



**Anyone can
co-produce**

**HEALTH and CARE
RESEARCH ...**

**A little book about
knowledge and justice**



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About this little book

We all rely on health and care research to find better ways of preventing, diagnosing, treating and curing health conditions, so that we can live well. This can only happen if we can discover answers to important questions about health. To do this, we need everyone's brain on the job. This little book is designed to support members of research teams - healthcare practitioners, researchers, patients and members of the public - to learn more about the complexity of co-developed health and care research, so that they can undertake it successfully.

Many thanks go to the patients, carers, healthcare professionals, academics, researchers and members of the public who reviewed early drafts of this book and improved it beyond measure.

We have produced sections 1-6 of this book as written text and as a series of comics, to suit different ways of learning. Take your pick, or read both, and see if different thoughts arise! As this is a little book, we have simplified some ideas and concepts. Clicking on underlined words in the text version will take you to a source of evidence for the comment made and provides a more in-depth exploration where appropriate.

Amanda Roberts
January 2025

1

Patient and public involvement in health and care research

There are many different forms of health and care research. Often, the first type that comes to mind is clinical or randomised controlled trials (RCTs). Patients and members of the public are often used as research subjects in these trials: volunteers – sometimes ill and sometimes healthy – try out new medicines or medical approaches to see how well they work and if they are safe. Not all health and care research is like this however. Some research focuses more generally on learning about how to support people to live better with their ongoing conditions. This is particularly important as we are now living longer. Patients and members of the public are often included as members of the team undertaking the research in this broader health and care research. This is called Patient and Public Involvement (PPI). It is this type of inclusive research which is the focus of this book.

Patients and members of the public can play many different roles in a research team. In some research projects, they might be involved in just one part of the process, for example, reading and commenting on documents being written. In other projects, they are involved from start to finish, helping to set the questions to be explored, working out what we already know, collecting new information, analysing this information to decide what we can learn from it and deciding what needs to be done to change things. This way of working is often referred to as co-production - researchers, patients and the public producing research together, equal partners for equal benefit.

The title page to this book introduces some important issues about co-producing health and care research. The phrase ‘Anyone can co-produce health and care research ...’ starts us thinking. Is that true? Do you just put a mixture of people with different expertise and experience in a room and everyone works collaboratively to produce research together? Most people don’t think so. They acknowledge that there are many complexities in co-production. These include the additional time and money it takes research team members to work through differences in order to work productively and respectfully together. We also have to consider the potential for unintentional harm to team members through others’ comments and attitudes.



There are lots of resources which support members of research teams to tackle these co-production challenges. These include 'easy to read' resources which aim to simplify more complex documents so that everyone can learn from them. There are also frameworks to help us to develop our own resources which can be uploaded to share with others. However, a challenge not always adequately addressed by these guidance documents is where a research team is dominated by particular individuals and the voice of others is not given equal value. This behaviour can be based on a belief that one person's way of understanding and talking about the subject being researched or the research process is more valid or worth more than another person's way of understanding and sharing their thoughts about it. This judgement can be due to the listener's place in society or their previous experience. It is important to address this inequality as it can negatively affect both individuals and the research itself. We express this problem here as a proposition:



In some health and care research teams, some forms of knowledge are valued more than others and this makes both the co-production approach and the research itself less effective.

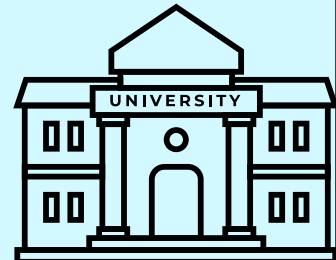
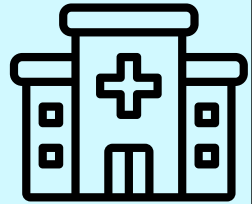
This book is designed to help anyone interested or involved in co-produced health and care research to think about how knowledge is developed and used in research teams. This increased understanding can then be used to support just and productive collaborative knowledge-building.

1 Patient and public involvement (PPI) in health and care research

Patient and public involvement?
So what's that all about then?

It's patients and the public contributing what we know to health and care research teams

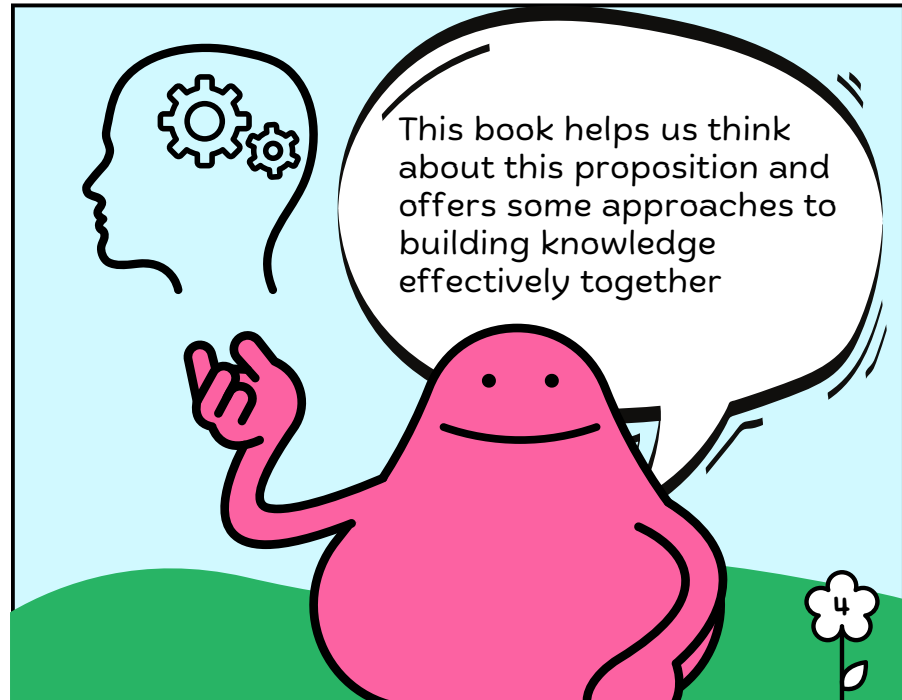
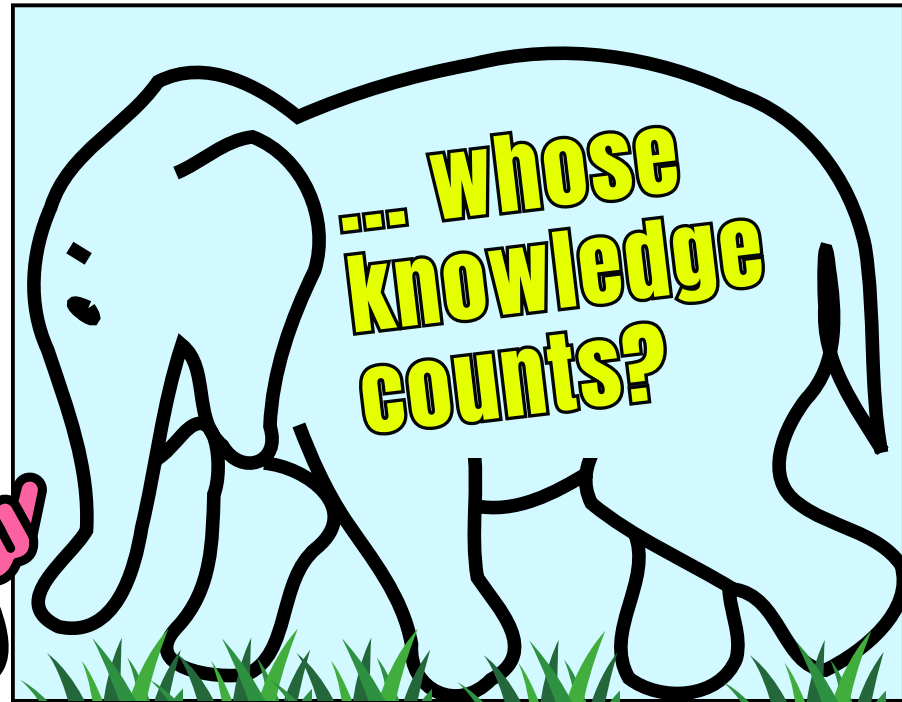
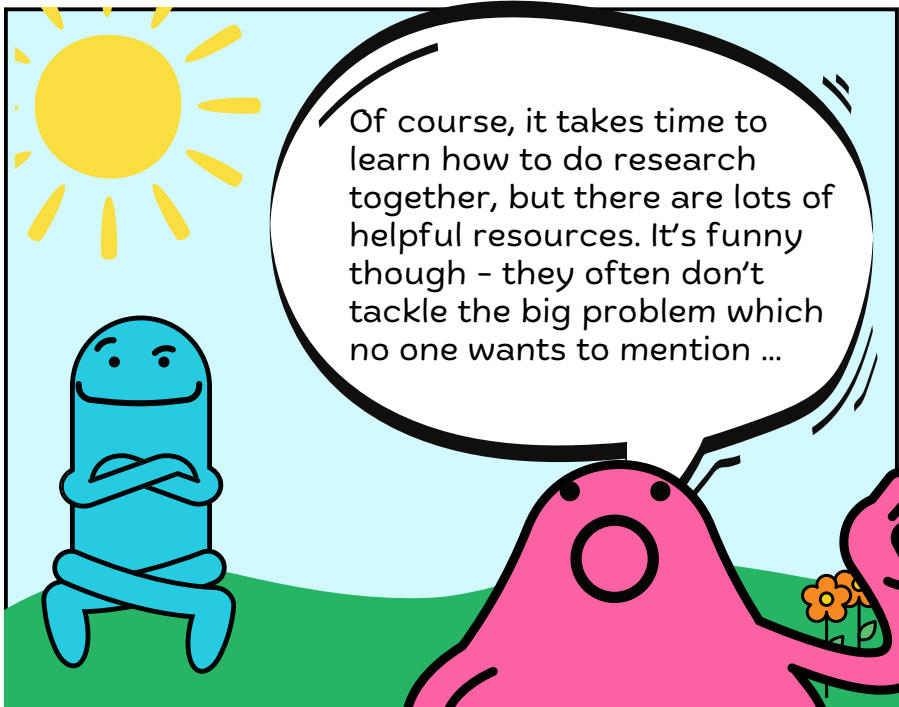
We don't **really** contribute to health and care research!
It's only scientists and doctors and who do that.
We're just people who help them test things



It's not just people working in laboratories and universities who help to improve healthcare. It's also people like us! We can be full research team members, share our ideas for research and explain what helps us to live well

So why are **we** drawn like blobs and not proper people?

Everyone is drawn like a blob here! It's making a point about equity and justice ... but I'm jumping ahead ...



2

Different forms of knowledge in a research team

We are proposing in this book that some forms of knowledge are valued more than others by members of health and care research teams. We need to explain what we mean by that. A good place to start is by thinking about what we mean by ‘knowledge’.

There are many different ways in which we can know something. Person-centred, evidence-based practice is encouraged in healthcare. By evidence-based practice we mean that decisions about how best to care for someone are based on a combination of research, a healthcare professional’s own experience and the patient’s perspective and preferences. Combining these different sources of knowledge mean that it is more likely that the patient will receive the best possible care.

Health and care knowledge based on currently-known facts is mostly held by healthcare professionals and scientists. This type of knowledge comes from accepted scientific theories and from experimentation, observation and measurement. It forms part of the university curriculum for nurses, doctors and scientists. It is updated through being involved in research, attending conferences and reading and writing academic articles for publication. This is often called propositional knowledge.

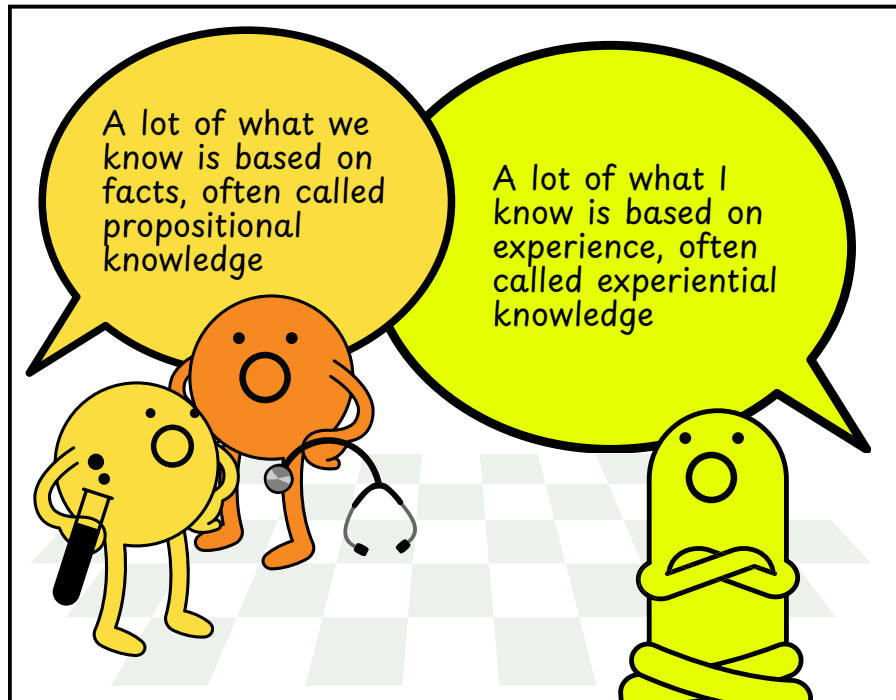
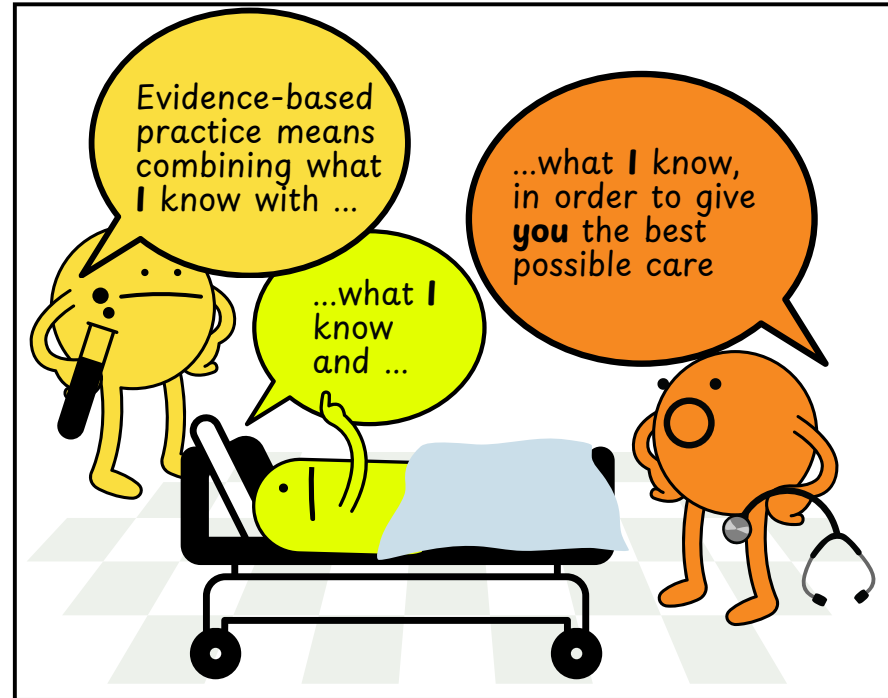
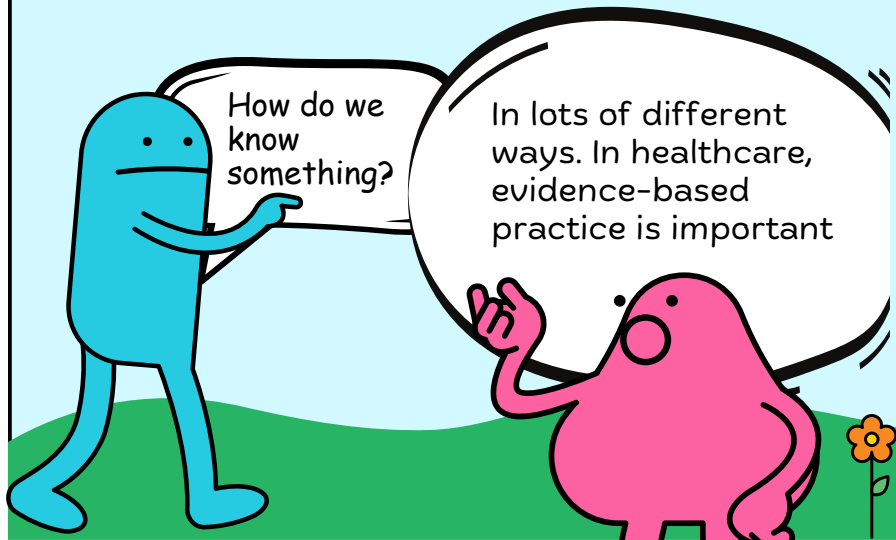
Health and care knowledge held by patients or members of the public is likely to be gained through their own experience of illness and healthcare services. This is often called experiential knowledge. Of course, patients also learn facts about their illness as it progresses and their experience itself can lead to new facts coming to light. Healthcare professionals also build up experiential knowledge through their day-to-day work. However, this experience remains a medical professional’s way of understanding a health issue from the outside, not a patient’s way of understanding it from the inside.

When we are trying to develop effective evidence-based practice through research, we need to bring together healthcare professionals, patients and members of the public. The research will then be based on multiple perspectives, understandings and types of knowledge and have the best chance of changing things for the better for patients.



2

Different forms of knowledge in a research team



3

Whose knowledge counts?

In a research team, propositional knowledge, often expressed as generalisable facts, can sometimes be seen as more valuable than experiential knowledge, often expressed as beliefs or feelings. This hierarchy of knowledge can lead patients and members of the public to feel that their particular experience of something is worth less than more general facts about that topic.

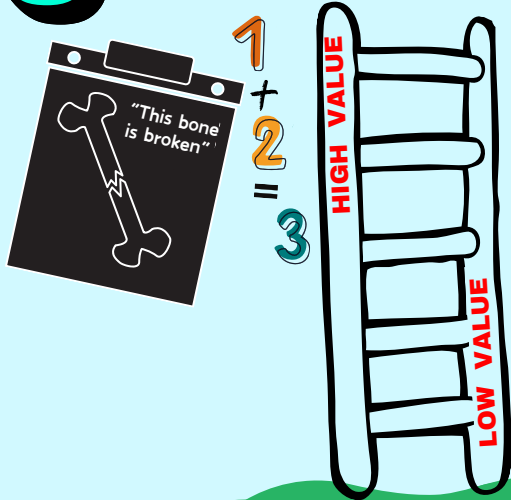
Actually, someone living with an illness can understand how it affects them physically and emotionally and what help they need to live with it, just as well as many medical professionals. Distance and neutrality are not necessarily always a good thing. The insider knowledge gained by someone experiencing or caring for someone with a health condition can be equally valid. Moreover, patients and members of the public also bring a wider set of knowledge and skills and the wisdom of being an outsider to a research team. Therefore, propositional and experiential knowledge should be equally valued within the team. Both perspectives enhance one another and are key to the successful development of healthcare initiatives.

The statement on this book's title page - Anyone can co-produce health and care research - is only true if research team members give equity of opportunity to each person and recognise everyone's contribution as valid. Without this, team members will feel they cannot share things openly, important perspectives will be missed and the value of the research will be diminished. This can be a particular issue in health and care research teams where traditional assumptions about the nature of knowledge and who holds it can be held by professionals, patients and members of the public. This sometimes leads to a greater amount of attention being paid to the views of healthcare professionals and specialist researchers.

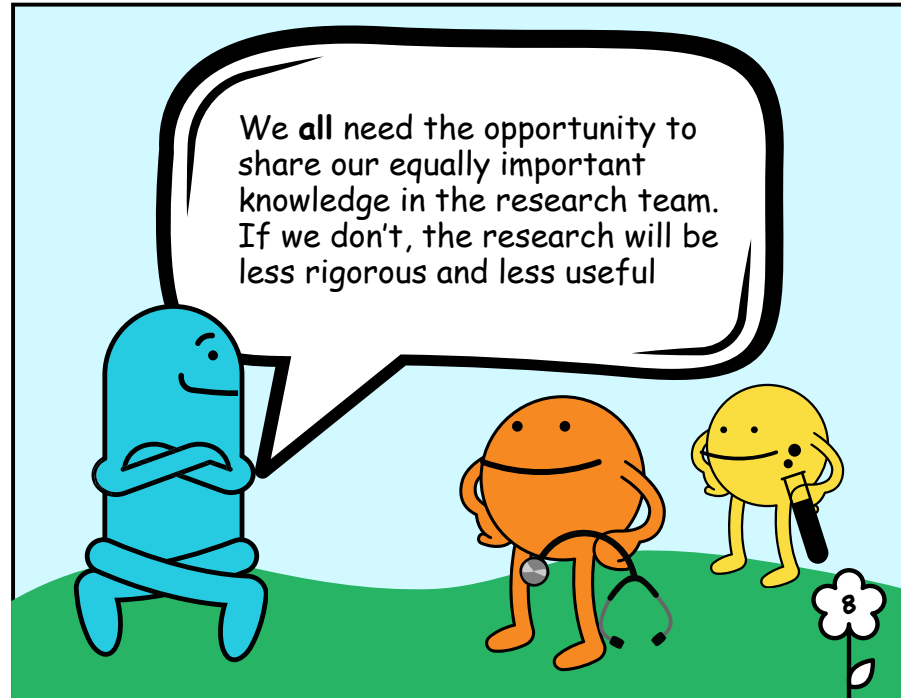


3

Whose knowledge counts?



I feel something is wrong



4

Knowledge and justice

The problem of some people's knowledge counting more than others does not just happen in health and care research. It is also seen in wider society. Some people refer to this problem as 'epistemic injustice'. 'Episteme' is an Ancient Greek word for 'knowledge'. Justice broadly means fairness, with 'injustice' meaning unfairness, someone's rights, and their obligations to others, not being properly upheld. So, epistemic injustice in healthcare refers to someone being discriminated against by not being listened to or heard when they speak about healthcare, not having their ways of knowing acknowledged or having their interpretation of something questioned. Such epistemic injustice can have disastrous consequences for the quality of care a patient receives.

For example, a patient's description of their pain level after an accident could be challenged by a doctor, who cannot see why the patient's injury should hurt so much. Here, the patient's specific experience of pain is denied, whilst the doctor relies instead on what she knows about this type of injury in general. Another example might be when society as a whole struggles to understand particular experiences. For example, in the early 1960s, society did not accept the concept of sexual harassment. This behaviour was therefore tolerated and women who tried to find the words to complain were victimised.

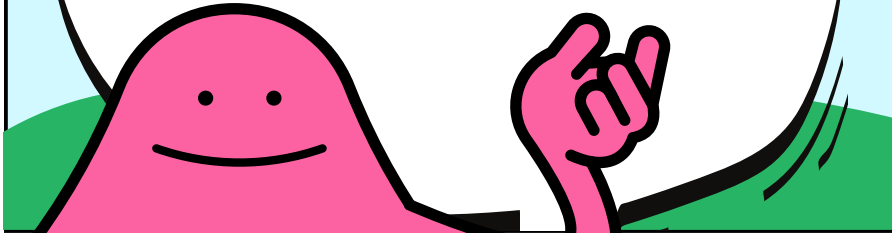
Epistemic injustice in healthcare remains a big problem. A report in 2020 gave detailed examples of the physical and psychological harm which can be done by medicines and medical devices when patients' voices are not listened to and they are not believed. An NHS report on patient safety estimated that improvements could save up to 1,000 lives and £100 million in care costs each year. These reports conclude that the patient voice and influence within the NHS and the overall delivery of healthcare needs to be strengthened. We would extend this to include patients' and the public's role in health and care research. So how could this be done?



4

Knowledge and justice

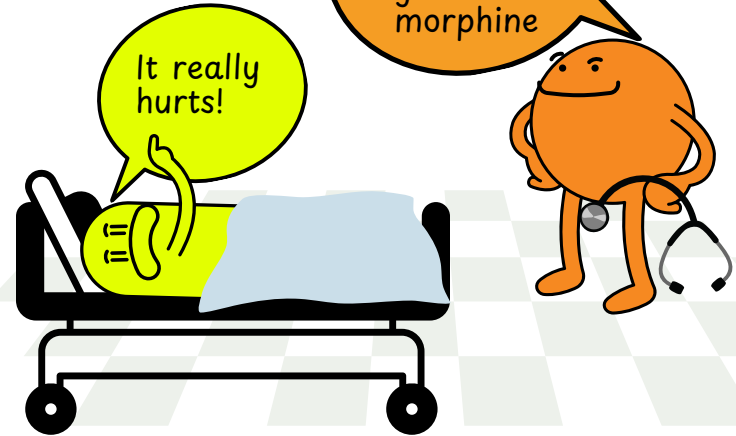
One person's knowledge counting for less than another person's is called **epistemic injustice**. It means someone is discriminated against by not being listened to by others or having the way they understand things questioned by wider society



For example ...

It really hurts!

It can't. You've already had your morphine

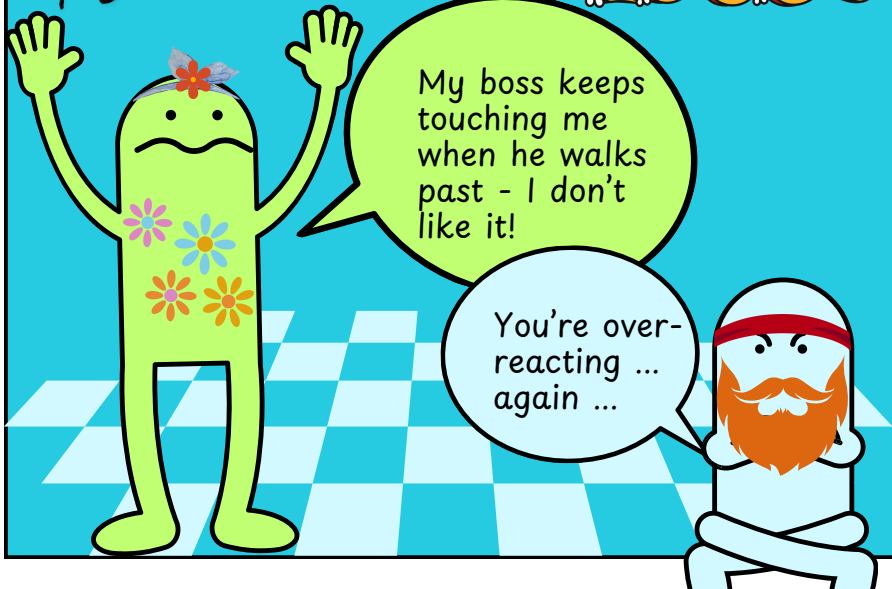


For example ...

1960'S

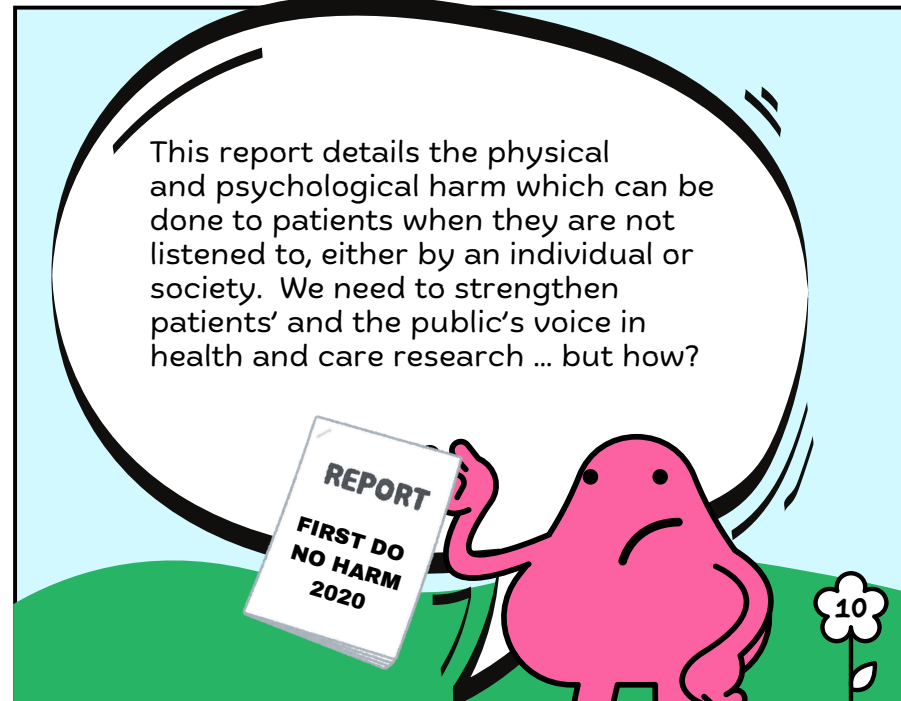
My boss keeps touching me when he walks past - I don't like it!

You're over-reacting ... again ...



This report details the physical and psychological harm which can be done to patients when they are not listened to, either by an individual or society. We need to strengthen patients' and the public's voice in health and care research ... but how?

REPORT
FIRST DO
NO HARM
2020



5

Working towards epistemic justice in a research team

There are lots of tools and techniques designed to support fair co-production. However, a report produced by the Co-Production Collective suggests co-production should be seen as a practice guided by a set of values, rather than as a precise system to be followed. An example of a value would be a commitment to work towards epistemic justice, through acknowledging and building on diverse forms of knowledge in a research team.

The National Institute for Health Research's guidance for co-producing a research project uses this values-based approach, setting principles to guide practice. Of particular interest to us is its third principle: *respecting and valuing the knowledge of all those working together on the research*. This respect is built on an acknowledgement that everyone's knowledge is of equal importance. This matters to individuals because human well-being relies on our ability to contribute to society's pool of knowledge, ideas and understanding from our own experience. It matters to the research team as a whole because everyone's thoughts should be heard and considered, so that we know that any conclusions drawn by the research are informed by all perspectives and therefore more reliable.

Most of us would agree with this in principle. However, we do not always act on this in practice. Our assumptions and biases about people and what they know can cloud our judgement and affect our action. An assumption is a belief you take for granted, whereas a bias is a preference or prejudice which affects your judgement. Our biases may be unconscious, that is, we are not aware that we have them, but they can still result in discrimination. In order to be properly heard, individuals need people to listen to them without prejudice. We therefore suggest two key actions to support us in acknowledging everyone's knowledge and views and treating them as equally important in a research team. These are: get to know ourselves better and get to know our fellow research team members better.

Get to know ourselves better

If we want to work towards epistemic justice in our research team, we need to engage in the potentially uncomfortable process of uncovering our assumptions, biases and prejudices about different forms of knowledge and the people who hold them. Understanding more about ourselves can help us to spot our biases and prejudices and consider their potential impact on our thoughts and actions as research team members.

Getting to know ourselves better relies on us examining our values, considering where these values come from and acknowledging how they affect the worth we give to different types of knowledge. This may not be something we are comfortable in doing. We tend to be most comfortable keeping the beliefs we already have, until something comes along which makes us question them. Section 7 of this book offers some resources to help us think about these complex issues if you wish to do so.

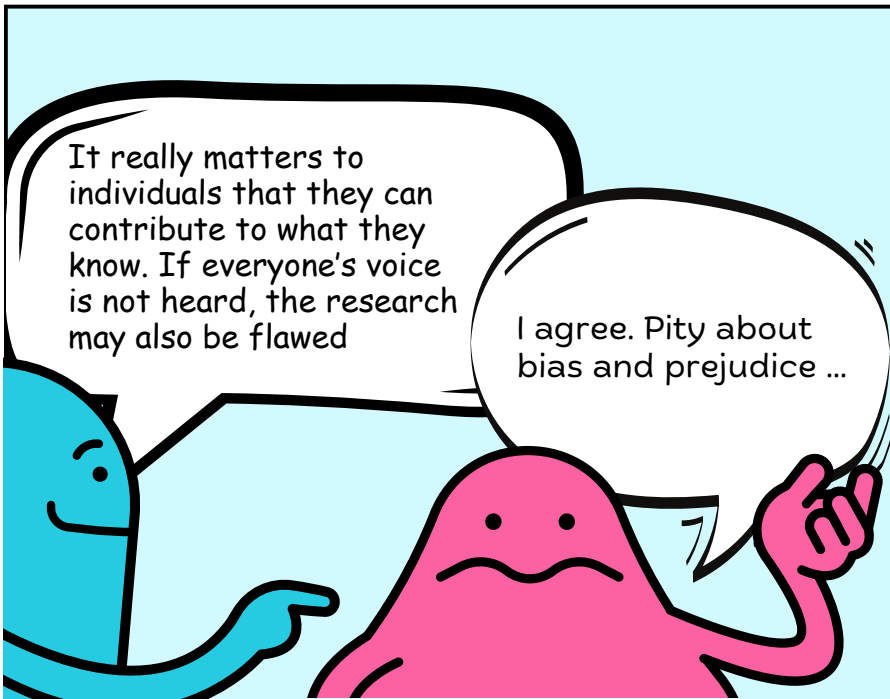
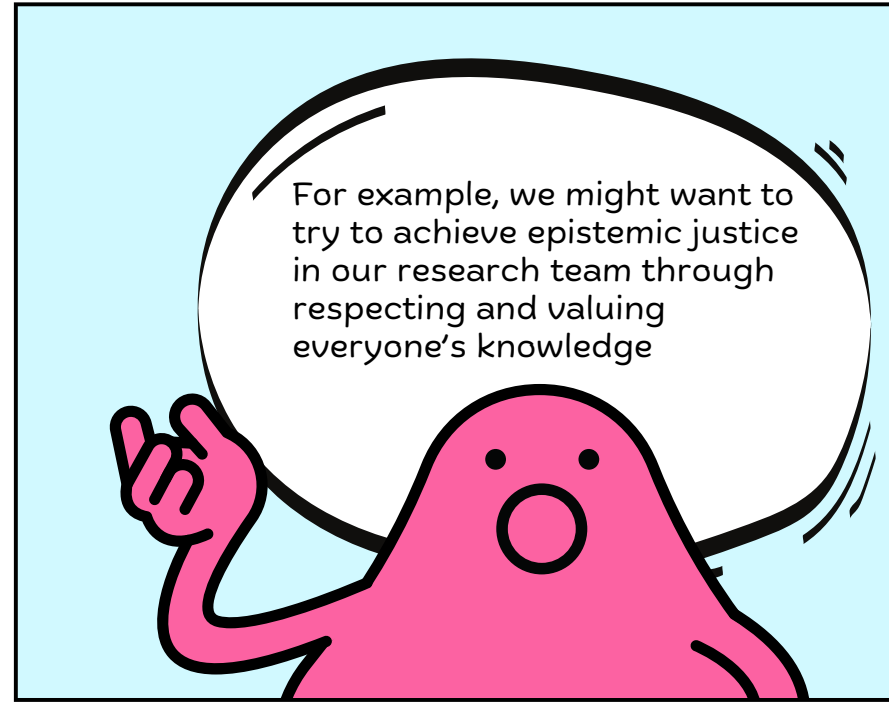
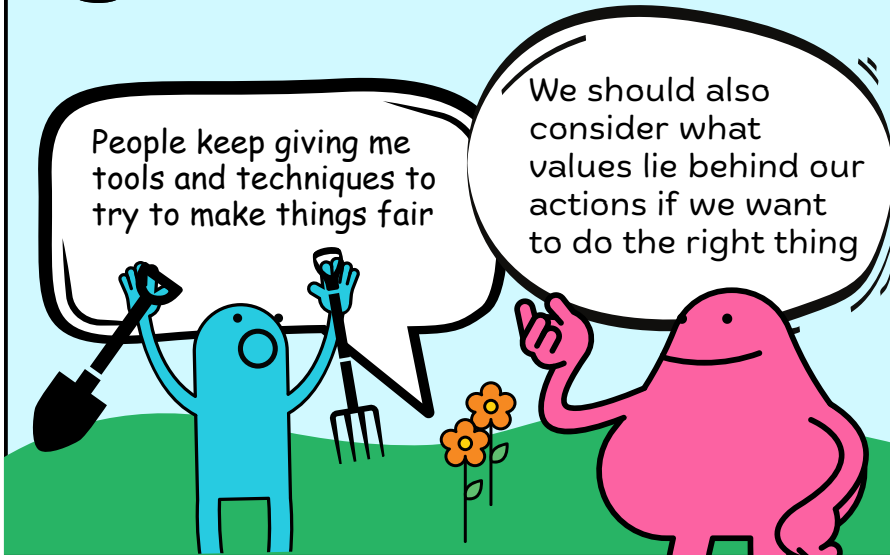
Get to know other research team members better

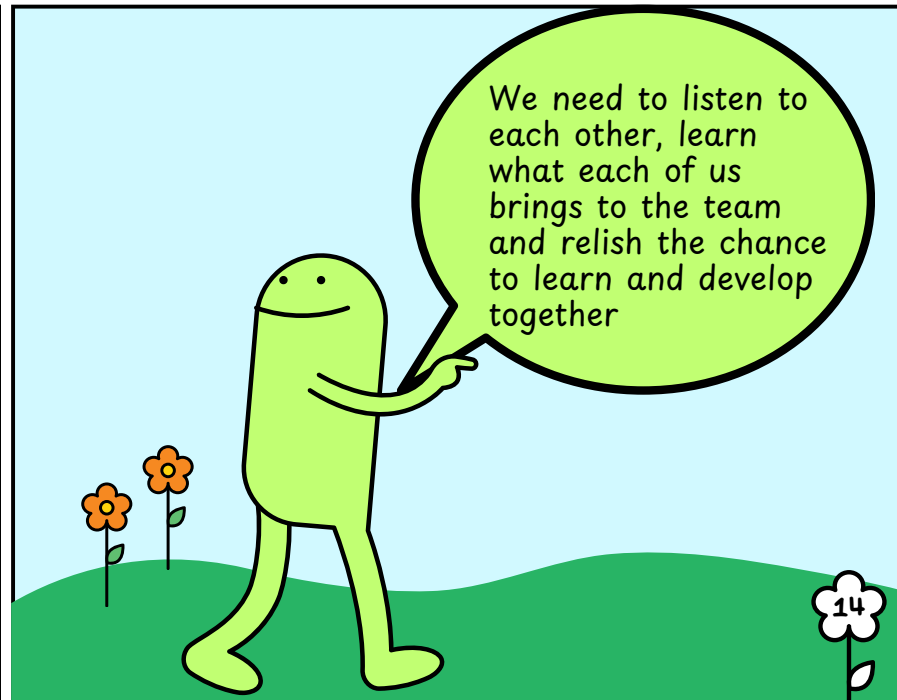
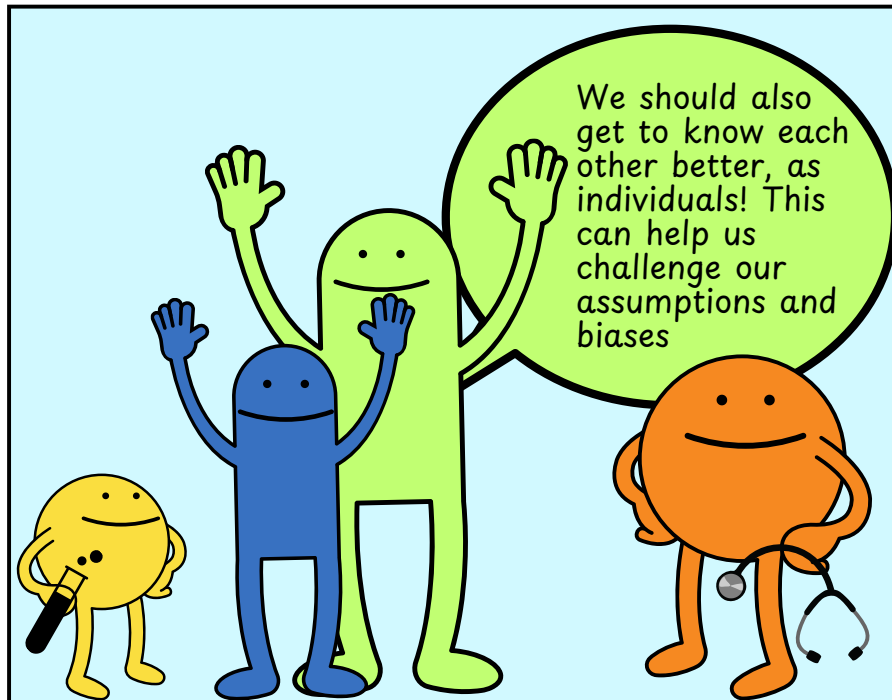
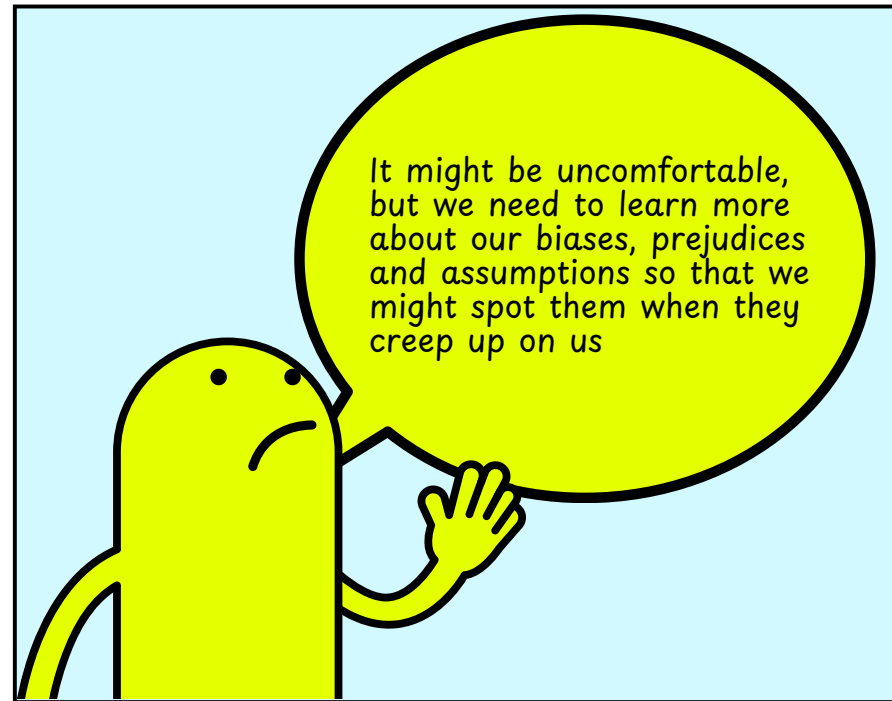
Co-production guidance generally advises that authentic relationships are key to working together successfully. If these relationships are based on a culture of openness and honesty, in which we seek to respect and value everyone equally, they can help challenge our biases. If we want to work towards epistemic justice in our research teams, we need to take time to get to know people as individuals, to learn what personal resources they bring to the team and to relish the opportunity of learning and developing together. We will then all have the opportunity to flourish. The best way to get to know other people is to listen to them. This sounds obvious but many of us would benefit from working on our listening skills.

Section 7 of this book offers some ideas about how to support the development of mutual understanding and reciprocal learning. These ideas can be used and revisited as appropriate in a research team's work.

5

Working towards epistemic justice in a research team





6

Concluding thoughts

At the beginning of this little book we made the following proposal:



In some health and care research teams, some forms of knowledge are valued more than others and this makes both the co-production approach and the research itself less effective.

We have suggested that social bias and blind trust in the truth of our own beliefs can cause this inequity. As people who know things, we are not all the same. We come from a variety of social worlds and are both limited and enabled by our specific experiences.

We have suggested in this book that, in a research team, we need to surface and acknowledge our assumptions and biases about other people and about different forms of knowledge in order to move towards treating everyone as equal in their capacity to contribute. This approach will help ensure that individuals benefit from being openly valued by the group. It will also help ensure that the research we undertake together has the best chance of being rigorous and useful, because it takes account of everyone's knowledge and perspectives. In the future, we hope to be able to make this alternative proposal:

In most health and care research teams, many forms of knowledge are recognised as equally relevant and valuable. This makes both the co-production approach and the research itself more effective.

We hope you have found the discussion useful and stimulating. We also hope that you will have been inspired to take some steps to avoid epistemic injustice in your own research team. If that happens, our initial proposal will be challenged by your practice, and we, and our research, will be the better for that.

6

Concluding thoughts

This is where we started ...

In some health and care research teams, some forms of knowledge are valued more than others and this makes both the co-production approach and the research itself less effective.

In this book, we've put forward the idea that we can change this situation through the actions we take

These include being open with ourselves about our own biases and prejudices and encouraging others ...

.... so that everyone in the team is properly valued and our research is the best it can be!

We don't appear in Section 7, so ... great to meet and think with you!

7

Resources to promote reflection

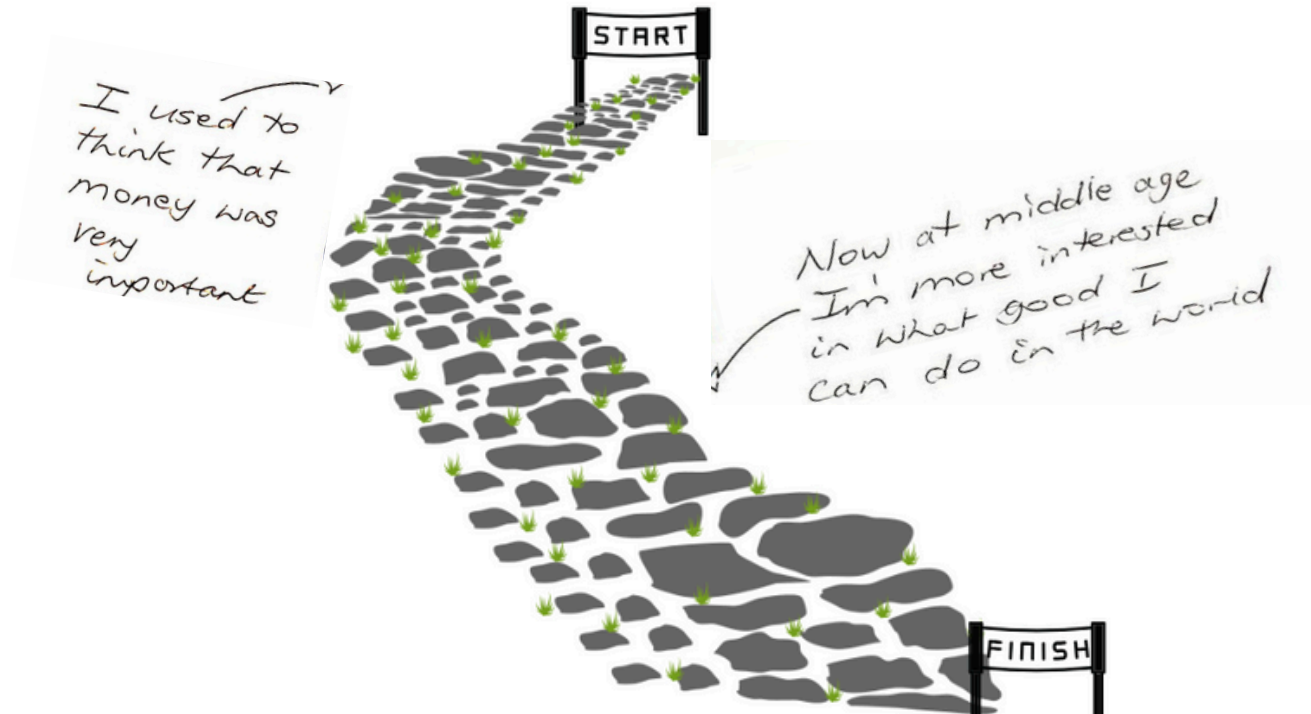
The resources below are offered as starting points in the complex process of getting to know yourself and your research team colleagues better. Some ideas about how each resource might be used are given. For resources 1 - 3, a completed example is given if you need help to get started!

1 - Getting to know myself: what values guide my life?

This resource asks research team members to consider what they care about in their life, how this has changed over time and how their values might impact on effective collaboration in the team.

An example to prompt your thinking

This resource can be completed by individuals privately outside of team meetings. You might, in a team meeting, ask if anyone wants to share what they learned from their reflections.

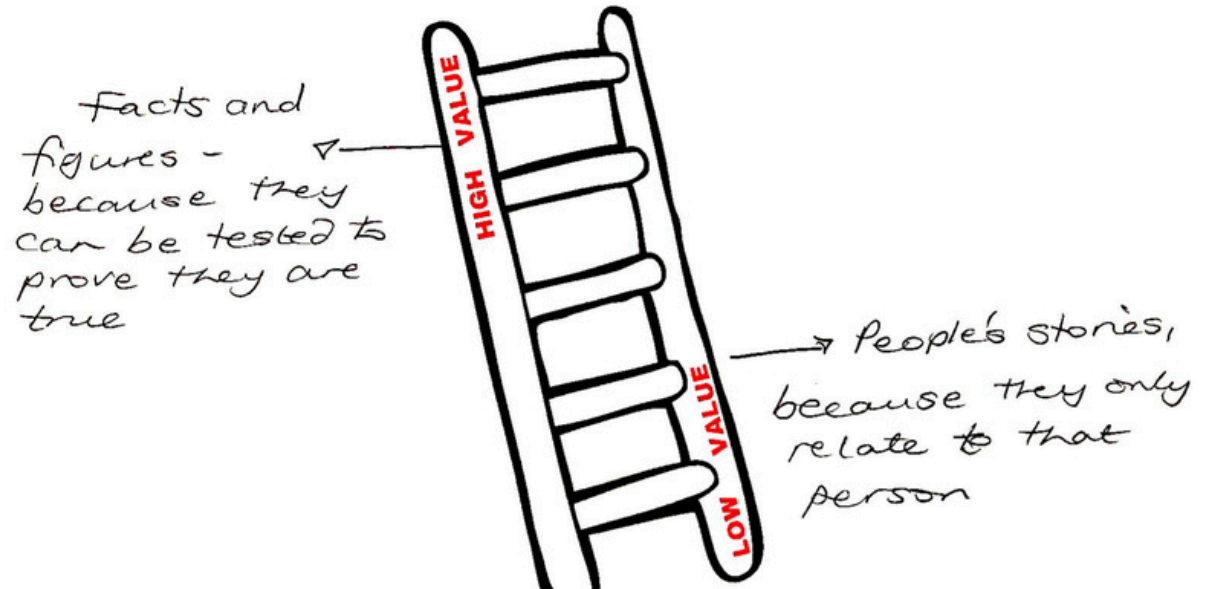


2 - Getting to know myself: how much value do I give to different forms of knowledge and why?

This resource invites you to consider what worth you give to different types of knowledge, either consciously or unconsciously, and why. You are asked to think about how this might impact on effective collaboration in the research team.

An example to prompt your thinking

This resource can be completed by individuals privately outside of team meetings. You might, in a team meeting, ask if anyone wants to share what they learned from their reflections.



3 - Getting to know myself: how has my life experience influenced my values and my beliefs about knowledge?

This resource invites you to consider the various influences on your developing values, explored in the first resource, and beliefs about knowledge, explored in the second resource.

An example to prompt your thinking

This resource should be completed by individuals privately outside of team meetings. You might, in a team meeting, ask if anyone wants to share what they learned from their reflections.



4 - Getting to know others

This resource offers some prompts to start you thinking about how you can encourage other team members to talk with you and how you can listen to them properly when they do.

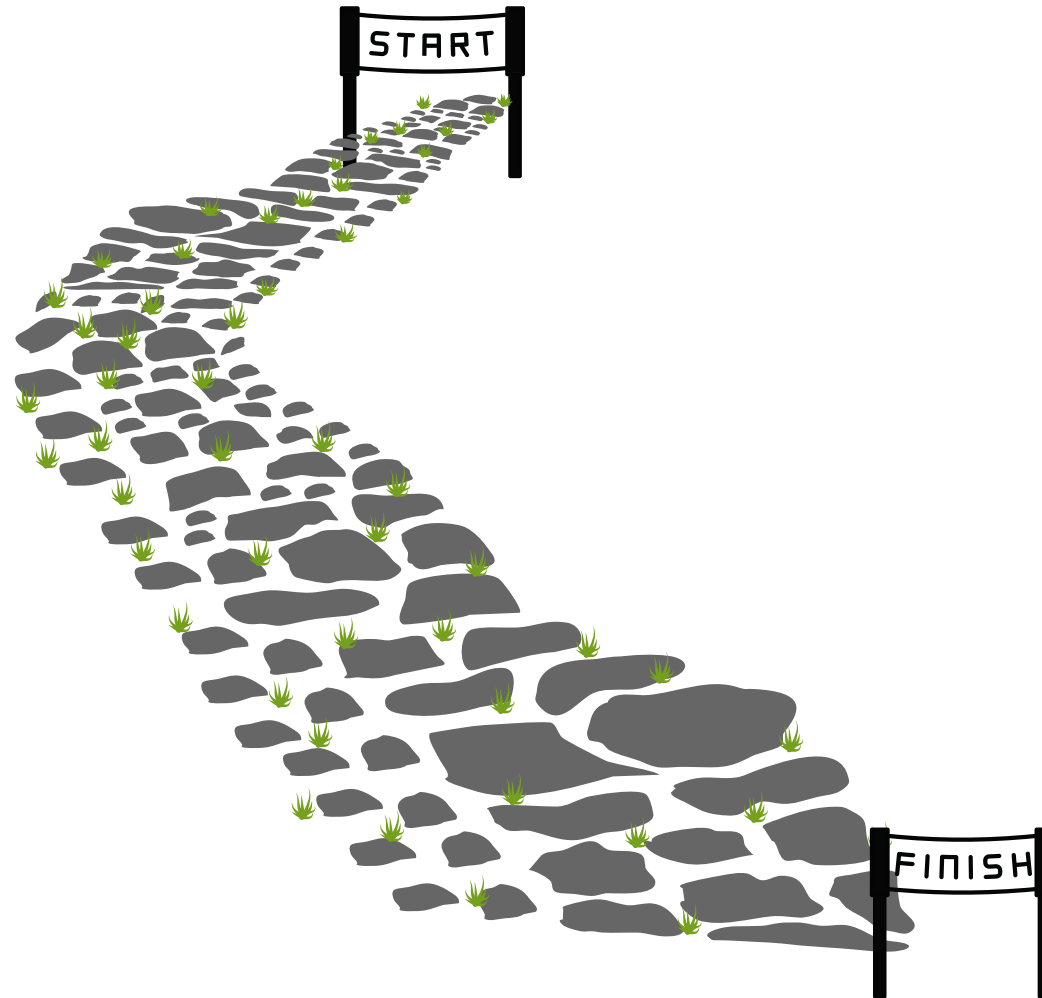
Blank copies of the resources are given on pages 21 - 24.

You may have other ideas for how to stimulate reflection on the issues covered in this booklet. A 3 minute animation produced by the NHS gives some examples of other kinds of tools you may wish to use, if you are leading the team.

The type of stimulus you use does not matter as long as it provokes reflection. This reflection should not, however be forced or be public. For example, you should not simply ask people to openly share their beliefs about knowledge in a research team meeting. This could cause personal embarrassment and a lack of authenticity. Instead, this reflection should be done individually and in private. Team members may choose to share within a later research team meeting on what they have learned about themselves through this individual reflection. This needs to be entirely their choice, initiated by them.

1- Getting to know myself: what values guide my life?

Consider what values have guided your life at different stages and note them below.

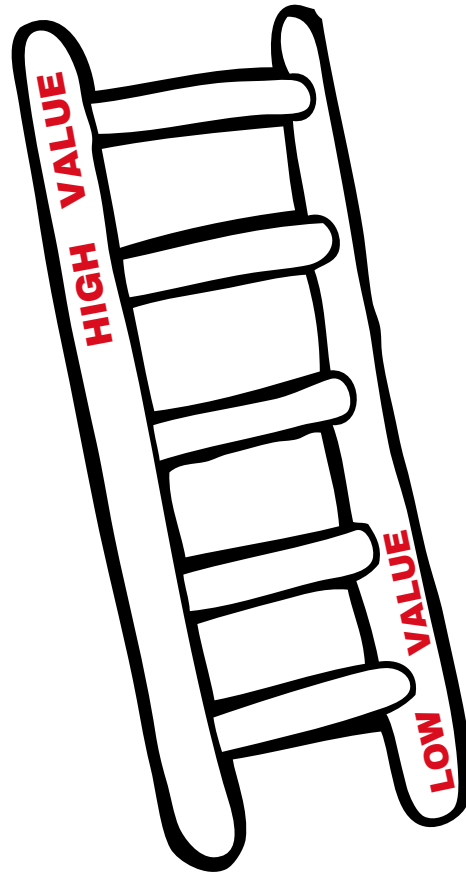


o_o How might these values support or challenge effective collaboration in our research team?

2 - Getting to know myself:

how much value do I give to different forms of knowledge and why?

Consider what value you give to different forms of knowledge and note them below.



How might this allocation of worth support or challenge effective collaboration in our research team?

3 - Getting to know myself:

how has my life experience influenced my values and my beliefs about knowledge?

Consider where your values and beliefs about knowledge come from and note influences below.





4 - Getting to know others

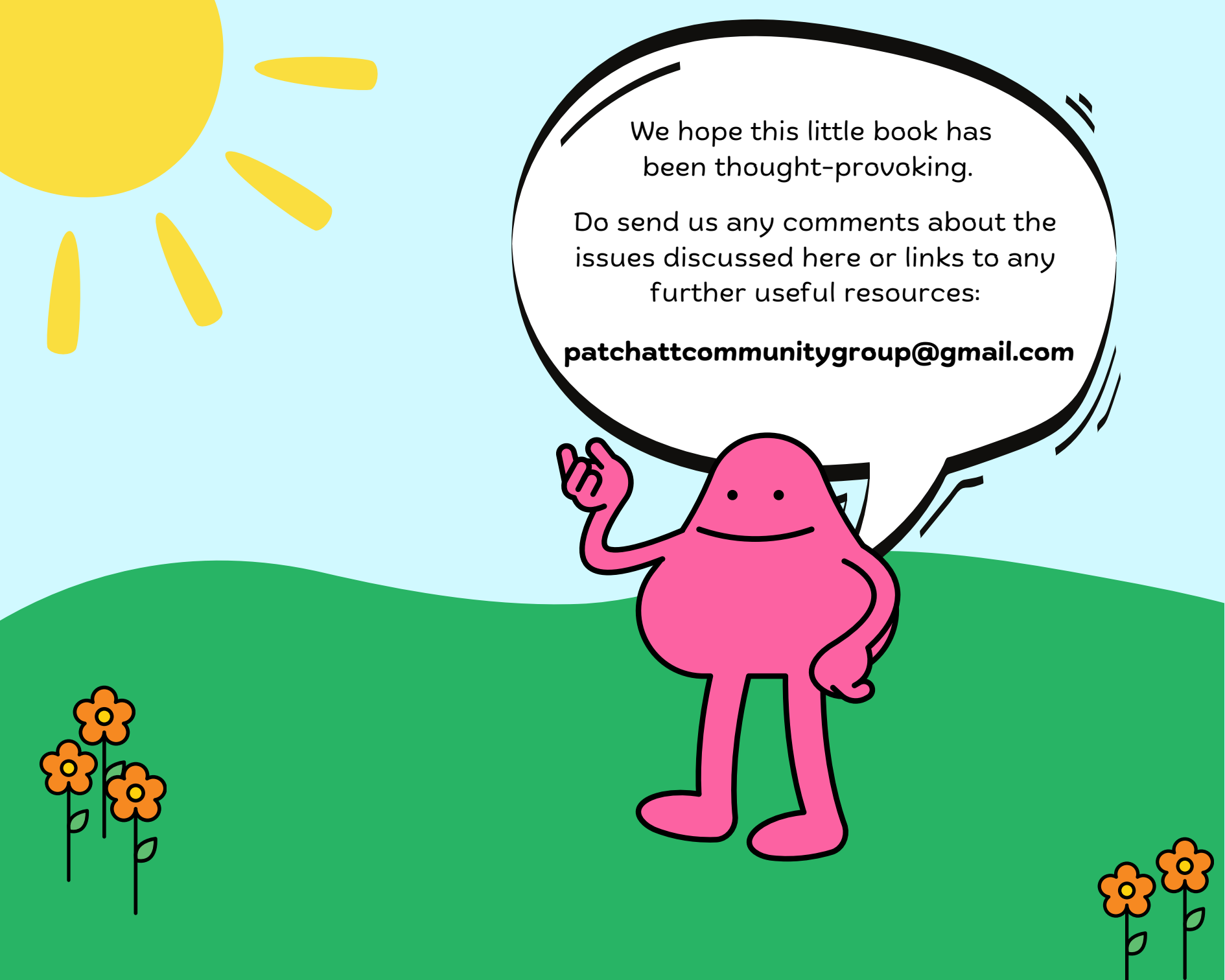
The best way to get to know other people is to encourage them to talk and listen to what they say.

Encouraging talk

- Face the speaker and make eye contact
- Nod and smile as the speaker talks
- Ask open-ended questions
- Be patient - avoid fidgeting
- Encourage sustained talk through verbal affirmation - 'yes', 'I understand' etc.
- Use phrases such as 'can you tell me a little more about that?' to indicate interest
- Paraphrase what the speaker has said to check you have understood correctly

Listening properly

- Pay attention to what the speaker is saying - try not to let your mind wander
- Listen without judgement
- Listen without planning what you are going to say next
- Ask open-ended questions
- Be curious
- Avoid interrupting
- Listen to learn



We hope this little book has
been thought-provoking.

Do send us any comments about the
issues discussed here or links to any
further useful resources:

patchattcommunitygroup@gmail.com