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? *Two-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 and involvement.

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 longer two scene version.

This script is designed to structure a two-stage discussion, based around planning and evaluating patient engagement or involvement events. The script explores how involvement can bring new perspectives but also new pressures to an organisation.

The workshop aims to prompt discussion and understanding around:
- The different roles, perspectives, and experiences to consider when running events involving people affected by health conditions
- The importance of early and inclusive planning for any involvement and engagement activities
- The kinds of training and support that people within and outside of the organisation might need

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 in the middle of page 7, to avoid sharing potentially unknown clinical information that may cause distress.

Scene Direction

Characters (in order of appearance):
Event Organiser – Postdoc in charge of the event, working with the Head of Project
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
Patient Representative – Person living with Parkinson's attending the event

This script takes place in two **settings**:
- **Scene 1**. The Head of Project's office, where event planning is being discussed
- **Scene 2**. A seminar room, where people mingle after a facility tour

The facilitator should state the setting at the start of each scene.

Scene 1

Workshop activity: Listen to or read through the scene. Discuss based on prompts identified at the end of the scene.

Follow the green stage directions if reading and acting out the scene in person and the red stage directions if the workshop is taking place over zoom. You may want to record the script in advance. If a recording of the scene is being listened to, stage directions can be ignored: simply start the recording.

Facilitator reads out the scene setting: The scene opens with a meeting between the *Head of Project* and the *Event Organiser* in the Head of Project's office. After the Event Organiser leaves, the *Animal Technician* joins when passing the Head of Project's office.

In person: Head of Project takes position in the centre of the room, as if in their office. Event Organiser enters.

Zoom: All workshop participants turn off their video and mute their microphones (if not already off). Event Organiser and Head of Project turn on camera and microphone.

Event organiser: Hi! I wanted to touch base on the patient rep visit tomorrow, for the SNCA-gene project.

Head of Project: Sure. Thank you for organising it, especially since it's your first one with us. I'd normally be much more involved, but with the report deadline tomorrow and Thursday's conference, everything's a bit tight!

Event organiser: No, it's fine. I organised some similar events at my last post-doc, with a view to patient involvement, and it's good to get stuck in early! I'm keen to make this kind of thing a large part of my work here. The project funding requires three events, and this being the first one, I want to see how it goes and build on that.

Head of Project: Good idea. Just looking at the funding outline, we want to do three things today: show patient reps how our work on zebrafish relates to Parkinson's, create openness about our work at the facility, and provide some information on animal research generally.

Event Organiser: Right. We have 15 people registered. They are people living with Parkinson's and family members. They'll arrive at 11:00. Would you be ok to greet them with me, as Head of Project?

Head of Project: Yes, of course. Apologies if I'm a few minutes late, I have a meeting that I'm hoping won't run over.

Event Organiser: Absolutely. After filling out consent forms and some housekeeping, we'll take them around the facility. We'll focus on seeing the zebrafish, where they'll meet the technician. Lunch is at 3:30, with informal chats with the other researchers, the technician and us. There will be refreshments during the day.

Head of Project: I'm sure you've thought about this, but we should give them any support they need during their visit. And also, I want to highlight how valuable their input is to our research and that we'd like to involve them more going forward.

Event Organiser: Of course. The attendees might have to guide us a bit when they arrive in terms of what assistance they need, as we don't know any individual details.

Head of Project: You know, it's interesting, the events I've done over the last three years have all been external, like town halls, meeting rooms. I'm excited about patients seeing the facility and the animals.

Event Organiser: And I think it'll be good for the technicians too. On my last project they said they found it really beneficial, thinking about their place in the facility and the scientific outcomes.

Head of Project: Yeah, absolutely. And, for all of us, this helps us focus the research, remembering the end game. I do it to *help* the research at the end of the day. Anyway, I have a meeting with the technician now, so I can fill them in. I think tomorrow's going to be great.

Event Organiser: I hope it all runs smoothly. See you later!

In person: Event Organiser exits. After a beat, the animal technician enters

Zoom: Event Organiser turns off camera and mic. After a beat, the animal technician turns on camera and microphone

Head of Project: Come in. I'm so glad I caught you. I wanted to say thanks for stepping in at the last minute on the tour tomorrow. We'll meet you at the tanks and you'll explain your work as an animal technician.

Animal Technician: I'm happy to help, of course. I'm slightly worried that the tour might be a little disruptive because it's busy time around then, the fish haven't been spawning well recently and we're worried that changes in the environment might not help. But we have a few days to play with, so it's probably fine.

Head of Project: An insight into your everyday work with the zebrafish will be really valuable. At the end of the tour, I'll be around to answer any questions about the research. We won't take up too much of your time, I promise!

Animal Technician: I've not done this kind of thing before, so I'm not sure what they'll want to know! But I'll ask Jenny. She's done a lot of this on her project with mice. She really enjoys it. Actually she says it's inspiring.

Head of Project: Thanks. Are you heading to the lab meeting now? I'll come with you.

In person: Head of Project and Animal Technician exit.

Zoom: Head of Project and animal technician both turn off camera and microphone.

End of Scene 1

For Facilitator: discussion prompts for Scene 1

Ask participants to think about the scenario from the perspective of one of the characters – *Head of Project, Event Organiser, Animal Technician* and or the *Patient Representative* who will be visiting later. If they can, ask them to choose one that is not their normal role in research.

Lead a discussion based around the perspective of the different characters, using the following questions as a guide:

•   How are you feeling about the upcoming engagement event?
•   Why do you think this event is happening?
•   Who do you think it is happening for?

Scene 2

Workshop activity: Listen to or read through the scene. Discuss based on prompts identified at the end of the scene.

Follow the green stage directions if reading and acting out the scene in person and the red stage directions if the workshop is taking place over zoom. If a recording of the scene is being listened to, stage directions can be ignored: simply start the recording.

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 *Head of Project, Event Organiser, Animal Technician* and *Patient Representative* are present.

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 Parkinson's 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. We explore changes in the SNCA gene. This gives us insight into Parkinson's, as well as other CNS disorders and neurodegenerative diseases. At least 30 mutations in the gene have been found to cause Parkinson's.

Patient Representative: And do you need to use these specific fish for that?

Head of Project: Zebrafish are a model for studying Parkinson's because their aminergic structures, MPTP mode of action, and PINK1 roles mimic those of mammalians.

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

Head of Project: <u>Zebrafish are rich in behavioural repertoire, have a small body size, you can perform easy *in vivo* experimental manipulations, and they have good genetic tractability.</u>

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

Head of Project: Did you enjoy seeing the <u>zebrafish</u>?

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 them 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: 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: Fish are useful for studying disease progression too, including how <u>Parkinson's can lead to developing dementia …</u>

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: So we'll finish here for today. Thank you so much for your time. It's important to us that you know what work is being done, and how we keep you in mind when we do it. We strongly feel your voice should be heard throughout the scientific processes that impact you in the long run.

Event Organiser: We'll follow up on your feedback, and we hope you'll be interested in being involved with us further in future. Our funding means that we will have more events like this, and we'll keep you informed of those. Thank you for coming.

In person: All exit

Zoom: All turn off their cameras and microphones.

End Scene 2