Westmorland & Furness Council

NIHR | National Institute for Health and Care Research

People First

Community Change Lab

Accessible Research Training Materials

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Contents

About this project 8
What is Co-Research 9
Why Co-Research Matters 9
How These Materials are Organized 10
Credits and thanks 13
Part One: Accessible Training Materials 14
Session One: Session Plan 16
Session One: Resources 20
Research Passport 21
Payment for Public Involvement Information 29
Letter to Job Centre Plus 35
Reflection Sheet 38
Review Cards 40
Session One: Examples of Work 43
How we want to work together 44
Session Two: What Is Research? 46
Session Two: Session Plan 47
Session Two: Resources 53
Definitions of Research 54
What is Research? 58
Images of Research 59
Types of Research 65
Learning Disability Research Fact Cards 67
Research Stages Cards 69
Session Two: Examples of Work 74
Group Definition of Research 75
Session Three: How To Write A Research Question 76
Session Three: Session Plan 77
Session Three: Resources 83

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Criteria for a good research question 84
Research Questions – Accessibility Checker 85
Session Three: Examples of Work 86
Identifying different research topics. 87
Identifying research questions. 88
What ingredients do these questions have? 89
Session Four: Keeping People Safe (Ethics) 90
Session Four: Session Plan 91
Session Four: Resources 101
Ethical Principle Cards 102
Consent Game 108
Creative Inclusion Consent Activity (University of Leeds) 111
Creative Inclusion Withdrawal Activity (University of Leeds) 113
Keeping People Safe Game 115
Privacy Game 117
Creative Inclusion Anonymity Exercise (University of Leeds) 118
Easy Read Ethics Application 119
Session Four: Examples of Work 136
Acceptable Researcher Behaviour 137
Reducing the Risks of Taking Part in our Research 138
Session Five: What Is Already Known About Our Topic (Literature Reviews) 140
Session Five: Session Plan 141
Session Five: Resources 146
About literature reviews 147
Which is most trustworthy exercise 148
Session Five: Examples of Work 152
Advantages and disadvantages of different types of literature 153
Session Six: Finding People To Take Part (Participants) 155
Session Six: Session Plan 156
About participants 161
Participant Exercise 162

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Session Six: Examples of Work 165
How to prepare for research participants 166
Our Easy Read Participant Advert 168
Our Easy Read Participant Information Sheet 170
Our Easy Read Consent Form 178
Our 'Thank you' and follow up information 182
Session Seven: Designing Survey and Interview Questions 184
Session Seven: Session Plan 185
Session Seven: Resources 190
About interviews 191
Does the question fit exercise 192
About Number (qualitative) and word (quantitative) information 195
Qualitative or quantitative exercise 196
Open and closed question information 201
Open and Closed Question Exercise 202
Leading question information 206
About Questionnaires (Surveys) 207
A Bad Survey 208
About Individual Conversations (interviews) 210
A very bad interview 211
Session Seven: Examples of Work 214
Learning from the Bad Interview 215
Session Eight: Designing Group Discussions and Art and Drama Tools 217
Session Eight: Session Plan 218
Session Eight: Resources 224
About Group Discussions (focus groups) 225
About Art and Drama Tools (creative methods) 225
About Watching People (observation) 226
About Document Reviews 226
Session Nine: Planning How We Will Collect Our Data 227
Session Nine: Session Plan 228

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Session Nine: Resources 231
Data Collection Matching Exercise 232
Session Nine: Examples of Work 234
Advantages and disadvantages of data collection tools exercise 235
Session Ten: What Does The Information You Collected Mean? (Analysis) 238
Session Ten: Session Plan 239
Session Ten: Resources 244
Number Test Data 246
How many of something there is – (counting) 247
How spread out the data is (the range) 247
Most popular thing (mode) 247
The average amount (mean) 248
How much there is of one thing (ratio) 249
How much of one thing is there (fraction) 249
How much of one thing is there (percentage) 250
How to show your data in rows (table) 251
How to show your data as a pie (pie chart) 251
How to show your data in bars (bar chart) 252
How to show your data as a line (line graph) 252
Working out what words mean (thematic analysis) 253
Writing out what people said – transcription 254
Developing codes and themes 254
Word Test Data 255
Session Eleven: Writing Up What You Found Out 256
Session Eleven: Session Plan 257
Session Eleven: Resources 262
British Journal of Learning Disabilities Guidance on Writing Up Research 263
Review form for different types of publication 271
Session Twelve: Sharing What You Found Out (Dissemination) 273
Session Twelve: Session Plan 274
Session Twelve: Resources 278

THE CONTENT OF THIS GUIDE IS LISENCED UNDER A CREATIVE COMMONS ATTRIBUTION LICENSE TO BE USED NONCOMMERCIALLY AND ALL USE AND ADAPTATIONS TO BE CREDITED TO THE AUTHORS.

Sharing research findings (dissemination) 279
Working out who to tell (stakeholders) 279
Working out how to tell them (communication channels) 280
Writing a sharing (dissemination) plan 280
Session Twelve: Examples of Work 281
Accessing Healthcare Research Sharing Plan 282
Session Thirteen: Did We Do A Good Project? (Evaluation) 283
Session Thirteen: Session Plan 284
Session Thirteen: Resources 288
About Reviewing (evaluation) 289
Reviewing how we worked (process) 289
Listen, Include, Respect: The International Guidelines for Inclusive Participation, written by Inclusion International, 2026. 290
The Learning disability and Autism Research Access Group (LARA) 294
ACCESS framework evaluation 294
Reviewing what we gained (impact) 296
Body Maps 296
Body template 297
Session Thirteen: Examples of Work 298
Examples of Body Maps 299
Session Fourteen: Celebration 304
Session Fourteen: Session Plan 305
Session Fourteen: Resources 309
List of Research Knowledge and Skills 310
Part Two: Research About Co-Research With People With Learning Disabilities 311
Our easy-read summary of a review on inclusive research 312
Co-research with adults with intellectual disability: A 313
systematic review 313
Our Recipe for Good Inclusive Research 314
In the physical to digital transition with friends – A story of performing inclusive research together no matter what life throws at you. 314

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Co-producing ethics guidelines together with people with learning disabilities .. 315
''Ethno...graphy?!? I can't even say it": Co- designing training for ethnographic research for people with learning disabilities and carers 316
Evaluation of a Co-Research Program: Optimising 317
Engagement in Research 317
University Researchers and Researchers With Learning 318
Disabilities Co-Interviewing as Part of an Inclusive 318
Research Team 318
'I'm a researcher!' Working together to gain ethical approval for a participatory research study. 319
The Conundrum of Training and Capacity Building for People with Learning Disabilities Doing Research 320
Participatory data analysis: a step too far? 321
Co-researching with People who Have Intellectual Disabilities: Insights From a National Survey 322
Nothing About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up? 323
Peer- reviewed articles on inclusive research: Do co- researchers with intellectual disabilities have a voice? 324
Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis 325
Developing a training course to teach research skills to people with learning disabilities: "It gives us a voice. We CAN be researchers!" 326
'Working together is like a partnership of entangled knowledge': exploring the sensitivities of doing participatory data analysis with people with learning disabilities 327

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People First

Community Change Lab

Introduction

About this project

- Westmorland and Furness Council and People First applied for a National Institute for Health and Care grant for a Public and Community Partnership.
- We were awarded £10,000 to co-create research training that was accessible to people with learning disabilities. From our work in different settings we think the materials are accessible to anyone and everyone not just people with learning disabilities.
- A team of seven people with learning disabilities and neurodiversity's, one person from Westmorland and Furness Council and one person from People First worked together to test out accessible learning materials and to design this pack.

What is Co-Research

Co-research is when people with lived experience do research with researchers. Co-research is an equal partnership. People do what they are able to and what they enjoy – no one has to take part in everything. Co-research can use any tools and techniques and its focus is making people's lives better.

Why Co-Research Matters

- About 2.5% of the population have a learning disability, but only 1.4% of academic grants are spent on research about learning disability.
- Despite a push for inclusion, populations with learning disabilities remain heavily underrepresented in research, for example, less than 1% of medical trials include people with learning disabilities, despite them experiencing a significantly higher prevalence of many conditions.
- People with learning disabilities have lives 19 years shorter than the rest of the population and 38% of their deaths are avoidable. This highlights the need for more research into the inequalities they

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experience, and people with learning disabilities are best placed to design and do this research.

- A review of health and social care research that included people with learning disabilities found only 17 papers written in the UK since 2000 and they only involved people with learning disabilities in the design process, they did not do the research themselves.
- We believe that with the right training and support people with learning disabilities and other needs can design, conduct, analyse, write up and communicate research themselves. There are no excuses for not involving people with lived experience as co-researchers.

How These Materials are Organized

These materials are written for someone who does not have a learning disability who would facilitate a research project. Facilitating a project means managing a budget and organizing the resources, dates and meeting places for a group to do their own project.

Part One gives you all the materials you need to train people to be co-researchers step by step as they do their own co-research project.

There are fourteen sets of materials covering each stage of the research process.

For each stage of the research process there is; a session plan with activity options, images you can cut and paste into your own documents or presentations, examples of what completed exercises might look like and resources created by other organisations.

The session plans are written for the person facilitating the project and are not in an Easy Read format under the assumption they are not learning disabled. All other materials are in Easy Read format. We have used simple language throughout the materials but also added the research language as

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our co-designers said it was important that people can learn what they mean without having to use them themselves.

These are flexible tools giving you options of activities and suggested timings – adapt and adjust them as you need for your group. We have created space throughout so your co-research team can learn about each stage of the research process and then apply it to their own research step by step. You could, however, run the whole training programme and then go back planning and doing your own research afterwards.

We hope you find these useful in supporting more people with learning disabilities and neurodiversity, or in fact anyone, to lead research themselves.

The thirteen sessions are:

1. Introduction – setting up the project
2. What is research
3. How to develop a research question
4. How to keep everyone safe (research ethics)
5. How to work out what is known about our topic (literature reviews)
6. Who to invite to take part in our research and how to meet their needs (research participants)
7. How to collect data 1 – questionnaires (surveys) and individual discussions (interviews)
8. How to collect data 1 – group discussions (focus groups), arts and drama tools (creative methods), watching people (observation) and document reviews
9. Designing your data collection tools
10. How to work out what your information means (analysis)
11. How to write up your research

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12. How to share your research with other people (dissemination)
13. How to evaluate your project
14. Celebration.

Part two provides summaries of 15 examples of learning about co-research from real co-research projects with people with learning disabilities.

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Credits and thanks

Thanks to the National Institute for Health and Care Research for their Public and Community Research Grant.

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Thank you to People First for providing all the venues, support, infrastructure and consultant time to make the project a reality.

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Part One Accessible Research Training Materials

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Session One: Setting up the project

Session One: Session Plan

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Session Plan: One

Topic: Getting to know each other and the project

Aim: To develop relationships between people and to ensure everyone is clear about the project.

Time needed	Activity	Resources
10 mins	**Welcome** Getting to know one another Set up an informal space where you can all relax and start to share who you are and why you joined the project. Some icebreaker questions might be: • Who are you? • How did you find out about this? • Why do you want to be involved? • What else do you do? • Where do you live?	None Fidget toys Snacks Reaction cards
30 mins	**Project overview** Explain: • What the project is about and how it got set up. • Who is working on the project • What we will do – aims of the projects overall • Project timeline– talk through each session • What it means to be a co-researcher	Project calendar Project timeline and work agreement, bring reactions cards and fidget toys each

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	• What each session will look like – agenda in advance, work in session, reflective log, what is coming up next • What you hope the end result will be. An example of a co-research project timeline can be found here from Learning Disability England: https://doi.org/10.48785/100/405 Task: Develop a work agreement with expectations / commitments. There is an example of this pack, you might also like to look at the 'terms of reference' developed by Learning Disability England for their 'No research about us without us' project.	week(display each week)
20 mins	**Practicalities** Explain: That you have research passports to record skills and experiences along the way. They are not compulsory, you're happy to support people to fill them in, or can fill them in for them if they would like a record of what they did. Tasks: Complete the introductory sections of the passport if wanted. Complete any registration forms needed for payment etc.	Research passport Payment information booklet

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	Ensure everyone is clear on how and when they will be paid. (n.b. This guide from Learning Disability England is full of helpful tips of how to include people with learning disabilities in research projects which might be helpful background reading before continuing your project: https://doi.org/10.48785/100/399)	
15 mins	**Review** Complete the reflective log together. What's coming up in the first session.	Reflective log

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Session One: Resources

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Research Passport

About Me

	Name:	
	I like to be called:	
	How I travel here:	
	My favourite drink at break time is:	

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Contact details

	Email:	
	Phone:	
	Address:	

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My likes and dislikes

	Things I like:	
	Things I dislike:	

Why I want to be involved

	

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Skills I want to use in this project

	Listening to other people	
	Reading information	
	Writing things	
	Drawing things	
	Making things	
	Deciding if something is good or bad	

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	Working on a computer	
	Designing documents	
	Giving my ideas	
	Doing maths	
	Teamwork	

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	Speaking to people I don't know in small groups	
	Speaking to large groups	
	Presenting to a room full of people	
	Having fun	

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Session Record - What I did each time I came

Date	What did I do?	Did I enjoy it? Did I learn any new skills?
Session 1:		
Session 2:		
Session 3:		
Session 4:		
Session 5:		
Session 6:		
Session 7:		
Session 8:		
Session 9:		
Session 10:		
Team Meeting		

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Emergency contact information

 Support	Who is your support worker?	
	Who should we contact if there is an emergency?	
	Do you need to take any medications when you are with us?	
	Do you have any allergies?	

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Payment for Public Involvement Information

Thank you for helping us with some project work at the Community Change Lab.

We would like to offer you a thank you payment for the skills and expertise you have brought to the project. We will also refund your public transport expenses.

It is important that you are clear what you have agreed to do. Work with XXX to write down what you have agreed.

	Project name:	
	Start date:	
	End date:	
	What have you agreed to do?	

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	How many hours have you agreed?		
	How much ‘thank you’ payment have you been offered per hour for your skills and expertise?		
	What travel can the CCL pay you for?	Public transport: Please keep all tickets	
		Taxi:	
		Mileage in a car:	

Working with us

We will ask you some questions about yourself so we can register you as a volunteer in a database called ‘Better Impact’.

This is a secure system that makes sure we know who you are, how to support you and how to make payments to you.

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Making payments to you



Each time you come and help us we will write down the hours you gave us and what you did.

We will also collect any tickets you paid for on public transport.

Kaz will give all this information to our finance team who will then be able to make your payment.

For example:



John does 10 hours work in and spends money on two bus fares in June.



He submits his timesheet on the 1st July.

He is paid for his ten hours at the end of July.

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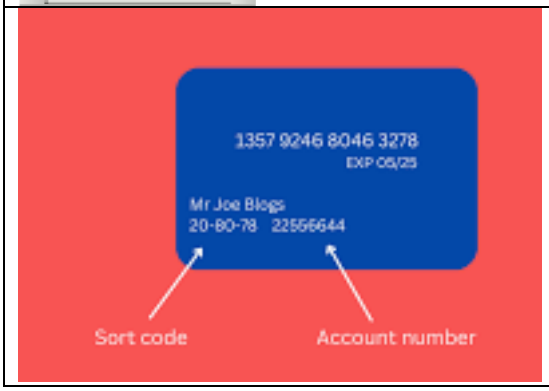
How would you like to be paid for your expertise?

	How do you want to be paid?	Money into my bank account 	
		A gift voucher 	
		Something else	

If you would like to be paid money into your bank account you will need to provide us with those details. These will be stored securely.

	The name of my bank:	
	The name of my bank account:	
	My bank account number:	
	My bank account sort code:	

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Tax and Benefit Implications

	This is not employment and the money you receive is not a salary or wage
	What you are doing is called ‘public involvement’ in research
	The payments you receive are a thank you for helping with the research
HM Revenue & Customs	The Tax Office says: There will be no tax or national insurance liability for an individual if the sums received do no more than reimburse the individual’s reasonable costs of participating in the trial or research, including costs of travel and subsistence. However should the sums paid exceed those reasonable expenses then the excess may fall to be chargeable to tax as Miscellaneous Income, potentially giving rise to personal tax liabilities of the individuals which should be notified to the HMRC under Self Assessment”. https://www.gov.uk/hmrc-internal-manuals/employment-income-manual/eim71105
NIHR	The National Institute for Health Research says: “As a public contributor, you are responsible for declaring your income. Involvement payment could be considered taxable income.

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	Whether or not you will have to pay tax will depend on how much other income you have. Tax for the year will only be due on a person's income that is over their personal tax allowance". "If public contributors are receiving welfare benefits, any involvement payment may affect their benefit claim. The public contributor should notify the relevant authority or office (for example Jobcentre Plus in England or the or the jobs and benefits offices in Northern Ireland) of any paid or voluntary activity before they do it. They may also need permission to undertake any paid activity in the first place". https://www.learningforinvolvement.org.uk/content/resource/payment-for-helping-health-and-social-care-research-a-guide-for-members-of-the-public-who-want-to-help-with-research/
 	You should check with a benefit advisor whether these payments will affect your benefits. I have written you a letter in a formal style to give to your benefit advisor.

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Letter to Job Centre Plus

To Jobcentre Plus

Mr XXX has been requested to assist People First's Community Change Lab with public involvement in an NIHR funded project. We wish to ensure that the purpose of public involvement is understood and is not mistaken for work.

What is the NIHR

The National Institute for Health and Care Research (NIHR)'s mission is to improve the health and wealth of the nation through research. Working in partnership with the NHS, universities, local government, other research funders, patients and the public, NIHR delivers and enables world-class research that transforms people's lives, promotes economic growth and advances science. NIHR is primarily funded by the Department of Health and Social Care, but also receives UK Aid funding to support research for people in low- and middle-income countries.

What is public or service user involvement?

People who can offer a service user perspective because of their personal experiences of using health and/or social care services are requested to assist in our work.

At NIHR, when using the term 'public' we include patients, potential patients, carers and people who use health and social care services.

DWP has a full description of service users that applies to all benefits and can be found in Advice for Decision Makers Chapter H3: paragraph 3161.

The difference between service user involvement and work

Involvement in research activities should not be mistaken as capacity for work, and recruitment for service user involvement should not be confused with recruitment for employment. People are recruited because of their

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personal experiences of using health and social care services.

Service user involvement activities:

- are intermittent and people can withdraw at any time
- vary in length and in frequency, and usually last for a few hours (or less) in any one week
- are individual activities and do not imply future involvement
- may include attendance of quarterly or annual meetings
- may include contributing to intermittent meetings or telephone conferences
- may include helping to prepare for meetings, telephone conferences or events
- may include some follow-up activities after meetings or events

Any payment that is offered for service user involvement is intended to cover preparation, attendance and appropriate follow-up activities.

Support provided

Organisations provide support measures that are appropriate for each individual, so that members of the public can attend and contribute to our meetings and events. Some people who we involve may be in receipt of benefits for mobility or care needs. Involvement in activities should not be interpreted as a reduction in the care or mobility needs of service users involved.

Support for care or mobility needs is offered as required by the service user and may cover preparation, travel to and from a venue, and contributions both during and after the activity. For example, support may include provision of childcare, or provision of a personal assistant or a support worker.

Payment for service user involvement

Good practice guidance for service user involvement in research recommends that members of the public should be offered payment for

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activities such as attending meetings and events, and that reasonable out-of-pocket expenses should be covered. Please note that:

- as involvement activities are often arranged on an ad hoc basis, organisations often pay service users monthly in arrears
- to assist service users who receive welfare benefits which have earnings limits or disregards, organisations offer involvement on a voluntary basis, or at a lesser amount, if requested
- as the payment period may be over a month or more, we anticipate that Jobcentre Plus will treat these payments as averaged over the payment period. See DMG Chapter 48 paras 48080-81 and for a cycle of work para 48094.
- the Department for Work and Pensions legislation exempts 'service users and carers' from the application of notional earnings and treats reimbursed expenses for service user involvement as ignored (see ADM Chapter H3, paras 3160 and 3241)
- service users can withdraw from involvement activities at any time to attend 'employment-related' activities
- the Department for Work and Pensions legislation for persons who receive Employment and Support Allowance on exempt work now allows earnings at the higher level of Permitted work without time limit (see Memo DMG 7/17)

Please do not hesitate to contact me if you require further information.

Signed:

xxx

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Reflection Sheet



We will spend time in every meeting thinking about how well the project is going.

	What is today's date?	
	What has gone well today? What did you enjoy?	
	What did we do badly? What did you dislike?	
	How was power shared today?	

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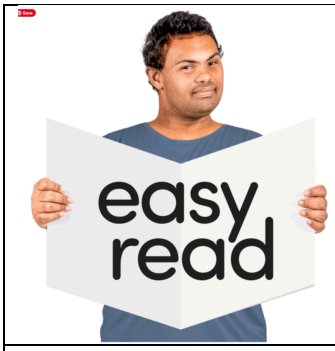	How were resources shared?	
	What was meaningful about your involvement today?	
	Were you involved in different things and / or in different ways today?	
	Did you feel supported and included in the session today?	

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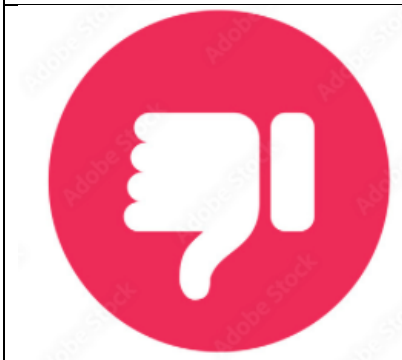
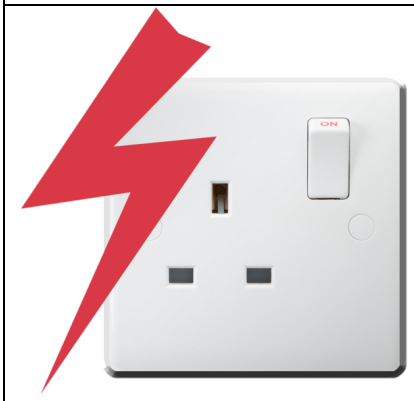
Review Cards

	What went well today? What did you enjoy?
	What didn't go well? What could have been even better?
	What power did everyone have in the room? Was power shared well?
	What resources were used?

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	How accessible were they for everyone?
	What did you get out of taking part today? - Skills? - Knowledge? - Ideas? - Friendship?
	How much variety was there in the activities? How well could you take part in them?
	Did everyone get the support they needed to take part? What other support might be helpful?

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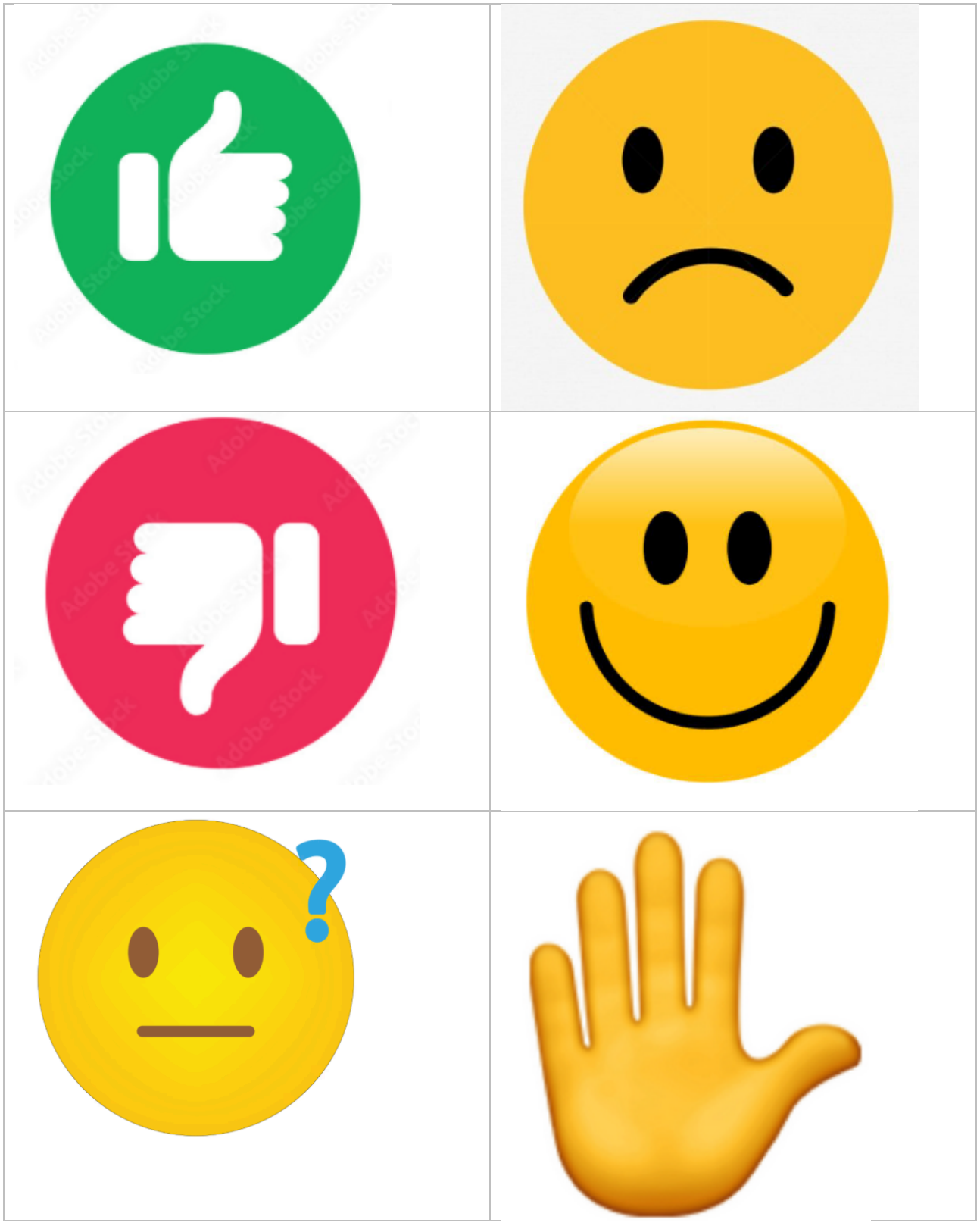
Reaction Cards



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Session One: Examples of Work

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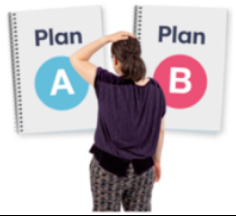
How we want to work together

	Checking in to see how we all are
	Respect and include one another
	Variety – working all together, in small groups and individually
	Choice in how we do things
	Using our existing skills – not all having to do the same thing

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	Chance to learn and try out new skills
	Help and support each other
	Breaks with drinks and snacks
	No cancellations
	No work between sessions
	Keep any personal discussions confidential

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Session Two: What is research?

Session Two: Session Plan

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Session Plan Two

Topic: What is Research?
Aim: To understand what research is and what it involves

Time Needed	Activity	Resources
15 minutes	**Welcome** Check in – how have you been? Recap on what we did last time – share group rules Payment – share guidance, give out letters, collect bank details What we are looking at in this session – how to explain what research is to people with learning disabilities	Group rules Payment details
30 minutes	**What is research?** Explain: We're going to talk about the word 'research' and make sure we all understand what it means. Discussion: Can you give us an example of any research you have taken part in or heard about? (Write on flip chart) Activity: We're going to look at a few different definitions of research and take out the bits that we like to make our own. Read out / review / take out parts that you like and dislike. Come up with your own definition. Optionally – explain - This is an easy read definition of research – read out the Easy Read definition included in this pack.	Flip chart Definition printed Photo cards

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	Do you have any more examples of research now you've heard the definition? (Write on flip chart) You may also want to watch this video by the National Institute for Health and Care Research: https://www.youtube.com/watch?v=Gv8yBdcawoQ Research activity: Here are some photographs of different types of research. Some of them might not look like research, but they are all different ways of doing research. What does each photograph show people doing? Explain – there are two main ways of doing research, scientific and social. Can you put the photographs into those two types of research? Explain: We are doing social research. Some social researchers do co-research, which means researching together. Which of the photographs show things you would like to try out in this project? Option – just explain the scientific and social types of research.	
10 minutes	Break	
15 minutes	**Research and learning disability** Explain: We'd like to share why we think research is so important for people with learning disabilities.	Three fact cards Flip paper and pens

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	Share the three fact cards – Research on people with learning disabilities and examples how bad it was Research about people with learning disabilities – example of a project Discuss: Why do you think researchers did research about people rather than with them? What were the barriers? Write a list on a flip chart and add more until there is a full list that includes: Inaccessible information Over protectiveness Ethics processes excludes them Lack of support Time pressure Discrimination. Research by people with learning disabilities (called co-research) – example of a project Why do you think research by people with learning disabilities is important? Write ideas on a flip chart and add more until there is a full list that includes: It makes research better It treats people equally Everyone has an equal voice People with learning disabilities know what their issues are Research is kept real Everyone gains new skills and knowledge.	

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	Explain: In this project you will be co-researching a topic that is important to you with our help. As we have learned today it is important that research is done with people with learning disabilities and we disagree with the reasons why they are excluded from research.	
10 minutes	Break	
20 minutes	**What doing research involves** Explain: There are lots of different steps to doing research. You might like to think of a research plan as a recipe – you need to know what you are going to make, what you need to have, how to make it, and what it should look like at the end before you can start. Research steps activity: Read each one of the 'steps' and see if you can put them in an order – what would you do first, second and third and so on? Explain: You are likely to find it impossible to put the keeping people safe in one place, this is because it is important all the way through the project. Options for follow up activities: A – Discuss and write why each of the steps is important on each one B – If this was a recipe, what stage of the recipe would each card represent? C – Which step do you think you would be best at and where would you need help?	Footprint cards
15 minutes	**Review**	Reflective log

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	Discuss what has worked well in the session and what could be even better on the research reflective log. Give support to complete individual evaluation in research passport. Explain what is coming up in the next session (writing a research question) and remind of the time and date.	Research passports

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Session Two: Resources

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Definitions of Research

Definition One:

Research is a systematic process of inquiry aimed at discovering new knowledge, interpreting existing information, or solving specific problems. It involves gathering, analyzing, and interpreting data using established methods to expand our understanding of the world.

Definition Two:

Research is the careful and organized way we look for information to answer questions, learn new things, or solve problems. It is just like being a detective! You gather clues by reading books, doing experiments, or asking experts to discover true facts about a topic.

Definition Three:

Research is a way of finding out new information. It involves carefully studying a subject to answer questions, learn something you did not know, or solve a problem.

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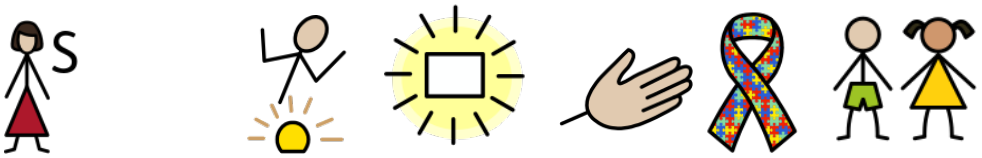
Definition Four:




What is Research?



Sarah studies at university.



Sarah wants to find a new way to help autistic children with their



mental health.

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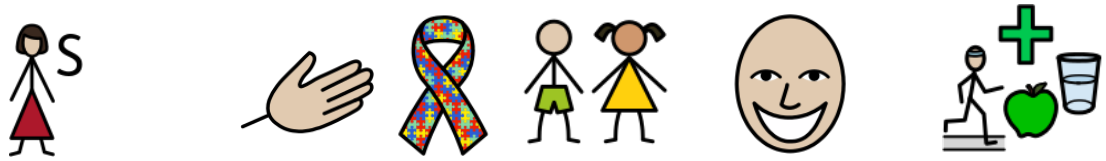
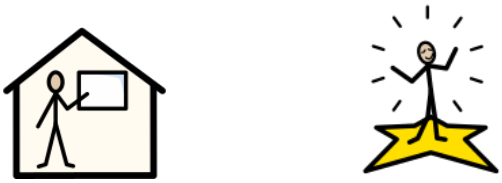


Sarah wants to help autistic children be happy and healthy in



school and be their best self.



When we want to find something out, it is sometimes called



research.



Research is investigating and exploring.

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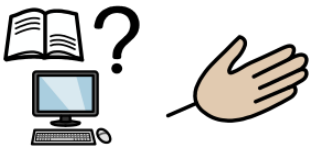
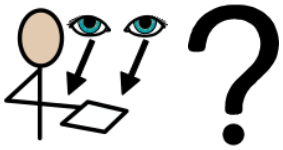
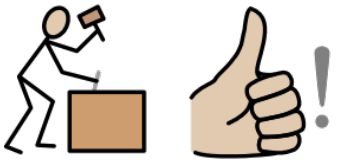




Research helps us learn new things and can show us how



to do things better.

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What is research?



- Research means finding something out.



- Researchers investigate and explore answers to questions.



- It is a bit like being a detective!



- There are lots of different types of research and ways of doing research.



- We can use the information to learn new things and to make things better.

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Which of these pictures show research?





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Types of Research



Scientific research

- These pictures show scientific research
- This is when scientists test things
- This research is done in a laboratory
- It is usually used to test new medicines.



Social science research

- These pictures show social science research
- This is where researchers explore what happens in people's lives
- Social science often involves looking at things and talking to people
- It is usually used to find out what will make people's lives better.

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Co-research

- Co-research is when people with lived experience do research with researchers
- It is an equal partnership
- Co-research can use any tools, but often involves creative tools to help different people take part
- Its focus is making people's lives better.

Co-production



- Co-production happens when people with lived experience work with people in charge of services to design new services.

- When we research together we co-produce research, but this is usually called co-research.

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Learning disability research 1



- A long time ago doctors used to do research on people with learning disabilities
- The people they did the research on had no choice in whether to take part
- In one experiment in the 1950's children with learning disabilities in a school in America were deliberately given an illness called hepatitis so doctors could see how it developed.

Learning disability research 2



- A while ago researchers realised people with learning disability were treated badly
- They often had no freedom or choice and were locked in asylums
- Researchers started to do research about the poor treatment of people with learning disabilities
- The 2023 Learning Disabilities Mortality Review, for example, highlighted that people with learning disabilities often live 19 years less than other people and the reasons why.

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Learning disability research 3



- Recently research has been done with people with learning disabilities
- This means they design and do the research themselves
- For example, the Purple Patch Researchers in Leeds who are learning disabled researched why creative methods are so useful and published their results in a comic book.

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Research question



- Research usually starts with deciding on a topic, setting out what you will research
- Once you have a topic you will write a very clear and focused research question so everyone know what you are doing
- Everything else follows the research question.

Keeping everyone safe (ethics)



- All the time we are doing research we need to think about how to keep our research participants safe and ourselves safe.
- We will do this at the start and at every step of research.
- Thinking about keeping everyone safe is called ‘ethics’.

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Choosing what to do (method)



- Once you have a research question you can decide how to do the research
- You will decide whether you are doing scientific, social or co-research.
- You might decide to mix it up too and do a mixed research project.

Finding people to answer your questions (participants)



- Once you have a research question and a method you will need to decide who has the answers
- People who take part in research are called research participants
- You will decide who you want to take part and how you will invite them to take part.

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Research activities (data collection)





- Now you need to decide what you will ask people to do
- Some people like to fill in surveys, others prefer to talk, and some might want to draw or act
- You need to match the research activities to the question and the people taking part (participants).

Doing the research



- You have written lots of plans and now you need to carry them out by doing the research activities.

Making sense of your information (analysis)



- Once you have collected your information you will need to work out what it is telling you
- You do this by looking for things that are the same or different
- There are different ways of analysing words and numbers
- This is called analysis.

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Writing up



- Once you have made sense of your information you will write it up
- You might write a report or a presentation, or a play, or design a display.

Spreading the word (dissemination)



- Once you have written up your research you will want to share it with people to help make change happen
- You will think about who you want to see it, how you can get it to them, and what you want them to do with it
- This is called dissemination.

Reviewing what you did (evaluation)



- Once everything is finished you will have a discussion about what went well and what could be better
- This makes sure that everyone learns how to do research better in the future
- This is called evaluation.

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Session Two: Examples of Work

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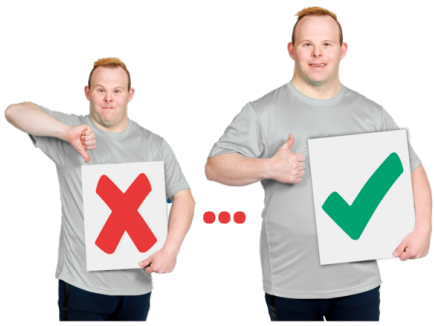
Group Definition of Research

	Research is about finding out new things. It is a bit like being a detective.
	Doing research means you collect information to help you answer a question or solve a problem.
	There are lots of different ways of doing research.
	We do research to learn how to improve services and make people's lives better.

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Session Three: How to write a research question

Session Three: Session Plan

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Session Number: Three

Topic: Writing a good research question

Aim: To write guidance on how to write a good research question

Time Needed	Activity	Resources
10mins	**Welcome** • Check in – how have you been? • Recap on what we did last time – share group reflections and questions from the last session • What we are looking at in this session – how to write a good research question	Group rules
30 mins	**A research topic** Explain: When we start a research project we need to agree what we will do, this is called a research topic. This is what the research will focus on. Research topics are often focussed on a problem or issue that you want the research to improve. Task: Support the group to write a list of the problems people with learning disabilities face that you could research – this could be their ideas captured on a flip chart, or a range of easy read cards that they choose depending on their abilities. Explain: Now you have a list of research topics you need to agree on which one to do. Task:	Flip chart Easy read question cards if appropriate Slides 2-4

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	Offer the group a choice in how to decide on a topic, or decide yourself how they will reach a decision: We can agree in different ways, we could: • Vote / show of hands • Discuss and agree • List the advantages and disadvantages of each one • Nominate someone in the group to decide.	
15 mins	Break	
30 mins	**Research questions** Explain: A research topic might be quite general, like 'employment for people with learning disabilities'. This is a big topic and might have lots and lots of research questions. For example, 'employment' might explore why employers are so bad, why recruitment isn't accessible, why people with learning disabilities find it hard to get a job, how unfair employment is etc. The research questions set out exactly what you want to know. We can make the topic more specific by making it about: A group of people or a place – e.g. people in Carlisle A particular activity or practice – e.g. online applications One outcome – e.g. success or failure.	Flip paper and pens Slides 5-8

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	Task: With the topic the group chose, write down as many questions as you can fto explore it further. You might want to try to come up with a question for each of the question starts (who, what, why, where, when, how, so what). You may need to prepare some examples or easy read cards to support the group to do this depending on their abilities.	
15 mins	Break	
30 mins	**What is a 'good' research question** Explain: We'll now have a look at what makes a 'good' research question. This isn't about how well the question has been written. If you can say yes to all of these questions, it is a good research question. Task: Here are seven different research questions, let's look at them together and decide what is good or bad about them. • How do adults with learning disabilities aged 18-30 in Carlisle look for jobs? (GOOD) • Does artificial intelligence help job applications? (DOES NOT SAY WHO OR WHERE) • How many job applications for people with learning disabilities are successful? (DOES NOT SAY WHO OR WHERE)	Research questions Slides 9-11 Slides 12-18

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	• How bad are employers? (LEADING QUESTION AND TOO GENERAL) • How long do people with learning disabilities keep their jobs if they are well matched to the job, and they have passed induction and they have not had any performance issues? (TOO COMPLICATED) • Is employment good? (TOO SHORT AND GENERAL) • People with learning disabilities experience discrimination. (NOT A QUESTION). Review in teams and share back. Task: review your each of your research questions - • Does it make sense? • Does it ask a question? • Does it say who will take part and / or where it will happen? • Is it too long and complicated to understand? • Is it too short and general to be practical? • Is it a leading question, trying to get a certain answer? • Is it interesting and worth doing? • Is it possible to answer with data? Explain: We can only research 3 or 4 questions under our bigger research topic. Task:	

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	Choose the questions you feel are the best (got the most yes's in the last exercise) or are the most important.	
15 mins	**Review** • Discuss what has worked well in the session and what could be even better on the research reflective log. • Give support to complete individual evaluation in research passport. • Explain what is coming up in the next session (ethics) and remind of the time and date.	Reflective log Research passports

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Session Three: Resources

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Criteria for a good research question

- Does it make sense?
- Does it ask a question?
- Does it say who will take part and / or where it will happen?
- Is it too long and complicated to understand?
- Is it too short and general to be practical?
- Is it a leading question, trying to get a certain answer?
- Is it interesting and worth doing?
- Is it possible to answer with data?

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- Could someone understand this without support?
- Are the sentences short (less than 20 words)?
- Is the language clear?
- Do we need pictures or symbols?
- Is there too much text?
- Is the font clear?
- Is the text large enough?
- Is there wide enough line spacing?

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Session Three: Examples of Work

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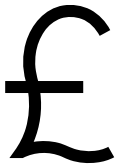
Identifying different research topics.

We thought these were issues people with learning disabilities face:

	Not having a job
	Poor services
	Poor housing
	Difficulties with transport
	Bullying
	Lack of funding and resources
	Loneliness

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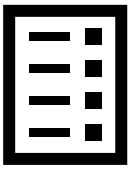
Identifying research questions.

We chose the topic of public transport to health care and came up with these research questions:

	Why do bus drivers change routes?
	Why do buses run late making people late for appointments?
	Why are bus drivers rude?
	Why do bus drivers leave before the passengers have sat down?
	Where are there no bus services?
	What can be done to improve them?

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What ingredients do these questions have?

We mapped out the ingredients of the first three research questions:

	Question	What are we trying to find out?	Who will have the answers?	How will we find it out?	What change do we want to see happen?
	Why do bus drivers change routes?	Are there roadworks? Are there accidents?	Passengers	Interviews	Reduce the bus changes Tell people that buses change routes
	Why do buses run late making people late for appointments?	How late are people for appointments? How many patients are late?	Doctors and surgeons Patients who use public transport	Survey	More buses with more seats
	Why are bus drivers rude?	How were they rude? Why were they rude?	Managers Passengers	Social media Focus group	Stop drivers being rude Keep people safe

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People First

Community Change Lab

Session Four: Keeping people safe (Ethics)

Session Four: Session Plan

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Session Number: Four

Topic: Keeping people safe

Aim: Ensuring we are ethical in our research

n.b. this is a longer session taking up to a day or could be split into two half day sessions.

Time Needed	Activity	Resources
15 mins	Welcome Check in – how have you been? Recap on what we did last time – share group ideas or questions from the last session What we are looking at in this session – how to write a good research question	Group rules
45 mins	**Keeping People Safe** Explain: We have to make sure things are fair and no one is harmed in research. Doing research the right way is 'ethical'. Doing it the wrong way is 'unethical'. Today we will look at each of the ethical principles and play some games with them so we get used to using them. Task: Here is a short film by the University of York St John about your rights in research: https://www.youtube.com/watch?v=3kPZAkSfS_Y OR review the PDF.	Flip chart

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	Task: Discuss which of these rights feel easy or difficult to stick to? Explain: We're going to review a set of 11 ethical principles and we will play some games as we explore them to help us understand what they mean. (These are drawn directly from the University of Durham 2013 Guide – How to do Research Together which is an excellent easy read resource). Co-researching Principles 1-3 are about how we work together as a co-research team. Task: Discuss whether we think we are doing all of these as a research team. Task: Discuss what is 'acceptable behaviour for researchers' and whether it is different in any way to how we work together usually. List all the things the group would think were acceptable or unacceptable.	

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15 mins	Break	
60 mins	Explain: Principle four is about saying yes or no to taking part (read information). This is called giving consent. Task: Play a game where ask them to say yes or no to five different scenarios: • Someone asks you to go to a film with them • Someone asks you to tell them what a friend said to you at a party last night • Someone asks you to give a package to a friend, but you don't know what is in it • A journalist asks you to tell them what your volunteering job is like • A friend asks you to post something on social media you don't agree with • A researcher asks you to take part in research where you need to watch upsetting films and say how you feel afterwards OR Play Creative Inclusion's consent game. Discuss how they knew they wanted to say yes or no, and when they needed more information to make a decision.	Flip paper and pens

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	Share examples of easy read information and consent forms. Explain: Sometimes people with learning disabilities don't understand what they are being asked to do and this is called 'Mental Capacity' means (principle 4b). Explain what the law says about how people without capacity might be allowed to take part. This may be a useful easy read resource: https://www.mencap.org.uk/easyread/mental-capacity-act-2005-easy-read OR watch the National Institute for Health and Social Care video about consent: https://www.youtube.com/watch?v=Op8OkozpwJg Task: Write a list of the ways people could take part if they are not able to speak. Explain: Principle 5 is about being able to change your mind which is called withdrawal and how to manage it in a research project.	

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	Task: Review each one of the examples of consent and ask how they would be able to let the person know they had changed their mind. OR Play the Creative Inclusion game on withdrawal. Explain principle 6 is about keeping everyone in the research safe from harm. Task: Safety game - Sort the 12 cards into two different piles to show whether you think they are a risk to the researcher, the participant or both. Task: Ask the group to think of a way to reduce each one of the risks and note it down on each one. Explain: Principle 7 is a very specific type of keeping people safe called safeguarding. Safeguarding is about asking someone more senior to make sure someone who is at significant risk is protected.	

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	Task: Create a list together of things that you would have to pass on to a safeguarding officer. If this idea is new to the group you may want to give them some examples to work through.	
15 mins	Break	
30 mins	Explain: The next two principles are about keeping people's information safe. Principle 8 tells us to keep everyone's identity a secret so no one knows they took part in our research (privacy) and principle 9 is about keeping their information safe. Task: Play the privacy game. Decide whether the information cards are public or private knowledge and sort into two piles. Discuss how to keep the private knowledge safe. Explain: Under the Data Protection Act a researcher can ask for private information as long as there is a good reason for it and it I saved securely and deleted as soon as possible. Discuss:	Research questions

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	What data will you be collecting in this project, will it be public or private? OR use the Creative Inclusion exercise on anonymity. Explain: Principle 10 –is about how we share what we find out with other people. This is called dissemination. Task: Discuss why sharing your findings is part of being ethical. Make a list of the risks of being named in a research project as a co-researcher or participant. Explain: Principle 11 explores who has the power in a project. We hope that everyone in a co-research project feels they have power. Task: Discuss the forms of power that everyone has in this room.	

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	Discuss the power a researcher and research participants have. Explore some examples of when power could be used to bad effect.	
60 mins	Lunch	
60 mins	**Ethics Forms** If you are going to ask people questions about themselves you will need to get 'ethical approval' from an ethics committee. Some Councils, Universities and the NHS have these committees. Even if you do not need to apply for Ethical Approval formally, you should think through all the ethical issues in your project to make sure you keep everyone safe. Explain: We're now going to apply each of those ethical principles to our research project to make sure we keep ourselves and everyone who takes part safe. Task: Complete the easy read ethics form. You might find this video from the National Institute for Health and Social Care useful to explain ethics	

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	committees: https://www.youtube.com/watch?v=Op8OkozpwJg	
15 mins	**Review** Discuss what has worked well in the session and what could be even better on the research reflective log. Give support to complete individual evaluation in research passport. Explain what is coming up in the next session (what is known about your topic) and remind of the time and date.	Reflective log Research passports

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Session Four: Resources

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1. Respect each other



This means you will find ways to:

- Agree to treat each other well



- Make sure everyone is listened to
- Allow people to have different ways of seeing things.

2. Including people and treating everyone equally



This means you will find ways to:

- Include people from different backgrounds and beliefs, especially people who are often left out



- Do something about anyone behaving badly or treating other people badly



- Have accessible information and meetings so everyone can understand.

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3. Making sure all co-researchers can make decisions



This means you will:



- Help and support people to take part in making decisions
- Think about the skills and interests everyone has
- Share power more equally
- Use words everyone understands
- Use the skills people have and help them learn new skills to get better

4. Giving permission to take part (consent)



This means you will tell people:

- Who you are
- What the project is about, why it matters
- What you want them to take part in
- What you want to collect
- What information you will write down or record
- How you will store their information
- How you will publish the findings
- Whether you will pay them and how
- You need them to sign a form to say they are happy with everything you have told them

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4b Mental Capacity



- Everyone needs to understand the choices they are making. This is called having 'capacity'.
- Everyone needs to be able to remember what they are told long enough to make a choice.
- Everyone needs to be able to tell someone your choice, but they do not have to speak to make your choice.
- If someone's support worker thinks they do not have capacity, someone else might have to decide for them.
- This might be a family member, doctor or support worker.
- Mental capacity is complicated – the NHS has good information on the mental capacity act

5. Changing my mind (withdrawing)



This means you will tell people:

- Whether they can change their mind about you having their information
- How they let you know they have changed their minds
- How you will get rid of their information.

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6. Keeping everyone safe

This means you will:



- Think about any risks to the co-researchers – travelling, working alone, hearing difficult things
- Think about any risks to the people who take part – being identified and bullied, being upset, being hurt.

7. Involving others (Safeguarding)



- If someone tells you something that might need to be passed on to the police or a social worker like someone being in danger.
- At the start of talking to them you might want to say: "If you tell me information about you or someone else being in danger I will have to tell someone else".

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8. Privacy



This means you will:

- Talk about what might be good or not good about using people's names, organisations or places.
- Usually people's names are kept private, but they might want to be named.
- You must think about any dangers to them of being named.

9. Keeping information safe (Data Protection)



This means you will:

- Keep any information about who a person is locked away
- Keep information about who a person is separate to the research information they give you
- Protect computers and files with passwords
- Lock paper documents away.

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10. Sharing what you found out (dissemination)

- This means you will:



- Decide what the information is telling you
- Decide who needs to know this information
- Decide how to communicate it to them
- Make sure that everyone who took part is named if that is safe for them.

11. Power



- Power is an important idea in research. Power is the ability to influence people, decisions and outcomes.
- Power dynamics happened when people bring different amounts of power to a relationship.
- For example a doctor has more power than patient or a teacher has more power than a student.
- Power dynamics can create opportunities for abuse and we have to make sure they are used properly in research.

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Consent Scenario 1



- Someone asks you to go to a film with them

Consent Scenario 2



- Someone at work asks you to tell them what a friend said to you at a party last night

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Consent Scenario 3



- A delivery person asks you to give a package to your neighbour but you don't know what is in it

Consent Scenario 4

- A journalist asks you to tell them what your volunteering job is like



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Consent Scenario 5



- A doctor asks you to post something on social media that you don't agree with

Consent Scenario 6



- A researcher asks you to take part in research where you have to watch upsetting films and say how you feel afterwards

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Creative Inclusion

UNIVERSITY OF LEEDS

Purple Patch Arts

Consent — Mystery Box

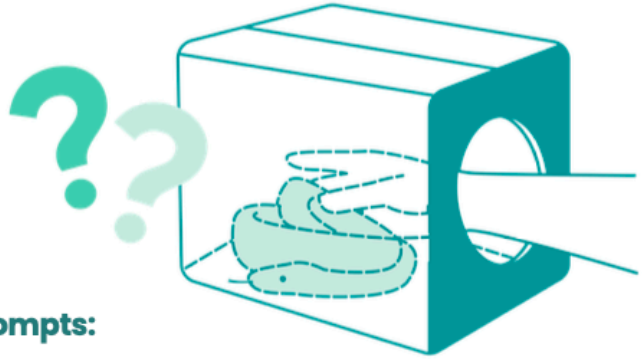
Aim: To explain the concept of informed consent.

Resources:

- ☐ A cardboard box with holes cut into the sides
- ☐ 'Good' and 'bad' mystery items. Use images of items (try cutting out the images provided) or use physical/sensory objects (e.g. a pot of beans, slime, rubber snake or chocolate coins)

How to:

1. Put a mystery item in the box without anyone seeing.
2. Ask if anyone would like to put their hand in the box! Emphasise that we don't know anything about what is in there (it could be a good or bad thing) and they can only use their hands.
3. Discuss their choice — why did they say yes or no?
4. Reveal the item — is it good or bad? Why might this be a risk or reward in research?



Prompts:

If participants are concerned that something in the box will hurt them — encourage them to ask questions to help them to decide if they should put their hand in the box? (e.g. will it hurt me? Is it a nice thing or a bad thing? What's in the box?)

Extending the activity:

1. After practicing with general objects, use images/items that represent risk and reward in your research.
2. End the activity by emphasising that before saying yes to doing research, it's important we have information about it. When we do research there can be good things and bad things to think about. We need to know the good and bad parts of taking part in research before we make a choice.

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creative inclusion

UNIVERSITY OF LEEDS

Purple Patch Arts

Withdrawal — Taking Information Back

Aim: To explain that it's ok to change your mind about being involved in research. If you change your mind, this is called withdrawal.

Resources:

- ☐ Paper cut into strips
- ☐ A bowl
- ☐ Pens



How to:

Round 1

1. Give everyone a slip of paper. Ask them a question (something related to your research, or unrelated like 'what's your favourite colour?')
2. Ask the group to write or draw their answers on the paper and fold it in half so you can't see it.
3. Add the slips to a bowl and mix them up.
4. Pick out a random slip. Without unfolding it ask whose it is. Can you tell? Explain that when your thoughts go into research often no one will know it was you who said it.
5. Ask the group what would happen if they changed their mind about sharing their answer? It would be hard to find their answer and take it back.

Round 2

1. Repeat steps 1-3 from round 1. This time, ask the group to draw something on the outside of the slip.
2. Add the slips to a bowl and mix them up. Ask someone in the group to find their information and pull it out of the bowl. If you wanted to take back your answer, could you this time? Sometimes researchers give your answers a code so that they can remove it if you change your mind. This is called withdrawing your data.

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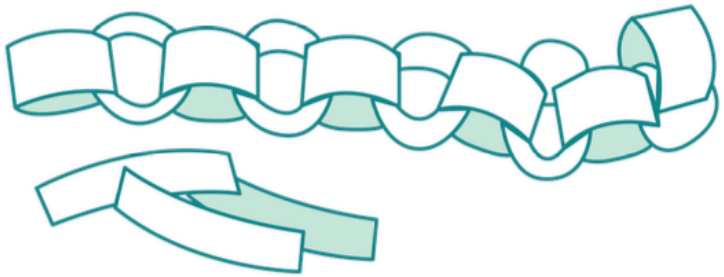
Round 3

1. Explain that you're going to make something out of their answers to show other people about what you've learned.
2. Using the slips from round 2, create a paper chain in a closed circle.
3. Ask the group if it would be possible to remove their slip now without damaging the chain? Explain that sometimes you can take your answers out of research up until a certain time. After researchers have looked at what you said and made it into something to show other people, it can be difficult to take your answers back.



Activity variants

You can adapt this method by swapping paper chains for other items (e.g. lego, pasta, plasticine). For example:

Round 1:

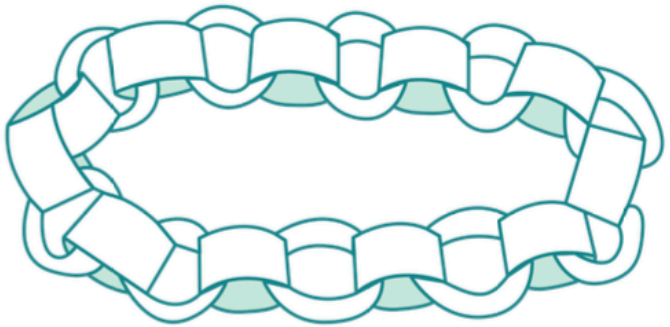
Use items of the same colour/type

Round 2:

Use different colours

Round 3:

Combine items (e.g. blend plasticine, mix together pasta, build something from lego)



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People First

Keeping People Safe Game



Get lost on the way



Fall over and hurt self



Get caught in bad weather



People in the group laugh at you



The public find out who you are and bully you



You lose some data

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The discussion is upsetting



It is all too much



I feel embarrassed and uncomfortable



I'm tired out from all this work



I feel triggered



Someone found out something private about me

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Are these public or private knowledge?

- Your name
- Your favourite food
- Your age
- Football team you support
- Your ethnicity
- Your national insurance number
- What jobs you have had
- Your blood group
- Your address
- What you saw on TV last night
- What you think of the prime minister
- Where you go to the GP
- Your religious beliefs
- Where you went to school
- Your date of birth

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Creative Inclusion Anonymity Exercise (University of Leeds)

Creative Inclusion

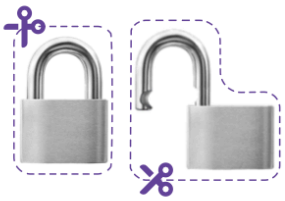
UNIVERSITY OF LEEDS

Anonymity — Keeping Information Safe

Aim: To explain that when we are involved in research, we might be asked to share information about ourselves. But we might want to keep some information about ourselves private.

Resources:

- ☐ Padlock (real or use our picture)
- ☐ Information ideas written on paper
- ☐ A hat



How to:

1. Pull pieces of information out of a hat.
2. Is this something it would be safe for anyone to know about you? Discuss as a group.
3. Sort the information examples into piles to show which information they would choose to share or not. Use the open and closed padlocks to represent these groups. This can be done individually or as a group.

Information ideas:

Your address	Your hair colour
Your favourite colour	Your favourite biscuit
Your phone number	Your full name

Extensions:

1. Repeat the activity with information that may be collected in your research — how will you keep this information safe?
2. If you will anonymise information, use this activity to discuss this (e.g. we will ask for your name, but we won't tell anyone else your name — you can make up a code name, a bit like a spy).

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Planning How to Make Your Research Project Safe (Ethics)

Project Details

	**1.** What is the name of the project?	
	2. What is your name?	
	3. What is the name of the organisation you work for?	

	**4.** What is your email address?	

4. Please tick one of the boxes below if they apply to you:		
	☐ Do you work for the	What is your role?

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	University of Cumbria?	
	☐ Are you a student at the University of Cumbria?	What is your course?
	☐ Do you work or volunteer somewhere else?	Where do you work?

5. If you are a student at the University of Cumbria, please give the contact details of your supervisor:		
	What is their name?	
	What is the job?	
	What department do they work in?	
	What is their email address?	

	6. Has anyone in your research team done ethics training with the University of Cumbria in the last two years?

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	☐ Yes ☐ No

	7. Please tick if someone from the research team has: ☐ Read the University of Cumbria guidance on research ethics and integrity? ☐ Checked the research does not need ethical approval from the NHS or other organisation? ☐ Confirmed that everything in this form is true.

8. Please give the contact details of everyone else in your research project.



Name	Job Title	Email address

9. Please tick one of the boxes below to tell us about any research funding you may have received.

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<table>
<tr><td rowspan="4">
</td><td colspan="2">☐ The research is not funded and we do not expect any funding</td></tr>
<tr><td colspan="2">☐ We have applied for funding but do not have the result yet</td></tr>
<tr><td colspan="2">☐ We have got research funding.</td></tr>
<tr><td>If you have applied or won funding please give the name of the funder:</td><td></td></tr>
</table>

<table>
<tr><td colspan="3">10. Please name any other individuals or organisations involved in the research but who are not part of your research team:</td></tr>
<tr><td rowspan="4">
</td><td>Partner Individual or Agency</td><td>Role in the Research</td></tr>
<tr><td></td><td></td></tr>
<tr><td></td><td></td></tr>
<tr><td></td><td></td></tr>
</table>

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To be completed by the researchers		To be completed by the Research Ethics Panel
	11. Dates When will the project start? When will the project end?	11. Comment (if applicable):

12. Do any of the researchers need a DBS or other legal clearance to be able to do this research?		12. Comment (if applicable):
	☐ Yes ☐ No	

13. All ethics applications to the University of Cumbria need to be reviewed by a colleague. Please tell us who has reviewed your ethics form.	13. Does the peer-review process

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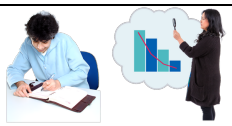
	Reviewer Name	Job Title / Role and Institution	Email address	appear suitable? Yes: ☐ No: ☐ Comment (if applicable):

Design and Recruitment

14. We would like to know what methods you are going to use in your research. Please tick all the methods you will use.		
	☐ Word or art methods (Qualitative)	
	☐ Number based methods (Quantitative)	
	☐ Both (Mixed Method)	
	☐ Questionnaires (Surveys)	

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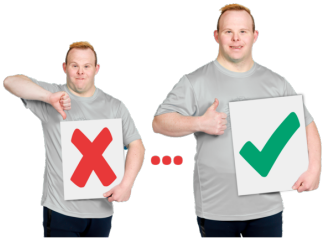
	☐ Interview(s)	
	☐ Group discussions (Focus Groups)	
	☐ Watching people (Observations)	
	☐ Social Media	
	☐ Improving practice (Action Research)	
	☐ Tests (Experiments)	

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	☐ Medical tests (Clinical Trial)	
	☐ Checking something works (Audit/Evaluation)	
	Other:	

	15. Please write a short summary of: • What the project is about • What you want to change Who will take part • How you plan to do it.	15. Comment (if applicable):

	16. Please tell us who can take part in your research project:	16. Comment (if applicable):

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	17. Please tell us about anyone that would not be suitable to take part in your research project:	17. Comment (if applicable):

	18. Please tell us the smallest number and largest number of people you would work with in your research project:	18. Comment (if applicable):

	19. How will you invite people to take part in your research project?	19. Comment (if applicable):

Information and Consent

	20. How will you make sure everyone who takes part understands what you are asking them to do?	20. Comment (if applicable):

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	How will you ask their permission to take part?	

	21. How will you let people know they can change their mind about taking part in your project?	21. Comment (if applicable):

	22. Please tell us if the people taking part will be able to change their mind about taking part afterwards? How long will they be able to change their mind? How will they let you know they have changed their mind?	22. Comment (if applicable):

Data Management and Participant Risk

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	23a How will you collect your information (data) – what tools will you use? 23b How will you work out what it means (analysis)?	23. Comment (if applicable):
References:		

	24. Will you tell the people taking part exactly what they will take part in? ☐ Yes ☐ No	24. Comment (if applicable):

	25. Have people with lived experience helped to design this research project? ☐ Yes ☐ No	25. Comment (if applicable):

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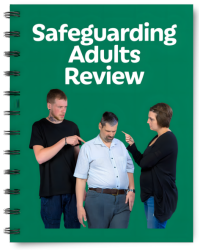	26. Might your researchers come across safeguarding or child protection issues in this project? ☐ Yes – please tell us more in the space below ☐ No.	26. Comment (if applicable):

	27. Please tell us about any risks you are aware of in your research project for the people taking part and the solutions you have thought of.	27. Comment (if applicable):

Risk	Solutions

	28. Are you giving the people taking part travel expenses or any other payments for taking part? ☐ Yes – please outline these below. ☐ No.	28. Comment (if applicable):

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Other Risks

	29. Are you being as kind to the planet as possible? E.g. not using paper or not travelling? ☐ No. ☐ Yes – please outline/justify below.	29. Comment (if applicable):

	30. Will any of the researchers need to work alone? ☐ No ☐ Yes - please describe any risks this may create	30. Comment (if applicable):

	31. Are there any other risks to the researchers, and if so what solutions have you thought of?	31. Comment (if applicable):

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Risk	Solution	

Data Storage and Deletion

	32. Will you make any recordings of the people taking part, i.e. using audio, image or video capture? ☐ No. ☐ Yes - please describe below.	32. Comment (if applicable):

	33. Please tell us how you will store information (data) and keep it safe.	33. Comment (if applicable):

	34. Will you share your data with any other researchers? ☐ No.	34. Comment (if applicable):

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	☐ Yes – please provide details below, telling us how participants' identities will be protected.	

	35. How and when will you destroy information from the people who took part?	35. Comment (if applicable):

Debrief and Dissemination

	36. How will you say goodbye to the people who took part so they are all okay? And how will you share the findings of your project with them?	36. Comment (if applicable):

Output	Details	
☐ Student thesis		
☐ Academic journal article(s)		

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☐ Conference presentation(s)		
☐ Report (for funders/stakeholders)		
☐ Exhibition/performance		
☐ Book chapter(s)		
☐ Long essay (Monograph)		
☐ Policy document		
☐ Educational materials		
☐ Other output(s) – please detail:		

	38. Are there any other risks you have not told us about? ☐ No. ☐ Yes – please provide details below.	38. Comment (if applicable):

Supporting Materials Checklist

Please attach all necessary supportive materials and indicate in the checklist below. An application cannot be reviewed without access to any key research instruments to be used. It is therefore expected that provisional interview and focus group schedules, draft surveys, screening tools (e.g. physical fitness assessments) etc. will be included either as a full appendix, or via an accessible link.

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	Supporting Material	Confirm
	Participant Information Sheet/Text	Choose an item.
	Consent Form/Text	Choose an item.
	Debriefing Sheet/Text	Choose an item.
	Invitations to take part	Choose an item.
	Other (such as interview schedules, questionnaires etc.). Please list below, adding rows if necessary.	
	1.	Choose an item.
	2.	Choose an item.
	3.	Choose an item.
	4.	Choose an item.

To be completed by the Research Ethics Panel:

Are the supporting materials satisfactory?

Yes ☐ No ☐

If 'no', please comment below:

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Session Four: Examples of Work

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Acceptable Researcher Behaviour

- Be respectful
- Don’t be rude
- Don’t swear
- Don’t lie
- Don’t harass people
- Think before you speak
- Speak up if you have been offended
- Be open with your feelings
- Tell someone if they are not polite
- Give them a second chance.

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Reducing the Risks of Taking Part in our Research

	• Risk	• Solution
	• Get lost on the way	• Give the address, directions, a map and additional support if needed
	• Bad weather on the way	• Wear protective clothing, use different transport or cancel the session
	• Fall over and hurt self	• Ensure spaces are safe with a health and safety check •
	• It's all too much • I feel triggered • I'm embarrassed • I feel upset • I'm too tired	• Plan sessions carefully • Get plans checked by someone with lived experience • Plan exercises with the right pace • Ensure there are break times • Give cards to signal if too much • Think before you speak • Have a quiet chill out space • Understand everyone's needs

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	• People in the group are laughing at me	• Put a group agreement in place and follow it •
	• I lost some data • The public found out who took part	• Collect and store data safely • Only collect what you have to • Get permission for everything you collect • Follow data protection rules • Report any loses to the people it involves and a safeguarding and data manager

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People First

Community Change Lab

Session Five: What is already known about our topic? (literature reviews)

Session Five: Session Plan

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Session Number: Five

Topic: What is already known about our topic?

Aim: Ensuring we start in the right place.

Time Needed	Activity	Resources
15 mins	**Welcome** • Check in – how have you been? • Recap on what we did last time – share group ideas or questions from the last session about ethics • What we are looking at in this session – working out what is already known on a topic and inviting the right participants to take part	Group rules
30 mins	**What is already known** Explain: We always try to make sure we start our research from where other people finished their last piece of research. This is so we don't waste time doing the same piece of research again. The posh term for this is a 'literature review'. That means reviewing everything that has been written about a topic. A literature review could include: - Books - Academic research papers - Magazine and newspaper articles - Webpages - Laws, policies and guidance - Social media. Task:	Flip chart Powerpoint slides Images Real items

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	Put each of these types of literature in a line to represent which you think are the most and least trustworthy. Ask why they do or don't trust them. They may say it depends….. which leads into the next exercise. Next, give the group some concrete examples – a real book, magazine and newspaper article, social media post, real research paper (or summary), real webpage and policy document and ask them to write down what makes each one of these concrete examples trustworthy or not. Explain: Here is an example of a literature review that was written about people with learning disabilities being co-researchers. https://onlinelibrary.wiley.com/doi/10.1111/jar.13100 The review was of all research papers written since 2000. They only found 17 that included people with learning disabilities in research. None of these projects allowed the people with learning disability to actually do the research. Instead they were asked to help: • Design the projects • Apply for money • Find participants • Share the findings. Task: Discuss what the group thinks about the findings from that literature review and what it means for your research. Explain:	Buzzers Papers to present

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	The first step in a literature review is to SEARCH for literature using some of the words from your topic map. The second step is to work out which literature you TRUST using the criteria for good literature. Finally you SUMMARISE what the different pieces of literature say.	
15 mins	Break	
45 mins	**Paper's Got Talent** We've done the first step for you finding some different pieces of literature on XXX (the group's research topic). Task: Papers Got Talent Game We're going to present a range of different papers to you as a panel of experts, just like Britain's Got Talent' (act out the papers for example: I am a Mencap webpage….. I was written in…. I say…….") The panel of co-researchers buzz the paper out if they don't think it is trustworthy. Task: Now work in small groups on each of the pieces of literature you thought were trustworthy and write out the key points that are important for your research project. Someone will then need to bring these together into one list which can then be the introduction to your research project.	
12.15	**Review** • Ask someone in the group to review the session with the reflection cards.	Reflective log

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	• Give support to complete individual evaluation in research passport. • Explain what is coming up in the next session (how to design data collection tools).	Research passports

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Session Five: Resources

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How to find out what is known about a research topic?

Doing a literature review

What is ‘literature’



Literature is any kind of reading material. This includes:

- Books
- Academic papers
- Magazine and newspaper articles
- Webpages
- Laws, policies and guidance.

How to do a ‘literature review’



1. Search for your topic words online
2. Decide which literature you trust
3. Summarise the things you think are good quality

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Which is most trustworthy exercise



Books



Magazines

I

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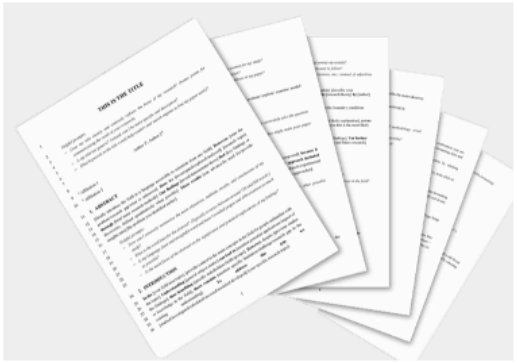
I



Webpages



Social media posts



Research papers

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Law, policy or guidance



Newspapers

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Reports

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Session Five: Examples of Work

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Advantages and disadvantages of different types of literature

	Advantage	Disadvantage
Books	Varied Lots of topics and points of view Text books to explain things Stories to give real life perspectives Many different authors	Not all peer-reviewed (read by someone else) Can be biased Can be made up and not real
Research papers	Based on real research Trying to find things out	The quality varies Might be paid to research something
Newspapers	Up to date Current issues Short to read, not too time consuming Pictures and stories Different view points	Only bad news Very biased Make money from sensational or exaggerated stories
Magazines	Pictures and text Summarised stories to easier to understand Different view points on a topic Professional magazines may be better than public ones	Make money from content – do not mean to be balanced Can be biased
Web pages	Quick information Easy to read Can be found via search engines so can find things quickly	Can be very biased Don't know who wrote them or why
Laws	The UK governments view Should be good	Might not be well evidenced Might not have been fully discussed

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		Might be the government's agenda, might not represent all MP's views
Social media	Wide range of public opinion Easy to read through	Too much content Unreliable Extreme

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Session Six: Finding people to take part in our research (participants)

Session Six: Session Plan

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Session Number: Six

Topic: How to find people to take part in our project?

Aim: Ensuring we invite the right people to take part.

Time Needed	Activity	Resources
15 mins	**Welcome** • Check in – how have you been? • Recap on what we did last time – share group ideas or questions from the last session about ethics • What we are looking at in this session – working out what is already known on a topic and inviting the right participants to take part	Group rules
30 mins	**Participants** Explain: When people take part in our research we call them research participants because they take part in your activities. Anyone can be a participant but some people might find it harder than others to take part. Task: Participant exercise Look at the pictures of research participants and think of the difficulties you might have in getting them to take part in your research. How can you contact them? What would they want to know about the project? Look at the pictures and discuss what particular needs each of these groups would have in order to join a research project of any kind. Task:	Flip paper and pens Participant pictures Flip chart and pens or cards

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	Thinking about everything that is needed to enable people to join a research project. Look at the statements and decide whether each one is: • Before the research event • During the research event • After the research event. OR Ask the group to think about what is needed at each stage and to write them up on three different flip charts.	
15 mins	Break	
	Task: Now we're going to make a list of all the people we need to invite to take part in our research. What do we know about each group? What places do we want them to come from? How can we get access to them, or get an invitation to them? Create a list of all your participants and how to contact them. Explain: Now we know who we will invite, we need to create some materials to invite them along. We need to write: • An advert • A participant information sheet telling them what to expect • A consent form so they can say yes or no • A thank you form with follow up support.	

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	Task: Use the examples to create your own participant information forms.	
15 mins	Review • Ask someone in the group to review the session with the reflection cards. • Give support to complete individual evaluation in research passport. • Explain what is coming up in the next session (how to design data collection tools).	Reflective log Research passports

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Session Six: Resources

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People who take part in your research

Participants

Participants



We call the people who give you information your ‘research participants’ because they are taking part in the research.

Anyone can be a participant.

Some people need more help than others to participate.

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Participant Exercise

Children



Police



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Ethnic minorities



People with a disability



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Older adults



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Session Six: Examples of Work

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How to prepare for research participants

Before the research activity	During the research activity	After the research activity
Information about: • What the research is about • What it is for • Who can take part • What will happen, where and when • What is provided • The support provided • Who the researchers are (photos?) • It is all voluntary and they can change their mind • How long they will be involved • How much we will pay and how • Send questions in advance Find out: • Ask if they want to be kept up to date with progress • Ask if they need any additional support /	• Comfortable environment for group • Consider lighting, stim toys, snacks, drinks, breaks • Make everyone feel involved and comfortable • Remind of what the research is about, how they will take part, what we do with their data, that they can stop whenever they like • Remind that if they disclose a safeguarding issue will need to pass it on • Provide a variety of ways to take part • Provide support materials – pictures, easy read etc. • Keep things focussed on the topic so time is	• Tell them how to keep up to date with the progress • Provide a debrief – if a heavy topic, provide an option for free counselling or wellbeing resources • Let them know how to change their minds and the deadline for withdrawing • Provide access to topic related resources • Inform participants how their data will be used and shared • Let them know of any changes to use of their data • Ask the participants if they can be identified in any way from the data collected and redact / alter it accordingly

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reasonable adjustments / personal emergency evaluation plan Room set up: • Book rooms – quiet and comfy, soundproof	managed and so people don't get confused • Keep answers simple, one thing at a time • Make sure everyone understands the next steps	• Make sure necessary payments are made • Check contact details.

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Our Easy Read Participant Advert

<table>
<tr><td colspan="2">Helping Everyone Access Healthcare
A research project designed and delivered by people with learning disabilities.</td></tr>
<tr><td colspan="2">About this research project</td></tr>
<tr><td></td><td>Hello! We are a team of eight people with and without learning disabilities.

We are based at People First in Carlisle.</td></tr>
<tr><td>
</td><td>We are doing research to find out how easy it is to access healthcare when you have a learning disability.</td></tr>
<tr><td></td><td>We think it is important to ask people with a learning disability what they think about this.
We are looking for people with a learning disability to take part in the research.</td></tr>
</table>

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	If you take part in the research, we will give you a gift voucher to thank you for your time.
If you want to take part in this research or want more information, please email xxxxx	

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Our Easy Read Participant Information Sheet

About this research project	
	Hello! We are a team of eight people with and without learning disabilities. The people in this project are xxxxx We are based at People First in Carlisle.
	We want to find out about how easy it is to access healthcare when you have a learning disability.
	We think it is important to ask people with a learning disability what they think about this.
Why do you want to talk to me?	
	Because you have a learning disability and we want to hear what you think about how easy it is to access healthcare.

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We want to find out whether people working in healthcare do anything special to help you access appointments and treatment.

These are called reasonable adjustments.

We hope that what you tell us may help to improve healthcare services.

This may help people with learning disabilities in the future.

Do I have to take part?



No. You can choose.

The information here will help you decide if you want to take part or not.

What will happen if I do take part?



Before we start, we will ask you to fill in a form to say you agree to take part. You can ask someone to help you if you want.



There are four ways you can take part:

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	You can have a conversation with two of our researchers about your experience of accessing healthcare. This is on the 13th October 2027 at 3pm for about half an hour. We will give you a Love2Shop voucher worth £15 for taking part.
	You can join a group discussion about your experience of accessing healthcare. This is on the 20th October 2027 at 3pm and will last for up to one hour. We will give you a Love2Shop voucher worth £30 for taking part.
	You can join us to make some pictures, stories or to play some games about your experience of accessing healthcare. This is on the 3rd November 2027 at 3pm and will last for one to two hours. We will give you a Love2Shop voucher worth up to £55 for taking part.

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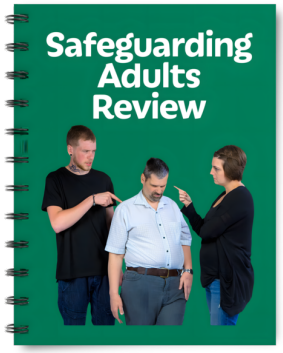
	If you come to any of these sessions we will ask you questions about how easy or difficult you find accessing healthcare.
	You can have someone you know with you if you want.
	We would like to audio record all the conversations we have on a recorder. This is so we can listen to you properly and keep an accurate record of what you say.
	If you tell us that you or somebody else might be in serious danger, we will need to tell someone about it. If this happens, we will talk to you first.
Do I have to answer all of your questions?	
	No. You do not have to answer any question you do not want to and you can take a break at any time. You can stop taking part at any time. You do not need to tell us why you want to stop.
What if I change my mind afterwards?	

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After you have taken part in an interview, you can tell us you have changed your mind about taking part for up to 1 month.

Please contact Kaz and tell her that you want to leave the project.

Kaz will delete all the information you gave us, including the recordings.

If you take part in a group activity, you cannot remove your answers after the activity has finished.

This is because we will not know which comments came from you and which came from other people in the group.

What will happen after we have talked to you?



We will write about what you tell us, this is called research findings.

We may quote things you have said when we do this. To quote means writing the exact words you spoke during the research session.

We will share what we write (our findings) with health services, researchers and others interested in our research.

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	We will send you an easy read summary about what we found out. We will also put this on our website.
	When we write our findings, we will not use your name or tell anyone you took part. But if we quote what you said there may be a small chance that someone who knows you will know who you are.
How will you store information about me?	
	We will store information from your interview, group discussion or creative workshop on a secure computer. This will include an audio recording of what was said and photographs of anything made. Only the researchers will have access to your information. We would like to store information from your interview until March 2027 when the project is finished. All electronic information (recordings and typed documents) will be stored safely on People First's, secure system

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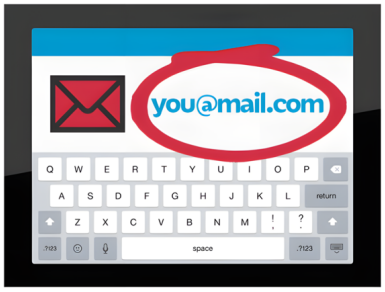
	Paper copies of written information will be locked away. All paper copies will be securely destroyed at the end of our project.
What do I get out of it?	
	To thank you for your time and for sharing your experience we will give you a Love2Shop gift voucher. We also hope you enjoy taking part and enjoy helping make healthcare better.
I have more questions…. Who can I ask? **I want to take part…. Who do I tell?**	
	You can talk to x or x This is our postal address: People First Conference Centre Milburn Street, Carlisle, CA2 5XB.
Who is funding and organising this research?	
NIHR | Research Support Service Specialist Centre for Public Health University of CUMBRIA	This research is paid for by the National Institute for Health and Care Research, Research Support Service. The researchers are based at the University of Cumbria and People First.

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People First	
Complaints:	
	If you want to complain, please email xxxx

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Our Easy Read Consent Form

	This form is to ask you to say yes or no to taking part in this research project.	
	Have you read the information sheet?	☐ Yes ☐ No
	Have you been able to ask questions about the project?	☐ Yes ☐ No
	Do you feel able to choose to take part or not?	☐ Yes ☐ No
	Do you agree to take part in a conversation?	☐ Yes ☐ No
	Do you agree to take part in a group discussion?	☐ Yes ☐ No

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	Do you agree to take part in a game or making a piece of art work?	☐ Yes ☐ No
	Do you know you can say no to any question?	☐ Yes ☐ No
	Do you know you can stop at any time?	☐ Yes ☐ No
	Do you know you can change your mind about taking part for one month after taking part?	☐ Yes ☐ No
	Do you agree to being audio recorded so we can hear what was said later?	☐ Yes ☐ No
(photo of team)	Do you understand that only the researchers will listen to the audio recording?	☐ Yes ☐ No

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	When we write our findings, we will not use your name or tell anyone you took part. But if we quote what you said there may be a small chance that someone who knows you will know who you are. Do you understand this?	☐ Yes ☐ No
	Do you agree that the researchers can use quotes from what you say in interviews, group discussions and creative workshops in presentations and publications?	☐ Yes ☐ No
	Would you like to be emailed the results of this research?	☐ Yes ☐ No
	What is your name?	

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	What is the date?	
	What is your email address?	
	Please sign in the box:	

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Our ‘Thank you’ and follow up information

	Thank you again for taking part in our research project.
	If you would like more information or help to access health care you can read these websites:
	NHS Guidance reasonable adjustments
mencap	Mencap https://www.mencap.org.uk/easyread/about-reasonable-adjustments
	If you would like to talk to one of the researchers about how you are feeling you can ask for a follow up conversation. We will try to help you as much as we can. People First contact tbc.
	You may want to book an appointment with your support worker or doctor to talk about how to get better help accessing healthcare.

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SAMARITANS	If you are feeling very upset or sad you might want to call the Samaritans on 116 123

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People First

Community Change Lab

Session Seven: Designing surveys and interviews

Session Seven: Session Plan

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Session Number: Seven

Topic: Designing surveys and interviews

Aim: Designing the best surveys and interviews we can

Time Needed	Activity	Resources
10 mins	**Welcome** Check in – how have you been? Recap on what we did last time – share group ideas or questions from the last session about our participants What we are looking at in this session – how to design and conduct surveys and interviews	Group rules
30 mins	**Designing questions** Explain: There are all sorts of different ways we can collect information (data), these are called data collection tools. We could use: Questionnaires (called surveys) Conversations (called interviews) Group discussions (called focus groups) Watching people (called observations) Creative methods (art, drama, poetry etc.) Discuss which would be best for each of your types of participants / research questions and why. We've got lots of questions with us today. We don't want you to answer the questions, we want you to help us sort the questions out. Some of them are a good fit for a research question, others are not.	Flip chart Powerpoint slides

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	Some ask for number answers and others ask for word answers. Some are open and others are closed questions. We'll explain what each of these mean as we go along. Task One – are these questions relevant? Give an example and explore what sort of questions you might ask and which questions fit the best (you might want to tailor these to your research topic or use the example provided). Explain: The difference between qualitative and quantitative questions with some examples. Task Two: Ask the group to come up with five examples each of qualitative and quantitative questions (or use the examples provided for them to sort into the two categories). Explain: The difference between open and closed questions and give some examples. Task Three: Give examples of a four different questions that have an open and closed version – ask the group to sort them into the right category. Explain: What a leading question is. Give an example and discuss how to make questions less leading. If the group is able explore the topic of bias and how it can show up – leading questions, listening to	

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	some people more than others, more time on a particular topic. Explore the need to be neutral, keeping your own views out of it.	
15 mins	Break	
30 mins	**Designing Questionnaires (surveys)** Explain: The first data collection tool we will look at are surveys. When we design questionnaires (surveys) we have to think about when to use an open or closed question and when to ask for a number or a word based answer. We want to ask questions that are most likely to get us the information (data) that we want. Task Four: Here is an example of a badly designed questionnaire (survey). What mistakes can you spot and how would you improve them? Task Five: discuss – What could a questionnaire (survey) help you find out on your research project? Who would it go to? What questions would it have in it?	
15 mins	Break	
45 mins	**Designing and doing research conversations (interviews)** Explain: The word 'interview' sounds really formal, but research interviews are usually very informal. We want to make the person who is taking part feel comfortable so they can answer our questions well.	Flip paper and pens

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	Today we're going to explore doing an interview through a role play situation. We'd like you to watch XXX do the role play once without interrupting. We will then do it again and will give you buzzers so you can buzz every time we do something wrong. Role play using the script. (You can also watch a video if you do not want to role play: https://www.youtube.com/watch?v=43vFqIaK-1E&t=12s) Task Six – from your experience today can you create a set of top tips for doing a good interview. Task Seven: discuss – What could a conversation (interview) help you find out on your research project? Who would you invite? What questions would you ask them?	Role play script Flip chart and pens or cards
15 mins	**Review** Ask someone in the group to review the session with the reflection cards. Give support to complete individual evaluation in research passport. Explain what is coming up in the next session (how to design data collection tools number 2 – focus groups and creative methods).	Reflective log Research passports

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Session Seven: Resources

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Designing Questions for Surveys and Interviews

What makes a good question?



Research question: How can GP appointments be better for people with learning disabilities?

What sort of questions might you ask?

Which questions fit?

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How easy was it to get an appointment?



What is your favourite food?



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Did staff explain things clearly?



How did you travel here today?



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What team do you support?



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About Number (qualitative) and word (quantitative) information

Number information (quantitative)

- Quantitative questions ask for answers that are in numbers.
- They ask for a quantity of something in a number, scale or ranking.





- For example, how many times did you visit your GP last year?





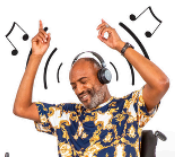
Word and picture information (qualitative)

- Qualitative questions ask for answers that are in words, stories or pictures.
- They collect a lot of information and provide a lot of detail.



- For example, tell me about your last GP appointment.





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How old are you?



What is your favourite food?



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How many people are here today?



How did you travel here today?



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How did you travel here today?



Did staff explain things clearly?



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What team do you support?



How many people in the UK support your team?



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What do you do in these sessions?



How often do you come here each month?



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Open and closed question information

Tell us more questions (open)



Open questions invite people to say a lot, to tell us more.

For example:

What are you enjoying about this session?

Yes and no questions (closed)



Closed questions only ask for a yes or no answer. These are not very helpful in research.

For example:

Are you enjoying this session?

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What is your age?



Do you have a favourite age?



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Tell me about your first time at People First.



Do you come to People First?



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Do you use public transport?



What do you like about public transport?



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What makes you feel most happy?



What makes you feel most happy?



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What is a leading question?

A question that might try to push someone towards an answer.

For example: The GP was very helpful wasn't she?

What might this question do?

How might we write a better question?

What do you think of this question?

Don't you think GP waiting rooms are too noisy?

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What is a questionnaire (survey)



- Asking people to answer questions on their own is called doing a survey
- You can create paper based or online surveys.

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A Bad Survey

Your Plans for the Future

1. How old are you?

   ☐ 11-13 ☐ 13-15 ☐ 15-17 ☐ 17-19

2. Do you know what job you want to do in the future?

   ☐ Yes ☐ Not sure ☐ No

3. Do you agree that it is best to go to university after school?

   ☐ Yes ☐ No

4. Do you disagree with the idea that university fees should not increase?

   ☐ Yes ☐ No

5. Do you think that it is important to choose your university based on its location and number of student societies?

   ☐ Not important ☐ A little important ☐ Fairly important ☐ Very important

6. What is important to you about your future job?

   ☐ High salary ☐ Flexible hours ☐ Location ☐ Personal interest

   ☐ Other, please state_____

Thank you for taking pary!

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Answers

1. Categories overlapping
2. Too vague – in the future could mean any period of time
3. Leading question
4. Double negative
5. Double-barrelled question – question mentions two things
6. Unclear how many categories meant to select – one or multiple?

   Other issues:
   - Tells participants to answer every question
   - Font randomly changes in the middle
   - Spelling error in 'Thanks for taking part!'
   - Question order – not clear why the questions about jobs are in different places

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What is an interview?



The word 'interview' sounds formal, but research interviews are informal.

They are not a job or social services interview. They are an individual conversation about what someone knows or has experienced.

We want to make the person who is taking part feel comfortable so they can answer our questions well.

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A very bad interview

Based on a You Tube Film by Professor Irene Tuffrey-Wijne

We're going to do some theatre for you, some acting, to show you a research interview and we would like you to see if we do anything wrong.

But don't say anything. We will act it once for you to watch and then we will act a second time for you to stop us and tell us if we make a mistake and what you would do better.

Interviewer: Hello, are you here for the interview?

Participant: Yes, I'm looking forward to…..

Interviewer: Great, I didn't think you would turn up. Well let me tell you a little bit about myself. I am a professor and a very important researcher, my name is Kaz, and I am important because I am the interviewer. And I am a professor of inequality at the University of Cumbria, and I work at People First. I do a lot and know a lot. And today I want to find out how we can make healthcare more accessible and so it that okay?

Participant: Erm, er, yes…. I guess so….

Interviewer: Great, can you just sign here then.

Participant: What am I signing?

Interviewer: Just the form to say I can talk to you, done it? Good. What's your name:

Participant: Julie Jones, Julie, nice to meet you (extends hand to shake hands)

Interviewer :(Ignores) Good, and what's your age?

Participant: How old am I? Is that relevant, do I have to answer?

Interviewer: Well it's a professional question so yes, how old are you?

Participant: Well, erm, okay, I'm 30.

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Interviewer: Do you live here in Carlisle?

Participant: Yes.

Interviewer: Good, and how often do you go to your GP?

Participant: Let me think, erm, its been a while, erm, I think it was maybe a year ago, maybe a bit more.

Interviewer: Would you say it was every week or every month?

Participant: No I'm saying its not that…..it was a year ago, but more than a year….okay let's just say a year ago…

Interviewer: Right, once a year.

Participant: (looks uncomfortable)

Interviewer: Now here is the main question.

Participant: right

Interviewer: How could staff at your GP surgery help you to access appointments and treatment more easily?

Participant: More access and more treatment…..hmm…. (interrupts)

Interviewer: I mean some people think that GP appointments are too short, or the doctor uses too much jargon, some people don't like waiting rooms, or there is no appointment available when you want it. And so people find access really bad. Do you find that too?

Participant: Er, yes…. I had that experience as well…..(interrupts)

Interviewer: So you think GPs need more appointments, longer appointments and quiet wating spaces?

Participant: Er, yeah, sure…..

Interviewer: And when you get to see the GP, what could he do better, or she, I mean I suppose it could be a woman!!

Participant: Yes of course it could be a woman….sorry what was the question again?

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Interviewer: What could doctors do differently to increase reasonable adjustments to make access easier?

Participant: Okay ….well I have a lot of ideas just thinking about the last time I went….(K ignoring, so pauses)

Interviewer: (Rolls hands, like go on…)

Participant: Well the last time I went I had a really bad health issue….

Interviewer: (phone rings and interrups the interview) starts answering… No, no go on I can do both.

Participant: And they were not really listening to me and were typing on the computer the whole time

Interviewer: (Starts sending a text)

Participant: And then I forgot what I was trying to say because they were writing on their computer, so I wish they would just stop and look at me.

Interviewer: Sorry, sorry, what was that last bit you said?

Participant: Erm, I wish they would look at me and not look at the computer all the time

Interviewer: (looks at watch and yawns)

Participant: So I wish…. Yeah….did you get my point?

Interviewer: (looks at watch) Yes, that's fine, thank you. Is there anything else you would like to say?

Participant: Did I answer any of your questions?

Interviewer: Yes, that was very good thank you. Thank you for your answers, that is us all done, thank you very much.

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Session Seven: Examples of Work

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Learning from the Bad Interview

Don't talk too much about who you are – give an appropriate introduction. Don't overshare.
Ask who the other person is, chat a little, make them feel welcome and comfortable.
Be friendly and open throughout the interview in body language and tone of voice.
Ask the person if they want any support or accommodations in the interview.
Introduce the consent form early on if it has not been covered already and allow them time to read it, or read it out to them.
Explain you will be recording or taking notes so they understand what you are doing. Alternate asking questions and taking notes as you have two people if that helps.
If someone asks why you are asking a question give a clear and simple explanation and let them know they do not have to answer it, particularly if it is private information.
Give the person enough time to think and to answer each question.
Check on the person throughout to make sure they are okay.
Don't ask leading questions.
Don't indicate which questions are the most important as it might stress the person out.

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Avoid your thoughts and beliefs showing up – this is about the person you are interviewing.
If you repeat a question don't reword it – say it the same way but perhaps give an example.
Manage your body language don't yawn or look bored.
Keep phones off or out of the room, do not look at any other devices.
Keep appropriate eye contact – match the eye contact of the person you are interviewing, or look at a point on the wall just behind them.
Say thank you at the end, remind them they can withdraw if they want to, give them the results and next steps and a debrief sheet.

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Session Eight: Designing group discussions and art and drama tools

Session Eight: Session Plan

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Session Number: Eight

Topic: How to design group discussions and art and drama tools

Aim: Designing the best focus groups and art and drama tools.

Time Needed	Activity	Resources
10 mins	**Welcome** • Check in – how have you been? • Recap on what we did last time – share group ideas or questions from the last session about survey questions and interviews • Check in on the project timeline • What we are looking at in this session – how to design and conduct focus groups and creative methods.	Group rules Timeline
45 mins	**Designing and running group discussions (focus groups)** Explain: When we get a group of people together for a research conversation we call it a focus group as the discussion is focused on your research topic and questions. Sometimes we do focus groups because we think people will be more comfortable talking together or because we want people to learn from each other as they discuss the topic. Sometimes we do them because you can talk to more people in a short period of time so they save money. Managing a conversation with a group is very different to managing one person.	Power point slide Buzzers Research questions

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	We're going to have a group discussion today about the topic of our research. You will take it in turns to ask one of our research questions and to manage how people answer. As we have the discussion X and X will act out some common problems. We'd like you to buzz and tell us what the problem is and how you would manage it. • Person talking too much – how to interrupt • Person who says nothing – how to draw in • Two people who argue – how to reconcile • Safeguarding disclosure – how to manage • Two people know each other really well and keep chatting quietly together • Someone gets really angry • Someone gets really upset • Someone is just there for the money. Task: Get the group to design a 'top tips' sheet for running focus groups. Task - discuss: How could a group discussion be useful in your project? If you used a group discussion, who would you invite and what would you ask them?	Flip paper and pens
15 mins	Break	
60 mins	**Designing and using arts and drama tools (creative methods)** Explain: Sometimes people find putting things into words difficult. An art or drama activity might help people to reflect and say the more.	Flip paper and pens Powerpoint slide

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	When we want people to think in different ways, reflect deeply, and have some fun, we use creative method. A creative methods could be art, dance, drama, music, poetry or puppetry. They all produce qualitative information. Today we're going to answer some research questions ourselves using some creative tools. Task: Either one exercise at a time, or as a choice for three different groups: 1. Journey map – draw a line across a piece of paper that shows your journey through this project so far. There may be ups and downs, straights and bends. Add images or words to show key points on that journey. 2. Lego – build a model that shows something about your new research skills and knowledge. Task - discuss the advantages and disadvantages of these techniques and how structured they are. Explain: All the issues experienced in focus groups can also show up here, and more (e.g. don't like drawing). Task: Design a 'top tips' sheet for creative methods sessions. Task – discuss:	Lego Art materials and stickers

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	How could a creative activity help your research project? Who would you invite along? What activity would you get them to do? What questions would that help you answer?	
10 mins	Break	
20 mins	**Watching people and reading documents** Explain: There are two ways to understand what people do in an organisation. Lets take the example of a doctor. We could watch a doctor to see what he does. This is called an observation. We can only watch what people do, watching people will not help us know what they think or feel. If we want to observe someone we usually write a list of all the things we want to see. Watching someone can be awkward – and they might change what they do because they are being watched. Task: Is there anyone we could watch to help us answer our research questions? What would we watch? How could we make it as natural as possible? Explain: Another way of understanding what people should do is to read the documents their organisation publishes. For example, we could read about what a doctor should do in his work policies. We could compare these to what the doctor actually does to see if there are any differences.	

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	The main problems with document reviews are getting hold of the documents and reading a lot of information. Task: Are there any policy documents or plans that would help you answer your research question? How would you get hold of them? How would you get information out of them?	
15 mins	**Review** • Give support to complete individual evaluation in research passport. • Explain what is coming up in the next session (planning how we will collect our data).	Reflective log Research passports

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Session Eight: Resources

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About Group Discussions (focus groups)



What is a group discussion (focus group)?

- A group discussion is often called a focus group
- It is a small group of 5 to 10 people
- It is a discussion used to gather opinions, feelings, and ideas about a specific service or topic.

About Art and Drama Tools (creative methods)

What is an art and drama tool (creative methods)?



- Art and drama tools ask people to make, draw, dance, write, sing or act something
- These are called creative methods
- It is a way of getting people's opinions, feelings and thoughts that is not reliant on speaking.

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About Watching People (observation)

What is watching people (observation)?



- If you watch someone it is called doing an observation
- An observation involves watching to see what someone does
- You would make a list of everything you are looking for and tick it off when you see it. This is called a checklist.

About Document Reviews

What is a document review?



- You might want to read lots of documents in an organisation to find out what they say they do
- This might mean reading policies, or plans, or timetables
- You would make notes on what these documents said.

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Session Nine: Planning how we will collect our data

Session Nine: Session Plan

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Session Number: Nine

Topic: Designing how we will collect our data

Aim: Designing the best ways to collect our data

Time Needed	Activity	Resources
10 mins	**Welcome** • Check in – how have you been? • Recap on what we did last time – share group ideas or questions from the last session • Check in on the project timeline • What we are looking at in this session – designing our data collection tools	Group rules Timeline
45 mins	**Refresher** Explain: We have talked about different ways of collecting data: • Questionnaires (surveys) • Individual conversations (interviews) • Group discussions (focus groups) • Arts and drama tools (creative methods) • Watching people (observations) • Document review. We're going to remind ourselves about each one with a couple of exercises. Task one: If the group is large enough, split into pairs and review one way of collecting data each, or working as a group, list the advantages and disadvantages of each of these methods. Task two:	 Flip paper Matching exercise

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	Different ways of collecting data suit different questions. See if you can match the right data collection tool to the right question.	
15 mins	Break	
60 mins	**Designing our data collection** Explain: Let's now remind ourselves of our research questions and the people we thought we would want to answer them (our participants). We now need to think which data collection tool will help us to answer our questions and suit the people we want to take part. Task: Discuss which tool is best for each question and group of people. Design what each one will look like – how will you introduce it, what resources you need, what questions you will ask, and what you will do to wrap up.	Research questions Research participants Flip paper and pens
15 mins	**Review** • Give support to complete individual evaluation in research passport. • Explain what is coming up in the next session (working out what our data means).	Reflective log Research passports

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Session Nine: Resources

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Data Collection Matching Exercise

You want to know what different people think about public transport. You want to explore their experiences. You have a lot of time to do the project.		Conversation (interview)
You want to know what a lot of people think about public transport. You want to know about their shared experiences. You do not have a lot of time to do the project.		Group discussion (focus group)
You want to find out how often everyone in Cumbria uses public transport and whether they think it is good enough.		Questionnaire (survey)
You want to learn about the experiences of using public transport with people with low language skills.		Arts and drama tools (creative methods)

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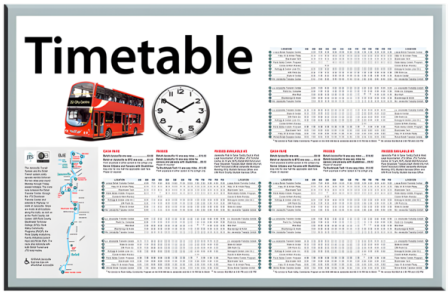
You want to see how often public transport is on time or late and how rude public transport staff are.		Watching people (observation)
You want to know how often buses are scheduled to run.		Read the timetable (document review)
You want to know who has researched public transport before and what they found out.		Read other research (literature review)

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Session Nine: Examples of Work

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Advantages and disadvantages of data collection tools exercise

Data collection tool		Advantage	Disadvantage
	Conversation (interview)	A person feels comfortable to say what they think You will have a set of questions you want to ask but can also follow new or interesting themes in the conversation You can collect detailed and individual views You can pay attention to body language, expressions and tone of voice as well as the words they use.	People might feel nervous about coming to talk with you People might say what they think you want to hear They are very time consuming.
	Group discussion (focus group)	People can build on each other's ideas People can learn from each other You will have a set of questions you need to follow, but also have space for new or interesting conversations that were not planned	It might be difficult to get people together at the same time People might not want to say what they think in front of other people People might agree with one another and not say what they really think

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		You can collect lots of views in a short space of time.	It can be hard to record or write down what everyone says Managing a lot of people having a discussion can be tricky.
	Questionnaire (survey)	People can answer questions easily without having to meet a researcher A lot of data can be collected quickly The data is easy to make sense of (analyse).	People might not understand them People might not want to fill them in You only capture what people want to tell you and you miss out on expressions and tone of voice You can't add any questions to follow up interesting leads.
	Arts and drama tools (creative methods)	A person can spend more time thinking A person can enjoy what they do A person can express themselves without language.	People might feel nervous about making something It is difficult to draw meaning from what people make and do without a conversation about it.
	Watching people (observation)	You can see what people do in real life situations	People might feel nervous about you watching them

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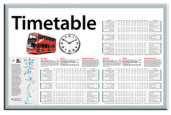
		You don't have to rely on someone telling you what they do.	People might change their behaviour because you are watching them They are consuming.
	Read the timetable (document review)	You can find out what different organisations say they will do.	It might be hard to get hold of documents Organisations do not always do what the documents say.

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Session Ten: What does the information you collected mean? (analysis)

Session Ten: Session Plan

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Session Number: Ten

Topic: Working out what our information tells us - analysis

Aim: Skillful and appropriate analysis

Time Needed	Activity	Resources
10 mins	**Welcome** • Check in – how have you been? • Recap on what we did last time – designing data collection tools • Check in on the project timeline • What we are looking at in this session – how to make sense of what we have collected	Group rules Timeline
60 mins	**Working out what our information says** Explain: Working out what our information says is called analysis. Analysing information (or data) is about sorting it into different categories and looking for patterns. A few sessions ago we looked at the difference between number data (quantitative) and word data (qualitative). People usually find that working out what number data says is easier than the word data, so lets start there! We're going to start with some data I've made up about ten different people who took part in a project. Task one: Count how many people are male and female?	Powerpoint slides Test data

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	What is the range of ages? Which is the most frequent age? Can you turn the number of each gender into a ratio, fraction and percentage? Can you turn either of these into a chart? Explain: Great stuff – so you have now learned how to work out: • A count of something (how many) • The range of something (start and end number) • The frequency of something (the most popular) • The percentages of something (how many out of 100) • How to make charts. Task: Now look at the number data you have collected and see how you can analyse them with these new skills. (May need more time)	
10 mins	Break	
40 mins	Explain: We're now going to look at how we sort out word data. When we look at words we are basically looking for patterns. To do this we 'sort' them in different ways. So let's have a go at sorting. Task:	Powerpoint slides

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	• Sort the lego as many ways as you can (colour / size / shape / function). • Each way you sort the lego is called a 'theme'. For example, sorting by colour is a theme. How many colours are there? Each one of these is called a category. • Which is the most and least common colour category? How many different ways of sorting it did you come up with? Are any better than others? (no) You will need to decide how to sort your data to best answer your questions. Discuss that now. Task: • When you have put your data into different categories and themes you need to build your research picture. • This is a bit like doing a jigsaw puzzle. • Some of you will have a picture – sometimes as researchers we know what picture we want to build and we fit the pieces together to make it (deductive analysis). • Sometimes you don't have a picture and you build it as you go along (inductive coding). Sometimes you have all the right pieces to build an image and sometimes you have some missing, or the wrong pieces. You have to decide what to do about that. Task: Build the jigsaws I've given you. • How do you think you will manage missing pieces – how many can be missing for you to still see the picture?	Lego Jigsaws

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	• What will you do with the wrong pieces – include them in some way or just leave them out? • Which is easier, having a picture or not? • What strategies did you use (e.g. looking for edges or pieces of the same colour)? Task: Now I've made up some data from the ten people we looked at before. How can you sort their words? What patterns can you see? You might have a group of words for the theme 'hobbies' – how many categories are there in that theme? You might have a group of works for 'enthusiasm'. How many categories are in this theme? Explain: This process is called 'thematic analysis' as you look for patterns and themes in your data. There are often different ways to make sense of the patterns, you need to decide which is the best one. Task: Now look at the word data you have collected and see how you can use analyse them with these new skills. **(May need more time)**	
15 mins	**Review** • Give support to complete individual evaluation in research passport. • Explain what is coming up in the next session (how to write up what we have found).	Reflective log Research passports

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Session Ten: Resources

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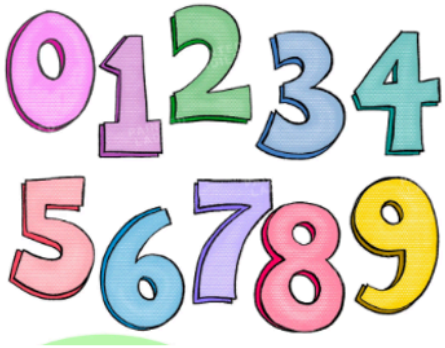
Working out what numbers mean



- Working out what numbers mean is called statistical analysis
- There are several ways you can look for patterns in numbers.

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Number Test Data

Person	Age	Gender
Person 1	23	Male
Person 2	24	Male
Person 3	26	Female
Person 4	21	Male
Person 5	23	Female
Person 6	28	Female
Person 7	20	Male
Person 8	27	Female
Person 9	23	Male
Person 10	22	Prefer not to say

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How many of something there is – (counting)

How many are there – (counting)



- Counting means how many there are.
- For example, if you were looking at gender you would count how many people were men or women.

How spread out the data is (the range)

How spread out is the data (range)

Youngest					Oldest
10	21	32	41	55	60

This data ranges from 10 to 60.

- Looking at the range means you say what the smallest and largest numbers are in the data you have collected.
- For example, if you were looking at age you would state the youngest to oldest age of people – in this example 10 to 60.

Most popular thing (mode)

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The

Which is the most popular thing (mode)

Category	Frequency
10-19	0
20-29	1
30-39	3
40-49	7
50-59	9
60-69	12
70-79	7
80-89	3
90-99	1
	43

- If you have lots of different items, like ethnicity, you might want to know which is the most popular. This is called the mode.
- For example, if you were looking at ages you would see which age range included the most people.

The average amount (mean)

What is the average (mean)

Toy	Cost
Rabbit	£10
Train	£15
Ball	£5
Car	£10

- The average of a set of numbers is called its 'mean'.
- To work out the average (mean) add all the numbers together and divide them by the number of things you have.
- For example, the toys here cost £40. There are four toys, so the average cost is £10.

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How much there is of one thing (ratio)

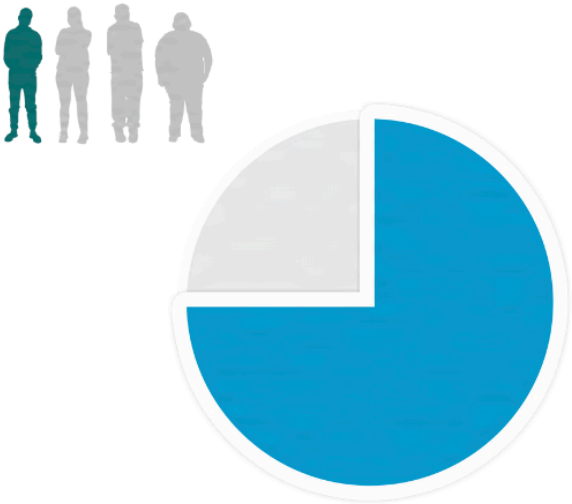
How much is there of one thing (ratio)



- You might want to know how many people have one thing compared to everyone else. You can do this as a ratio.
- For example, if you were looking at epilepsy, you might say one in four people has epilepsy.

How much of one thing is there (fraction)

How much is there of one thing (fraction)



- You might want to know how many people have one thing compared to everyone else. You can do this as a fraction.
- For example, if you were looking at epilepsy, you might say one in four people, or a quarter of them has epilepsy (1/4).

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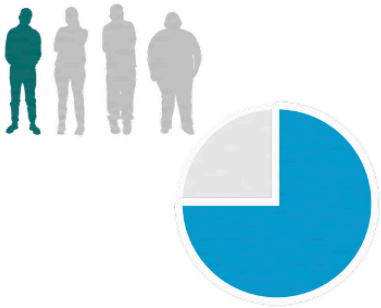
How much is there of one thing (percentage)





- You might want to know how many people have one thing compared to everyone else. You can do this as a percentage.
- For example, if you were looking at epilepsy, you might say one in four people, or a quarter of them has epilepsy, or 25%.
- To work out a percentage, divide the number of people with epilepsy with the total number of people and times by 100.

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How to show your data in rows (table)

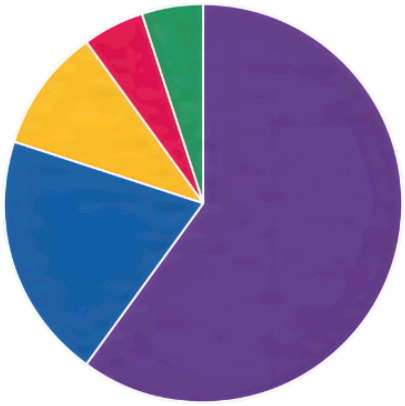
How to show your data in rows (table)

	Age	Gender	Epileptic?
Sue	10	Female	Yes
John	15	Male	No
Amir	12	Male	No
Mary	11	Female	No

- You might want to show the detail of the data you collected. You can do this in a table.
- A table is a set of rows and columns that show different things for different people.

How to show your data as a pie (pie chart)

How to show your data as a pie (pie chart)



- A Pie Chart is a round shape divided into pieces to show how much of each bit of information there is.
- It's called a pie chart as it looks like a pie that has been cut into different sized slices.

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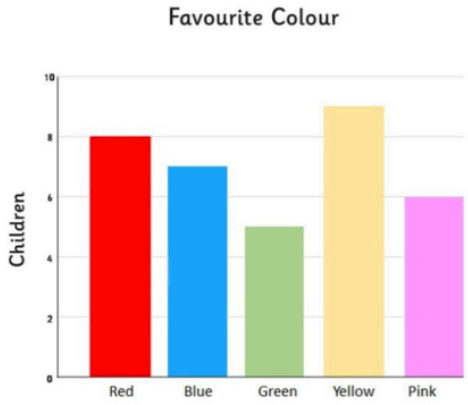
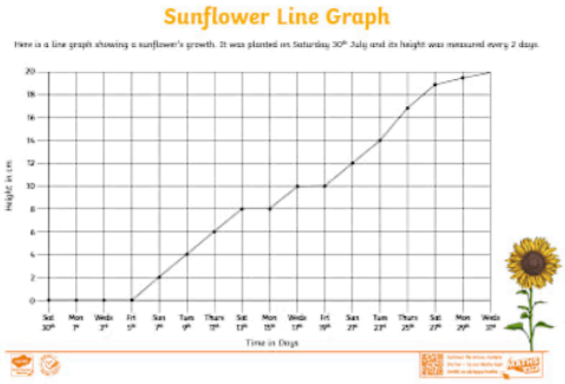
How to show your data in bars (bar chart)



- A bar chart (or graph) organises information into a picture using bars of different lengths.
- The length of these bars show the size of the information they represent.
- For example, here is a vertical bar graph showing the popularity of different colours among a group of children.

How to show your data as a line (line graph)

How to show your data in a line (line graph)



- A line graph is used to show changes over time by plotting points and joining them with straight lines.
- It would be useful, for example, for showing changes in temperature through a day, or how a flower grows over time, or changes in number of population.

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Working out what words mean (thematic analysis)



- Working out what words and images mean is called thematic analysis
- There are several steps in looking for patterns in words and images.
- To do this analysis you have to have a written copy of everything that was said.

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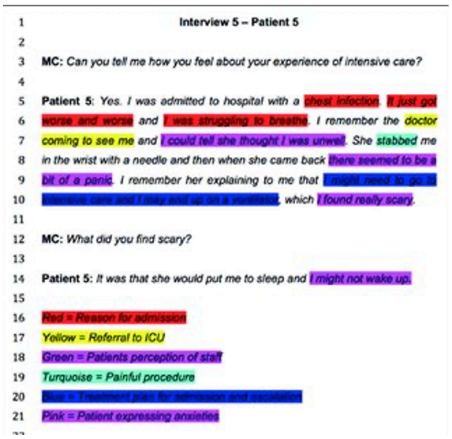
Writing out what people said - transcription



- If you have a recording of what people said you need to write it out on paper so you can work out the patterns in it.
- This is called transcription.
- It can take a long time.

How to work out what word-based data means



Interview 5 – Patient 5

MC: Can you tell me how you feel about your experience of intensive care?

Patient 5: Yes. I was admitted to hospital with a chest infection. It just got worse and worse and I was struggling to breathe. I remember the doctor coming to see me and I could tell she thought I was unwell. She stabbed me in the wrist with a needle and then when she came back there seemed to be a bit of a panic. I remember her explaining to me that I might need to go to intensive care and I may end up on a ventilator, which I found really scary.

MC: What did you find scary?

Patient 5: It was that she would put me to sleep and I might not wake up.

Red = Reason for admission
Yellow = Referral to ICU
Green = Patients perception of staff
Turquoise = Painful procedure
Blue = Treatment plan for admission and escalation
Pink = Patient expressing anxieties

1. Colour code all the words that are similar
2. Give each colour code a name – this will be a category
3. See how many categories you have and if any of them are similar – group them into themes
4. Write up how many themes you have and how many categories were in each one.

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Word Test Data

Person	Comments
Person 1	I love doing exercise
Person 2	I really like playing online games
Person 3	I love getting out into nature
Person 4	I'm always playing online games, I love them
Person 5	Walking is the best thing ever
Person 6	I like going partying at nightclubs
Person 7	I spend all my money on books and reading
Person 8	I think being social and meeting friends is the best
Person 9	I'm always out at exercise classes I love them
Person 10	I don't do anything.

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Session Eleven: Writing up what you found out

Session Eleven: Session Plan

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Session Number: Eleven

Topic: Working out how to write up our results

Aim: To create a high-quality write up.

Time	Activity	Resources
10 mins	**Welcome** • Check in – how have you been? • Recap on what we did last time – how to analyse our data • Check in on the project timeline • What we are looking at in this session – how to write up our research.	Group rules Timeline
60 mins	**Telling our story** Explain: Writing up your research is a bit like telling a story. We need to get the reader used to our story, tell them what we did, what we found, and how they can use what we did. The story has these five parts: 1. What is this about and why is it important (introduction) 2. What we did (method) 3. What we found out (results) 4. What does this mean (discussion) 5. Summary (conclusion). The British Journal for Learning Disabilities has Easy Read guidelines and a writing form for learning disabled writers to help us write each part of that story. Task: Working together as a group write down some key points that need to go into each section and what information (data) we want to use where. Now, working in smaller groups, draft each section. Swap sections and peer review it.	BJLD paper and writing frame Research results Powerpoint slides

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	If your group are able: In your peer review consider whether there is any bias or conflict of interest in your writing and how add a statement about them. Put all the sections together so you have a completed story.	
15 mins	Break	
60 mins	**How to publish it** Explain: Now we have got a story we can decide how to publish it. Task: Discuss how many different ways can you think of to publish what we have written. Explain: I've got some examples of how we might write up our research story for us to look at together. They are all examples of co-research with people with learning disabilities. When we look at each one, let's work out who would like each one (e.g. people with learning disabilities, parents, practitioners, managers, commissioners, academics) and its strengths and weaknesses. 1. Comic book - https://eprints.whiterose.ac.uk/id/eprint/237665/1/Keeping%20Blobs%20Blobby%20Comic.pdf 2. Film - https://www.facebook.com/1MLMC/videos/last-night-we-held-a-small-and-friendly-event-to-	Flip charts

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	launch-our-new-film-the-film-sh/814508961387937/ 3. Infographic - https://repository.lboro.ac.uk/articles/poster/DECODE_Infographics_-_9_in_10_people_with_learning_disabilities_are_likely_to_develop_more_than_one_health_problem_during_their_life_/30720137?file=59870834 4. Exhibition - https://feelingathome.org.uk/exhibition/ 5. Performance (song / dance / play) - https://www.youtube.com/watch?v=X23I3sOuMfU 6. Academic paper - https://pmc.ncbi.nlm.nih.gov/articles/PMC5060532/pdf/HEX-13-174.pdf Task: Having reviewed these different types of publication, what suits the research we have done and the people we want to reach? (discuss or vote depending on the needs of the group). Explain: We will now think about how to turn our story into the type of publication we have selected. Task: Agree what needs to be done? Who will do it? When by? N.B. You will probably need to plan an additional session to develop the publication you have chosen. You may need to discuss resources and whether you have the skills, time or money to produce a film, for example.	

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15 mins	**Review** • Give support to complete individual evaluation in research passport. • Explain what is coming up in the next session (reviewing what we have done).	Reflective log Research passports

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Session Eleven: Resources

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Part 3: Writing



The **British Journal of Learning Disabilities** asks people to write in a certain way.

You should write 5 steps.



These steps are:

1. What is this about? Why is this important?
2. What we did
3. What we found out
4. What does this mean?
5. Summary



You can use the **Form for Writers** to help you plan and write your article.



Next you can find out more about what to write in each step.

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Step 1. What is this about? Why is this important?

This is called the **introduction**.

In this step,:



- Write about why you did the project.

  OR

- Write about why you want to tell this story.



- Tell people what the **article** is about



- Tell people why it's important

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Step 2. What we did

This is called the **method**.

In this step, you tell people what you did.

If you did a project, answering these questions will help you:



- Who did you talk to?



- Did people make their own choice about taking part?



- When did you do the project?



- What questions did you ask?



- Did you use easy read materials?

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Step 3 What we found out



This is called the **results**.

In this step, you tell people what you found out.



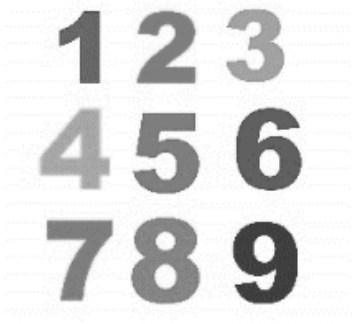
If you did a project, you can write about what people said.

OR

You can tell your story.



You could use words to tell people what you found out.



You could use numbers to tell people what you found out.

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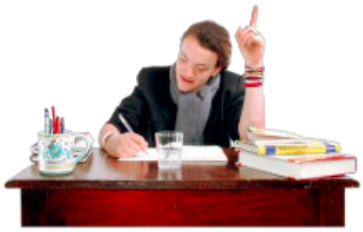
Step 4. What does this mean?

This is called the **discussion.**

In this step, you tell people what your project means.

OR

You tell people how your story can help other people.



You can tell people if you found out anything new.



You can write about your ideas for what to do next.



You could tell people your ideas about other projects you want to do.



You could tell people your ideas about how to make things better.

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Step 5. Summary

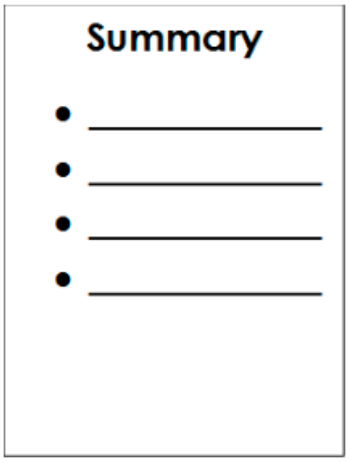
In this step, you tell people the most important things in your **article.**

This goes at the start of your **article**. But it is easier to write it last.



This part is short.

You only need to write a few sentences.



You could use bullet points.

Your bullet points could include:

- The most important points in the **introduction**
- The most important points in the **method**
- The most important points in the **results**
- The most important points in the **discussion**

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Writing Framework

	Section	Questions to answer
	Introduction	What is the project about? Why did you want to do this project? Why is the topic important? Who was involved in doing the project? Where did it happen? How long did it last? What did you aim to do?
	What we did (method)	What research activities did you plan? Who took part in the research? What questions did you ask them? What did they do? How much information did you collect? How did you make sense of the data? How did you write up your report? How did you keep everyone safe? Who was involved in each step?
	What we found out (findings)	What did the numbers you collected tell you? What did the people you spoke to say? How similar or different were the things you heard?
	What we think that means (discussion)	What do you think the project tells you? Why is that important? Who will it influence? What do you want to change as a result?
	Summary (conclusion)	In a few sentences, what did you do and what did you find out? What do you want people to do differently as a result?

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Personal Views (Bias)

Personal views (bias)



- Bias is when a writer lets their own personal opinions or preferences unfairly influence how they present information. Instead of giving a fair, full picture, a biased writer leans heavily toward one side of a story.
- Bias includes leaving out facts or evidence, using emotive words or making huge claims about a topic with no real proof.

Conflict of Interest

Conflict of interest



- A conflict of interest is when you have a hidden connection to the project that could bias your writing.
- This might mean you know the funder or publisher, or you are being paid, or you get something free in return for doing the writing.
- All conflicts of interest must be stated in the writing.

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Review form for different types of publication

Publication	Who would like this?	What is its strength	What is its weakness	Would we want to use this?
Comic 				
Film 				
Infographic 				
Exhibition				

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Performance 				
Academic paper 				

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Session Twelve: Sharing what you found out (dissemination)

Session Twelve: Session Plan

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Session Number: Twelve

Topic: Sharing our findings (dissemination)

Aim: To work out how to share what we have found out.

Time Needed	Activity	Resources
10 mins	**Welcome** Check in – how have you been? Recap on what we did last time – writing up our data Check in on the project timeline What we are looking at in this session – sharing our findings.	Group rules Timeline
45 mins	**Sharing our research findings** Explain: We've written up our research project into a format that we think people will like. Now we need to work out how to get our research to them. Task: Let's make a list of people in different jobs who might want to know about what we have done e.g. teachers, doctors, social workers, nurses. Now let's think about all the people who can make decisions and spend money that we might want to know about what we have done e.g. managers, decision makers, funders, policy makers. People who work in universities (called academics and researchers) might also be interested in what you have done so they can take it further.	Different evaluation forms

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	Are there any particular organisations or networks you think might be interested in your work, for example, Learning Disability England, or the Learning Disability and Autism Research Access group? Explain: Now we have a list of types of people, organisations and networks that we want to know about our research. Next we need to decide how we will get our research to them. Options include: • Email the research • Write to people • Invite people to an event about the research • Put the research on a website • Post the research on social media • Talk about the research at conferences • Publish an article in a newspaper or magazine • Publish an article in an academic journal. Task: What are the strengths and weaknesses of each of these for our project? Which will work best for the people on our list? How confident do you feel about each one? How skilled do you feel to do each one? What support might you need to be able to do these?	
15 mins	Break	
30 mins	**Let's do it!** Now we know who we want to tell and how we want to tell them we can write a sharing plan.	Flip chart.

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	Task: Write your sharing plan for your project. Now we have our plan we will take one section each and start to do all the actions.	
15 mins	**Review** Give support to complete individual evaluation in research passport. Explain what is coming up in the next session (reviewing how well we did)	Reflective log Research passports

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Session Twelve: Resources

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Sharing research findings (dissemination)

Sharing research findings (dissemination)



- Sharing your research with people is called dissemination.
- To work out a plan to share your research you need to know who to tell and how to tell them.

Working out who to tell (stakeholders)

Working out who to tell (stakeholders)



- The people who need to know about your research are called stakeholders.
- They could include: the people two took part, practitioners, managers, commissioners, politicians, funders and academics.

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Working out how to tell them (communication channels)

Working out how to tell them (communication channels)



- The different ways of telling are called communication channels
- These include; events, newspaper articles conferences, websites, emails, letters, exhibitions etcetera.

Writing a sharing (dissemination) plan

A sharing (dissemination) plan

Who to tell	How to tell them	What to do
Social care workers	Presentation at a social care team event	Book a slot Prepare presentation
Academics	Present at an academic conference	Write abstract Submit abstract
People who took part	Email to them individually	Draft email Send to everyone

- Once you know who you want to tell and how you want to tell them, you can make a sharing (dissemination plan).

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Session Twelve: Examples of Work

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Accessing Healthcare Research Sharing Plan

Who to tell	How to tell them	What to do
Healthcare workers, managers and commissioners	Email	Email everyone who took part in the research
	Website	Put the research on the People First website
	Promote through the Integrated Care Board	Contact the research leader in the health board
Academics	Present at an academic conference	Find a conference Write a summary Submit abstract
	Write an academic paper	Write up our paper Submit to a journal
Families, friends and funders	Hold a celebration event	Write an invitation Write an invite list Book room and refreshments Plan what to say

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Session Thirteen: Did we do a good project? (evaluation)

Session Thirteen: Session Plan

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Session Number: Thirteen

Topic: Did we do a good job?

Aim: To evaluate how well we did in the project.

Time Needed	Activity	Resources
10 mins	**Welcome** • Check in – how have you been? • Recap on what we did last time – writing up our data • Check in on the project timeline • What we are looking at in this session – reviewing how well we have done in this project.	Group rules Timeline
45 mins	**What is a review (evaluation)** Explain: It is important to review our project to make sure we did a good job. This is called an evaluation. There are three different types of evaluation, and we will do each one. Evaluating how well we worked together (our process) Explain: First we're going to take a look at how well we worked together – this is called a process evaluation, as we review the process of co-research. Task: OPTION ONE: Use an evaluation form developed from the international listen, include, respect guidelines https://www.listenincluderespect.com/how-to-guides	Different evaluation forms

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	Answer all of the questions and give a reason for each one (you may need someone to write for the group for this activity). OPTION TWO Use an evaluation form developed from the Learning disability and Autism Research Access Group's (LARA) ACCESS guidelines. Answer all of the questions and give a reason for each one (you may need someone to write for the group for this activity). OPTION THREE (You can also develop a set of evaluation questions that reflect what you promised to do at the start of the project – this might be helpful if your project was funded and you need to report back to the funder).	
15 mins	Break	
30 mins	**Evaluating what changed for us and others as a result (our impact)** Explain: Now we're going to look at the impact of the project on each of us. This is impact evaluation. We may have learned about research, learned how to work together, learned about ourselves, gained confidence, practiced new skills and so on. We're going to evaluate what each of us has gained using a body map. Task:	Paper, pens, stickers.

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	Draw the outline of a body on a large piece of paper. Inside the outline add words, images or stickers to show what skills, knowledge, qualities, friends, and other things you have gained from the project. Finish with a group discussion of the individual strengths everyone showed, fully celebrating each person.	
30 mins	**Now putting it all together** Explain: We now need to put together our evaluation of how well we worked together and what we all gained. Let's write a few statements together that sum up everything we have talked about today. • How well did we work together? • What did we all gain? • How good or bad was the project?	Flip paper
15 mins	**Review** • Give support to complete individual evaluation in research passport. • Explain what is coming up in the next session (celebrating our achievements)	Reflective log Research passports

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Session Thirteen: Resources

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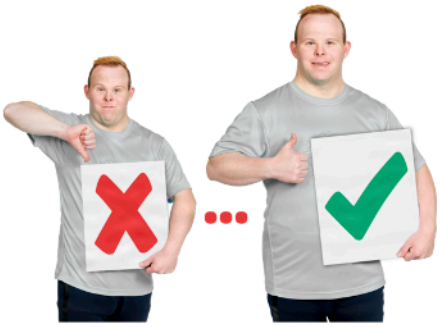
About Reviewing (evaluation)

Reviewing what we did (evaluation)



- Reviewing how well we did in the project is called an evaluation.
- In a review we think about what we did well and what we could have done better.
- At the end of that we decide if the project was good enough or not.

Reviewing how we worked (process)

Reviewing how we worked (process)



- When we think about **how** we worked together it is called a process review or evaluation.
- This will mean thinking about what people did and what made working together easy or hard.

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Include Standards for Projects - https://www.listenincluderespect.com/copy-of-planning-projects

1. How easy was it to physically access the project, for example, getting to and around the building?

	Very hard 	Quite hard	Okay	Quite easy	Very easy 
Tick					
Reason					

2. How accessible were the tools and resources?

	Very hard to access 	Quite hard to access	Okay	Quite easy to access	Very easy to access 
Tick					
Reason					

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3. How often did you use the 'ways of working' you agreed at the start of the project?

	Never 	Occasionally	Sometimes	Most of the time	Always 
Tick					
Reason					

4. How often did people get to design things and have choices?

	Never 	Occasionally	Sometimes	Most of the time	Always 
Tick					
Reason					

5. How many resources were there, like time and payment?

	Way too little 	Not enough	Adequate	Enough	Plenty 
Tick					
Reason					

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6. How much training and support was there to help people take part?

	Way too little 	Not enough	Adequate	Enough	Plenty 
Tick					
Reason					

7. How often did people in the group help to manage the project (e.g. deciding what you would do in the next session or deciding what resources would be helpful)?

	Never 	Occasionally	Sometimes	Most of the time	Always 
Tick					
Reason					

8. How often was accessible language used?

	Never 	Occasionally	Sometimes	Most of the time	Always 
Tick					
Reason					

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9. How well were the resources matched to the group?

	Very bad match 	Quite a bad match	Okay	Quite well matched	Very well matched 
Tick					
Reason					

10. How often were the group invited to help review and evaluate the project?

	Never 	Occasionally	Sometimes	Most of the time	Always 
Tick					
Reason					

Overall how well do you think the project did?

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The Learning disability and Autism Research Access Group (LARA)

ACCESS framework evaluation

1. ACCESSIBILITY – To what extent were information and activities easy to access?

1 	2	3	4	5	6	7	8	9	10 
Example:									

2. COMMUNICATION – To what extent was information easy to understand?

1 	2	3	4	5	6	7	8	9	10 
Example:									

3. CO-WORKING – Were there good working relationships and was everyone involved?

1 	2	3	4	5	6	7	8	9	10 
Example:									

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4. EXPENSES AND RECOGNITION – Was everyone paid and named in the final reports?

1 	2	3	4	5	6	7	8	9	10 
Example:									

5. STRENGTHS – To what extent were people's strengths recognised and valued?

1 	2	3	4	5	6	7	8	9	10 
Example:									

6. SUPPORT – To what extent was the right support in place for each person?

1 	2	3	4	5	6	7	8	9	10 
Example:									

How well do you think the project went overall?

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Reviewing what we gained (impact)

Reviewing what we gained (impact)



- When we think about **what** we gained from the project it is called an impact review or evaluation.
- This will mean thinking about what changed for people.

Body Maps

Body maps



- A body map is an outline of a body filled with words.
- We use body maps to help us think of and write down all the things we gained from the project.
- What new knowledge do you have? (head)
- What new skills do you have? (hands)
- What new places did you go to? (feet)
- What friends did you gain? (heart)

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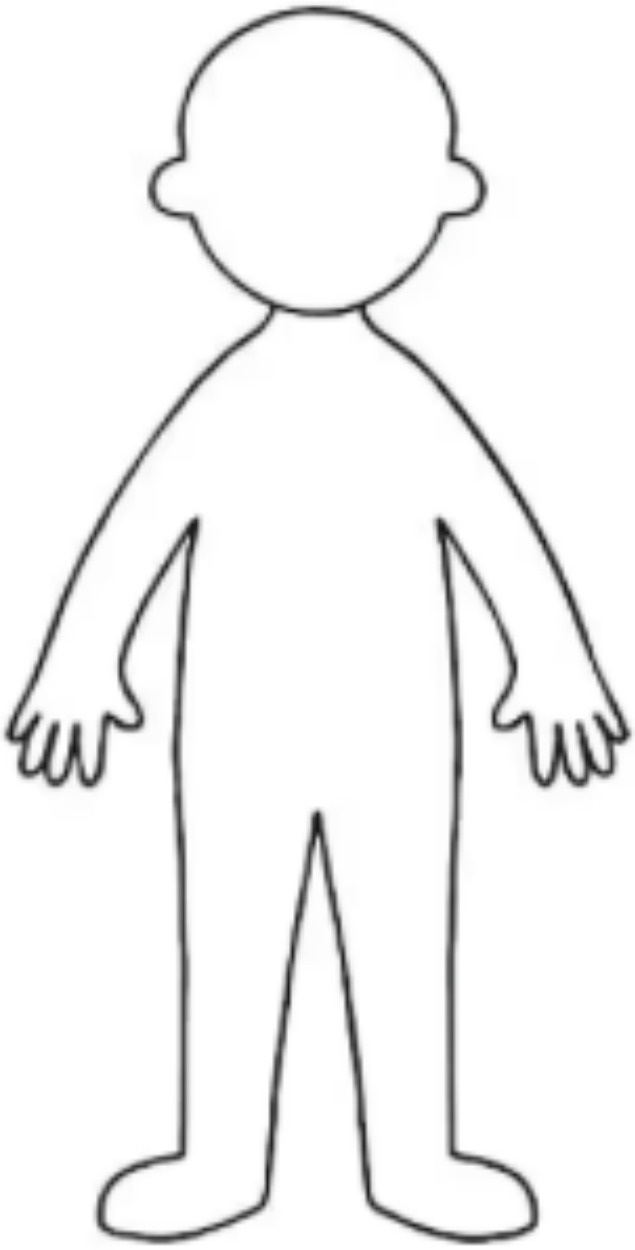
Body template



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Session Thirteen: Examples of Work

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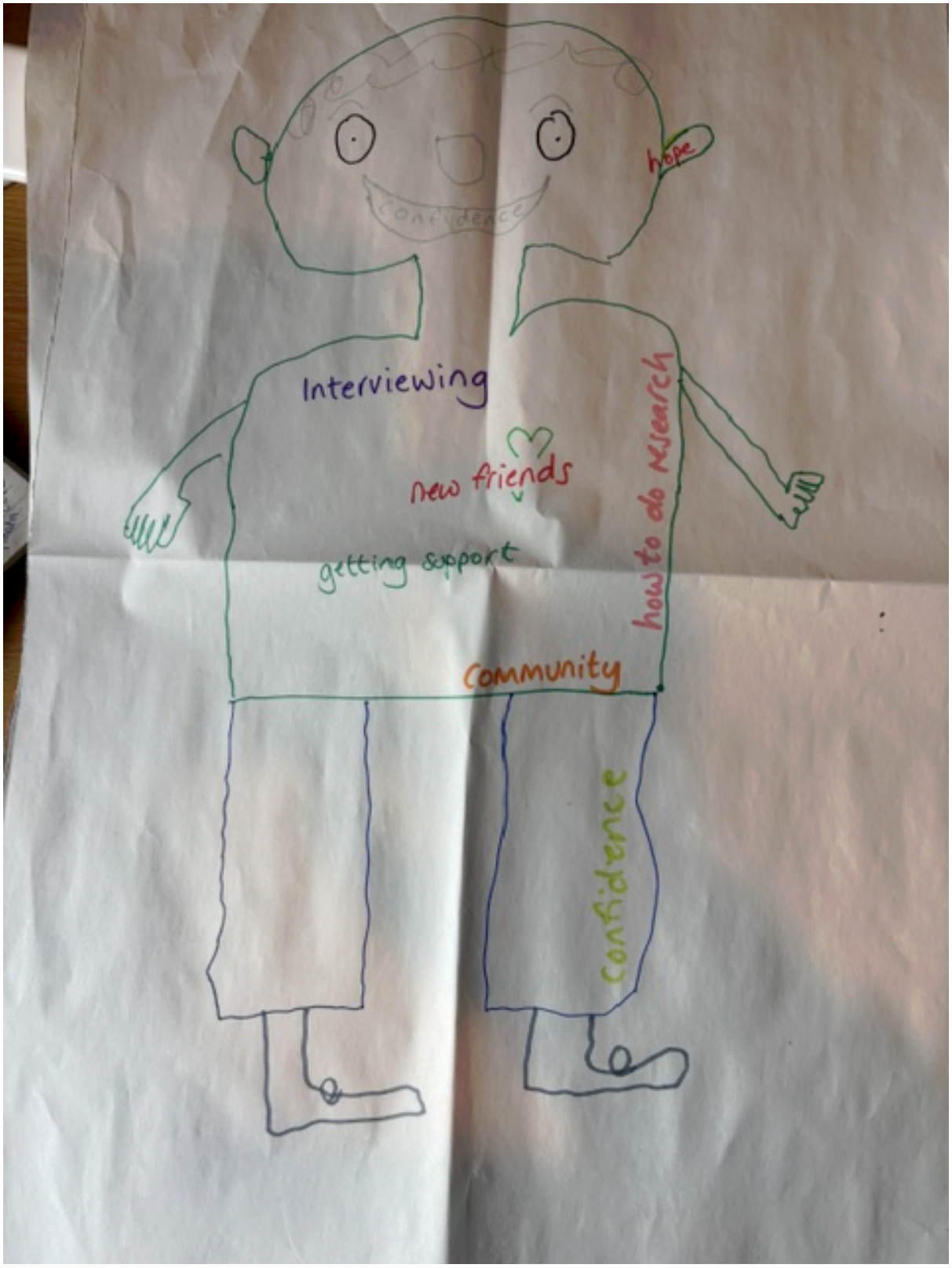
Examples of Body Maps



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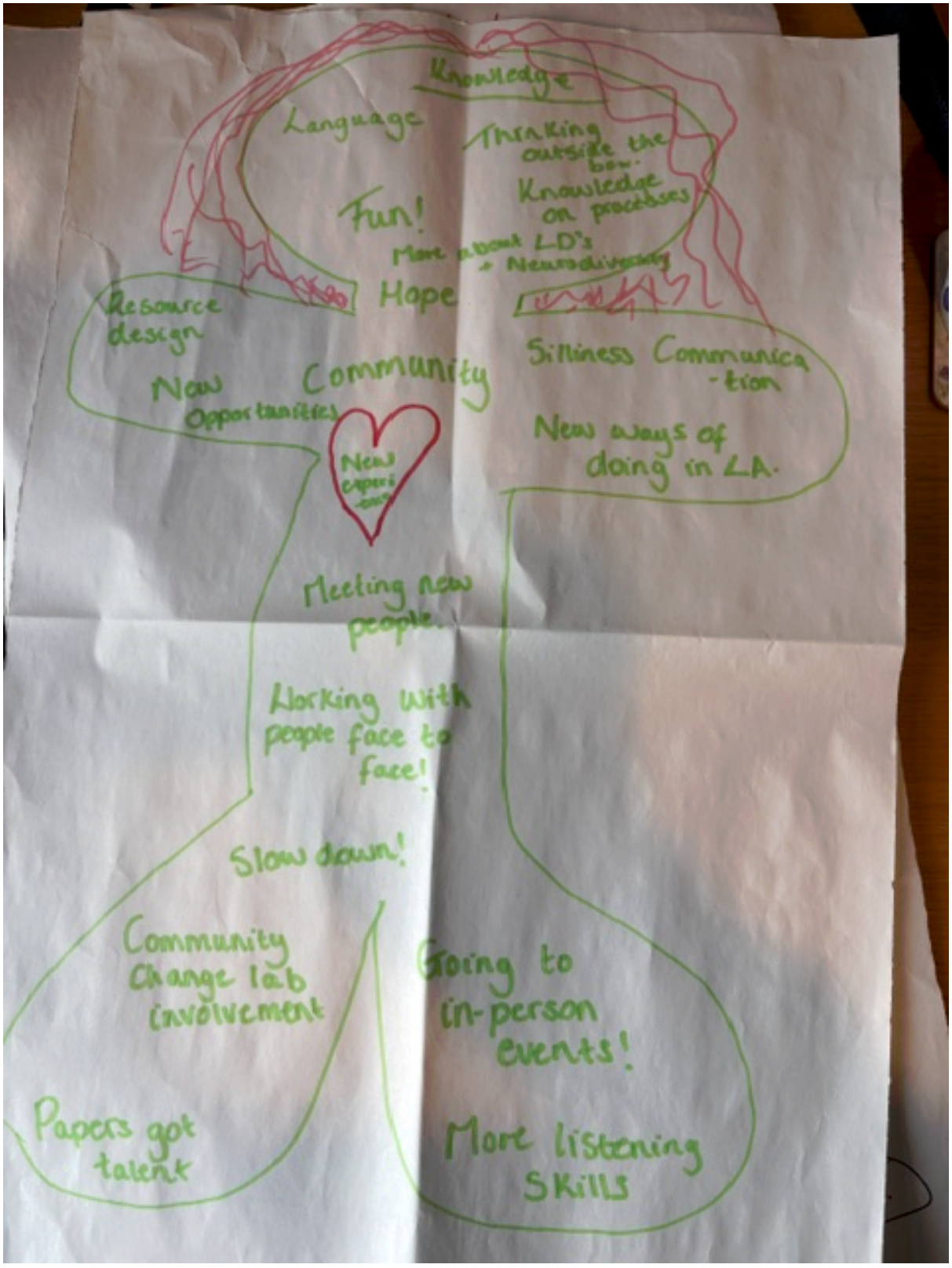

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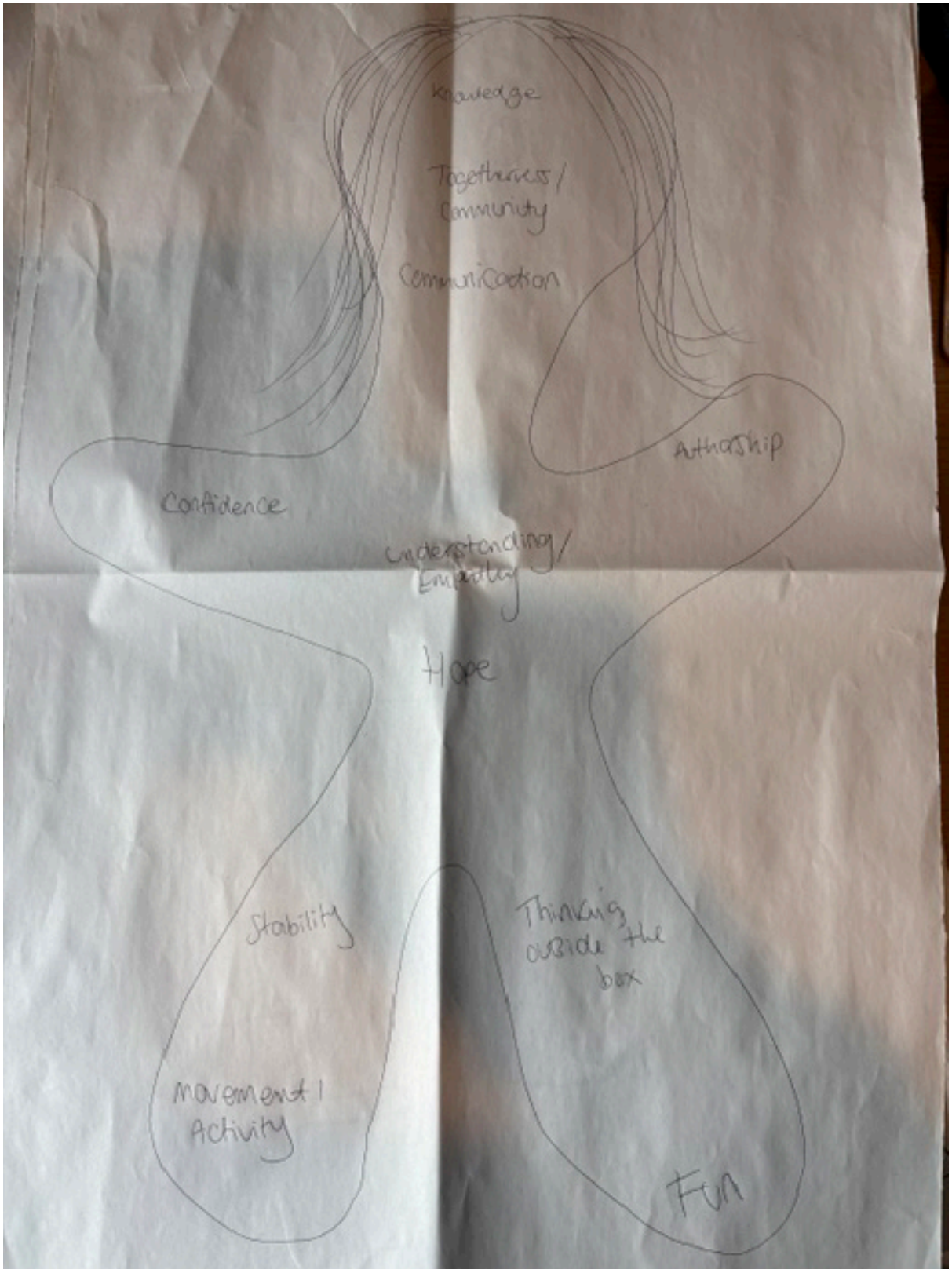

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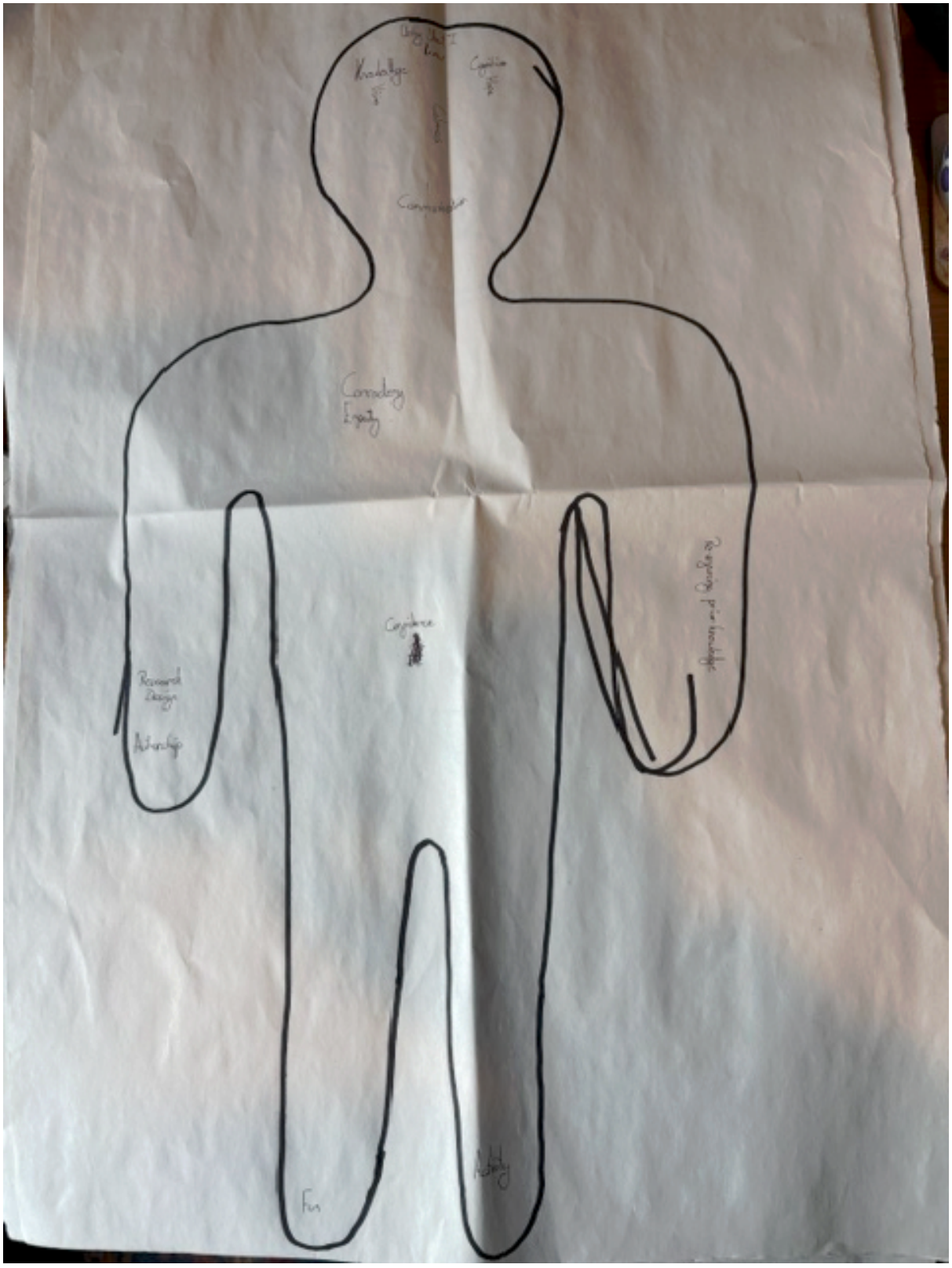

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Session Fourteen: Celebration

Session Fourteen: Session Plan

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Session Number: Fourteen

Topic: Celebration

Aim: To help everyone celebrate what they have done and to achieve closure.

Time Needed	Activity	Resources
15 minutes	**Welcome** Check in – how have you been?	Group rules
30 minutes	You will know your group and how to best celebrate what they have achieved – here are just a few ideas of how you might go about celebrating what they have achieved and giving them a good closure. **Recap** Use the project timeline, work you have done and any photos you have taken to review the project. Ask individuals for their best and worst moments. Ask individuals what they feel most proud of. Ask people when they gained the most or least. **Celebrate** Ask the group to list the skills they might have gained by taking part by looking at the timeline. Share that you have a research skills list for them each to take away – read the skills out. Share that you have a group photo printed for everyone so they can remember the project.	Timeline Project work Photos Skills lists Group photo Certificates Research passports

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	Give out an individual certificate, photo and list of skills that person has gained to a hearty round of applause. Remind everyone that they will be taking their research passports home with them today too.	
60 minutes	Break – if time and budget allow have a meal together. Share some food and drink and socialise.	Food and drink
30 minutes	**Next Steps** Discuss how the group could use their new skills and knowledge. Would they like to do more research? What sort? What on? How could we fund it? Would they like to use these skills in a job? What sort? What support would they need to find one? **Closure** One person holds the end of the wool. Pass the ball to someone that you want to say thank you to. E.g. thanks Sue for always listening to me. Sue puts her finger in the loop of wool and passes it to someone she wants to say thank you to, creating a spiders web of wool.	Ball of wool Key ring loops

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	When everyone has thanked everyone they want to, cut yourself out of the network, with 10cm loops. Tie this off and thread it onto a keyring loop. Go around and do the same for everyone else. You all now have a keyring memento of all the connections you made in this project.	

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Session Fourteen: Resources

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List of Research Knowledge and Skills

This person has worked in a co-research team to:

- Understand what research is and how it is carried out
- Map out a research topic and design research questions
- Identify what is already known about a topic through a literature review
- Plan how to keep everyone in the research project safe with research ethics
- Identify who would be good participants for the research study and how to reach them
- Understand different data collection tools, when to use them and how to design them
- Collect and save data from people with learning disabilities in response to the research questions
- Analyse the data to develop research findings
- Write up the research and disseminate it to key stakeholders
- Review whether they conducted a good research project or not.

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Part Two Research about co-research with people with Learning Disability

Title	Our easy-read summary of a review on inclusive research (A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: How are co-researchers involved and what are their experiences?)
Authors	Hewitt, O., Langdon, P., Tapp, K., Larkin, M.
Year Published	2023
Project	No Research About Us Without Us
Number of People	None
Topic or question	How many research projects about health and social care have involved people with a learning disability in making decisions about how the research was run since 2000?
Findings about Co-Research	There were only 17 articles. These projects asked people with learning disability to: • Help apply for money, decide what • Help design the project and how to do it • Think about what the findings mean • Help decide how to share the findings with others. None of the projects had people with learning disability involved in collecting or analysing data.

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Title	Co-research with adults with intellectual disability: A systematic review
Authors	Claudio Di Lorito1 | Alessandro Bosco1 | Linda Birt2 | Angela Hassiotis3
Year Published	2017
Number of People	None
Topic or question	What was the process of co- research in social and healthcare research.
Findings about Co-Research	There were only 13 articles. The co-research in these papers involved: • The culture of research had to change to enable inclusion – researchers being less in control, and people with learning disability being encouraged to think independently. • Whilst involvement in every stage of research was desirable, the limited ability of some people with learning disabilities means they may not be able to contribute to the more intellectually demanding tasks such as data analysis. • Co-research significantly increases the costs of research projects. • Training is of great importance including technical and relational skills. • Roles need to be negotiated for academics, people with learning disability and their support workers. • Good planning is needed to manage time, budgets, access, resources, all of which can be barriers to participation. • All people in co-research projects benefit from their engagement and may make the research more user friendly and insightful.

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Title	Our Recipe for Good Inclusive Research
Authors	Crowther, F., Beinke, H., High, R., Ru, C., Rillotta, F.
Year Published	2024
Project	PhD project.
Number of People	Three people with learning disabilities with one PhD student.
Topic or question	How do people with intellectual disabilities experience having or wanting pets.
Findings about Co-Research	• The team reflected that they each brought their own strengths to the project and have connected and made friendships. • Challenges came up and were overcome and the team concludes that people with intellectual disabilities are capable of leading research.

Title	In the physical to digital transition with friends – A story of performing inclusive research together no matter what life throws at you.
Authors	Cook, L., Rothstein, P., Emeh, L., Frumiento, P., Kennedy, D., McNichols, D., Orjiekwe, I., Overton, M., Snead, M., Steward, R., Sutton, J., Bradshaw, M., Jeffreys, E., Charteris, S., Ewans, S., Williams, M., Grierson, M., Chapko, D.
Year Published	2021
Number of People	Co-research team of 18 included 8 people with learning disabilities.
Topic or question	How do people really feel about learning disability and autism?
Findings about Co-Research	• Because of Covid-19 the team had to move their research online. • The relationships and trust between the co-researchers and their commitment to making a difference was vital to making the change to online working a success.

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Title	Co-producing ethics guidelines together with people with learning disabilities
Authors	Mary Bottomley, Jodie Bradley, Lisa Clark, Bryan Collis, Bojana Daw Srdanovic, Victoria Farnsworth, Annie Ferguson, Dan Goodley, Andrew Fox, Nikita K. Hayden, Charlotte Lawthom, Rebecca Lawthom, Claudia Magwood, Robert McLean, Ian Middleton, Alison Owen, Matty Prothero, Simon Rice, Simon Richards, Katherine Runswick-Cole, Kelly Scargill, Rohit Shankar, Toni Ann Wood
Year Published	2023
Project	Humanising Healthcare
Number of People	Does not specify, just says the team had “many” people with learning disabilities.
Topic or question	What should Participatory Ethics Good Practice Guidelines contain
Findings about Co-Research	The co-designed guidelines say: • Pay our research partners for their time. • Always start a research meeting with some friendly introductions. • Always use Plain English and supporting images. • We use Photosymbols. • Always start a research meeting with a reminder of what the research is. • Spend time explaining consent. • Always recap on previous meetings. • Explain the research context. • Spend time together understanding and co-producing research methods. • Make sure Information Sheets and Consent Forms are co-produced in accessible ways.

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Title	‘'Ethno...graphy?!? I can't even say it”: Co- designing training for ethnographic research for people with learning disabilities and carers
Authors	Magdalena Mikulak, Sara Ryan, Pam Bebbington, Samantha Bennett, Jenny Carter, Lisa Davidson, Kathy Liddell, Angeli Vaid, Charlotte Albury
Year Published	2021
Number of People	Team included 4 people with a learning disability
Topic or question	Exploring how people with learning disabilities and their carers can be better support in later life.
Findings about Co-Research	• Research training, appropriate for people with learning disabilities is needed to enable them to engage in research. • Ethnography is a type of research that can be easier to do other types of research. This is because ethnography uses the skills lots of us already have the following: watching, listening and talking to people.

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Title	Evaluation of a Co-Research Program: Optimising Engagement in Research
Authors	Ashley Scott, Sophie Rowland, Aniqua Mehdi, Eric Rubenstein
Year Published	2025
Project	DS-TO-THE-MAX
Number of People	7 co-researchers with Downs Syndrome
Topic or question	How well did our co-research project work?
Findings about Co-Research	• Team connection was important alongside the mutual recognition of each person's contributions and the use of multiple forms of communication. • Co-researchers reported their interests and experiences drove contributions, and they saw benefits from collaborating with each other and said they had • made decisions and felt heard and valued.

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Title	University Researchers and Researchers With Learning Disabilities Co-Interviewing as Part of an Inclusive Research Team
Authors	Dawn Cavanagh, Sue Caton, Umesh Chauhan, Chris Hatton, Christine Hutchinson, Matty Prothero, Nathan Rawcliffe, Francesca Ribenfors, Katherine Runswick-Cole
Year Published	2026
Number of People	Seven people with learning disabilities
Topic or question	How can we support people with learning disabilities to co-interview?
Findings about Co-Research	• Researchers with learning disabilities brought a unique perspective to the project due to their lived experience, which resulted in benefits for the whole research team as well as research participants. • Interview materials were relevant and accessible and there was often common ground, increased trust and a strong rapport with interview participants with learning • disabilities. Interviews were conducted with a health professional and person with learning disability together. • The team concluded that co-interviewing can be a more inclusive, equitable interview approach, leading to more relevant, meaningful and impactful research outcomes.

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Title	‘I’m a researcher!’ Working together to gain ethical approval for a participatory research study.
Authors	Maria Ham, Nicola Jones, Ian Mansell, Ruth Northway, Louise Price, Glayne Walker.
Year Published	2004
Number of People	6 people, three with learning disabilities
Topic or question	To understand with intellectual disabilities what they think about health and what helps them to be healthy, and to enable people with intellectual disabilities to develop their skills as researchers.
Findings about Co-Research	The team drew out advice for other co-research teams applying for ethical approval: • Give everyone the chance to take part in the process of developing the materials for the ethics committee and attending the meeting. • Work together as a team so that those team members with less research experience are able to contribute their own ideas and develop their own skills whilst learning from the experiences of others. • Attending the Ethics Committee meeting itself was important both in reinforcing the fact that people with intellectual disabilities are able to take on the role of researcher in a meaningful rather than tokenistic way, and in maintaining a sense of ownership over the project. • This will take training and preparation so everyone feels able to contribute.

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Title	The Conundrum of Training and Capacity Building for People with Learning Disabilities Doing Research
Authors	Melanie Nind*, Rohhss Chapman†, Jane Seale‡ and Liz Tilley
Year Published	2016
Number of People	None
Topic or question	To tease out models of training and capacity and the challenges for making this fit with the aims of inclusive research as training for inclusive research is more complex than it may at first seem.
Findings about Co-Research	• It would be all too easy for discussions about training for inclusive research to fall back on traditional roles regarding expertise, with knowledge and training in research skills flowing from the academic researchers to the researchers • with learning disabilities. • Partnerships, though, need to be reciprocal; training and capacity building, however it develops, should not undermine this.

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Title	Participatory data analysis: a step too far?
Authors	Melanie Nind
Year Published	2011
Number of People	None
Topic or question	Why is participation in analysis is often neglected?
Findings about Co-Research	• Some peoples life experience or impairments will mean they cannot participate in data analysis. • However, analysis can be made accessible enough to allow people to contribute and can include a range of approaches that are: informal and formal, • unstructured and structured, trained and untrained, explicit and implicit.

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Title	Co-researching with People who Have Intellectual Disabilities: Insights From a National Survey
Authors	Patricia O'Brien, Roy McConkey and Edurne Garcıa-Iriarte
Year Published	2013
Project	All We Want to Say
Number of People	20 people with learning disabilities, four university staff and three support workers.
Topic or question	Exploring what life was like in Ireland for people with intellectual disabilities
Findings about Co-Research	• 168 people took part in this national study. • Together the team grew into a community of researchers where the university co-researchers shared their research skills and people with intellectual disabilities • shared what it was like living with a disability. • People with learning disability improved the questions and gave invaluable insight to themes that arose in the data. • Learning disabled participants said they found it easier to be open with a learning disabled interviewer. • The learning disabled co-researchers also helped ensure the findings were accessible. Some of the co-researchers went on to other research roles.

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Title	Nothing About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up?
Authors	Erin Stack and Katherine E. McDonald
Year Published	2014
Number of People	None
Topic or question	To understand how well action research with adults with developmental disabilities reflect core action research principles
Findings about Co-Research	21 papers written since 2005 were reviewed. They found: • Most of the papers commenced with a motivation to empower people with learning disabilities, yet relatively few projects could be classified as high on the continuum of shared power. • Half of the papers described project outcomes that can directly benefit adults with developmental disabilities. • They conclude these studies often did not reflect core action research principles.

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Title	Peer- reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice?
Authors	Iva Strnadová, Jan Walmsley
Year Published	2017
Number of People	None
Topic or question	How is the voice of co- researchers with intellectual disabilities represented in peer- reviewed journal articles reporting on inclusive research
Findings about Co-Research	• 52 articles were reviewed. The review showed that although inclusive research has proliferated in the 21st century, more attention needs to be paid to the ways in which the voices of co- researchers with intellectual disabilities are heard in formal academic contexts. • Guidelines for future practice are offered.

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Title	Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis
Authors	Irene Tuffrey-Wijne and Gary Butler
Year Published	2009
Number of People	One person with learning disabilities and one academic.
Topic or question	To examine the potential contribution of people with learning disabilities to data analysis in qualitative research.
Findings about Co-Research	• Reflecting on one research project, the two authors conclude the researcher with learning disabilities coped well with the emotive content of the data and with the additional support provided. • He was able to extract themes that added validity to the overall analysis. • His contribution complemented those of the other members of the research team. • There were unexpected benefits, in particular, in terms of a more reciprocal and supportive relationship between the two researchers.

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Title	Developing a training course to teach research skills to people with learning disabilities: “It gives us a voice. We CAN be researchers!”.
Authors	Irene Tuffrey-Wijne, Claire Kar Kei Lam, David Marsden, Bernie Conway, Claire Harris, David Jeffrey, Leon Jordan, Richard Keagan-Bull, Michelle McDermott, Dan Newton, Diane Stapelberg.
Year Published	2020
Number of People	Ten people with learning disabilities who did a course at a university in London called ‘Learning how to do research’.
Topic or question	For the tutors to describe the course and for the participants to say how it felt.
Findings about Co-Research	• There were 8 training sessions with a focus on understanding the research process and gaining practical skills in collecting, analysing and presenting research data. • Training methods focussed on learning in a fun, experiential way. • The participants showed great enthusiasm and commitment. • The students went on to develop and conduct their own research project. They had increased confidence and new work opportunities arose for many of the students.

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Title	'Working together is like a partnership of entangled knowledge': exploring the sensitivities of doing participatory data analysis with people with learning disabilities
Authors	Elizabeth Tilley, Iva Strnadová, Sue Ledger, Jan Walmsley, Julie Loblinzk, Paul Anthoney Christian & Zara Jane Arnold
Year Published	2021
Number of People	Ten people with learning disabilities who did a course at a university in London called 'Learning how to do research'.
Topic or question	We present the experiences of two inclusive research teams (from the UK and Australia) who developed ways of working together to collaborate on data analysis. One project was an evaluation of a series of history workshops with young people with learning disabilities; the other was an exploration of effective models of peer support for parents with learning disabilities.
Findings about Co-Research	• The paper argues that the pressures of being seen to do 'good science' and 'emancipatory inclusive research' can serve to silence us when it comes to describing our experiences of participatory data analysis. • The desire to demonstrate rigour and efficiency in the academy can make it challenging to approach the sensitivities of collaborative interpretive work in an honest and reflective way. • Anxieties of power take-overs when working within an inclusive paradigm can further constrain our confidence to approach the process of data analysis in an open way. • But to engage with our co-researchers on these matters is a mark of respect.

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	They offer seven guidelines: 1. Plan ahead – seek to get the additional resource that participatory data analysis will require, both in time and money; 2. Collect the data with an awareness that you will be analysing it inclusively; 3. Build trust between members of the research team – this takes time and effort and needs to be accounted for when developing research proposals; 4. Be imaginative – think of different ways to present data to support co-researchers to engage with the interpretive process; 5. Be prepared to be selective in the data you work on together; 6. Recognise, and celebrate the unique expertise everyone brings to the task; 7. Create opportunities for reflexive conversations about the process.

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