



Public engagement: a practical guide



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*National Institute for
Health Research*

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Scoping

Look at what people are saying and the underlying assumptions.

2

Involving people

Work out the significance for different groups and how to involve them.

3

Planning

Propose content and formats that are relevant for the people accessing it.

4

User-testing

Develop your material together.

5

Dissemination

Continue to engage people and use feedback.

A five-step guide to involving the public in communicating your research.

INTRODUCTION

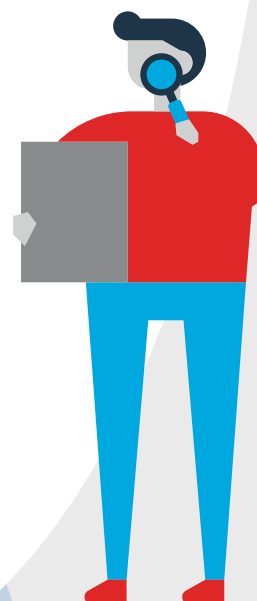
This is a practical guide for researchers on involving the public in working out how to communicate findings - from the earliest stages of projects, and on the most challenging of subjects.

Public engagement is now strongly encouraged in the research community: by funders, institutions and scientific bodies. Many researchers are persuaded of its importance, but wonder how to do it.

At Sense about Science, we have worked with researchers on many of the most sensitive subjects - some fraught with misunderstanding - to improve the communication of their research findings. We only undertake such partnerships where there are high stakes for the public and communication is difficult. Communicating the survival statistics of children's heart surgery at different treatment centres in 2016 was among the toughest of these, with potentially major consequences for all involved. Our public engagement team worked with researchers funded by the National Institute for Health Research (NIHR) to develop new ways of presenting information: we used a five-step process to help them discuss and present research information in a way that is shaped from the outset by people who will use it.

At the request of the NIHR we have set out our experience from this project, and drawn on some others, to help researchers who are planning their next project, writing their next grant proposal, or thinking ahead about how their work could have an impact.

Note: This guide focuses on involving the public to shape and co-design how research findings or information are presented. If you are interested in how to involve people in shaping the research itself, you can find helpful resources at the end.



OVERVIEW: CHILDREN'S HEART SURGERY (CHS) WEBSITE

In June 2016, a new website called *Understanding Children's Heart Surgery Outcomes* (<http://childrenshearturgery.info/>) began to publish the results of different surgical units in the UK and Ireland in a new way. Parents, patients, regulators and doctors could now see and understand why a hospital's survival rate for children's heart surgery needs to be shown in the context of how severely ill their patients were. It was a complex proposition, but from the website and animations, parents understood why direct comparisons between units, for instance in league tables, would be crass and misleading. The website was welcomed by parents and doctors alike. Representatives from both groups had helped to design it.

The website development was part of a project funded by the NIHR, led by Dr Christina Pagel, a mathematician from University College London (UCL). Christina's role was to work out the formula used to take into account the complexity of surgical cases in monitoring hospitals that carry out children's heart surgery. This was an emotive subject that had repeatedly created political debate and misleading news headlines. Christina believed that making this information clear and accessible to parents and to others who rely on it, such as journalists and regulators, was important and part of her responsibility as an academic.

Dr Christina Pagel, reader of operational research, UCL:

"Before applying for the NIHR grant to update the statistical formula, I'd realised that my responsibility extended beyond developing as good a formula as I could – I also had to communicate how the formula works and what it can and can't do. So in my application, I asked NIHR for funding to build a website to explain how my work is used to monitor survival rates. NIHR was very supportive – in fact they asked me to be much more ambitious in this part of the project, to really engage parents and the public. This pushed me far outside my comfort zone and I'm so glad it did."

NIHR's encouragement led Christina to gather together a multi-disciplinary team to deliver the website. The team included:

- David Spiegelhalter, professor of public understanding of risk, University of Cambridge.
- Tim Rakow, reader of psychology, King's College London.
- Mike Pearson, web developer, University of Cambridge.
- The Children's Heart Federation (a UK charity).
- Emily Jesper-Mir and Joanne Thomas from Sense about Science's public engagement team.

Together, we developed the website through different kinds of public exposure. We took a good look at all the voices, questions and concerns in public discussion about children's heart surgery, and created an initial website to 'speak' to those discussions. We held two streams of user-testing workshops from its earliest version: with parents of children who had heart conditions, and with other interested users and people whose view of the material might flag up problems. They included press officers and policy advisors from medical charities and professional bodies, people from parent support groups and patient advocates.

Over a year, we held four stages of workshops. Participants' responses to versions of the website significantly shaped and developed the content at each stage. Their participation continued through the website launch, which attracted media attention. (You can find links to this at the end, as well as to the academic papers and a blog that one parent wrote on Mumsnet about her involvement.)

The project was transformative for the participants and researchers. Parents of children who are waiting for heart surgery feel they now have an impartial website explaining the latest data that the NHS is using to monitor survival at children's heart surgery units. The researchers and NIHR are keen to share the value of involving them from the start with the wider health research community.

Both the website and this project were funded by the NIHR Health Services and Delivery Research programme.

¹ Project number NIHR HS&DR 14/19/13

So how do you involve the public in
deciding how research is communicated?



A FIVE-STEP APPROACH

STEP ONE: SCOPING

How is your research topic talked about in the public domain? How well is information used? What are the misconceptions? What context is missing? What are the key underlying assumptions?

1

Scoping

Look at what people are saying and the underlying assumptions.

2

Involving people

Work out the significance for different groups and how to involve them.

3

Planning

Propose content and formats that are relevant for the people accessing it.

4

User-testing

Develop your material together.

5

Dissemination

Continue to engage people and use feedback.



STEP ONE: SCOPING

The first step, ideally before you start your research, is to look at 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 gives a picture of where people are starting from when they engage with the issue, and also where you might find the people you need to engage.

Scoping

Don't restrict yourself to your specific research topic – look at everything that might be creating its context. We found the following list useful:

- Media coverage of the subject and related research (and blogs and opinions).
- Policy discussions: is any regulation or policy development in progress? Does the subject have political voices or choices?
- What advocacy groups, campaigners or charities say.
- Questions on forums and conversations on social media.
- Debates and disagreements in the field and related professional sectors.
- Existing resources, such as websites, patient information, policy briefings.
- Fads, 'cures', out-dated remedies, scare stories, advertising claims, lifestyle advice.



Analysis

Drawing out the underlying assumptions is not easy, but here is what you should try to work out:

Questions and priorities:

What questions do people have? What are their main concerns, and how do they differ?

People frequently ask things that are actually a composite of several different questions. For example, "Why do people still die of bowel cancer?" This is a mix of: Why aren't we preventing it? Why aren't we diagnosing it? Why aren't treatments working? It's easy to start answering the wrong one.

Underlying assumptions:

What assumptions are people making about the science, the context, the research or how it is applied? How are your assumptions different?

Information & context:

If there is conflicting information on this topic, why? What information is missing? What context or concepts are needed?

Consider too:

Have there been high-profile events that might influence how people see your findings, for example a promise of improved treatment in this area that hasn't materialised?

Language and examples:

What language and terminology is commonly used?

Your goal in context

Researchers usually find that reviewing these discussions influences the scope and goal of their planned communication, so the earlier the better. Christina Pagel was already sensitising herself to these issues as she began to imagine the research proposal for updating the maths behind the prediction formula. But it helps at any stage to understand how people might engage with the research findings, even if you have little scope and budget.

Loosely, there are two types of project:

- Those that aim to use research communication to change how people see an issue, perhaps change how they behave.
- And those that want to make the products of particular research accessible and clear, with no broader outcome sought.

Don't assume this context review will make your goal broader: sometimes it becomes clear that one user group or interested party should be the focus of your efforts. While the CHS review identified many relevant discussions, the focus was on access to information for parents of children undergoing surgery.

You may not have decided the extent of the content, or the form that your communication will take, and even if you have, it may change through the next steps. But you need to set out your goal for communicating so that your team is clear and the people you involve know what the limits and opportunities of the project are. The CHS team started early, had funding and the only fixed idea was explaining the survival statistics on a website. How to do this was up for discussion with users and partners.

Step one in practice

Emily Jesper-Mir, *Sense about Science*:

"Christina had already scoped much of the area through her work. With her help, we analysed public discussion, to identify where conversations had gone wrong in the past and why. We looked at the media coverage of the monitoring of children's heart surgery units, notably the controversy around the temporary closure of the unit at Leeds Infirmary in 2013. There was also confusion about how and why hospitals were monitored, even among professionals, and we also counted many misleading comparisons of the performances of different hospitals.."

Other examples

Making Sense of Screening²

Some years previously, when Sense about Science worked with patients, doctors, researchers and service providers to produce a guide to cancer screening, we started with a review of discussions in health magazines and online forums, and messages from campaigning groups and newspapers. There were a lot of calls for more screening, for more diseases, for more groups of people and more often. These were dominated by concern about people being denied access to life-saving investigations, and few had examined the (often unrealistic) assumptions about what screening can deliver. So we knew that to achieve clearer communication of the risks and benefits, we needed to draw out this assumption, and to show the risks associated with screening and the different risk/benefit calculations for different groups of people.

Making Sense of Radiation³

This collaboration with engineering and medical researchers also began with a review of the public discussion. It included not only media and policy statements, but a group of products being advertised as giving protection from non-ionising radiation, as well as national newspaper adverts proposing whole-body CT scans (and therefore potentially dangerous levels of exposure to harmful radiation) as a regular health check. It was through this that researchers drew out two underlying assumptions: that all radiation causes cancer and that 'scans' are often not seen as radiation. This led them to realise that the essential context showing a spectrum of radiation – the electromagnetic spectrum, from harmless radiowaves to harmful X-rays - was missing from many research communications. This was a turning point in the project to improve communication with the public. Once the public knew they could ask, "What type of radiation is it?" they were able to consider whether they needed to be protected from it.

² *Making Sense of Screening* (2015), <http://senseaboutscience.org/activities/making-sense-of-screening/>

³ *Making Sense of Radiation* (2008), <http://senseaboutscience.org/activities/making-sense-of-radiation/>

STEP TWO: INVOLVING PEOPLE

Which individuals and groups are most interested, concerned or involved in this issue? Who isn't but should be? Who is driving the public conversation? Who should be part of the project team? Who should you invite to user-testing? Who can help share your findings?

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STEP TWO: INVOLVING PEOPLE

Scoping the current discussion in step one will have given you a good sense of the audiences who could engage with your research, perhaps beyond the usual voices. Steps two and three develop together, but start exploring the 'who' at once to maximise opportunities to get their input.

Questions to guide your thinking about people to consider or involve:

- Which individuals or organisations are interested in your broad research area?
- Who is most affected by it?
- Who is already talking or writing about it?
- Who has influence in this area? Are there people known for commenting on it (for example, an author, columnist or advocate)?
- Who will use the information? And *how* will they use it?
 - Would they use it in their personal lives?
 - As part of their job or volunteer work?
 - To make decisions?
- Who may be asked questions based on the information, for example, an ombudsman or councillor?
- How do you ensure variation and diversity?⁴
- Think about both informal and professional communication networks, for example:
 - **Informal:** patient networks, voluntary and community groups, advocacy groups.
 - **Professional:** health care professionals, learned and professional societies, press offices, charities, policy professionals, research funders, local government, the media.

There are three ways to involve these audiences, and you should consider:

- i. Who should be involved in your project team?**
Multi-disciplinary groups can extend your ability to respond to what people suggest. For example, a web developer can figure out whether there is a way to layer information using the design, to improve understanding.
- ii. Who should be involved in user-testing?**
Think about the kind of input you would ask them for and what information they would need to understand what they are being asked to do.
- iii. Who should be involved in sharing the end result?**
You may want to involve many of the people you hope would share the end result in user-testing too. Pay attention to whether some of these could help to keep your resources current as well as extend their reach. Your academic website may get a burst of attention if there is publicity, but a year later a link on a charity website may be the only way non-specialists will access your findings - if they remain relevant!

⁴ Strategies for diversity and inclusion in public involvement: from INVOLVE, with easy tips to follow, <http://www.invo.org.uk/wp-content/uploads/2012/06/INVOLVEInclusionSupplement1.pdf>



STEP TWO: INVOLVING PEOPLE

How to find and contact people

Note: this is for the purpose of bringing different perspectives, texture and insight into your project. It is not equivalent to sampling as part of research into representative views, so be careful not to claim that 'patients think x'. Here are some tips on how to find people:

- **Use networks that already exist.** This is the most likely way to find contacts and build relationships.
- **Contact organisations that work in the area.** Ask how they contact their networks: whether they have membership groups or forums and what methods work best. If you bring them into your thinking about what you are trying to achieve and how it might benefit their members, they may agree to champion some of this for you.

The Children's Heart Federation sent out emails and posted on Facebook to find parents who would be interested in getting involved. Christina then got in touch with those who had showed an interest with an online survey to find out their availability.
- **Look for informal support groups.** Facebook can be particularly useful for finding informal groups and a broader range of people.
- **Look for discussion strands on more generalist forums** such as Mumsnet. Many large towns and London boroughs also have forums.
- **Think about the networks, media and activities that people you are looking for might be connected to. Here are some examples of those thought chains:**

Looking for midwives:

- Training (universities, alumni newsletters, trainers' professional networks).
- Which body qualifies and registers them (newsletters, websites, officers of these organisations will include practitioners).
- Professional news publications.
- Online forums for professional exchange.
- Search on news subjects such as home birth.
- Employers, hospital staff rooms and notice boards.

Looking for a mixed non-specialist group who might help shape communication about healthy diets:

- Playgroup associations.
- Allotment societies.
- Youth club leaders.
- Meals on wheels services.
- Sports clubs and associated Facebook groups.
- College welfare officers.
- Recipe exchange websites and dining clubs.
- Parent groups.
- Food bloggers.
- Carer networks.
- A food packing company (many companies encourage staff to be involved in community activities and are pleased to have something interesting for the staff newsletter!).
- Shift-workers eg HGV drivers & security guards.
- Hospitals, hospital charities, GP surgeries, councils and libraries display notices of **local groups**. These are more relevant for some topics than others; children's heart surgery networks were national for example.
- **Don't forget your own networks:** alumni, friends and family, clubs and societies, if you're comfortable with it. People are often pleased to help promote socially useful activities that they have even a loose connection to.
- **Snowball:** once you have contact with some individuals from your target group, ask if they know of other relevant groups, networks or individuals who might be interested.

STEP TWO: INVOLVING PEOPLE

And some tips on motivating people to get involved:

- When approaching potential participants, start with why this project matters and why their involvement will help. People who don't have a professional role on an issue (and even some who do) tend to worry that they're being asked for something they won't be able to give. Here's what we sent to CHS parent participants:

Sense about Science responds to lots of questions and discussions about statistics and health outcomes. We are therefore helping to prepare the online web tool, to make it as useful and accessible as possible to patients, parents of children who have had or will have surgery, the media, NHS England and family liaison services at hospitals.

At this early stage in development, we will discuss what people need to make sense of data from different hospitals. Your feedback will have a big influence on how we improve the website and its content.

- Indicate why you hope they might be interested but don't tell them they should be.
- If you have the choice, don't just post an ad on a forum: address yourself to the people on it and identify yourself as the contact. You may need to join a forum to post. With a forum limited to people affected by a problem, don't pretend to be one, email the organiser.
- You might ask one person who is influential or a member of a group to write an introductory note: *'We all know how difficult it is to get reliable information. I hope some of our members will be able to help here.'*
- For workshops and meetings, consider factors such as childcare, working hours and whether participation is likely to be seen as part of their job. Some parents in the CHS project found weekends more convenient or week days but avoiding school pick-up times. You could contact groups to ask if you could join one of their existing meetings.
- Budget for travel expenses and honoraria for their time and contribution. See further reading for some guidance on this. The CHS project was typical: participants were motivated by improving the information, but to ensure no one is excluded as a result of costs, it is important to offer travel expenses and an honorarium. Tell people up front rather than forcing them to ask.

- Tell them who else is involved. Make sure there's some networking time over refreshments too. Some participants find this the most rewarding part of being involved, especially if they don't often meet other people facing similar issues.
- Use the terminology that you've picked up in step one.

Step two in practice

For the CHS website, having people from different fields in the working group (a mathematician, statistician, psychologist, web developer and communications experts) made it both imaginative and practical in thinking of how to respond to participants' feedback. The Children's Heart Federation (CHF) — a charity trusted by patients and families — was so central to the work and the recruitment of parents that they were invited to be part of the working group. To recruit parents, with CHF's help we posted on Facebook support groups, used online surveys to give options of workshop dates and times (including weekends) and provided food and travel expenses. We also emphasised throughout their involvement that they could leave at any time if conversations became difficult or uncomfortable for them.

Another example: UbbLE (UK Longevity Explorer)

In 2015, Sense about Science worked with the UbbLE research team to design and test a public-facing website that generates the risk of mortality for an individual based on a series of questions (<http://www.ubble.co.uk/>). Our role was to enable the public to use the findings of the research, and to prevent misinterpretation. After scoping and analysis, we determined that the user-testing and dissemination planning should involve members of the public with no particular interest in health, as well as researchers in both similar and unrelated fields, medical communicators and an expert in communicating risk statistics. Rather than providing a sensational prediction the final risk calculator used very clear language and visuals to responsibly communicate the risks.

STEP THREE: PLANNING

What is the best format to communicate your research: website, graphic, video, events, publications? What is the key content you need to include? What language and style should you use?

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STEP THREE: PLANNING

Based on the first two steps, now consider:

Format

- How people are used to accessing information – on your topic and generally.
Although many of the examples in this guide are website or publication based, there are other formats to consider, eg social media graphics, videos and events.
- Don't forget about the skills you need to deliver a format, eg graphic designer, software developer, web designer, event organiser – you might need to involve them early too.

This might seem obvious, but do look in other areas for examples you'd like to emulate. Look at the previous work of people you bring in. Website design or public events might sound like a standard activity but providers can differ hugely in ethos and style, and also in the type of experience they're used to - which may not include taking unstructured feedback from people with no knowledge of their profession.

Content

Look at resources that already exist in this area (eg web pages, patient information leaflets, policy briefings, videos etc).

- What could be used, improved, adapted or promoted?
- What content is missing?
- What additional context is required? (User-testing will help you flesh this out.)

The terminology and phrases seen in your step one review will be useful.

Generally, the further you reach into non-specialist conversations, the clearer you will need to be about the limitations of your research – what it *can't* be used for.

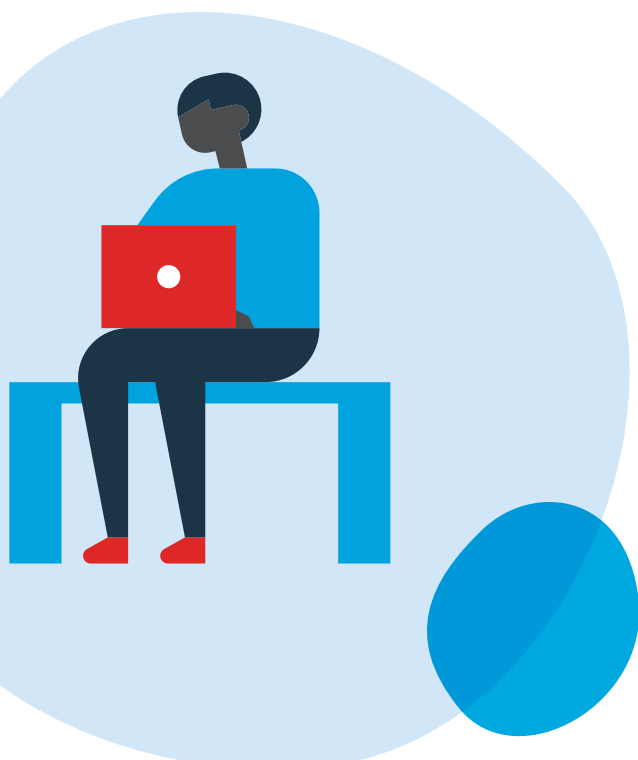
- If there is a risk that users will make comparisons or inferences that aren't backed up by the data, it's important that this is addressed in designing the resource.

You will find a tension as you create a draft and develop it in consultation: simple, clear sentences will become loaded up with caveats and quite important detail, then pared back to simplicity as it's clear the material has become unapproachable, and back and forth. A better option is to **layer your information** as much as possible, so detail is clearly there but not interrupting a quick grasp of meaning.

Emily Jesper-Mir, Sense about Science:

"Even if people don't understand all parts of the content, they may still want it to be there, eg in a 'further detail' dropdown, as a sign of a trustworthy resource that specialists could check, or to look into it themselves once they've grasped the general idea."

Consultative workshops can help with developing content and format. However, your best input is likely to come once you have developed something that people can respond to and which helps them to see what you're trying to achieve. Step four describes this. Ensure you leave enough time to prepare and plan what you will user-test. The CHS website took 18 months to co-create.



Step three in practice

The CHS project team reviewed the existing materials used to convey children's heart surgery outcomes. The main issue was the way these materials invited comparisons between hospitals, rather than comparison with the expected results for each hospital given its intake. A graph with hospitals running across the bottom had been used for years to display all of their outcomes. The web developer had the idea of rotating the graph 90 degrees and aligning it with a table. This means that in a single row, users can run their eye along to see the hospital name and its survival results both in numerical form (the table) and visualised (the graph). When we compared the two variants (A/B testing) at a user workshop with parents of patients, we discovered this change transformed what they focused on.

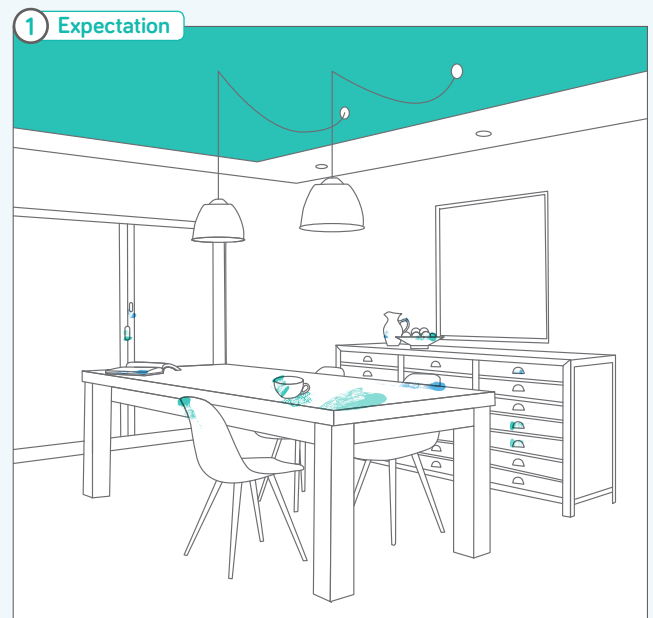
There was enough flexibility in the project to respond to new format suggestions too. For example, participants had difficulty understanding two of the technical aspects of the content, and felt an animation might help to make this more accessible. We therefore created two short animations on the website.

A different example: forensic genetics

In January 2017, Sense about Science published a guide developed with forensic geneticists who were part of the EUROFORGEN network. Making Sense of Forensic Genetics set out the role of DNA analysis in the criminal justice system, what its limitations are, and what might be possible in the future.

At the scoping stage it was clear that crime fiction creates the false impression that DNA is a silver bullet; once it is found at a crime scene, we have a DNA profile of the person who committed the crime, right? No. The forensic geneticists raised many reasons why this is so misleading. Everyone sheds DNA all the time, it is transferred by third parties and objects, it can stay around for a long time, and highly sensitive forensic DNA techniques can now detect tiny amounts. DNA evidence must be used in the context of other evidence.

It was immediately clear that this was a key insight, so we recruited a designer to put it into a shareable graphic that we could test with potential users. Good graphics take time to develop, and need to be checked by researchers for validity, just like anything else.



STEP FOUR: USER-TESTING

How can you carry out user-testing? Who should facilitate the discussion and how? Which parts of your research output should you user-test? What questions can you ask?

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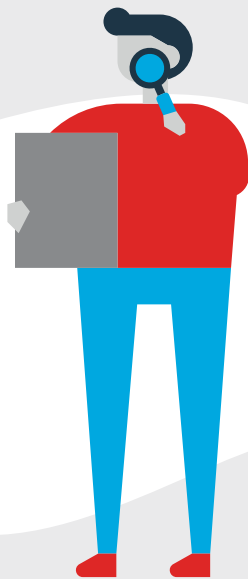
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STEP FOUR: USER-TESTING

We strongly advocate meeting people to work with them in the development of your communication tools and plans. Some user-testing can be conducted online, or by sending people things to review. Along with tailoring your material through step one and two, this would probably result in something more effective than not involving people at all. Something better might be achieved by outsourcing user-testing (an agency conducts it and you get a report). However, it would be quite limited and it isn't really a process of co-creation.

User-testing workshops in the CHS project made a profound difference to the output and transformed the way the researchers as well as the participants approached the issues.

Conducting user-testing workshops

Timing

- We recommend workshops of no more than 90 minutes, with an additional 30 minutes for refreshments and chatting (avoid using this time to compare notes among yourselves, rather stay involved – you often learn even more).
- Allow time for participants and organisers to introduce themselves and the project and purpose of the session.

Material

- Given this timeframe, it's important to prioritise which elements of your research communication you most want feedback on, for example, the language you've used to explain a finding or a chart to calculate a risk. You should also consider whether you want to send anything to participants in advance. To help decide, consider whether you want to observe initial reactions or whether it is more important for people to read detail. It helps them to feel prepared if they are sent something, even an outline of the session.
- With early stage user-testing, you can start simply, with one sheet of paper, and develop in later workshops as you build in the earlier feedback to develop your material.
- At each workshop test out whether users are picking up the points you intend them to grasp. We use a very simple technique sometimes, telling people: wavy underline what you don't understand, hard underline what you find interesting or useful, bracket things you find boring or unnecessary (and electronic variants).
- If you want people to review a website, you will need to supply the tech to do it and consider what

kind of discussion this will create. Individuals at the CHS workshops navigated the resources on laptops. At other workshops we have chosen to use a projector, to have a more closely facilitated discussion.

Facilitation

- Where possible, involve facilitators from outside the primary research group to run the workshops. This makes it easier for the facilitator to detach from the research itself and probe concerns, criticisms and questions more thoroughly (and avoid the temptation to answer them at once, which can shut down discussion). It is important that the facilitator is well briefed or part of the project though, so that they grasp the significance of responses and can make good judgements about whether to let the workshop go in an unexpected direction.
- It is valuable to have members of your research group present. We find 2-4 members is about right. Try not to cut in too much (which can come across as defensive) but do contribute your own developing ideas and explain if there are some things you can't take on board.
- At the end, thank them and ask whether they would like to stay updated and involved. Inform people about what you plan to do next (and how they can be involved in that, through further workshops, consultation and sharing plans as they develop). Even if those plans change, don't leave them wondering what came of their help.



STEP FOUR: USER-TESTING

Emily Jesper-Mir, Sense about Science, facilitator of the CHS workshops:

"Before the user-testing workshop we briefed the researchers to wait and answer workshop participants' questions towards the end. We wanted any difficulties in understanding the information and language to be captured and explored. It's of course important that participants do get their questions answered eventually and get the researchers' responses to their input."

The professionals in the workshops were more used to putting their views forward. But the fundamental changes to the project came from the group of parents: especially when they made it clear that they would be unable to resist the temptation to rank hospitals by their raw survival rate, or thought others would, even though they knew this gave misleading results."

User-testing is a chance to see how people respond to your content, as well as to see where participants are starting from: what do they know of the issue already?

Some prompts for getting feedback from users include asking:

Before showing the resource:

- What's your experience/understanding of this subject already?

After they've had chance to explore:

- What is your overall impression?
- What have you understood from it?
What do you feel are the most important points?
- What questions do you still have?
- What are the most and least clear things in the way it is presented?
- What information is missing?

- What information is unnecessary?
- What information is new to you?
(Did it change how you saw the subject?)
- Does any of the language jar? Why?
Is any content too technical?
- Does this format work for you?
- Did you find the information you expected?
Did the order work?
- What did you think of the design, layout, navigation?
- Did your first impressions give you a sense of what to expect from the resource?
- Could you see yourself using this? How?
Who should use it?

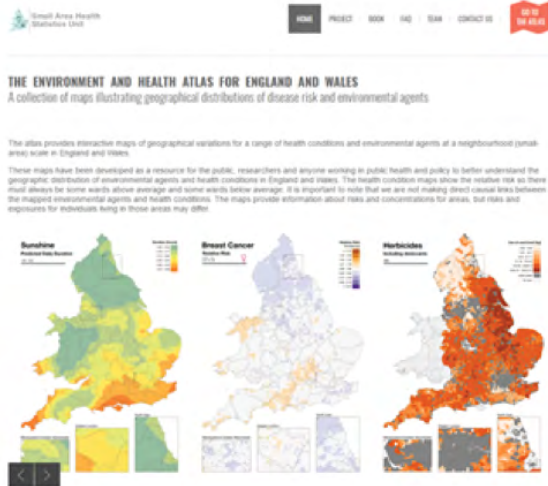
You can test understanding and find the right language by asking participants to recount points — ask them how they would describe this to someone else. This alerts you to potential pitfalls as well as offering unexpected solutions. It may also give you more straightforward, conversational language to incorporate: no matter how hard researchers try, it is almost impossible to write material as a non-specialist would.

User-testing is also a great chance to work out how to layer your information appropriately.

Joanne Thomas, Sense about Science:

"Getting diverse perspectives and ideas in the room is a really effective way to shape and refine resources. But for projects of smaller scope or if you can't get people in the room, there is still plenty you can do to get feedback. You could hold informal one-to-ones or visit the meetings of existing groups and organisations. The CHS project is just one example of how it can be done with a project of this scale, but it isn't the only way."

STEP FOUR: USER-TESTING



Step four in practice

The participants' feedback was instrumental in shaping the whole CHS website. They altered the priority of the layers of information: the hospitals were all within the expected range of outcomes, so they wanted this up front, instead of as a conclusion of looking through the data. As one parent said, "I've enough to worry about, so if I don't need to worry about the hospital, tell me straight away".

They changed the language and descriptions of significant points. David Spiegelhalter tried out several terms to express why there was unpredictability in the statistics. The first version of the website had also talked about death rates. Parents reframed it in terms of *survival rate*.

One thing we noticed here, which we have seen often, is that researchers tend to create compound nouns out of things they are familiar with, and these then need to be separated back out, eg: *The observed 30 day post operation survival rate was 97.8%.*

became:

*30 days post operation, there were
663 survivors and **15 deaths** had been
recorded.*

Dr Christina Pagel, reader of operational research, UCL⁵:

"I learned so much from listening to other people's perspectives. I am particularly proud of the fact that I believe that every workshop participant could look at the website today and spot at least 3 things that their participation directly influenced."

⁵ Pagel C et al. Improving risk adjustment in the PRAiS (Partial Risk Adjustment in Surgery) model for mortality after paediatric cardiac surgery and improving public understanding of its use in monitoring outcomes. NIHR Journals Library; (2017). Appendix 5, What each team member has taken from the project, <https://www.ncbi.nlm.nih.gov/books/NBK442309/>

Professor David Spiegelhalter, professor of public understanding of risk, University of Cambridge:

"This has been a humbling and invaluable experience. I thought I knew something about communicating statistics, but sitting listening to enthusiastic users struggling to understand concepts made me realise my inadequacy. For example, we spent months trying to choose a term to describe the unavoidable unpredictability of the number of survivors in a group of children experiencing surgery: standard technical terms such as 'random variation' are clearly unacceptable in this context. We finally arrived at the phrase 'unforeseeable factors', and after appropriate testing this was adopted.

If we want to genuinely communicate statistical evidence, I am now utterly convinced that users have to be involved from the very start. And there are so many other areas that could benefit from this approach, which might help dislodge the obsession with simplistic league tables."

Another example: Environment and Health Atlas

One of our past public engagement partnerships was with the Small Area Health Statistics Unit (SAHSU). We worked with them on the release of their potentially controversial Atlas, which mapped potential environmental agents and a range of diseases across England and Wales over a 25-year period. We held user-testing workshops where the SAHSU team had a chance to test the material on different audiences to identify areas of possible misinterpretation.

Dr Rebecca Ghosh and Dr Anna Hansell, SAHSU:

"It became clear from the very first workshop that what we as academics thought was an accessible publication had been written in a very formal academic style! We depended upon user-testing to decide upon colours for the atlas. Different colours convey different meanings. So we even ended up taking a screen and laptop into Paddington station to get feedback from members of the public."



STOP

REVIEW

Steps three and four may need several iterations. Ensure that your timeline and budget have capacity for revising and improving the output. Many researchers find at this stage that they would like to arrange further testing, to review their responses to user input. For big projects, this iterative process can take months. The CHS project involved four stages of user-testing, iterations and revisions over one year.

STEP FIVE: DISSEMINATION

Who should know about your research findings? Who will talk about and publicise them? How can you share it – with the media; with professionals; with the public?

1

Scoping

Look at what people are saying and the underlying assumptions.

2

Involving people

Work out the significance for different groups and how to involve them.

3

Planning

Propose content and formats that are relevant for the people accessing it.

4

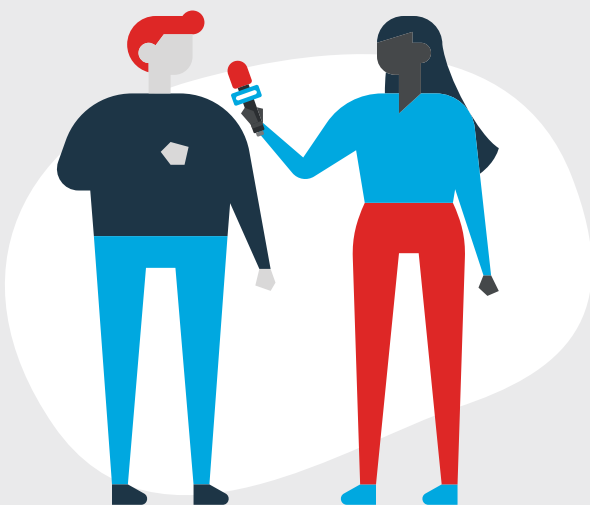
User-testing

Develop your material together.

5

Dissemination

Continue to engage people and use feedback.



STEP FIVE: DISSEMINATION

This stage is best thought out towards the end of the project, but well before it's finished. Revisit step two to consider your target audiences and how to reach them. Has this list changed since you started? Some individuals and organisations will now have been involved and given you ideas about how to describe your project output and you may be able to enlist them in disseminating it.

How to share your project

A: Media

If you aim to achieve press coverage (not everything is newsworthy!), involve your institution's press office to get support. They will appreciate an early warning about your project so they can help you prepare.

Consider whether there is a news peg - something in the public eye that will show the relevance of your project. This can be useful but also look out for getting caught up in stories that aren't yours.

Give journalists enough notice. If necessary, use an embargo to allow them time to explore your resources before they are published.

Think well beyond the national press: consider local media outlets and specialist press, blogs and online bulletin boards. This is a huge area and some narrow publications, such as a membership magazine, may better serve your target audience than high profile briefer coverage.

Your experience of co-creating the resources with users will help you work out which of the team would be suited to broadcast media and interviews. Broadcast reaches many people that newspapers do not, but it's less shareable after the event.

Write it up yourself. Media outlets or blogs might consider an article written by you or one of the participants or project partners. For complex or sensitive projects this is a good way to mitigate any mistakes or omissions in the way others describe

your project. It also gives you an opportunity to give a personal introduction to your team's work and how the resources were developed.

B. Social media

Instead of just sharing a link to a webpage, consider whether any of your content should be adapted into graphics, images or key points to share on social media. If your aim is to disseminate a finding as widely as possible, this might be most effective.

Look for groups or individuals who are active on the topic.

If you want others to share – via a web link or news item, informally with friends or on social media – think about what is shareable for them: short, clear and not over-committing the sharer.

Work with the intermediaries and voluntary organisations to share your message with public and patient groups. (Send early views and launch plans to all those you involved in user-testing.) After attending workshops, participants often feel they have more ownership of a project and will be more likely to share with their networks.

Enlist charities, organisations, and professional and learned societies with an interest in this area, as well as research councils, your university and funder(s). Ask them to share with their members and networks through newsletters, websites and social media etc.

STEP FIVE: DISSEMINATION

For health research, for example, consider medical charities, the Association of Medical Research Charities (AMRC), NIHR, the Medical Research Council (MRC), Public Health England, Scotland or Wales.

C. Events

Look for relevant conferences, events, and meetings – both public and professional – where you could share your project. For example, 500 copies of *Making Sense of Forensic Genetics* were requested for the international crime writing festival, CrimeFest. Where appropriate, you could even organise a launch event or feedback session at an event.

Think about what could be achieved at professional events in your field: could the resource be featured, publications distributed; should other research groups in the field add your resource to the material they use in public outreach activities?

Remember to thank people and refer to their help on your resource and in publicity.

Make sure that you have factored this dissemination time into your grant. We see many good efforts dropped too quickly by researchers at this point, as they find that their time is called on elsewhere. The CHS project team remained active during dissemination and we kept the user-testing groups in touch with the publicity. The researchers also went on to use what they had learned to change the way that they were conducting other projects.



Step five in practice

The CHS website addressed a significant enough public issue for Sense about Science to engage its own networks, which extend across many social groups and different types of media. But the success of the dissemination owed a lot to this being a well-planned project and the researchers having provided for a thorough launch plan in their grant application. Projects of smaller scope should set out clear aims for dissemination, and prioritise where resources should go. A huge benefit of co-creation is the insight into the type of communication, access and networks that will enable you to reach people with your findings, and to know how to avoid misinterpretation. The project team should plan to remain active during this time.

Another example: Environment and Health Atlas

Emily Jesper-Mir, Sense about Science:

"When developing the press release for the Environment and Health Atlas, we made sure that what the maps DON'T tell us was just as clear as what they DO. This project was such an admirable effort to make statistics accessible but had the potential for the most alarming headlines about the worst town for brain cancer in the UK, or advice on where to move to 'for less breast cancer risk'. As well as anticipating all this explicitly in the launch material, our project team gave a briefing at the Science Media Centre⁶ to make sure it could be raised and addressed. The result was balanced national broadcast and press coverage; the researchers were in back-to-back interviews. The coverage made the limitations as well as the value of the research clear."

⁶ Science Media Centre, <http://www.sciencemediacentre.org/working-with-us/for-scientists/>

VIEWPOINTS

Mike Pearson, web developer in the children's heart surgery website team:

"I learnt that involving users right from the start — even when you still have nothing to show but paper — is incredibly liberating. It enables you to try ideas out before change becomes expensive and allows users to guide the decisions."

Alex Smith, mum of a child with a heart condition, wrote up her involvement in user-testing the CHS website in a Mumsnet blog:

"I need straightforward information, and I need that information to be clear, even when I might be in a state of panic or distress. Martin and I now have a better understanding of the critical questions to ask - especially if hospital statistics hit the news again. We know how the NHS monitors hospitals and we find it reassuring to know there is a site we can go to for impartial and trustworthy information."

The Lancet published an editorial⁷:

"Understanding Children's Heart Surgery Outcomes...does an excellent job of explaining what these statistics can and cannot tell parents and how they should be used. Together with a wealth of background information, it stresses that hospitals should never be ranked by their survival rates, that actual survival rates of hospitals should only be compared to their own predicted range of survival rates, and that published data mean little for each individual child's risk. Many more areas of medicine requiring risk communication should take this initiative as a long overdue and most welcome example."

Dr Christina Pagel, reader in operational research, UCL:

"This has been a truly transformative project for me. The website would have not have been fit for purpose without the early and continuous involvement of parents and other users - there is a huge amount of effort involved in accessibly presenting abstract and difficult concepts. People will interpret things in ways you had no idea were possible — but in retrospect were entirely obvious. Repeating these checks over and over with fresh eyes is priceless."

⁷ Communicating risk about children's heart surgery well, The Lancet (2016), [http://dx.doi.org/10.1016/S0140-6736\(16\)30888-1](http://dx.doi.org/10.1016/S0140-6736(16)30888-1)

Sonya Crowe, lecturer in operational research, UCL

"Comparing the final website with the early thinking is striking: I'm not sure any of the team would have imagined just how much things would evolve over the course of the project! It has been a privilege to see the benefits of genuine user engagement, and the extent to which that influenced the final product has surprised many of us. Christina and the core team's commitment to listening and responding to user feedback has been admirable, as has their openness to working across disciplines. Both the process and output will be seen as exemplars for others to emulate. The project has already directly informed my plans for engagement and dissemination in related work and, more fundamentally, prompted me to reflect on my priorities and responsibilities as an academic."

Dr Laura Meagher, critical friend who facilitated feedback sessions with the working group throughout the project:

"An unusual feature of this project was the extent to which stakeholder input was not only sought but also then actually used. The evolution of the website, its content, language and portrayals, went through several iterations, each drawing upon and responding to another workshop's input... This could serve as a case study for other such efforts seeking to involve stakeholders and their perspectives in a genuine way, to feed into the project per se. This sort of effort is hard work; it takes time and resources. As a funder, NIHR is to be commended for being unusually sensitive to the effort required to do this right."

Dr Tim Rakow, reader of psychology, King's College London:

"Collaboration has been key to the success of this project: working with the mathematicians and statisticians who generate these kind of risk models, and using what we know from psychology about people's understanding of statistical concepts, the team has thought carefully about what needs to be presented, and how. Then, having a highly skilled web developer and experienced science communications team from Sense about Science to refine and implement this – and with regular input from cardiologists, from the families of children with heart disease and the charities that support them – I believe we have developed something that should allow people to engage with what would otherwise be some fairly opaque information."

FURTHER READING & REFERENCES

Organisations behind this guide

Sense about Science

<http://senseaboutscience.org/>

National Institute for Health Research (NIHR):

Improving the health and wealth of the nation through research.

Established by the Department of Health, the NIHR:

- Funds high quality research to improve health.
- Trains and supports health researchers.
- Provides world-class research facilities.
- Works with the life sciences industry and charities to benefit all.
- Involves patients and the public at every step.

For further information, visit the NIHR website <http://nihr.ac.uk/>

This project was funded by the NIHR Health Services and Delivery Research programme. Project number NIHR HS&DR 14/19/13. The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR programme, NIHR, NHS or the Department of Health.

Thank you to the following who user-tested this guide:

Amara Anyogu, University of Westminster; Danielle Ashworth, King's College London; Yan-Shing Chang, King's College London; Leah Fitzsimmons, University of Birmingham; Rebecca Geary, London School of Hygiene and Tropical Medicine and Royal College of Obstetricians and Gynaecologists; Becky Ghosh, Medicines and Healthcare products Regulatory Agency; Marian Knight, University of Oxford; Claire Marriott, University of Brighton; Ed Parker, Imperial College London; Claire Singh, St Thomas' Hospital.



**National Institute for
Health Research**

Children's Heart Surgery project

The Understanding Children's Heart Surgery Outcomes website

<http://childrensheartsurgery.info/>

Read the full account of our public engagement approach with the Children's Heart Surgery website in this journal article published in the **Annals of Thoracic Surgery**

<http://dx.doi.org/10.1016/j.athoracsur.2016.11.080>

A Guardian Sifting the Evidence blog written by Christina Pagel and David Spiegelhalter: <https://www.theguardian.com/science/sifting-the-evidence/2016/jun/21/making-nhs-data-public-is-not-the-same-as-making-it-accessible-we-can-and-should-do-better>

Alex Smith, mother of a child who had heart surgery, was involved in user-testing and wrote a **Mumsnet blog**:

https://www.mumsnet.com/Talk/guest_posts/2699023-Guest-post-I-hope-weve-helped-others-preparing-for-their-childs-heart-surgery

Sense about Science publications and public engagement partnerships

The Environment and Health Atlas

<http://www.envhealthatlas.co.uk/homepage/>

Making Sense of Forensic Genetics

<http://senseaboutscience.org/activities/making-sense-of-forensic-genetics/>

Making Sense of Radiation

<http://senseaboutscience.org/activities/making-sense-of-radiation/>

Making Sense of Screening

<http://senseaboutscience.org/activities/making-sense-of-screening/>

Making Sense of Statistics

<http://senseaboutscience.org/activities/making-sense-of-statistics/>

Making Sense of Uncertainty

<http://senseaboutscience.org/activities/making-sense-of-uncertainty/>

The UK Longevity Explore (UbbLE)

<http://ubble.co.uk/>

Voice of Young Science guides to Standing up for Science: these are particularly aimed at early career researchers who want to engage with the public, media or policymakers

- Standing up for Science (2006), <http://senseaboutscience.org/activities/standing-up-for-science-guide/>
- Standing up for Science II (2008), <http://senseaboutscience.org/activities/standing-up-for-science-2-the-nuts-and-bolts/>

Additional organisations and useful resources related to public engagement

INVOLVE

<http://www.invo.org.uk/>.

See useful resources such as case studies for budgeting:

- <http://www.invo.org.uk/wp-content/uploads/2014/11/10002-INVOLVE-Budgeting-Tool-Publication-WEB.pdf>

Ten briefing notes for researchers on how to involve members of the public in research

- <http://www.invo.org.uk/resource-centre/resource-for-researchers/>

National Co-ordinating Centre for Public Engagement

<https://www.publicengagement.ac.uk/>.

Useful resources on why to engage, who to include and how to plan, eg:

- <https://www.publicengagement.ac.uk/blog/can-public-really-be-meaningfully-involved-research>
- <https://www.publicengagement.ac.uk/plan-it/understanding-your-audience>

- <https://www.publicengagement.ac.uk/do-it/techniquesapproaches/panels-user-groups>
- <https://www.publicengagement.ac.uk/plan-it/project-management>

NHS England

<https://www.england.nhs.uk/>. Useful resource on participant diversity:

- <https://www.england.nhs.uk/wp-content/uploads/2016/07/bitesize-guide-divers-inclusive.pdf>

Science Media Centre

<http://www.sciencemediacentre.org/working-with-us/for-scientists/>

Wellcome Trust

<https://wellcome.ac.uk/>. Useful resources on planning public engagement eg:

- <https://wellcome.ac.uk/what-we-do/our-work/planning-your-public-engagement>
- <https://wellcome.ac.uk/sites/default/files/planning-engagement-guide-wellcome-nov14.pdf>
- Wellcome: video: Beware double meanings when you talk science, <https://wellcome.ac.uk/news/what-weve-learned-expertdebate>

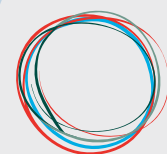
The Winton Centre:

Aims to ensure that quantitative evidence and risk is presented to people in a fair and balanced way. You could consider a collaboration with them or request risk communication advice: <https://wintoncentre.maths.cam.ac.uk>

SENSE ABOUT SCIENCE

Sense about Science is an independent campaigning charity that challenges the misrepresentation of science and evidence in public life. Our public engagement team draws from extensive public networks and over a decade of working with the public on some of the trickiest issues concerning evidence. Our ethos is public-led, expert-fed - which means engaging early and leading with people's questions and concerns. Our practical five-step approach replaces tokenistic projects with meaningful and transformative public engagement partnerships.

We hope that many researchers will take up this approach and adapt it for themselves. But if you think you need our help, we will consider public engagement partnership for socially or scientifically difficult issues where researchers make a convincing case that it is a matter of public interest and that evidence is neglected, conflicting or misunderstood. To apply for partnership, or to discuss your project, you can contact Emily Jesper-Mir (hello@senseaboutscience.org).



SENSE
about **SCIENCE**
Because evidence matters

NHS

**National Institute for
Health Research**