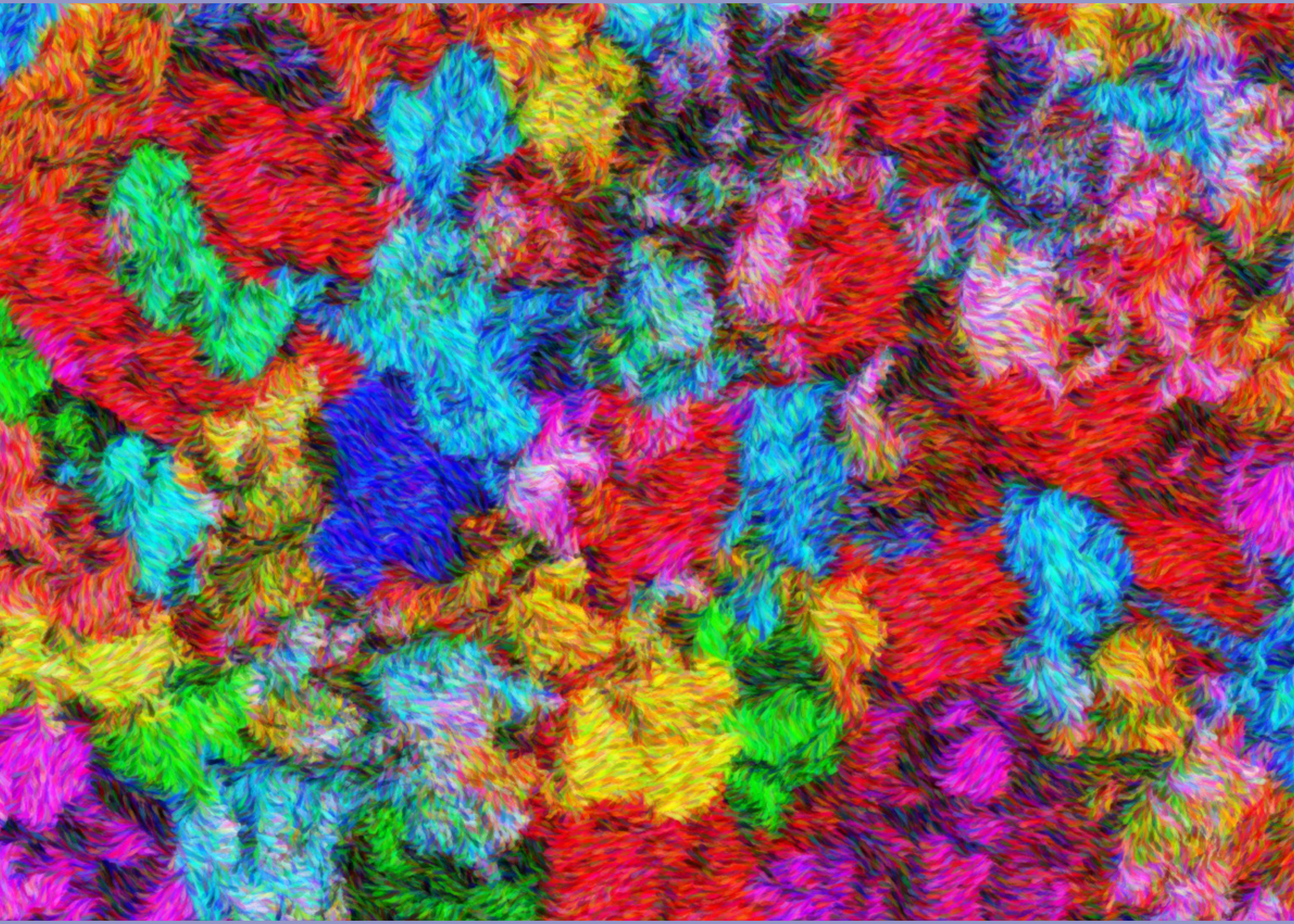
NIHR | Policy Research Unit
Dementia and neurodegeneration
University of Exeter



What works when working together?

A practical guide for involving people with different neurodegenerative conditions in policy research

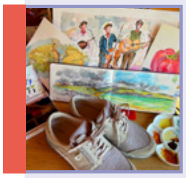
July 2024

University of Exeter
Newcastle University
LSE The London School of Economics and Political Science
University of Bradford
UNSW Sydney
Innovations in Dementia

Introduction

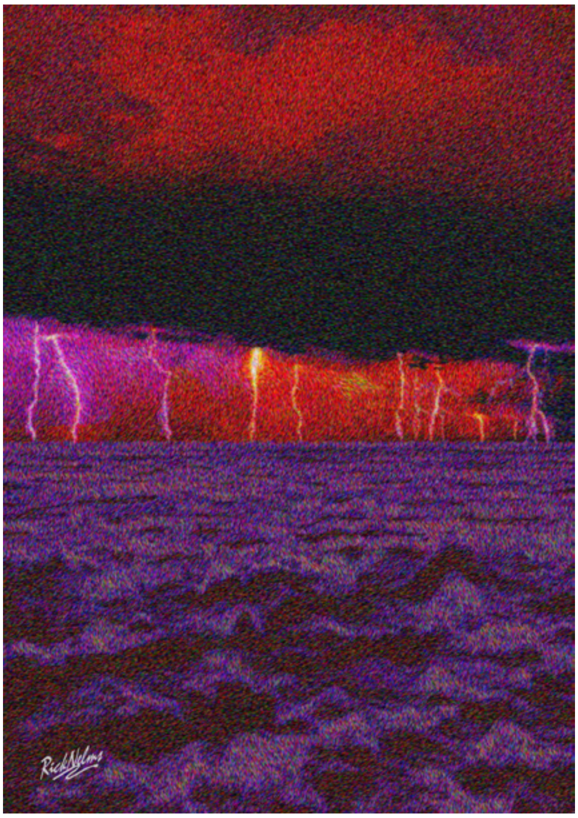
People living with neurodegenerative conditions and those who support them are the experts when it comes to what experiencing that condition is like. Most involvement work (or Patient and Public Involvement and Engagement, PPIE, as it is often known) focuses on one condition at a time. However, we are part of the NIHR Policy Research Unit in Dementia and Neurodegeneration, University of Exeter (known as DeNPRU Exeter), which works across Dementia (of all types), Parkinson's Disease, Motor Neurone Disease, Huntington's Disease, and rarer neurodegenerative conditions.

Supporting people with a range of conditions to work together in an involvement group is new for us. We hope this practical guide is helpful and that it encourages you to try working together yourselves.



> I think we could say that a 'mixed group' is a good idea in terms of research. I think this is working. We are learning and making suggestions.
> **Julia, carer**

This co-created guide focuses on **online** involvement meetings. Online has proved to be helpful not only because of the geographic spread of members, but also because of the additional flexibility it offers for those with various commitments (i.e. work, caring) and conditions to navigate.



'Hope in the Storm' by Rick Nelms

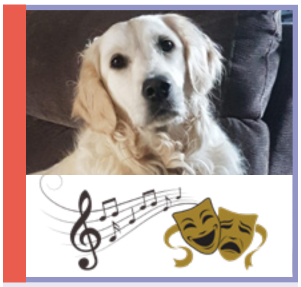
'Emotional Challenges in Neurodegeneration' by Rick Nelms

Contents

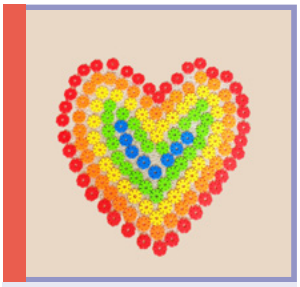
‘Scroggy’ by Rick Nelms

Meet the team

We are using photos and pictures to represent our identities. As well as showing that we are so much more than our conditions, or caring roles, it is a useful way of preserving anonymity (which might be important for people). Our tag line, based on some inevitable Zoom mishaps and our commitment to speaking out, is “we are not on mute! 😉”

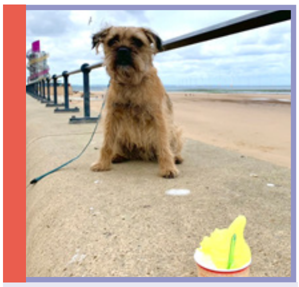


Allison – lives with Alzheimer’s disease



Becky – from a family affected by Huntington’s disease

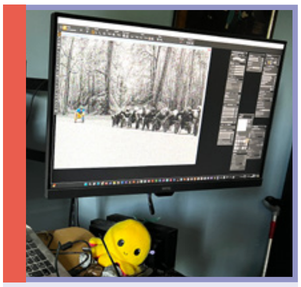
Emma – lived experience of Huntington’s disease and dementia



Jackie – cared for her brother with Huntington’s disease

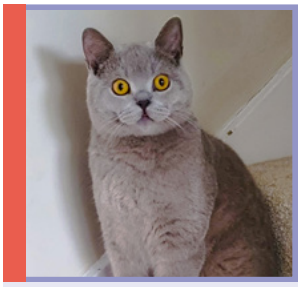
Jagdish – former carer for her mum

Julia – carer



Rick – lives with motor neurone disease

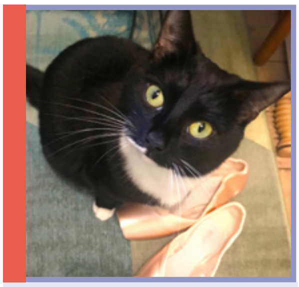
Samantha – tested positive for Huntington’s disease



Shafaq – lives with Parkinson’s disease

Sue – carer for husband with MND (and the grit in the oyster)

Rachael – lead for involvement in DeNPRU Exeter, from Innovations in Dementia

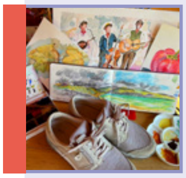


Cathy – DeNPRU Exeter Stakeholder Engagement and Impact Manager

Forming a group

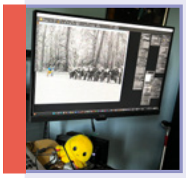
This stage includes reaching out to people and then bringing them together as a new group. It is often a time of uncertainty, because we may not know about each other's conditions, have different adjustment needs and not want to upset or offend. However, there are ways to make everyone feel welcome.

- Create an **accessible, eye-catching flyer** which makes clear: what the project is, who is running it and the duration. The flyer should answer the following questions: What are you trying to find out? Why is this important? What will I be doing and why do you need my experience? Where can I find out more?
- **Advertise in a variety of places and in a variety of ways**, including social media. Once you work across neurodegenerative conditions, the age range of people to involve is much wider than would be expected in, say, dementia (even including young-onset dementia).
- It can often be easier to involve carers than people living with conditions themselves, but **ensure you're not over-representing carers**.



> "I think researchers should really try to find people living with the condition. That extra effort must be made.
> **Julia, carer**"

- Remember people's **motivations for being involved** and make it clear how your project aligns with that.



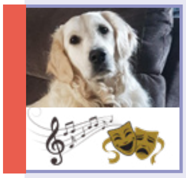
> "I'm really trying to make something good out of things that are difficult.
> **Rick, lives with motor neurone disease**"

- Have **clear and reasonable expectations** of group members, so that no-one is worried: we want our experience to count, but not to take on something we cannot handle.
- Make it clear that you're **setting up a supportive group**, where we treat each other with kindness, honesty and respect.
- **Acknowledge differences between conditions** rather than pretend they are not there.
- **Acknowledge that we all have things to learn** about each other's conditions and we might have to do more explaining than would be necessary in a single-condition peer support or research involvement group.

Preparing for involvement meetings

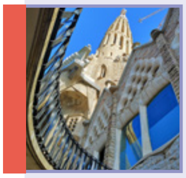
Time is precious, perhaps even more when your life is affected by neurodegeneration. To make the most of the time we have together in an involvement meeting:

- Share the **meeting details in an 'easy-to-read format** with the date written out in full (including the day of the week) in the body of the email.
- Send out a **reminder of the link** on the morning of the meeting, so that it's easy to find and click on.



> Quite often, they [meeting links] sort of get lost.
> **Allison, lives with Alzheimer's disease**

- Include an **agenda** so that we know what's coming. This can both help remind us of the project and reduce anxiety about the unexpected.
- Having the meeting's **discussion points or topics in advance** is helpful. We might want to think ahead, make a few notes, or just to know what's coming.
- If any preparation is needed for a meeting, give plenty of **advance warning**.



> Don't spring it on me! … I have to juggle things and I'll allocate a slot for something happening. If I suddenly get something unexpected, it throws more than just your stuff out. … I've got to do my full-time caring role first, before I can think about other things.
> **Sue, carer for husband with MND (and the grit in the oyster)**

- We are keen on having **goals to work towards**, so make it clear what we are trying to achieve in this meeting and how this fits with the broader project goals.
- Be aware that **what we will need may change**. Keep a flexibility to proceedings.
- We are all individuals: **ask the members in your group** what they might need beyond the above.

Some of the recommendations in this guide are about running high-quality involvement activities at all times. There are also specific pointers to working across different neurodegenerative conditions. Share this learning widely so that we can get more experts by experience involved in research.

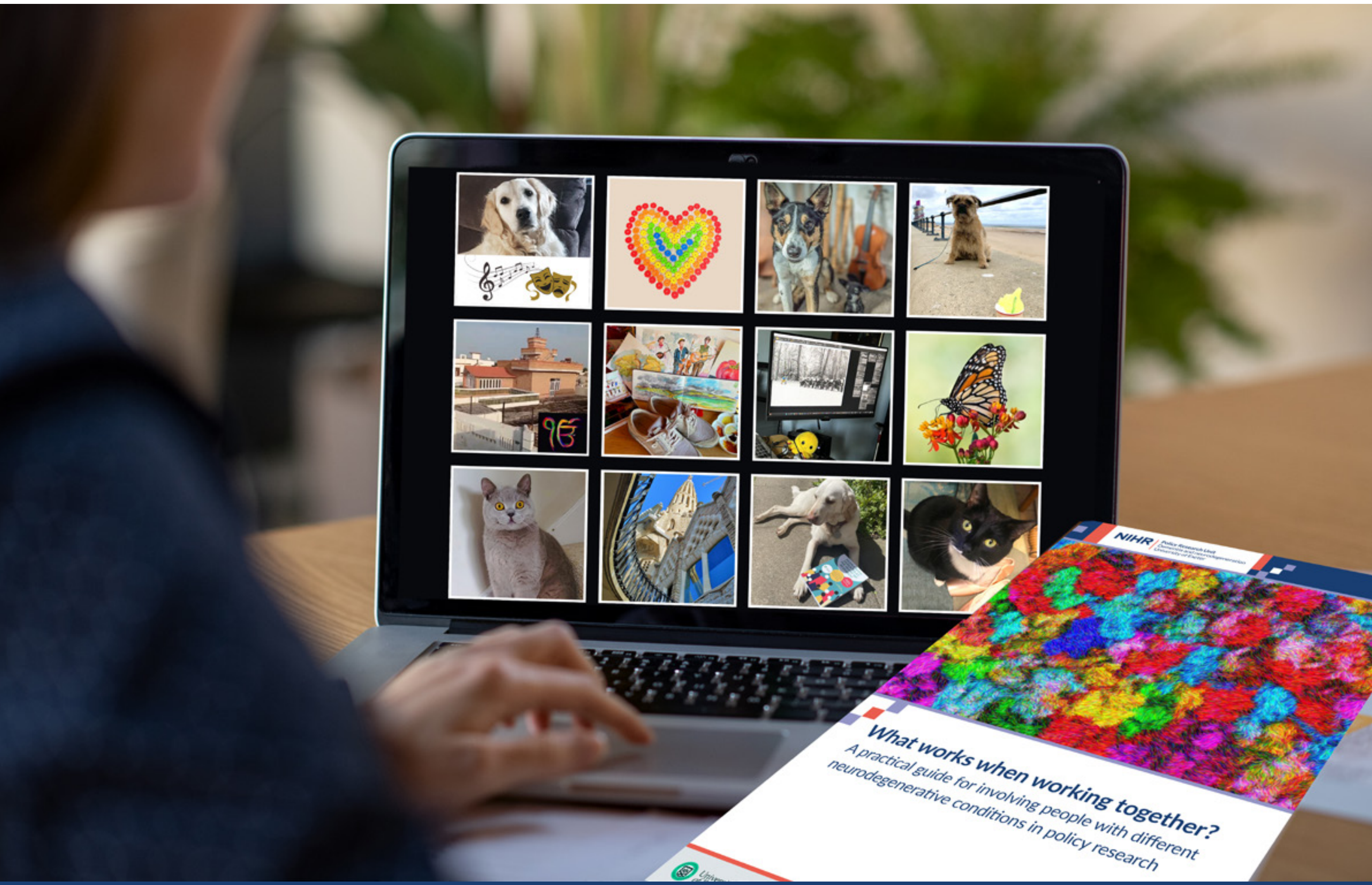
Starting well

By ‘starting well’ we mean both the beginning of a whole project and the start of individual involvement meetings.

- **Spend time getting to know each other** initially and hearing each other’s stories, so that we can learn about each other’s conditions and make those connections.

> “It’s been interesting to hear the similarities between conditions. We all present differently – it’s nice to hear, I thought it was just in Huntington’s.
> **Samantha, tested positive for Huntington’s disease**”

- **Build in time at the start of each meeting to catch up**. This is not just about relationship-building, but everyone has good and bad days with these conditions, or as a carer/supporter. Circumstances outside the meeting can affect what happens in the meeting and these need space and time, too.
- If we do not seem our usual self, then **check in with us** after the meeting.

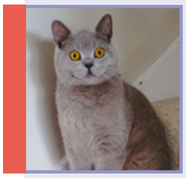


What works during meetings?

Practical pointers

Timing:

- **Don’t schedule meetings too early**. It can take a while to get going. When taking Parkinson’s medication first thing in the morning, for example, it can take some time for symptoms to settle down. For carers, the morning can be an un-interruptible time to get everything sorted for the day ahead. We agreed that 10:30 am onwards suits us better.
- **Not too long!** Concentration can be tricky, as can staying still. For instance, pain is a factor in motor neurone disease. An hour is the absolute cut-off for an online meeting with no breaks.
- **Stick to advertised timing and breaks**. We may have been banking on that stretching break or chance to get a drink. We don’t want to have to ask.



> “People with Parkinson’s disease are averse to change, especially last-minute changes.
> **Shafaq, lives with Parkinson’s disease**”

Facilitating meetings:

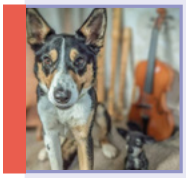
- **Keep presentations simple**: no animations; wiggly lines can be visually disturbing for people with neurodegenerative conditions. If in doubt, use more slides rather than fewer slides with more information. Use reasonably large type!
- **Have a co-facilitator or two if you can**: there is a lot to keep track of with hands up and comments in the chat, even if it’s not a big group. Accidentally missing someone’s comment or hand feels the same as being intentionally overlooked.
- **Prioritise hearing first from people who may find holding onto their point hard**. If you live with dementia, remembering what you want to say can be hard and waiting your turn to speak increases anxiety. This can be agreed within the group. For instance, you could use the **“I want to speak, please” cards** Innovations in Dementia make available. You can download a pdf here https://bit.ly/4cHBpsV

“I want to speak please”

How we interact: talking, typing and resolving differences

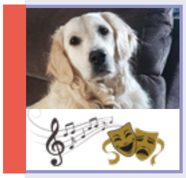
Online meetings can be very convenient and allow you to be in the comfort of your own home. However, we navigate technology differently, and our respective needs might conflict.

- Zoom allows you to talk to share or to type to share. **Let us know we can use our preferred method** (typing can be preferable if you're shy or emotional).
- However, dealing with the chat and the conversation is hard for some of us. Facilitators need to **pick out important things from the chat and share them live** with the group. Send out links from the chat in the minutes afterwards.
- Make it clear that **it is fine for us to 'bring' the realities of our lives with us to involvement meetings**, be it tremors, concentration struggles or something else. We accept each other as we are.
- Make it clear that **it is fine for us to turn off our camera** at points if we feel uncomfortable, want to stretch or just need to take a moment.



> "There can be a nervousness about appearing on screen because of some of the movement issues in Huntington's, a self-consciousness.
> **Emma, lived experience of Huntington's disease and dementia**"

- For those of us with dementia or a cognitive impairment it can be hard to concentrate when you can't see the person. However, if you can **teach us how to put a profile picture on our Zoom account**, then we would still know who to associate with the voice.*



> "It can be hard for me if someone has their camera turned off. I find it hard if it is a stray voice. But I could cope with it if it was really important for that person to be comfortable.
> **Allison, lives with Alzheimer's disease**"

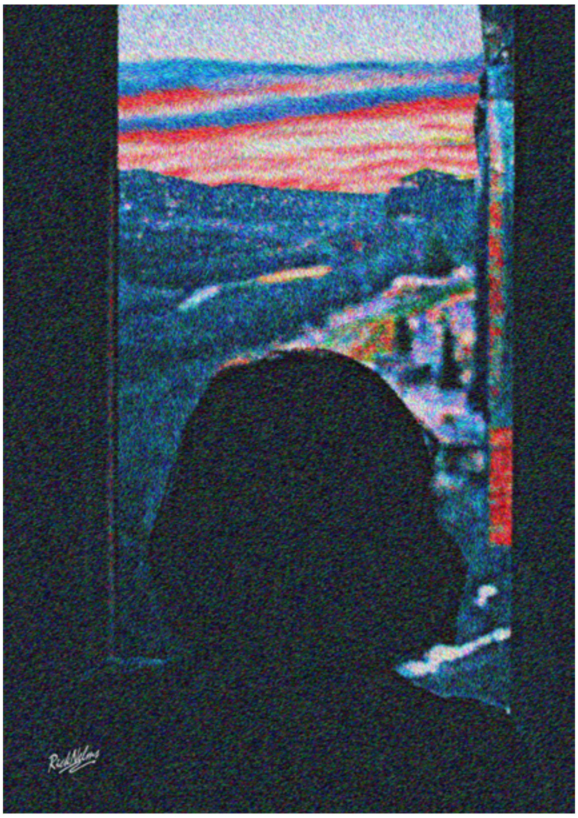
*Be aware that some organisational Zoom accounts are set up centrally and do not allow for profile pictures. Work around your situation as best you can.

Identity and anonymity

In discussing appearance on screen and some, perhaps, preferring not to, we ended up thinking about the consequences of being ‘public’ about your condition. Everyone knew people who were not open about their condition, or felt they couldn’t be.

- With Huntington’s disease especially, being open about your status of living at risk of Huntington’s disease, or with Huntington’s disease, has implications for your family because it is a genetic condition.
- **Enable people with Huntington’s disease to contribute anonymously** if they wish. Their views can then still inform the work.
- Work with us to understand how we view condition and how open we feel we can be about it. **Allow us to be involved flexibly**: a need for anonymity doesn’t mean we don’t want to contribute.
- **Decide as a group what is needed to make the involvement meetings a safe space**: what can and cannot be shared and in which ways.

> “People may have tested positive but not told everyone in the family, so there’s those issues.
> **Becky, from a family affected by Huntington’s disease**”



‘The Carer’ by Rick Nelms

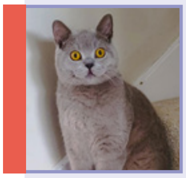
‘Long Grief’ by Rick Nelms

Discussing emotional topics

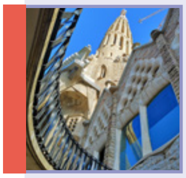
Sometimes involvement meetings ask us to delve into topics which are emotionally loaded.

> Caring and advocating for my dear Mum on all fronts, to keep her safe in her own home, nearly broke me. It's imperative that our lived experience as carers is central to research to influence policymakers. Dementia doesn't discriminate, but services can. Culturally appropriate and inclusive representative voices matter. I want to help effect a change.
> **Jagdish, former carer for her mum**

- **Make it clear that no-one needs to talk** about things we do not feel ready to share.
- **Give appropriate time** to each of our stories so that no-one feels rushed.
- **Ask open and honest questions**, but be prepared that we may choose not to answer.



> Ask anything, I will never mind genuine questions.
> **Shafaq, lives with Parkinson's disease**



> Questions are always good because they can remind us of things we hadn't necessarily thought about.
> **Sue, carer for husband with MND (and the grit in the oyster)**

Keeping in touch between meetings

While involvement meetings gather us together and allow the opportunity for vibrant discussion and shared purpose, these are the exception rather than the norm. How can you keep people involved between project meetings?

- Send out **accessible minutes** soon after the meeting to make it clear what was decided (and why) and what will happen next (and why).
- It's rare that everyone's calendars line up nicely. If some of us couldn't make a meeting, **offer a one-on-one catch-up** to gain our perspective on the topics discussed, or to ensure we understand where the project is up to.
- If you haven't heard from us, **check in** to see if we're ok. We might have missed your email and be pleased to receive the reminder, or be finding things challenging and welcome hearing from someone.
- The 'between meetings' time **can easily be overlooked** by researchers. Don't forget that you might have people eagerly awaiting news!

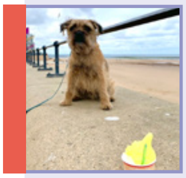
> Knowing that I can develop Huntington's is lonely, but the lack of understanding of Huntington's in particular is lonely.
> **Samantha, tested positive for Huntington's disease**

- Cognitive changes can make it hard to remember what happened when and why. **Reminders** are welcome to help piece together the journey. We need repetition.
- Some people are involved in lots of research projects. Some people are not. Either way, **we want our contribution to feel valuable and meaningful**.

Ending well

Research projects are time-limited and involvement in them ends. Life and lived experience of a neurodegenerative condition continues, often with challenges. It takes time for research findings to be finalised and published. How can researchers keep us involved in the ongoing process?

- Plot out the **project's next steps** for us. We want to know what is going to happen because of our combined efforts.
- Allow us to **feed back on outputs before they are made public**. We can help strengthen the final product and want to feel that what goes out into the world is something we recognise and feel associated with.
- The lead for the research is responsible for **keeping us in the loop** so that we don't feel used and dropped.
- **Enable us to help communicate the research findings** in our networks: can you create an accessible package of the findings with key points explained which we can take out into the world?
- **Maximise windows of opportunity** for involvement. We feel an urgency to see change happen, because the reality is that the speed at which our condition changes can be rapid (such as in motor neurone disease).
- Keep in mind that as experts by experience we have different motivations for being involved in research projects. This is not a job. **Our involvement with the condition pre-exists a project and outlasts it**.



> “It's my family story. It's important to share.
> **Jackie, cared for her brother with Huntington's disease**”

An involvement group can be a supportive space and it is hard when this ends. Facilitators need to be mindful of the need to close gently. Offer opportunities for those who want to remain connected to do so (where possible).

- Involving people with different neurodegenerative conditions in policy research **works**.
- We **encourage** you to try it – look for funding to create new involvement opportunities.
- Having voices from different conditions **strengthens** our conclusions and creates an environment **better equipped to test out ideas and offer insights**.

For our 'ending' (given that we continue to be involved in DeNPRU Exeter), we have loved the opportunity to explore connections and been inspired by each other. As more than one of us said, “I feel privileged to be part of this group.” Our message is: bring us together – we will all learn so much.

This project was funded by the Public Engagement with Research (PER) Springboard Fund at the University of Exeter. We are grateful to the University for making our work possible.

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This guide is free to use to encourage other researchers to involve people with lived experience of different conditions in research and especially policy research: do share it widely. Please do get in touch to let us know how you are using this guide: our group love to hear about the difference we are making. You can email us on denpru@exeter.ac.uk.

To find out more about DeNPRU Exeter, please visit:

https://denpruexeter.nihr.ac.uk

@DeNPRUExeter

Enormous thanks to Rick, the artist within our group, from whom we commissioned the cover artwork:

> “The painting is called ‘Heterogeneity’ to reflect the very apparent variability in the expression of neurodegenerative conditions in different people. The tufts of colour, painted using generous swirling brushstrokes, using my computer as I can no longer hold a brush, were originally tufts of cloth or fabric, perhaps originally love tokens, some of which were newer than others which had become altered by exposure to the weather over time, again expressing each individual person’s different health status. The newest ones represent those who are carers and who may or may not one day develop a neurodegenerative condition, but have yet to show any symptoms. The older, more variable and more heavily weathered tufts of cloth represent those of us living with a neurodegenerative condition, with a wide range of symptoms caused by the heterogeneity both within and between conditions as well as our personal time along our personal journey living with a condition.”

You can read more about Rick’s other artworks in our project report and on his blog https://drrickblog.wordpress.com/

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