

What works when working together?

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What works when working together? Involving people with different neurodegenerative conditions in policy research – final report

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Front Cover Image:

Original artwork by Dr Rick Nelms entitled ‘Heterogeneity’.

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Main Messages

Cross-condition involvement can not only work but lead to enhanced outcomes for researchers and public contributors alike. ‘What works when working together?’ was an experimental project exploring how people with experiences of different neurodegenerative conditions could be enabled to work together.

These are our main messages:

- There are similar and different experiences across conditions. It is best to acknowledge these differences than pretend they are not there. But humanity connects us all.
- Kindness, respect and trust helps people to be open with each other in order to work together. These values create a safe space in which to be emotionally open.
- There are many practical adjustments that can be made to support people with neurodegenerative conditions to work together. Where these adjustments may be contradictory, keep talking and share experiences to work out solutions together.
- Working on a tangible task provides a great way to explore cross condition working and gives people ownership of the process.
- Be brave, commit to co-production. And do it!

We will conclude our main messages with words from our members.

Jackie described the work as “A tapestry of people who knit together and are stronger together”.

Meanwhile Rick reflected on how profound is the level of trust that is needed to do involvement work well: “It was the courage of everybody in the group to reveal about themselves and their own situation and that courage encourages courage. The fact that other people were being brave and baring their souls helped everyone else to do that.”

Involvement work is never an ‘added extra’ – it cuts to the fundamentals of the impact of a condition and reveals important truths about how research can be improved.

Main Report

Background

“What Works When Working Together?” is a co-created guide about the best ways of working together across different neurodegenerative conditions. Involvement of experts with lived experience is at the heart of the NIHR Policy Research Unit in Dementia and Neurodegeneration, University of Exeter (known as DeNPRU Exeter). These experts are people living with, or at risk of, dementia (of any type), Parkinson’s disease (PD), motor neurone disease (MND), Huntington’s disease (HD) and other rarer neurodegenerative conditions, and their families. We wanted to work together to create a digital guide about the best ways we could approach cross-condition involvement. This could also serve as a template for future work within DeNPRU Exeter, which other Policy Research Units, organisations and researchers could draw on.

This report looks at the process of creating the ‘What works’ digital guide – how we felt about the different stages and what we had to negotiate. It incorporates our reflections about the project and, at points, we have transcribed parts of our conversations in meetings because they were so illuminating.

The project took place between March and July 2024. There were 4 online meetings, and email/phone contact between meetings. The project culminated in the publication of “What works when working together? A practical guide for involving people with different neurodegenerative conditions in policy research.”

Setting up the project

We were fortunate that due to the funding application, we had a clear timeframe, budget and aim for our project. We created a simple two-page project information sheet which was colourful and inviting to advertise our project.

Importantly, this flyer featured photos of Rachael, Cathy and Julia (Expert by Experience Co-Investigator, DeNPRU Exeter) so that people could see who they would be connecting with. The flyer answered key questions:

- What are we trying to find out?
- Why is this important?
- How are we going to do it?
- Who is involved?
- How will we share our findings?

The flyer was then distributed both within our own burgeoning DeNPRU Exeter Involvement Network and disseminated by related organisations (like Huntington's Disease Association) to ensure cross-condition representation.

Introducing the project

The “What Works” project was a useful early piece of work for some members of the involvement network of DeNPRU Exeter. Being a member of a network in its early days can be exciting and pioneering – but also feel a little rudderless. A focused project was a good way of connecting people to the broader purposes of DeNPRU Exeter whilst eliciting knowledge from people who are experts in the best ways for them to be involved. By working together, we could generate more knowledge about the best ways for people to be involved *together*.

This project began within the first few weeks of the formation of the wider DeNPRU Exeter involvement network.

We had a job to do – “come and be part of a group that is going to work out the best ways that we can all work together” – and this appealed to a subset of people from our wider involvement network.

Membership of the group

This is the working group for the “What Works” project:



Allison – lives with Alzheimer’s disease



Becky – from a family affected by Huntington’s disease



Emma – lived experience of Huntington’s disease and dementia



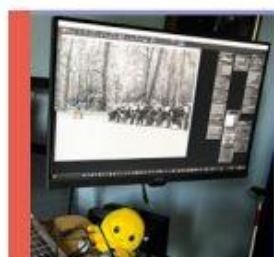
Jackie – cared for her brother with Huntington’s disease



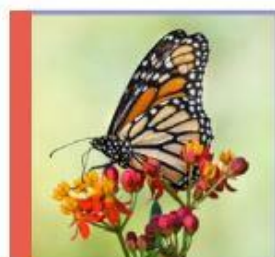
Jagdish – former carer for her mum



Julia – carer



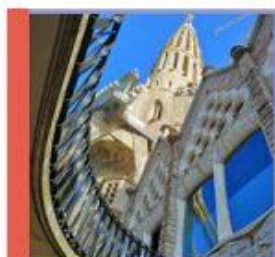
Rick – lives with motor neurone disease



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

The ten experts by experience represent four different neurodegenerative conditions: dementia, Parkinson's disease, motor neurone disease and Huntington's disease. Even though people were 'representing' one condition, we found that many had experience of other conditions, through family, friends and neighbours.

As you will read, identity is complex and people might want anonymity. Therefore, we decided not to use photos of ourselves, but of things which express our identity in some way. Everyone was also allowed to choose their exact role title, so that rather than be labelled 'carer' or 'person living with X' by facilitators, individuals could choose how they wanted to phrase it. Later in this report you will hear about the story behind Jackie's picture.

Forming a group and how that feels

Meeting for the first time

Joining a new group can provoke some anxieties, especially as it was still early days in the wider involvement network. Worries around communication, not understanding each other, wondering if you can ask questions about different conditions (or is that nosy?), will the online technology work....?

However, actually, everyone was excited!

"I was excited. It seems very interesting. With working with Cathy and Rachael – I wasn't anxious. I felt safe. I knew it would feel supportive".

Allison, lives with Alzheimer's disease

"I'm excited to be part of this group. I was also grateful for the reminder with the link!"

Rick, lives with motor neurone disease

"I was excited. I'm always excited about doing new things and research things. The only concern was how helpful I can be".

Shafaq, lives with Parkinson's disease

"It's very interesting to hear about each other's conditions. I think we could say that a 'mixed group' is a good idea, we are learning and making suggestions."

Julia, carer

Introductions are, of course, an important first step to connection. We necessarily had to explain a bit more about who we are and why we were here the first time we met. One wonderful introduction came from Shafaq who ended up starting out with “I’m a 45-year-old human!”. This made everyone laugh but was also an important reminder that our existence far outstrips our experiences with a particular health condition.

Straight away group members brought up how important it is to look at experiences and ideas across different neurodegenerative conditions. There will be similarities and important differences, but together we are stronger.

“I think there are several conditions which have some form of overlap, whether in the way they work or in the way that people cope with them, and I get really frustrated that information is not shared. I hope that we can break down some of the barriers and the boxes, and work together.”

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

As people shared their stories, we started to see patterns emerge. Diagnosing a neurodegenerative condition tends to be a long process. Lots of other possible conditions need to be excluded first before people get to a definitive diagnosis. It’s also a very individual process: some people are navigating their job at the same time; other people initially have their symptoms dismissed.

“I think Parkinson’s disease is similar. It’s a big umbrella and we start off with very different symptoms and very different responses to medications, but we get to the same condition.”

Shafaq, lives with Parkinson’s disease

The working group were motivated to see change happen because of this project. This was a new way of working for all of them – connecting with people with other neurodegenerative conditions in an involvement group.

“I’m really trying to make something good out of things that are difficult”.

Rick, lives with motor neurone disease

While many of the experiences shared were difficult, there was also a shared importance to recognising the magic moments.

“Amidst the constant challenges, desperation and layers of grief, there were also some beautiful moments caring for my mum”.

Jagdish, former carer for her mum

From a facilitator perspective, there is a need to suspend disbelief that any initial awkwardness or anxiety can be overcome.

“There’s something about the power of the group, as we all get to know each other and become a group. That can be hard in the early days.”

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

Connections across conditions

We found that we had more connections to different experiences than we might first realise. People might have got involved because of one experience, but had other connections, too. Here are some examples:

- former and current dementia caring experience; had friends with Huntington’s disease and a friend’s husband had MND
- living with Parkinson’s disease; father has vascular dementia
- living with MND; mother had Alzheimer’s disease
- living with dementia; mother-in-law had Parkinson’s disease and has a friend with MND

While we all had more to learn about the conditions we did not know personally, it was interesting to see how much more connected we were than we might first have thought.

Motor neurone disease and Huntington’s disease are considered rare, but they are not as rare as you might first think. Sue taught us that 1 in 300 people develops MND, which surprised the group. We realised that we are part of a wider community, a wider society and have a certain amount of shared knowledge. While systems and services might insist that these conditions are separate, we found some immediate overlap in our own experiences. We discovered that there are lots of misunderstandings about what people can and can’t do across all the conditions.

However, it is important to remember that there isn’t equal understanding or knowledge of these conditions within wider society, and that can be difficult.

“If it’s not in your family, you don’t need to learn about it. With Alzheimer’s, it can affect anybody in the population.”

Jackie, cared for her brother with Huntington’s disease

There’s a strength in numbers, and perhaps we can lend our shared voices to raise awareness for conditions which are lesser-known.

“It’s been interesting to hear the similarities between conditions. We all present differently – it’s nice to hear, I thought it was just Huntington’s.”

Sam, tested positive for Huntington’s disease

It’s also important to acknowledge differences between conditions rather than pretend they are not there.

“Some people with Huntington’s disease do not want to be public about their condition. Perhaps they haven’t told family or friends or work”.

Becky, from a family affected by Huntington’s disease

Pre- and post-meeting feelings

We wanted to understand more about how involvement feels, especially at the start of a project. It is a big ask to share your personal experiences and feelings. We were also aware that some of the group members had worked with Rachael and Cathy (and each other) before, while many were entirely new.

To find out more, we gave group members a little bit of ‘homework’ and asked them to write down or voice note their reflections on two questions

- How did you feel during the meeting?
- How did you feel after the meeting?



Table 1. Group members' reflections

How did you feel during the meeting?	How did you feel after the meeting?
<p>I was very nervous prior to the meeting as really wasn't sure what it would be like.</p>	<p>I felt a lot better & really think I learnt a lot. It was also reassuring to hear from people who feel the same so afterwards I felt a lot more positive & glad to be a part of it.</p>
<p>I'm a bit of a technophobe but the zoom worked well . Really interesting hearing the similarities and differences in people's experiences</p>	<p>Hopeful I've got something useful to contribute and hoping I can join in the next meeting albeit later.</p>
<p>Initially I was a bit apprehensive and nervous, especially as some of the others seem to know each other anyway and our area (MND) was slightly different from the areas they were coming from. However, I became aware that you have put together an interesting group of people who all seem really approachable and friendly so as the session went on I settled into it and began to enjoy it.</p>	<p>After the meeting I felt that I had enjoyed it and that there is potential for a lot of shared experiences to come together and help people researching and even living with the various conditions. Whilst the conditions may be different, I think that there are also a lot of similarities and it would be good to draw these similarities together for the benefit of both people living with different neurodegenerative orders and the people studying them and trying to support them. So often we seem to re-invent the wheel when the knowledge and experience is already out there. There are some really interesting people in this group and I think that it will be a really good experience working together with them and you.</p>
<p>During the meeting I felt excited, that I could be contributing to something positive. I was happy to meet different people, and excited about making a difference. Nerves didn't really feature.</p>	<p>After the meeting I still felt excited, but felt happier that I was working with a good bunch of people. I'm also excited to see where this will lead.</p>
<p>I was really looking forward to the meeting & to getting the chance to meet people I hadn't met before. Also learning the challenges faced by people with other conditions & not just dementia.</p>	<p>After the meeting I was super excited about how this project was looking. I learnt a little about other conditions & realised that stigma isn't only for people with dementia but others face the same. I really look forward to working with this group again. Like other projects the more we get to know each other the more open we will be with each other.</p>

Preparing for involvement meetings

Being part of projects like this should be enjoyable. It was the job of Rachael and Cathy to get everything as organised as it could be so that people considered their involvement to be a positive experience. This means that members can get on with contributing their lived experience expertise, feeling that they were in safe hands.

- We provided a reminder in all correspondence, and at the beginning of each meeting, about the **purpose** of the group. People wanted clear and reasonable expectations. They wanted their experiences to count, but did not want to worry about this role, or take on something they couldn't handle.

“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)

- An accessible agenda and discussion points or topics in advance are very helpful. This can both help remind people of the project and reduce anxiety about the unexpected.

“It helps to know what will be discussed at a meeting beforehand. It can help you to prepare what you want to say”.

Becky, from a family affected by Huntington's disease

- Practical reminders before meetings were important. For example, sending out a reminder of the meeting link on the morning of the meeting so it is easy to find and click on.

We discussed how, although researchers are used to sending out Microsoft Outlook calendar invitations to colleagues, these can be very unhelpful when you do not work within a large Microsoft-subscribing organisation (like a university). Many experts by experience use their personal email addresses and it can be confusing if clicking 'Accept' on an Outlook invitation causes it to disappear and not have a linked calendar to appear in. Group members preferred having all the details of the meeting (including the link) in the

body of an email and they could update their own paper and/or electronic diaries and calendars as they chose.

“Resending a meeting link on the day helps to compensate for memory problems”.

Allison, lives with Alzheimer’s disease

People needed to feel confident that their varying needs could be incorporated into this working group. Members of the working group were encouraged to describe, honestly, what worked best for them in online meetings (Cameras on? Use of the chat box facility? Microphones off? Turn taking?) with as many adjustments being made as possible, unless they contradicted each other. A major part of our learning was around these contradictions, and we explore these in more detail in the section “What works during meetings?”.

Supportive “ground rules”

From the outset, the group agreed it was important to be kind and respectful of each other. This was to be a guiding principle throughout the project as we opened up to each other about life with different neurodegenerative conditions.

“We should acknowledge differences rather than pretending they are not there. We can be here as we are. And then some of our differences might be accommodated more”.

Shafaq, lives with Parkinson’s disease

Out of this work came a set of ground rules that have been adapted and adopted by the FRIEND (For Research Involvement Experts in NeuroDegeneration) group at DeNPRU Exeter, the Policy Research Unit’s core involvement group for all our work.

The group wanted to do their best to create a safe space for openness and honesty, which they knew would come with time, respect and trust. By working together in this way, we would learn about each other’s conditions and experiences, but also set up the building blocks for the project report. The knowledge that our meetings would be supportive, scaffolded by principles of working, encouraged people to keep coming back.

Timings and how we think about time

We were instructed by members of the group to make the most of time! Time is precious, and people did not want to waste time at meetings, especially if nothing was going to change because of their involvement.

Timetables were important in this project. We knew from the beginning what our end point would be – the publication of a guide. We planned and ran four meetings in order to reach this end point. There was a timeliness to the project that people knew from the outset.

We were also guided on some practical pointers around timing:

- Don't schedule meetings too early. It can take a while to 'get going' for example Parkinson's symptoms can take a while to settle down after medication. For carers, the morning can be an un-interruptible time of getting sorted for the day ahead.

"My mum's concentration levels were better in the earlier part of the day".

Emma, lived experience of Huntington's disease and dementia

- Meetings shouldn't be too long. Concentration can be tricky, as can staying still. For instance, pain is a factor in motor neurone disease. An hour is an absolute cut-off for an online meeting with no breaks.
- Stick to advertised timings and breaks. People may be relying on the stretching break or a chance to get a drink.

Our work together was very practical in its intention. But on many occasions we moved into broader (and sometimes philosophical) discussions around life with different neurodegenerative conditions. Time for these kinds of discussions grew trust and understanding between each other.

An example of this is our discussion around time and emotions.

"I spent so much of my time chasing the fragmented services and resources, micromanaging culturally appropriate private carers (who knew nothing about dementia) that I was robbed of quality time with mum."

Jagdish, former carer for her mum

This led to an interesting discussion of how we use time and what happens if that choice is reduced, or if you feel time is short and therefore precious.

Cathy: It seems even more immoral to do anything that would reduce the time of a person whose time is already reduced by a situation out of their control.

Shafaq: I don't like to think of it like that. We're just trying to do as much as we can in every day, because no-one – whether they have a neurological condition or not – knows whether they'll be here tomorrow. The thing Parkinson's disease and my Dad's dementia has taught me is make the most of every day, every day – you shouldn't not just because you have a condition. Unfortunately, it took the condition to teach me that.

Time is indeed precious.

Taking part in involvement meetings

There are many practical things that can be done to make involvement in meetings as positive as possible. Some of these apply to all involvement meetings e.g.

- Build in time at the start of the meeting to catch up. This is not just about relationship-building, but everyone has good and bad days. Circumstances outside the meeting can affect what happens in the meeting and these need space and time as well.
- Keep presentations simple.
- Have a co-facilitator or two if you can: there is a lot of 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.
- Send out accessible minutes of the meeting as soon as possible.
- If people do not seem their usual selves, then check in with them after the meeting.

But we were particularly interested in finding out if there were particular adjustments that would help people with different neurodegenerative conditions to participate in meetings and projects. And, most importantly, whether any of these adjustments contradicted each other across conditions.

Interacting across conditions

Our starting point in creating recommendations across conditions was togetherness and kindness towards each other to find the best solutions for us to all work together. It was important to group members that it was acknowledged that it is absolutely fine for people to 'bring' their realities of life with them to meetings e.g. tremors, concentration problems. There was a strong message that everyone is accepted for who they are.

However, we did want to pinpoint the things that would help people to be involved in this project, building on more general practical pointers above. Some of these we could all get on board with and did not need any debate, for example:

- Prioritise hearing first from people who may find holding onto their point hard. For example, people with dementia may find remembering what they want to say can be hard and waiting for their turn to speak increases anxiety. Tools can be used to take turns such as raising a yellow hand on Zoom, or using **yellow "I want to speak please" cards available from Innovations in Dementia.**

One of the things we did need to debate was around the use of the chat box in Zoom. Some people were comfortable speaking in a meeting. Other people found it easier, or preferable, to write comments and viewpoints in the chat box facility. Perhaps people feel shy, emotional or awkward in the moment and prefer to write.

"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

However, dealing with the chat box conversation can be hard for other people, who take their cues from people speaking out loud 'in the moment'.

By discussing this issue, we were able to compromise. It was agreed that facilitators would pick out important things from the chat box and share them live with the group. We would also make sure that any comments in the chat box were always captured in the minutes of the meeting.

Identity and anonymity

We spent a lot of time discussing “cameras on or off” on Zoom. This started as a practical discussion. We accepted that at some points people might want to turn off their camera during a meeting. Perhaps people feel uncomfortable, want to stretch or just need to take a moment. We agreed that was absolutely fine.

“It can be hard for me if someone has their camera off. I find it hard if it is a stray voice. But I could cope if it was really important for that person to be comfortable.”

Allison, lives with Alzheimer’s disease

But in discussing appearing on screen (and perhaps some people not wanting to) we ended up thinking a lot about being ‘public’ or not about life with a particular condition. Everyone knew people who were not open about their condition or felt they couldn’t be.

The experience of people and families with Huntington’s disease, in particular, brought this issue into stark focus.

“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

We acknowledged that with Huntington’s disease especially, being open about your status of living at risk of or with Huntington’s disease has implications for your family because it is a genetic condition. As a group, we needed to enable people with Huntington’s disease to contribute anonymously if they wish. Although we can create safe spaces within meetings (and ensure identities remain private outside of meetings) this might actually translate into some people not wishing to be seen on the screen. A proper “cameras off” scenario.

Acknowledging that stray voices on Zoom meetings can cause confusion for some people, we needed a solution. We came up with the idea that people could have an image or an icon that represented them – even a photo. And so, if they didn’t want their camera on that day we would still know who to associate with the voice.

You will have seen how to represent yourself with an image when we introduced the working group earlier in this report. You probably noticed an array of pets as image representatives!

To bring this to life, this is how Jackie chose her image:

“Spike is my dog and came to all the meetings. Rather than a big funeral, I did #icecreamformark and there are still people who use that hashtag to this day when they photograph themselves having an ice-cream. The helter skelter in the background also lit up in Huntington's Disease Association colours to raise awareness”.

Jackie, cared for brother with Huntington's disease

Discussing emotional topics

Sometimes involvement meetings ask us to delve into topics that are emotionally loaded. Members of the group were clear that we shouldn't shy away from these emotional areas. That's why it is so important to quickly create a safe space full of trust.

“I want to be involved in highlighting and addressing the lack of inclusivity within the dementia pathway for South Asian and marginalised communities as an 'expert with experience'. Our communities also need educating. Creating something positive out of my negative experience will also prove cathartic and healing”.

Jagdish, former carer for her mum

Part of being prepared for emotions is accepting that sometimes we might need to ask 'nosy' questions to gain an understanding of each other's conditions.

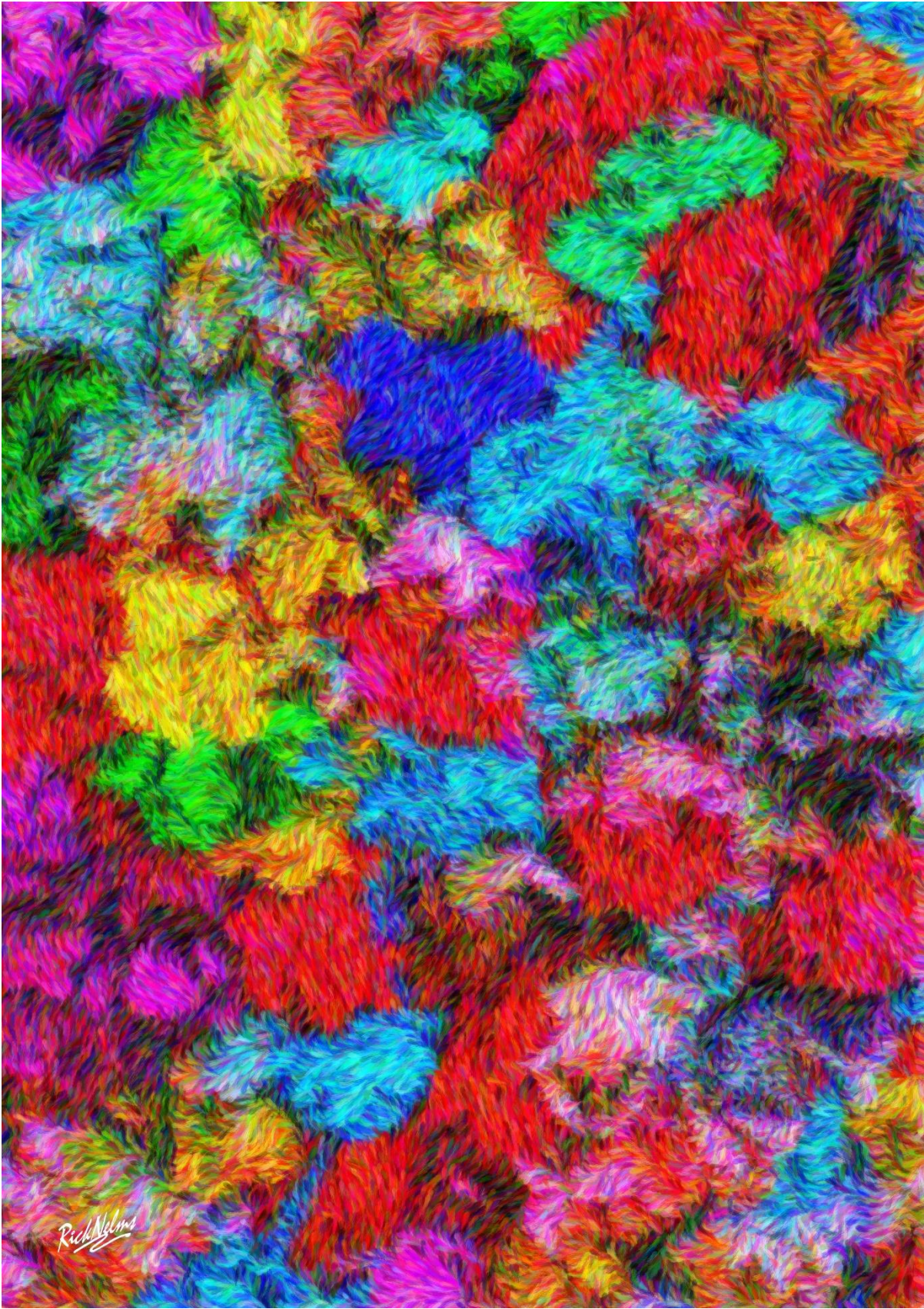
“Ask anything. I will never mind genuine questions”.

Shafaq, lives with Parkinson's disease

More than words

Our goal as a group was to create a digital resource about the best ways to involve people with different neurodegenerative conditions in policy research. We shared lots of words to create this resource. We also shared lots of feelings which we hope have been conveyed throughout this report.

We were also reminded that a “picture speaks a thousand words” by our resident artist Rick, who lives with MND. Rick creates computer-based artwork using a giant mouse he calls 'the rat', an illuminated high contrast keyboard and “one inaccurate finger!” We have described already how and why our identities were represented by a range of pictures and photos. Pictures bring reports to life; Rick’s artwork called “Heterogeneity” was the perfect accompaniment to our words:



As Rick explained:

“It’s 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 brush strokes, 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 and altered where they had been exposed 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. And the older, more variable, 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 the condition. I think it is probably, originally, a chain link fence. People tied tufts of cloth to it. It, effectively, has become what looks almost abstract in the painting. Hopefully it represents what I set out to represent.”

The groups reactions were quite emotional. Some tears were shed!

“Wonderful!”

“Inspiring”

“Just beautiful, so vibrant, very talented, I’m very emotional”

“I love it”

“It fits the description perfectly”

“Creative and technical”

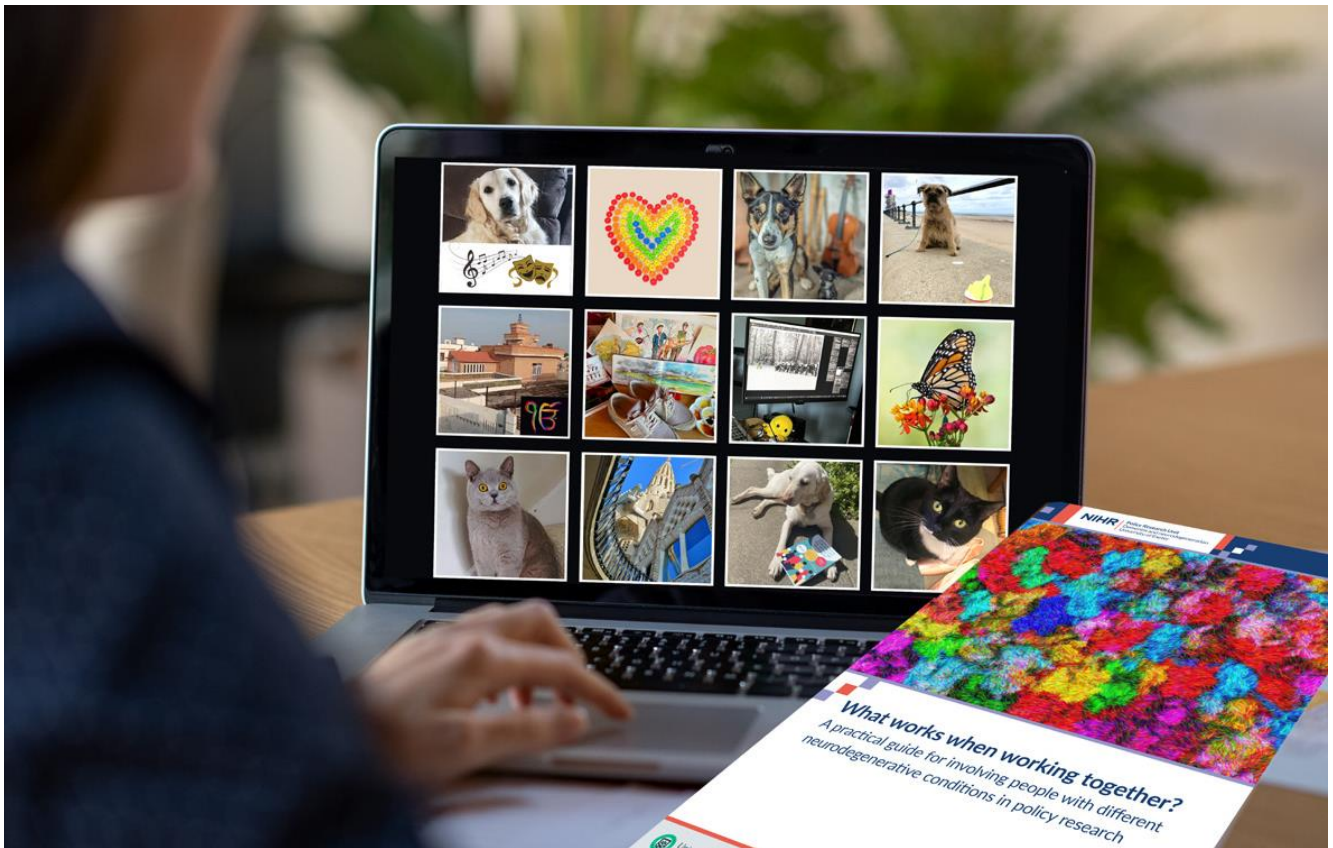
“Mesmerising”

The inclusion of Rick’s artwork gave the group a real sense of ownership of the whole guide:

“It describes us!”

The group were also involved in the design of the guide as a whole. Once we had a draft, it was circulated to the group for feedback and amends were sent to the designer. This resulted in more of Rick’s artwork being featured to avoid the need for generic or stock imagery, which the group felt detracted from the personalised feel of the guide. They also asked the designer to make the mock-up Zoom meeting ‘look like them’ by using their

chosen pictures (see below). This reinforced the importance of co-producing the design of an output so that groups members feel connected to it.



A word on 'carers'

Our working group included people living with, at risk of, and carers of people with different conditions. This mix is reflected in the broader involvement network of DeNPRU Exeter. We wanted to think about whether there are any implications around this mix. Sometimes the perspectives of carers and people living with conditions can be at odds to each other.

We agreed it was important that this mix is maintained, with different people bringing different perspectives due to all lived experiences. However, the space for all views needs to be actively maintained, one set of views should not drown out the other.

"It is much richer if the person with the condition can be involved – not just the carer".

Allison, lives with Alzheimer's disease

Making sure there are multiple people involved (e.g. not just one solitary carer) shares the load and means that experiences and views can be shared and reinforced.

“In another involvement group there were equal numbers of people with dementia and carers. It worked really well and was very rich. One person does not create a feeling of solidarity.”

Julia, carer

For some conditions, e.g. Huntington’s disease, it might actually be very difficult to involve people who are living with symptomatic Huntington’s disease.

“It might be difficult to find people who have symptoms of Huntington’s disease to get involved. Often there are implications for people in being public (e.g. work, insurance, family, genetic implications) which means that people can be reluctant to come forward.”

Emma, lived experience of Huntington’s disease and dementia

Carers are an important part of describing lived experiences. Involvement work should consider thoughtfully how to support a mix of people to be involved.

Endings

Ending involvement activities well is essential.

People’s neurodegenerative conditions pre-exist involvement activities, and they outlast them. People bring so much of themselves to their involvement work and should be supported well as it comes to an end.

“There is this wealth of lived experience. I don’t think it is used enough. It is important to share my family’s story and to raise awareness of Huntington’s. We can’t walk away.”

Jackie, cared for brother with Huntington’s disease

Involvement activities are usually time limited, even if the ending is some way off. People want their contribution to feel valuable and meaningful, the whole way through.

“It can be very frustrating to be very engaged and involved, and then the delay. You feel left out. Your input may have been important at earlier parts of the project, but when it comes to the writing or dissemination stage you drop off the list. We have the right to be there right at the end.”

Julia, carer

People talk about “windows of opportunity” to be involved. There is often an urgency that comes with living with a neurodegenerative condition – an urgency to finish a piece of work, create reports, recommendations and guidance, and to see change happen. The reality of the speed at which people’s conditions change can be very rapid (such as in motor neurone disease).

It is therefore important that people know what is going to happen because of their combined efforts. People want to make sure they can feedback on outputs before they are made public. They want to strengthen the final project and feel that what goes out into the world is something they recognise and feel associated with.

We hope that involvement is a positive experience for everyone. This can then be especially hard when projects end. People that you have worked with and formed trusting relationships with may no longer be such a part of people’s lives.

“Living with Huntington’s disease is a lonely experience.”

Sam, tested positive for Huntington’s disease

Be gentle in taking people to the end of a project. It may be appropriate to support people in the group to stay connected to each other outside of this work. Or perhaps there are other opportunities and activities that people could be invited to. Often getting involved in one thing gives people confidence and experience to get involved in more.

One final question

In our final meeting together, we asked the group ‘Why should other researchers bring people with experiences of different conditions together?’ so that their words might inspire future work. This is what they said:

“We are dealing with things in the brain. Whilst each condition might present with different symptoms, for most people the end destination will be the same. There are also some similarities between conditions – it seems stupid to sit in your own box doing your own thing, when actually you could help people in lots of different boxes.”

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

“I’m so grateful to be a part of DeNPRU – ‘Amazing group and amazing people’. I’m hoping to share my experiences and raise awareness of the inequalities and inequities afforded to South Asian and marginalised communities. Inclusivity matters.

Jagdish, former carer for her mum

“To learn about similarities and differences between conditions, and needs. Make new connections and learn. Ban the boxes!”

Juila, carer

“Help to shape research priorities. Priorities for people with lived experience are not necessarily the same as researcher priorities.”

Emma, lived experience of Huntington’s disease and dementia

“A lot of neurological conditions are difficult to diagnose, resulting in a delay of diagnosis and horrible experiences.”

Rick, lives with motor neurone disease

“There is a massive disconnect between health and social care, which needs sorting out.”

Jackie, cared for her brother with Huntington’s disease

Project follow-up

To launch our guide, we held a public webinar where group members could share their views. Not everyone wanted to speak, or to have their camera on, but many people did. Launching our resource together was an important way to have ownership of our shared creation. Below you can read some of our responses to the key questions. To borrow an excellent phrase from Rick, it was a statement of “here we are and we are going places together”.



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

It's really important to have the conversation so we can share our experiences and things which may or may not work for different conditions. It would be great to open people's eyes to some of the things that can be done and some that can't be done.

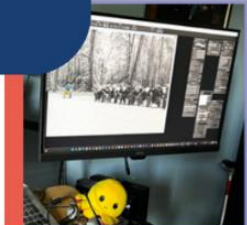
It validates you to some degree, that you've got something valid to contribute to a debate. You become isolated with the disease and isolated as a carer.



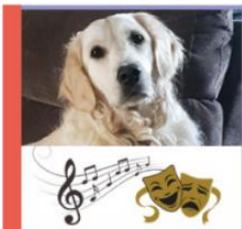
Jackie – cared for her brother with Huntington's disease

Why did you get involved in the project?

There are two genetic forms of MND which fundamentally work the same way as HD and in both of the MNDs we have medications that are actually slowing or stopping the progress of the conditions. It became very important to me that we had the opportunity to work together.



Rick – lives with motor neurone disease



Allison – lives with Alzheimer's disease

To stimulate a debate within research that not everybody is the same. It's so exciting to get to know a bit more about other conditions. You think you might know but really you haven't got a clue and you're making assumptions and that's something which frustrates me greatly when it comes to dementia that people assume they know what I need. So it's been a real eye-opener and fantastic to be involved in. I really look forward to seeing where we can go with it.

What have you learned from the project?



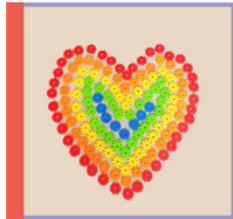
Julia – carer

When I started doing dementia involvement 18 years ago I wanted to know and I wanted other people to know and I wanted something to be done about it. Now I've learned there are so many other things that I feel exactly the same about.

I think a lot of people with HD feel a little bit more isolated because it is genetic so it's not something that everybody can get. Doing this group for me has made me feel a bit more included and also knowing how similar some of the illnesses are - I was not aware of that at all.



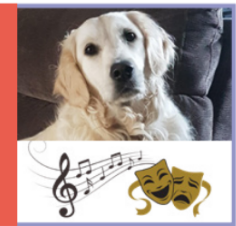
Samantha – tested positive for Huntington's disease



Becky – from a family affected by Huntington's disease

It makes it feel safe hopefully and that people will be confident to take part. Everyone's experience is different, but even so the common threads it bonds you - you feel a strong connection with one another. I think that's the amazing thing about groups like this.

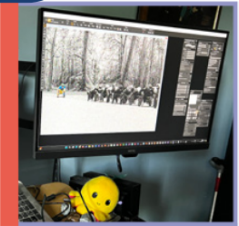
The importance of producing a safe space and everyone being equal.



Allison – lives with Alzheimer's disease

What is the most important message in our guide?

Researchers need to know that to keep people from different conditions involved you have to provide the scaffolding, the reinforcement of what's going on. Don't be shy about reminding us.



Rick – lives with motor neurone disease



Julia – carer

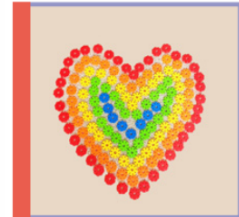
Trust can develop and humour can develop and friendship can develop. I can't believe we've only had four meetings! It feels like I've known you all for ages and I don't want to lose you. Researchers wanting or needing to involve people need to join in with that because it's the people who lead it that create that. We're all people - if you feel like a person not just a person living with something, or a person caring a researcher - that's an important step.



Allison – lives with Alzheimer's disease

It might give others more confidence to come forwards and think 'I have something to contribute here I'm not just a carer' or 'I'm not just somebody with this condition. I have a worth. I have a lot of experience if you are willing to listen to you will learn from.'
To get more people involved and to give people back their worth.

I hope it helps researchers understand a bit more about the different conditions and that it encourages other people to take part and to feel safe and confident to do so.



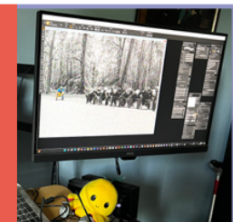
Becky – from a family affected by Huntington's disease

What do you hope might happen as a result of this guide?

What I hope will happen is that there will be bravery and courage in the people starting research to realise that it can work really well to everyone's advantage. Be brave: it has worked, it does work and it's interesting to learn by listening and by including.



Julia – carer



Rick – lives with motor neurone disease

This is a critical turning point. There's so much understanding developing across all these conditions about the cellular mechanisms involved. This is giving researchers new opportunities. I'm hoping that one of the outcomes of this guide is that it will encourage more research and it will encourage more research into the diversity of neurodegenerative conditions. Not only will it get more people involved, but it will get more researchers involved.

Policy and Practice Suggestions

With suggestions peppered throughout this report, we have distilled these down to a handful directed towards those who can take this work forward:

- Be brave in approaching co-production and involvement work
- Try bringing people from different conditions together – you do not know how much the research and those involved can benefit from this sharing of experience.
- Commit to doing co-production and involvement work inclusively and comprehensively throughout your project

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'What Works When Working Together? A practical guide for involving people with different neurodegenerative conditions in policy research' can be freely downloaded from our website denpruexeter.nihr.ac.uk. We encourage you to use and share it as widely as possible.

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