Using stories to develop capacity for Involvement around Animal Research

About the 'Care-full stories' approach

Care-full stories was developed by Professor Beth Greenhough with creative professional Ida Persson as part of the work of the Animal Research Nexus Programme (2017-2023): https://animalresearchnexus.org

It is an innovative resource aimed at supporting conversations about cultures of care for those who work in or around animal research. It uses scripted storytelling to develop discussions in which people can talk about what they care for and to listen to the perspective of others.

The full training resource currently consists of a set of instructions for facilitators (with a suggested agenda, warm up exercises and discussion points, as well as advice on creating a safe space for conversations) and a series of different scripts that users can select.

Within each session, volunteers read out the scripts, ideally taking on roles different to their usual position in relation to the workplace. Participants then collectively talk through a series of discussion points the script was designed to raise.

Many of the scenarios and characters are based on reality, but are exaggerated caricatures, which condense and simplify key points for everyone to debate.

You can find out more information about how the Care-full Stories approach was developed and evaluated in Beth Greenhough's Animal Research Nexus blog post here: https://tinyurl.com/2c3z237x

The following script was developed to help extend cultures of care to research involvement with people affected by health conditions by Gail Davies, Richard Gorman, and Gabrielle King in 2021. This work was supported by the Wellcome Trust.

This script explores the first steps in opening conversations about animal research with people affected by health conditions, through a site visit to a facility. It is designed to be adapted for use in different training workshops and research contexts. There is more information for facilitators on request.

If you have any questions or feedback on the script, please email Gail Davies at g.f.davies@exeter.ac.uk

Who is it all for? *One-scene version*

Thinking about Patient Engagement and Involvement with Animal Research

Patient and public engagement and involvement can play an important role in shaping the funding and the relevance of animal research, but it needs to be carefully planned from an early stage. This script aims to help people working in research to think through the first steps of incorporating careful patient engagement.

This script is available in two lengths. The two-scene version is designed for use in workshops and training sessions focused on patient and public engagement and involvement. The one scene version is designed to be used with other 'Care-full stories' scripts. This is the short version.

Focusing on Parkinson's

The script is focused on Parkinson's as one example. We encourage you to personalise the underlined scientific detail to another health condition to better fit your audience.

Please note that the script discusses some of the co-morbidities that can accompany Parkinson's. If working with members of a patient group, you may instead wish to swap the condition, or to take out the mention of co-morbidities on the middle of page 4 to avoid sharing potentially unknown clinical information that may cause distress.

Scene Direction

Aims: To explore experiences of those taking part in a patient engagement visit and generate discussion around planning events that accommodate everyone's needs.

Characters (in order of appearance):
Event Organiser – Postdoc in charge of the event, working with the Head of Project
Patient Representative – Person living with Parkinson's attending the event
Head of Project – Head of project looking at a specific gene related to Parkinson's
Animal Technician – Technician taking care of the zebrafish used for the project

Facilitator reads out the scene setting: This scene takes place in a seminar room in a research facility. It is set immediately after a group of people affected by a health condition have been on a tour to see the zebrafish. The tour was led by the event organiser and the Head of Project. The animal technician who spoke to people about their work and care for the fish had just stepped in for a colleague. They are getting together at the end to chat and exchange questions.

Set up options:

In person: All enter the space at the same time. Mingle around in the room or sit as desired/required. Any chairs to be brought in are to be arranged by the Event Organiser (either by carrying them or instructing someone else to carry them in.)

Zoom: All workshop participants turn off camera and microphone (if not already off). All characters turn on camera and microphone.

Event Organiser: That concludes the tour of our research facility. Sorry we're a bit behind schedule. Feel free to take a seat. We can get some more chairs. Anyway, as individuals directly affected by the work we do here, we hope you've been able to get some insight into how it all happens.

Patient representative: It was really interesting! I didn't know what to expect. I signed up via a newsletter, which didn't give a lot of detail. I've been to some events about <u>Parkinson's</u> but never an actual research facility! It was a trek to get here, but worth it.

Event Organiser: I'm so glad you could join us!

Patient representative: I'm retired, so my time is mostly my own. That seems to be the case for some of the others too. It's been good to meet people … Oh, here is my consent form. My partner had to fill it out for me in the break as I couldn't quite manage, hope that's all right.

Event Organiser: Of course, thank you. But the tour itself was okay for you?

Patient representative: Yes, fine for me. The tea and biscuits kept me going! But I think the chap in the red – John? – struggled with the changes in temperature. I'm glad of a little sit down now! So, remind me, what's your role here?

Event Organiser: I'm a post-doc researcher, and I work with the Head of the Project. They are here to answer any questions you have about the research now.

Head of Project: As promised I am happy to answer any questions about our research. <u>We explore changes in the SNCA gene. At least 30 mutations in the gene have been found to cause Parkinson's.</u>

Patient Representative: Can you do it without animals at all?

Head of Project: <u>Zebrafish mimic many elements of mammals. They are rich in behavioural repertoire and have a small body size. You can also perform easy *in vivo* experimental manipulations and they have good genetic tractability.</u>

Event Organiser: Sorry to interrupt, lunch has now arrived, feel free to help yourselves to sandwiches and feel free to keep chatting.

Head of Project: Did you enjoy seeing the zebrafish?

Patient representative: I wasn't sure what it would be like. I was surprised it was fish and not mice or something. They seem happy. If that's the right word! But still, poor fish … Odd to think that the fish swimming around here could affect my life.

Head of Project: Yes, from one gene to a fish to patients' lives. Of course this translation is a long journey, sometimes decades long. It takes a while for the vital research we do here to have an impact on patients like you.

Patient representative: Oh okay. I have to admit I'm not sure how I feel about being called a 'patient'. That's just me though. My diagnosis is fairly recent, you see. Everyone here seems to be at different stages.

Head of Project: Zebrafish are useful for studying disease progression too, including how Parkinson's can lead to developing dementia ...

Patient Representative: What? … I'm sorry … Just, I didn't know that could happen.

Animal Technician: I should get back to the fish. It was lovely to meet everyone!

Patient representative: And you. Thank you for all the information you gave us at the fish tanks earlier. I wanted to ask, is there something different I can do with my medication or diet to reduce this risk of dementia?

Animal Technician: I'm afraid I'm not really the right person to ask about that … But I was glad to be able to show you what I do.

Head of Project: We'll finish here for today. You are central to the work we do, and your voice is crucial for shaping our future research. Thank you so much for your time.

Event Organiser: We'll follow up on your feedback, and we hope to see you again.

In person: Each character, in turn, turns to the audience of the other workshop participants, takes a step forward and says their line.

Zoom: Each character looks into their camera and speaks in turn.

Animal Technician*:* That was quite the event. I got asked some questions I really couldn't answer. I felt a bit out of my depth.

Head of Project: That was quite the event. I hope all the information was clear. It's hard to know how to pitch the language. I hope I wasn't out of my depth there.

Event Organiser: That was quite the event. No two people are the same, so it's hard to know how to cater for everyone. I don't want to be out of my depth.

Patient representative: That was quite the event. I'm not sure I understood all the information; or got clear answers from people. I'd like to stay involved, but it's a big responsibility now when results seem so far away. I don't want to feel out of my depth.

End Scene

Discussion Prompts

- What practical, emotional, or ethical issues can you identify in this script?
- Have you experienced similar, or other related, issues in your work?
- Do you think a facilities tour was the right format in this case? What did it enable? What were the issues?
- What might you do to design and run an event differently in the future?
- What might help the different people not to feel so far out of their depth?