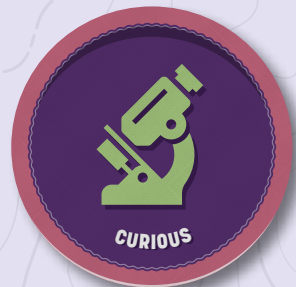
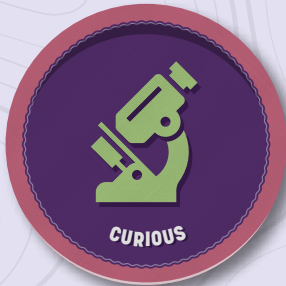




THE PEER RESEARCHER'S BACKPACK



CREATED BY THE "BACK PACKERS"...

RUTH CHALKLEY

JENNY JOYCE

GORDON WILLIAMS

JO WILSON

with...

Stephanie Kilinc, Teesside University

Jo Cole, Neuro Key

Eve Fitzgerald, Teesside University

We are a team of people who live with long-term conditions. We have worked as peer researchers on projects related to the self-management of long-term conditions.

Being peer researchers has increased our confidence, helped us to accept that we are valued members of society, validated how we feel about our own lived experience and enabled us to feel part of a community.

We believe this peer researcher handbook is important to support future peer researchers to be full partners in research projects, to have an equal relationship with the researchers and to promote the value of lived experience.



RUTH CHALKLEY

Hello! I'm Ruth and I'm a patient with two rare neurological conditions: gluten ataxia, so I have gluten sensitivity / coeliac disease; and an autoimmune related condition with an umbrella term of cortical hyperexcitability, which means that I have symptoms of Stiff Person Syndrome.

***"Being a peer researcher is enriching.
Its about living your best life"***



JENNY JOYCE

Hi, I am Jenny, I first became disabled 18 years ago and took a long time to come to terms with being disabled and using a wheelchair. Since then I have developed numerous long-term conditions alongside my disability and struggle continually with pain. I use my lived experience in my job at a Disability User Led Organisation.

***"As a peer researcher you feel valued
and you add value"***



GORDON WILLIAMS

Hi, I'm a lived experience ambassador. I raise awareness of living with hidden disabilities and am involved in many courses at Teesside University. I am a trustee for Neuro Key and I live with multiple neurological and mental health conditions. I use my experience to support others navigating life with similar challenges to my own.

"Not only does being a peer researcher give you purpose, it gives you friends"



JO WILSON

Hello, I am Jo. I live with a long-term condition. I am a Teesside University graduate from the psychology degree and I have worked as a lecturer at a local college.

"Being a peer researcher can give you the confidence to express your creativity"



"What we're trying to do is get away from the norm, get away from tick boxes"



"The backpackers - what we've brought and what we carry in our bags, and what's visible and what isn't visible, what's external and what's internal"

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Jargon Buster



A peer researcher partnership can start from the development of a research idea.

Part one of this handbook (Mapping our journey) supports and encourages you to learn about the project and consider your role in the project (what can you offer the project and what can you achieve from being a peer researcher).

Part two (What will be in our backpack?) considers what you need to be inclusive partners.

Part three (Travel updates) recognises the power of including you in communicating the research findings. This includes thinking about next steps and in that way and whether you can be involved in these plans.

In this way, the peer research process is a cycle of full involvement.

ABOUT THIS HANDBOOK

"What you get out of it is that you've overcome some boundaries, some barriers"

There are very few resources written for peer researchers, they are mostly written for the researchers/academics. By nurturing you as a team, research teams can support you to enhance your skills, build your confidence and give you a platform to make a contribution.

This handbook has been designed by peer researchers to enable people with lived experience to be inclusive partners in the research process. It is about the psychology of the research process – breaking down the research process and how your contributions matters.

Working as a peer researcher is a journey. We grow into the peer researcher role and we also grow as people. You wouldn't go on a journey without packing what you need for every eventuality, so in this handbook we have thought about the different things you might need.

This handbook is not prescriptive. You can be involved as little or as much as you feel comfortable and you should have opportunities to be involved in ways that are meaningful to you, play to your strengths and that help you to develop new skills. This is your journey, based on your experiences, your skills and your aspirations.

"Don't feel like you're just helping someone else's project – this is your work too"

YOUR JOURNEY LOG



You might know which destination you want to reach but you haven't travelled that road before so your journey could change direction. When you arrive at your destination it might be different to what you expected.

We have developed a Journey Log to accompany this handbook as a space where you can reflect on your journey. It is your own personal resource to create over the course of the research project but you can use the activities in the journey log to inform your participation in the project.

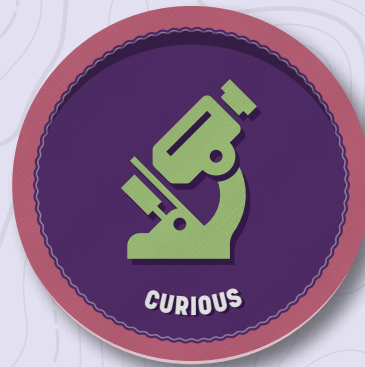
AIMS OF THIS HANDBOOK



- To establish collective values
- To encourage open conversations
- To develop your skills, assets and confidence
- To establish the team as equal partners
- To ensure inclusivity throughout the research process
- To grow as an ambassador for lived experience

"You will learn skills from other people around you"

PART ONE
**MAPPING OUR
JOURNEY**



SESSION ONE

LEARNING ABOUT THE JOURNEY

This session gives you the opportunity to meet the team and to start thinking about your position within the team. You will get to know the other peer researchers and learn more about the project.

AIMS OF THIS SESSION



- To learn and ask questions about the project
- To understand your role in the project
- To get to know the team
- To think about what you can bring to the project and what being a peer researcher can mean to you

Activity one: Getting to know each other

To help you get to know each other, let's start with a game of "Would you rather?". In small groups, you will each answer the questions below and talk through the reason for your answer.

- ? Would you rather travel on a budget for a year or travel in luxury for a month?
- ? Would you rather be able to speak and understand the language in every place you visit or know your way around every place you visit?
- ? Would you rather go on an epic trip where lots of things go wrong or a boring trip where nothing goes wrong?



Activity two: What is peer research?

This activity will explore what peer research is and how it is embedded in the research project. You will each get three post-it notes where you can write down your thoughts about what peer research is. Use the questions in the boxes below and there is also space in your journey log to note down your thoughts so you can look back on them as you move through the project.

What do you think peer research is?

What do you expect to achieve from being a peer researcher?

What do you think will be expected from you?

Next, we will put all the post-it notes on the wall and discuss the responses as a team.

Finally, the researchers will outline the aims of the project and what you will be involved in as a peer researcher. As they do this, it is useful to think about and note in your journey log, the following things:

- ? What interests you about the project?
- ? What can you offer the project in terms of skills and ideas?
- ? What can you achieve from being a member of the team?

Activity three: Principles of peer research

Peer research should recognise that everyone in the team is equal and has something to offer to the project; enable you to develop skills and confidence; give you a voice and value your lived experience; and make sure you feel comfortable and safe. Being peer researchers, has helped us to build confidence and new skills, understand we have value and become part of a community. However, things can get in the way of this, such as issues with accessibility and using jargon.

For this final activity, think about what could help you in your journey as a peer researcher and what that could get in the way. What adjustments could be made to help overcome any issues? You can write these in your journey log and discuss them with the team.



What will help you participate?



What will get in the way of you participating?



BEFORE YOU LEAVE..

We have a message book at the end of each session where you can write your thoughts about the session. You might want to send a message of "good luck", write a suggestion for future sessions, write a note about how you've benefitted from the session, or ask a question.



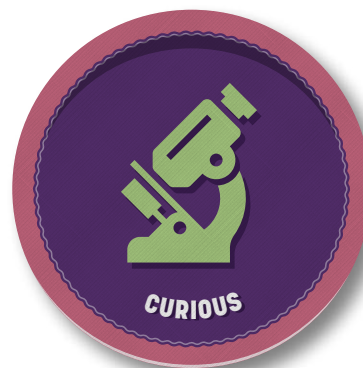
OUR PLEDGE

By the end of this session, we think it is important that everyone in the team (including the researchers) sign up to your own team pledge.

By signing the pledge you are all agreeing to follow the collective values of the team, encourage open conversations and uphold that you are all equal and have something to contribute to the project.

SESSION TWO

ME THE PEER RESEARCHER



Before going any further in your journey as a peer researcher, it is important to take some time to think about who you are, what are your strengths, your values and what do you want to achieve from being a peer researcher

AIMS OF THIS SESSION



- To consider what you can bring to the project
- To think about what you want to achieve from being a peer researcher
- To begin reflecting on your time as a peer researcher

Activity one: What do I bring to the table?

We all have something to offer as peer researchers. Start thinking about the skills, knowledge, qualities and experiences you can bring to this project. You can keep a note of these in your journey log.

- ? What skills do I bring to the table? (e.g. team player, organised, etc)
- ? What knowledge do I bring to the table?
- ? What experiences do I bring to the table?
- ? What qualities do I bring to the table? (e.g. honesty, trust, etc.)

Activity two: What can I get out of being a peer researcher?

Now think about the skills, knowledge, qualities and experiences you would like to share or gain from being a peer researcher on this project. Note these down in your journey log and discuss them with the team.

- ? What skills do I want to develop? (e.g. team player, organised, etc)
- ? What knowledge do I want to gain?



"For me, I'm no longer just someone out of work disabled, I'm actually a peer research assistant for a while"

Activity three: My Journey Log

When you are doing research where you have personal experience of the topic being investigated, it is easy for your own experiences and attitudes to affect your actions and thoughts during the research process. We need to be mindful of this as much as possible.

One way to do this is to reflect on your thoughts and experiences, attitudes and biases that you might bring to the research project.

We all have “baggage” that we bring into a research project but by recognising and thinking about these things, you can become more aware of when and how they could affect your thoughts and actions.

Throughout your journey it is useful to keep notes in your journey log. This will be your own private record of your journey – no one else will see it. You can think about your experiences as a peer researcher and anything that might affect your actions and thoughts as you work through the project.

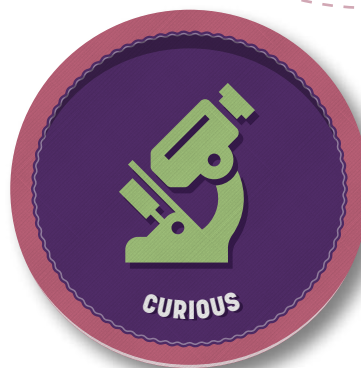
First, let’s think about what reflection actually is:

- ❓ What does “reflection” mean to you?
- ❓ What could get in the way of reflection?
- ❓ What could help you to reflect?



BEFORE YOU LEAVE..

We have a message book at the end of each session where you can write your thoughts about the session. You might want to send a message of “good luck”, write a suggestion for future sessions, write a note about how you’ve benefitted from the session, or ask a question.



QUESTIONS TO HELP YOU REFLECT

WHAT?	What was the event? What happened exactly?
SO WHAT?	How did you feel about the event? Why did you choose to reflect on the event? Why is it important to the research project? How could your experience of the event affect the research project?
WHAT NEXT?	What do you need to think about during the project as a result of this event? Do you need to do anything in particular because of this event? Would you do anything differently if this event happened again?

“Even something negative should be looked at in a positive way..
“How can I do that better?”, not,
“Why did I do that wrong?”

SESSION THREE

US THE PEER RESEARCHERS



In the last session you thought about what you can offer this project and what you hope to get out of being a peer researcher. Now we will think about how these skills, qualities, experiences and knowledge complement each other and what we can offer this research project as a team.

AIMS OF THIS SESSION



- To establish what we can offer the project as a team
- To support each other and respect what each person brings to the team
- To think about your values as a peer researcher - what you will and will not accept during the research process

Activity one: What we bring to the table

Look back at last session and as a team think about and discuss what you all offer the project in terms of skills, knowledge, qualities and experiences. You might realise that you have more to offer than you first thought – make a note of this in your journey log.

- ? What skills do we bring to the table?
- ? What knowledge do we bring to the table?
- ? What experiences do we bring to the table?
- ? What qualities do we bring to the table?

Activity two: With us, without us

Now that you have thought about what you, as a team of peer researchers, can bring to this research project, let's think about what this project would look like with peer researchers and what it would look like without peer researchers.

Doing this will help you build your confidence as a team and establish your value to the project.

With us...



Without us...



"What you get out of it is that you've overcome some boundaries, some barriers"

Activity three: Planning our journey

As a team, think about and discuss the research project and the different parts of the project that you could be involved in as peer researcher. In your journey log note down how you feel you could contribute to each part of the project and how your involvement will make the project even better. Think about any questions you might like to ask the researcher(s) at this point in your journey.



BEFORE YOU LEAVE..



We have a message book at the end of each session where you can write your thoughts about the session. You might want to send a message of "good luck", write a suggestion for future sessions, write a note about how you've benefitted from the session, or ask a question.

MY GROUND RULES

- ? What are your ground rules for this project?
- ? What are the things you will not accept as a member of the team?
- ? How would you like the team to work together?

Start writing your ground rules in your journey log and we will come back to this in session four.

PART TWO

WHAT WILL BE IN OUR BACKPACK?



SESSION FOUR

FEELING SAFE AND COMFORTABLE



Throughout the research project you should feel safe and comfortable to express your ideas and experiences. However, sometimes things happen that can be challenging, so this session will explore potential challenges and things that could help you through.

AIMS OF THIS SESSION



- To explore potential challenges you might face and ways to potential ways overcome them
- To establish a code of conduct that the team will follow
- To find out more about ethical principles

Activity one: Dealing with differences

We all have different experiences and views, so it is likely that there will be disagreements in the team at some point in the research journey. It is important to think about ways you could manage differences in opinions.

- ? How have you resolved differences in opinions in other situations?

In session three (page 12) you had space to think about your ground rules for the project and the values you hope the team will follow. As a team, use your ground rules as a starting point to create a code of conduct for the team.

Activity two: What challenges could I face?

The research team will do everything they can to avoid you experiencing harm or risk during the project but that does not mean you won't face some challenges on your journey.

In your journey log, there is space to think about what you might find challenging as a peer researcher on this project. Some examples are provided but it is helpful if you take some time to think about what you might find challenging. As a team, let's think about one potential challenge:

Imagine you begin struggling to commit time to the project – you have other commitments at work or in your personal life but you don't want to leave the research project. What can you do?

- ? What are the potential consequences - what could happen?
- ? Where and when might this happen?
- ? If it happens once, could it happen again?
- ? What could you do to reduce and manage the risk?

"Don't feel like you're just helping someone else's project – this is your work too"

Activity three: how can we support each other?

Having thought about potential challenges that you might face on this journey, now we will think about how the team can help you overcome some of these challenges. As a team, discuss each of the scenarios below and think about ways the team could offer support.



SCENARIO ONE

During one of the training sessions, Ali talks about some difficult things they have experienced in their life. Their experiences are relevant to the project and the team are grateful that Ali felt they could share their experiences with them. However, Ali starts to worry that they have been too open and feels embarrassed. They are also worried that what they said will not stay within the team. How can the team help Ali to feel comfortable and safe talking about their experiences?

SCENARIO TWO

Sam has a prior commitment and cannot make the next session. They are worried that they will miss something important and not be able to catch up. They think they will have to leave the team. What could you do as a team to help Sam catch up and not feel left out in the next session?

SCENARIO THREE

For the last three sessions, Alex has not taken part in any team discussions. They talk to individuals in the team but not in front of the whole team. There are some people with big personalities in the team and Alex has told one team member that they struggle to voice their ideas over those of others. What can the team do to give Alex the opportunity and confidence to voice their ideas and be part of discussions?

ADVOCATING FOR YOURSELF



You may be working with people and participants who have similar lived experiences to you. This can bring up difficult memories and can sometimes be challenging to process. Support will be offered by the researchers and your team but there may be times when you need more support. At these times it is important that you can advocate for yourself.

If you feel uncomfortable about anything or you come across challenges that you don't want to discuss in the team, write them in your journey log but don't be afraid to discuss them with one of the researchers. Or you could write something anonymously in the message book if you prefer.

You should be offered regular support where you can discuss your experiences as a peer researcher and anything you may find be finding difficult or challenging. Don't be afraid to ask for additional, perhaps one-to-one support as you go through the project.

PART THREE

TRAVEL UPDATES



SESSION FIVE

BEING AN AMBASSADOR



Towards the end of the research journey the team will want to tell other researchers and stakeholders about their results. This is an important part of the journey that can lead to change within practice and organisations and even across the country and worldwide.

As a peer researcher, you can be an ambassador for change and can be involved in how the findings are communicated to others. It is also an opportunity for you to think about what you have achieved from being a peer researcher.

AIMS OF THIS SESSION



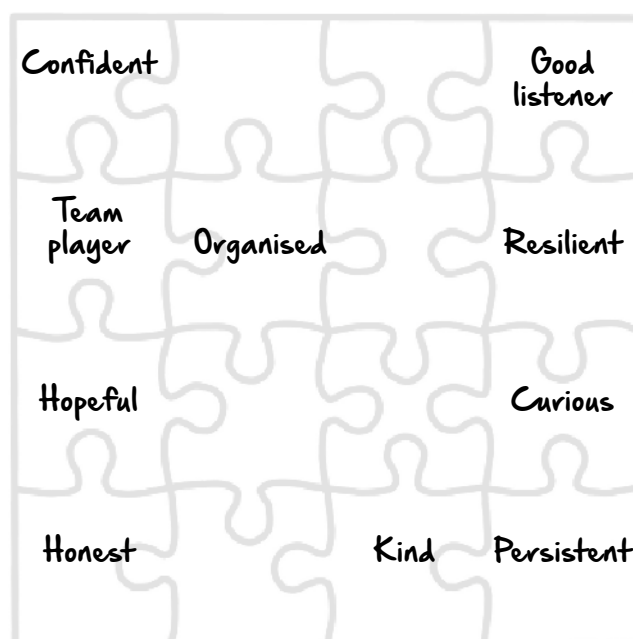
- To think about what being a peer researcher has meant to you
- To identify skills, knowledge and experiences that you have developed in your role as a peer researcher
- To develop as an ambassador for change and promote the value of lived experience

"You will learn skills from other people around you"

Activity one Reaching my destination

At the start of your journey you thought about the skills, knowledge, qualities and experiences you would like to gain from being a peer researcher on this project. Let's look back at these now and think about the skills, knowledge, qualities and experiences you have developed as a peer researcher and how they can help you grow as an ambassador for change.

- ? What skills have I developed? (e.g. team player, organised, etc)
- ? What knowledge have I gained?
- ? How can these skills help me grow as an ambassador for change?



Activity two: Spreading the word

No matter how we communicate our findings, we should think about our aims, audience and key messages. As a team, let's think about what these are:

Identifying our aims	<p>What are we aiming to achieve by communicating our findings to others?</p> <p>Do we want to influence practice or how an organisation works?</p> <p>Do we want to promote research in this area?</p>
Identifying our audience	<p>Who do we want to communicate our findings to?</p> <p>- we can think about job roles or organisations (e.g. occupational therapist; charity sector, local councils, etc).</p>
Identifying our key messages	<p>What are the key messages that you want the audience to take away with them?</p> <p>What is the best way to communicate these messages (e.g. data, quotes, images, diagrams, etc)?</p>



Activity three: Planning our next trip

This is not the end of our journey, it is just the beginning. Our research findings can inspire new research projects and activities. This activity will help us to think about the potential next steps in this research journey.

You will each get a card with four questions for you to answer:



BEFORE YOU LEAVE..



We have a message book at the end of each session where you can write your thoughts about the session. You might want to send a message of "good luck", write a suggestion for future sessions, write a note about how you've benefitted from the session, or ask a question.

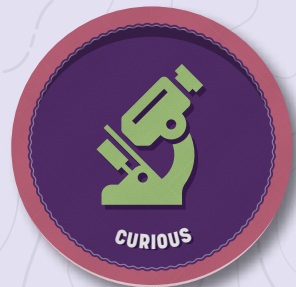
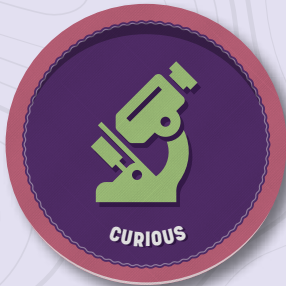
We will talk through the answers and make a list of ideas for future projects. We can then put our plans into order of priority.

JARGON BUSTER

"People drop out because they are thinking, 'everyone else knows what they are doing and I don't'... but they do know what they are doing"

This jargon buster is a plain English explanation of the typical words or phrases usually used by researchers in the course of their work. It is not intended to be inclusive but as a guide to help you, as peer researchers, to understand terminology when you are involved in research.

ABSTRACT	A brief summary of a research study and its results. It should tell you why the study was done, how the researchers did it and what they found.
BIAS	A systematic error or deviation in results or inferences from the truth when reporting the findings.
CONFIDENTIALITY	During a research study, the researchers must put data protection measures into place, to ensure that all of the information collected about the participants is kept confidential.
EMPOWERMENT	The process by which people are offered knowledge, skills and resources they need to take control over decisions and resources. People build confidence in their own strengths and abilities to achieve something but does not mean people take control over all decisions or all resources.
HYPOTHESIS	An unproven theory that can be tested through research. To properly test a hypothesis, it should be specified and clearly expressed. The study to test it should be designed appropriately.
PARTICIPATORY RESEARCH	This is a type of research where researchers and people who use services or carers are partners in a research study.
PATIENT AND PUBLIC INVOLVEMENT (PPI)	PPI means that members of the public, people with lived experience are active partners in the whole research process, advising, assisting or carrying out the research, rather than being the subjects of research.
PEER REVIEW	Where a research application or report is read and commented on by people with similar interests and expertise to those who wrote the application or report. Can check the quality of a report or research application.
PROTOCOL	A protocol describes in great detail what the researchers will do during the research.
QUALITATIVE RESEARCH	Research information that shows the value of something.
QUANTITATIVE RESEARCH	Researchers collect data in the form of numbers to measure or count things.
REFLECTIVE	Looking back at things that have been done or said in order to think calmly and quietly about them and what the impact was.
SYSTEMATIC REVIEW	A review of a clearly formulated question that uses explicit methods to identify, select and critically assess relevant research.



MYLIFE TOOL

Developed by



NEURO KEY

An Alliance supporting people
with neurological conditions

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