17]
- NHS England | The Facilitator's Toolkit[18]
- Wellcome | How to use an engaged research approach[19]
- NIHR | Guidance on co-producing a research project[20]

[15] National Co-ordinating Centre for Public Engagement, *Online Engagement: A Guide to Creating and Running Virtual Meetings and Events* (2020), https://www.publicengagement.ac.uk/sites/default/files/2023-08/creating_and_running_virtual_events_-_april_2020_v1.pdf.
[16] National Co-ordinating Centre for Public Engagement, 'Panels and User Groups Guide', October 2023, https://www.publicengagement.ac.uk/resources/guide/panels-and-user-groups-guide.
[17] Scottish Co-production Collective, *The Co-production Guide* (Scottish Community Development Centre, n.d.), accessed 4 September 2026, https://www.coproductionscotland.org.uk/guide.
[18] NHS Institute for Innovation and Improvement, *The Facilitator's Toolkit: Tools, Techniques and Tips for Effective Facilitation* (2009), https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Facilitator-Toolkit.pdf.
[19] Wellcome, 'How to Use an Engaged Research Approach', accessed 16 September 2026, https://wellcome.org/research-funding/guidance/prepare-to-apply/using-engaged-research-approach.
[20] National Institute for Health and Care Research, Guidance on Co-Producing a Research Project (2024), https://www.learningforinvolvement.org.uk/content/resource/nihr-guidance-on-co-producing-a-research-project/.

You can hold an in-person or online discussion to gather your group's feedback. It is important to identify areas of convergence and disagreement, noting that you will not be able to resolve all of these in the description. Listen out for the social and ethical issues the work may raise for people and consider these with your wider team. You may also be able to clarify how key parts of your research are described to minimise misunderstandings.

Edit the description according to the comments and feedback received. You may want to circulate the revised description by email to the group, outlining that you will now use this to create an interface so that other people outside of the core group can understand what the research is trying to do.

Step 4: Co-design a mock interface using the description

Use the curated description to design a simple, mock interface that reflects how your group wants to find, access and interact with your research description based on ***Step 2: Ask how people want to find information about your research***. We have found that setting up a simple webpage is often the most popular way for people to engage with research. Interfaces can be created and hosted using online platforms.

Resources you could use to create a web interface:

Free

WordPress (free plan with ads)
- No/low coding skills needed, with documentation available
- Suitable for blogging and project updates

Wix.com (free plan with ads)
- Fast + easy setup with no coding
- Limited storage and bandwidth

GitHub Pages
- Requires some coding experience to set up, but allows for a very custom experience

Paid

WordPress (subscription tier)
- Enables no ads and more customisation compared with the free tier

Wix.com (subscription tier)
- Enables no ads and more customisation compared with the free tier
- Allows for a custom domain/ URL

Notion
- Quick to set up with support for collaborative updates
- Useful for sharing resources and updates

Squarespace
- Easy visual user interface for design

Framer
- Free to start and design pages, but subscription required for use
- Easy to create interactive pages, storytelling

Activity 5: Layer information

Depending on your research topic, you will likely have to 'layer' information. This means organising the description so that the most important information (as defined by your core group) is immediately visible, and additional information, links, further descriptions and resources remain available **for those who want it** in the second or subsequent layers.

- Discuss with the core group what the priority is for the top layer of information, and what can be put in secondary links or pages
- Ask whether any information can be expressed as graphics or videos
- Think about the order in which someone who is new to your research will see important points.

Consider how people will get assurances to common worries or misunderstandings, e.g. who is funding your research, how secure any participant data are, what research findings will be used for. Some of these assurances might need to be given in the top layer of information, e.g. who is funding your research, to avoid suspicion that this is being deliberately buried. The core group can help you think about how to word assurances.

Activity 6: Act on feedback and produce a mock interface

Put the content into the interface you agreed to use in ***Step 4: Co-design a mock interface using the description***, organising the information in line with the layered description. You can now:

- Ask the group to test the interface by themselves and write down any feedback they have on aspects like how easy the descriptions are to understand and navigate, whether it answers questions they may have and if content is where they expect to find it
- Test the interface with other people who were not involved in co-creating the research description
- Invite the core group to come back and talk about their thoughts and to give feedback. If there are points you've not taken up, explain why to the core group

Remember: the aim of this interface is not to increase traffic to a website, but to create a version of your research and its benefits that makes sense and is accessible to anyone who might be interested in this research. This is a good time to consider:

- What would someone who is hostile to or worried about this research think?
- What might someone who briefly glances at this page think? Do you need an 'at-a-glance' or '1 minute' summary?

In practice

Community feedback showed that people were likely to access the research information on their phones, so climate researchers in Weymouth added a 1-minute scrollable summary highlighting the key points.

Step 5: Launch your interface and take care of the relationships you've built in the process

Now that you have created an interface with your research, you will want to share this with the people who have been involved so far and take care of these relationships.

You can:

- Send the final interface to your core group
- Thank them for their contribution and compensate them for their time
- Outline how the live interface takes their feedback and thoughts into account
- Share what the next steps will be.

You may want to hold another online or in-person meeting to go through the interface to reiterate when and how it will be updated and follow what you've agreed with communities in *Step 2: Ask how people want to find information about your research* to manage expectations. This includes how you plan to contact the group if there are changes in your research plans, if the research ends or if team members move on.

Moving on responsibly

When a project ends, or funding runs out it's important not to leave participants and interested stakeholders in the cold. You could:

- **Give participants notice** by letting them know about the project's end dates as early as possible. When the project ends, add a notice to your interface that updates stopped as of *[month/year]*, signpost outputs and provide a contact for any remaining questions.
- **Share ownership** where possible, by transferring tools, resources or project ownership to community partners who may want to continue the work.
- **Stay connected** by maintaining your network and letting people know about future opportunities for involvement — ending the project doesn't mean ending all contact.
- **Celebrate the end** by co-creating a way of marking the end, perhaps through a final report, showcase event, exhibition or community celebration.

Activity 7: Reflect on what you have heard

Try to answer the following questions about the immediate next steps in your research, how to continue to deepen the relationships you have built or how to bring the engagement to a close:

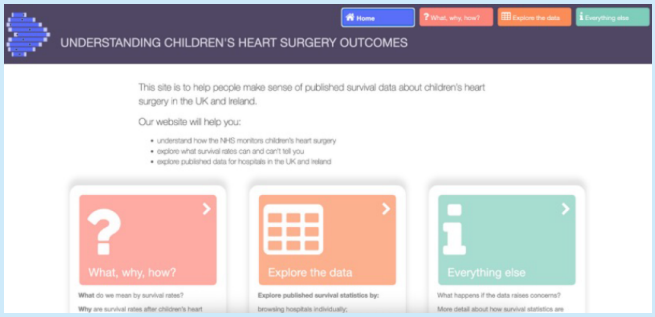
- What does the engagement tell you about the next stage of research? Which voices were not in the room? What additional activities are needed?
- How will you continue to engage the core group and widen to other individuals, groups, organisations and communities affected by or interested in your research?
- How will you reconvene people when something significant happens in your research? You might want to reconvene the core or wider group if the impact of your research on the community changes, and find out how they feel about that.
- How do you plan to end or transfer community relations if your research comes to an end?

Read on for examples of how research teams have co-created interfaces about their work with the public.

Examples of research interfaces

Infant Heart Surgery

Sense about Science partnered with National Institute for Health and Care Research (NIHR)-funded researchers and Dr Christina Pagel (University College London) in 2016 to improve communication about one of the most sensitive areas of healthcare: children's heart surgery survival statistics. Survival rates at different hospitals have often been misunderstood, leading to misleading media coverage, political debate and great public concern. Parents, patients, regulators and doctors needed to be able to understand a hospital's survival rate for children's heart surgery in the wider context of how severely ill patients were.



To address this, researchers, parents, health charities and others co-developed the website interface Understanding Children's Heart Surgery Outcomes.[21] The aim was to make information about surgical survival rates clear and contextualised to parents, patients, healthcare professionals, and others who needed it.

The research team developed the website through different rounds of public engagement. They carefully reviewed all the voices, questions and concerns in public discussion about children's heart surgery and created an initial website to 'speak' to those discussions. They held two streams of user-testing workshops: with parents of children who had heart conditions, and with other interested users, including press officers and policy advisors from medical charities and professional bodies, parent support groups, and patient advocates. Over a year, they held four stages of workshops with participants' responses shaping and developing the content, structure, language and presentation of the website.

The project was transformative for both the participants and researchers; parents of children waiting for heart surgery can explore the latest data that the NHS is using to monitor survival at children's heart surgery units through an impartial website. The website and animations can help parents to understand why direct comparisons between units would be inappropriate and misleading, while providing an ongoing resource that they can return to if they have questions. Each year the audit office releases the annual data, the website is updated and a link to the website is included in the letter sent to parents.

[21] 'Understanding Children's Heart Surgery Outcomes', accessed 4 September 2026, https://www.childrensheartsurgery.info/.

HDRUK INSIGHT hub

The INSIGHT hub research interface was co-created by Sense about Science and the Moorfields Biomedical Research Centre.[22] A need had arisen for a centralised health research data hub that enabled safe and trusted research access to de-identified routinely collected eye data to speed up research for new medicines and treatments and support faster diagnoses.



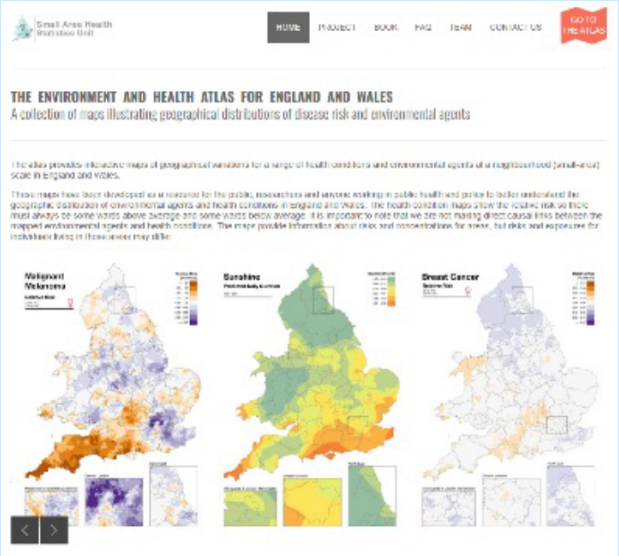
Public questions and concerns surrounding the relationship with corporate partners, the use of routinely collected patient data, the use of artificial intelligence (AI), and data privacy and safeguarding needed to be addressed.

A 'public-led, expert-fed' approach was taken to engage with these concerns. Patients, professionals and researchers were brought together to identify questions that should be included in frequently asked questions (FAQs), clarify the roles of industry partners, explain the potential benefits and risks of the project, and make medical terminology easier to understand. This was conducted across multiple rounds, iterating on the initial designs and content.

These workshops led to clearer, more accessible language with explanations on the INSIGHT hub website prototypes. Attendees of workshops were also asked if they wanted to be contacted in the future with updates or for further involvement and were used for user-testing and fine-tuning of website content. Sense about Science and the Moorfields BRC also conducted further events across the UK engaging with diverse communities to discuss how large-scale data would be used to develop AI models for treatment and diagnosis.

[22] Moorfields Biomedical Research Centre, 'INSIGHT Hub', accessed 4 September 2026, https://www.insight.hdrhub.org/.

Environment and Health Atlas



The UK Small Area Health Statistics Unit (SAHSU) at Imperial College London and Sense about Science collaborated to shape the Environment and Health Atlas[23] in 2012. Increased public interest in factors that influence disease created a need for a more accessible way of exploring geographic health data, but it was also imperative to avoid alarming headlines declaring a town the 'worst place for brain cancer in England' or advising 'where to move for lower breast cancer risk'.

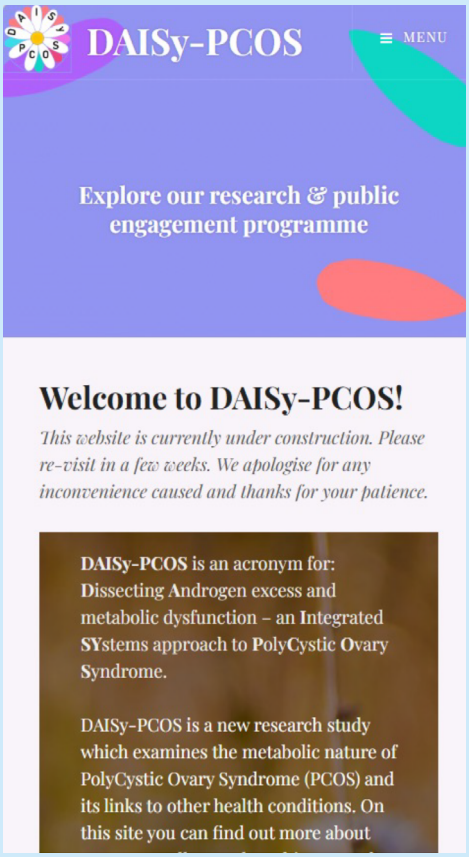
Through workshops including the public, experts, government and journalists, it became clear that the interface needed to make sure that what these maps don't tell us was just as clear as what they do. Several changes to the Atlas format were proposed and agreed upon to improve readability and provide insights needed for the public to make sense of the data to reduce misinterpretation.

The interface showed the relative risk category for specific health outcomes per ward or postcode, and signposted resources on how to interpret relative risks and uncertainties. It was also accompanied by a comprehensive FAQ developed through workshops to address common concerns and questions regarding data provenance, access, the kinds of data available and how the presented data were selected.

[23] UK Small Area Health Statistics Unit and Imperial College London, 'Environmental and Health Atlas', accessed 4 September 2026, https://web.archive.org/web/20250225203022/https:/www.envhealthatlas.co.uk/homepage/.

DAISy-PCOS

DAISy-PCOS (Dissecting Androgen Excess and Metabolic Dysfunction for an Integrated Systems Approach to Polycystic Ovary Syndrome)[24] was a Wellcome-funded project launched at the University of Birmingham in 2020.



While the project aimed to investigate PCOS-associated biomarkers and their links to women's broader metabolic health, it also placed a substantial emphasis on public engagement, with the team working alongside community advocates and specialists from the Queen Elizabeth and Birmingham Women's Hospitals to help raise awareness of the condition and reduce misunderstanding and stigma.

Central to this programme was the creation of a public website for the project, containing information about the research and updates on how engagement activities had progressed. This interface was designed for different stakeholders, including current and prospective participants, community advocates and interested members of the public. The website acted as the central public-facing interface, while the team also used X/Twitter as a channel for updates and ongoing communication.

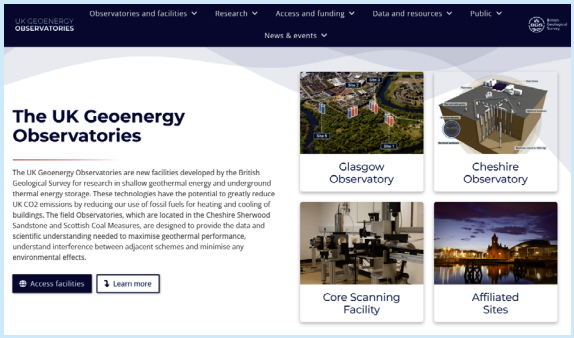
Patient information focused on the condition itself, describing its prevalence, who it affects, the symptoms and the causes; this was prefaced by a short (~2 min) YouTube video that summarised information about the condition in a digestible visual format with plain-language explanations. The website also contained links to resources and support networks for women with PCOS. Research content consisted of descriptions of the project's research activities, with links to associated publications, information about current studies and opportunities to participate, and webinars exploring the project's findings.

[24] DAISy-PCOS, 'Dissecting Androgen Excess and Metabolic Dysfunction for an Integrated Systems Approach to Polycystic Ovary Syndrome', University of Birmingham, accessed 4 September 2026, https://daisypcos.com/.

British Geological Survey

The UK Geoenergy Observatories (UKGEOS) represented a major national investment in research infrastructure designed to improve understanding of the 'world beneath our feet.' [25] The observatories in Cardiff, Cheshire and Glasgow were conceived as scientific test beds in contrasting geological settings. The scale and visibility of the proposed infrastructure, however, generated concern in some communities. The proposed activities raised questions about land use, drilling, local disruption and potential environmental impacts. These were amplified by the wider political and public debate surrounding fracking, with some groups concerned that the research might provide evidence that would pave the way for fracking.

In response the British Geological Survey (BGS) and the Natural Environment Research Council (NERC) worked with Sense about Science. Sense about Science adopted its 'public-led, expert-fed' approach to the public engagement undertaking a series of workshops: beginning with the questions, concerns and existing knowledge that people brought to the discussion before determining what evidence or expert input might be useful in addressing these. The workshops comprised professional and public stakeholders including BGS and NERC researchers and senior leaders, residents living close to proposed observatory sites, wider community groups, environmental campaigners, local policy stakeholders and journalists.



During 2018–19, public and professional user-testing workshops supported the development of an online open-data resource.[26] Participants contributed to the structure of the web platform, how the observatories and research were described and how information was organised. Prospective users were involved in shaping the interface through which research information and data would be accessed.

Sense about Science's UKGEOS work informed reflection within BGS about the need for and value of public engagement and co-creation. It demonstrated that technically complex research could be discussed directly with the public and highlighted the value of researchers hearing concerns first-hand rather than encountering them only through media reporting or formal objections. The UKGEOS web interface retains the open datasets, virtual 'tours' and learning resources developed through the co-creation work with public stakeholders. The Cheshire Observatory site,[27] for example, provides borehole maps (including borehole purpose and depth), open access to data and reports, details of funding, and links to subscribe to information bulletins.

[25] British Geological Survey, 'Joint Statement on UK Geoenergy Observatories Open Data', 30 July 2019, https://www.bgs.ac.uk/news/joint-statement-on-uk-geoenergy-observatories-open-data/.
[26] British Geological Survey, 'UK Geoenergy Observatories', accessed 5 November 2026, https://www.ukgeos.ac.uk/.
[27] See https://www.ukgeos.ac.uk/cheshire-observatory/.

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