



**Manchester  
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# Evaluation of the Experiences of the Greater Manchester Growing Older with Learning Disabilities (GM GOLD) Co-Researchers



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ambition  
for  
ageing



This research was funded by the National Lottery Community Fund through Ambition for Ageing programme. Ambition for Ageing is a Greater Manchester wide cross-sector partnership, led by GMCVO and funded by the National Lottery Community Fund, aimed at creating more age friendly places by connecting communities and people through the creation of relationships, development of existing assets and putting older people at the heart of designing the places they live.

Ambition for Ageing is part of Ageing Better, a programme set up by The National Lottery Community Fund, the largest funder of community activity in the UK. Ageing Better aims to develop creative ways for people aged over 50 to be actively involved in their local communities, helping to combat social isolation and loneliness. It is one of five major programmes set up by The National Lottery Community Fund to test and learn from new approaches to designing services which aim to make people's lives healthier and happier.



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The Greater Manchester Growing Older with Learning Disabilities (GM GOLD) team

# Executive Summary

This report is on an evaluation of the experiences of the 15 co-researchers who were part of the Greater Manchester Growing Older with learning Disabilities (GM GOLD) research team. Dr Sue Caton from Manchester Metropolitan University carried out the evaluation between November 2018 and February 2020. The evaluation draws on qualitative data collected from focus groups with the co-researchers.

The findings of the evaluation suggest that, pre-project:

- The co-researchers were recruited from different geographical areas across Great Manchester. Initially, most co-researchers only knew one or two other people in the research team.
- Most participants were unfamiliar with the term 'co-researcher' but did have aspirations for their roles in the project. Aspirations ranged from simply 'being involved' to specific aspirations such as asking interview questions and learning new skills. Participants talked about wanting to use their involvement in the project as a way to represent and promote the organisations they belonged to.
- The main motivations for wanting to be a co-researcher were around the opportunity to make new friends, talking to people, sharing their own experiences and becoming more confident.

Post-project:

- The co-researchers' aspirations for increasing confidence were met. Most co-researchers said that their confidence had grown as relationships had developed in the group enabling the sharing of power. As such, they developed the skills to speak up and make decisions.
- The mix of co-researchers with previous research experience and co-researchers with less experience was highlighted by participants as a strength of the project.
- The co-researchers appreciated being treated as individuals with unique skills. However, they did lack clarity about the role of a co-researcher and discussed group rather than individual roles.
- The co-researchers discussed the importance of the social aspects of the project for them as individuals. The importance of making friends and being part of a team mean that building and maintaining relationships happened during the duration of the project. Unfortunately, these friendships were yet to develop to the extent that the co-researchers connected outside of project team meetings.



# Introduction

The Greater Manchester Growing Older with Learning Disabilities (GM GOLD) project aimed to research ways to reduce social isolation amongst older adults (aged 50+) living in Greater Manchester. To meet this aim, 15 co-researchers who have learning disabilities were recruited to be part of the project team. This report describes the impact of taking part in the project on those co-researchers.

Co-production in research projects can be seen as a solution to criticism that research conducted in communities has often failed to meaningfully include the communities the research is relating to (Durose et al 2012). The concept of co-production includes not just research but also policy making and service delivery (Bovaird, 2007). Arnstein's 'ladder of participation' (1971) was an early model explaining the hierarchy of models of service development with the lower rungs of the ladder including therapy and manipulation moving up to informing and up again to delegated power. Co-production in research relates to the delegated power rung of Arnstein's ladder and builds on participatory research models. Co-production is varied in definition but includes concepts such as collaborative working, co-creating and co-delivering the project or research. In 2018, the NIHR organisation, INVOLVE (2018) produced guidance on co-producing a research project recommending that all parties work together to share the power and responsibility of generating new knowledge. Liddiard et al (2018) have detailed some of the politics and practicalities of co-produced disability research but there is a gap in the academic literature around the impact and experiences of co-researchers in taking part in a co-produced research project.

The GM GOLD project was co-produced with 15 co-researchers. The project was ambitious and unusual in the extent that it followed principles of co-production (e.g. to include data collection, analysis and dissemination) and in the number of co-researchers that were team members.

## Aims of the Evaluation

In order to evaluate the impact that taking part in the project had on the co-researchers, the evaluation aims were as follows:

1. To explore the expectations, aspirations and priorities of people with learning disabilities who are joining a research team.
2. To explore the experiences of older people with learning disabilities of being a member of a research team.
3. To describe the impact of being a co-researcher in an 18 month research programme, in particular in relation to social isolation.

# Methodology

The evaluation utilised pre and post project focus groups. Focus groups are a common methodological tool in qualitative research and have been identified as a legitimate methodological approach within area of research with people with learning disabilities (Gates & Waight, 2007). Sometimes defined as group discussions, other times the importance of the interaction between participants is emphasised (Kitzinger, 1995). The interaction between participants adds to the richness of data available in carrying out focus groups (Smithson, 2000).

## Pre-Project

In November 2018, 15 co-researchers took part in a focus group to discuss their aspirations and expectations of taking part in the project as co-researchers. The focus group schedule included questions about expected roles and motivations for taking part. The focus group schedule can be seen in Appendix One.

## Post Project

Fourteen months later, the follow-up focus groups took place. This time, two focus groups took place to make the group size smaller in order to facilitate discussion. The two groups were held on the same afternoon with four co-researcher participants (FG1) and six co-researcher participants and one supporter (FG2).

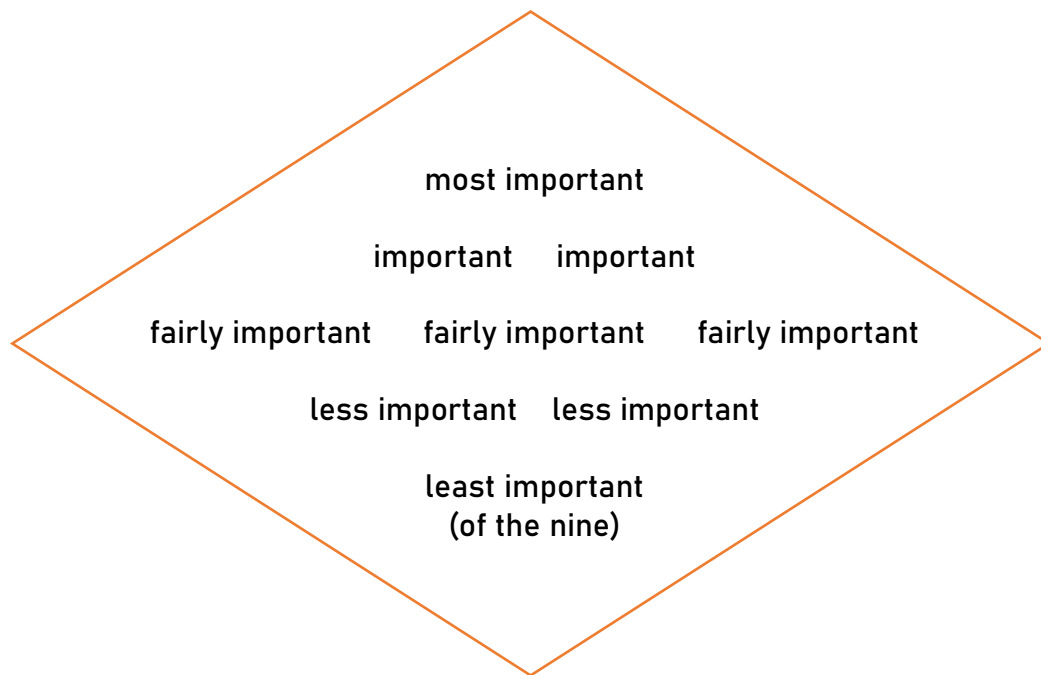
The post-project focus groups explored whether involvement in the project met the expectations of the participants, what were the benefits to taking part and ways that taking part in the project could have been improved. The interview schedule was largely developed based on the Involve Guidance on Co-Producing a Research Project (Involve, 2018) and can be seen in Appendix Two. The Involve guidance suggests that there are four key principles to coproducing a research project:

1. Sharing of power – the research is jointly owned and people work together to achieve a joint understanding Including all perspectives and skills – make sure the research team includes all those who can make a contribution
2. Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance
3. Reciprocity – everybody benefits from working together
4. Building and maintaining relationships – an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential.

Pre-and post- project focus groups included using a Diamond Nine card sorting activity (Clark, 2012). Participants were asked to identify nine factors that they

considered important. They were then asked, through group discussion, to rank the priorities from most important to least important. In order to make this activity accessible, there was a large poster sized piece of paper on the table with the shapes already arranged. Ideas were written on sticky notes and these were placed onto the paper identifying the highest priority, two high priorities, three middle priorities, two lower priorities and the lowest priority (so that the cards became a diamond shape):

**Figure One: Diamond Nine Ranking**



The discussion that took place during this activity highlighted justifications for choices and discussion of any disagreements.

## Ethical Considerations

Ethical approval for the evaluation was granted by the Health, Psychology and Social Care Faculty ethics committee at Manchester Metropolitan University. Participants were given easy-read Information Sheets and Consent Forms. These were also read aloud to participants. Participants were voluntarily taking part in the GM GOLD project but it was made clear that they did not have to take part in the evaluation if they did not wish to do so. At the pre-project focus group, four of the participants chose to sit on a separate table for most of the discussion but contributed to adding their ideas on sticky notes during the Diamond Nine activity.





# Key Findings

## Pre Project Focus Group

### Did you already know anyone from the group?

The co-researchers had mostly been recruited through self-advocacy groups across Great Manchester. Some had come from the same group so almost everyone knew one or two other people in the group. There were a few people who had known each other for over 20 years. Some had met in the past but not seen each other recently.

### What is a co-researcher?

Some members of the group shared their thoughts on what a co-researcher was but there was a limited response to this question with few people responding. Participants said it meant:

*“someone talking to people to see what they know and see what they’ll tell you”*

*“It is about information gathering”*

*“someone that works for like supporting someone like if they’ve got a disability or something and you can work with them to do the research with them”*

*“I think it’s partnership research as well so working with somebody who’s, because I’ve got partners who I work with...working with someone who’s got the same knowledge as you have”*

### What jobs you think you'd like to do to be involved in the project?

Participants were asked what roles they would like while working on the project and the answers to this suggested that the participants had greater understanding about the role of a co-researcher than the answers to the previous question suggested.

Some participants had quite vague aspirations such as:

*“I haven’t done this before but...I like to get involved”*

Others had more specific aspirations such as:

*“I’ll be the person asking the questions to other people.”*

*“I like to listen to people and talk to people and listen to people about jobs”*

Other participants talked about wanting to learn new things and to use their involvement in the project as a way to represent and promote the organisations of which they were members. Participants also talked about it being an opportunity to meet people from other self-advocacy organisations. Some of the roles participants mentioned were about directly answering the research aims. For example:

*“it's just isolation, I look at it that as you get older you get more lonely and there's nothing out there for people who are like, we've got...old age and fifty like sometimes we get forgotten so it's good to do this, this is the first research to try and see what, other people fifty and over getting involved in the community.”*

### **Why do you want to be a co-researcher?**

This question was explored using the Diamond 9 card sorting activity with the aim of deciding ‘what are the nine most important things that we want to get out of being involved in the project?’. This resulted in a detailed discussion about the groups’ aspiration.

Most of the discussion focussed around the impact on individuals from being part of the project. The group discussed the opportunity to make new friends, to talk to people, sharing their own experiences and becoming more confident. There was also mention of ‘travel training’ as coming to the research meetings would involve learning new travel routes.

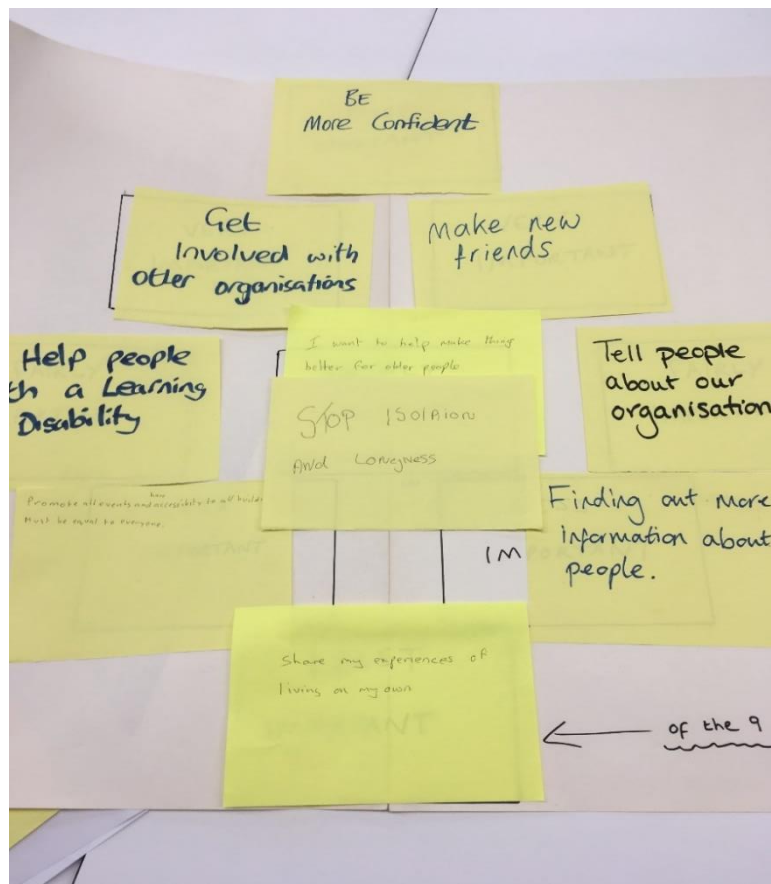
Some comments related to developing research skills such as finding out how to approach and talk to people, learning from other people, finding out information about people, learning about privacy and confidentiality and ‘asking the right questions’:

*“Because I think if you don't ask the right questions you won't get the right answer”*

To a lesser extent, the discussions also revealed community-spirited motivations and aspirations. The co-researchers wanted to tell other people about their organisations and hoped to attract more funding to support their organisations. There was also discussion around broader aspirations related to the aims of the project of helping people with a learning disability by reducing isolation and loneliness.

In the discussion about how to rank the ideas, the group decided that developing confidence, friendships and getting involved with other organisations should be at the top of the Diamond. These three suggestions were discussed considerably during the focus group. The ranking of the ideas further down the prioritisation process was probably less accurate as the Diamond ranking process was primarily

used as a discussion tool. Nonetheless, the ranking of ideas is shown below in Figure Two.



**Figure Two: Pre-Project Diamond Nine –  
What do you want to get out of being a co-researcher?**

## Post Project Focus Group

### What was the GM GOLD project about?

Post project, the co-researchers were able to articulate a clear understanding of what the GM GOLD research had aimed to achieve.

*“GM GOLD is all about people who are aging with a learning disability”*

*“To get people’s views about what it’s like being over 50.”*

*“I think it was about...looking at isolation and - isolation and loneliness.”*

### What is a co researcher?

Like the pre-project focus group, there were fewer responses to being able to explain what the term ‘co-researcher’ means but those that did respond highlighted the scope of the role.

*“It’s finding out things that people do and don’t do.”*

*“**WE** ask the questions - we got people...write the answers down.”*

### What jobs have you been doing as co-researchers?

The participants largely saw their role as being interviewers and listed the groups they had visited and the number of research interviews they had carried out at each group.

*“I’ve been talking to people what – like you say co-research, that kind of thing. I find it interesting really, what they were saying”.*

One of the two focus groups (FG2) discussed activities at the monthly team meetings, including contributing to data analysis:

*“We were put into groups weren’t we...one looking at transport, one looking at - we looked at the issues, what are the causes of isolation and loneliness and one of them was like the area you live in”*

*“And I think we got like a big piece of paper and you had to stick them on the big piece of paper if I remember.”*

### Have you had the power to make decisions?

In response to this question, co-researchers tended to talk about ways in which their confidence has grown while they had been part of the group and the development of relationships which in turn led to a more relaxed and enabling environment:



*“I think I learned, I learned a lot about different, different people, different cultures. I’ve learned a lot. Different things.”*

*“I think it’s helped me a lot to talk to different people.”*

The participants who had been part of the group who sat separately during the pre-project focus group commented on this and said that they now felt amongst friends and were happy and comfortable to participate.

A few of the co-researchers were experienced members of previous research teams, and board members of various organisations’ committees. As such, they were confident to speak up and make decisions:

*“Well yeh. And I have done at other places as well, apart from here.”*

*“I’ve been doing it nearly – over 28 years.”*

As one participant pointed out, the mix of people with experience and people with less experience was a strength of the project:

*“I think the thing that’s good about this, the whole GOLD project I think, it’s got that mixture of people who’ve got experience like myself with [name], [name], who’ve done all this before, whereas people like [name], [name] and [name] because they’ve done it, but not in – not such 100% focus in this group. So it’s letting that sort of idea, oh if they can do it, I can do it.”*

## **Have you felt like you’ve been an equal member of the GM GOLD team?**

In response to this question, there was a chorus of “yes” at both FG1 and FG2. Participants appreciated being thought of as individuals and referred to examples where the project lead had made specific arrangements for individuals. Some of the team also referred to having been proud to receive certificates for attending a university event.

People commented on feeling comfortable with each other having been nervous at first.

*“It’s so good!”*

## **What supports have been helpful?**

Participants were asked, in terms of doing the research and coming to the meetings, what had been helpful to support their participation. Participants said it was helpful that they already knew some members of the group.

At each team meeting, there were sensory props available and these were mentioned in response to this question. For example, there were jars with glitter in water to create a calming distraction. There had also been a discussion about

comfort zones and how learning new things sometimes places us outside of our comfort zone, this was also mentioned as helpful. A couple of participants at FG2 mentioned that it was very helpful to be sent minutes and agendas beforehand so that they had time to look at them before the meeting.

*“And it’s beforehand as well, because a lot of meetings I’ve been to you get them on the day and then you’ve no chance to read them.”*

## Has anything been difficult?

Most of the participants said they had enjoyed everything and did not find anything difficult. Where participants did talk about difficulties, they tended to mention situations where things had not gone according to plan. For instance, the film introducing the project did not play at some of the community visits due to technical problems and this was disappointing to some co-researchers.

The main difficulty that was raised was in relation to the co-researchers’ commitment to a project without having a clear understanding on whether it was likely to be a catalyst for change. One focus group member said that project interviewees had asked what would be done with the results and she was unable to tell them. Another participant similarly commented:

*“We’ve done all this sort of before when they’ve got promises, promises, and people have asked – people have asked I’ve said “what is your report” but nothing came out of it.”*

*“Cos a lot of the stuff that we’ve done, that me and [name] have worked on is more like a talking shop to them, to make them look glamorous”.*

## What’s been important to you in being part of the project?

This question was answered using the Diamond 9 card sorting activity and resulted in a discussion about the groups’ views on what had been important aspects of the project for them.

The co-researchers discussed the importance of the social aspects of the project for them as individuals, specifically around making friends and being part of a team.

*“Mixing with other people, talking to different people, making new friends. I enjoyed it”*

*“Like I enjoyed it, saw other people, talked to them, and it’s really good when I first came to the group I did not know anyone at all, cos I felt a bit, you know, with me being a bit quiet until I got to know [name] uh, I didn’t know everybody else, just, - you know what I mean?”*

A collection of fun activities were also mentioned as being important aspects of being involved in the project. Co-researcher enjoyed rewards such as getting certificates. They also enjoyed the sense of camaraderie in having GM GOLD badges and t-shirts. Fun events such as Christmas singing at the university and taking part in a

Christmas Quiz at the University's virtual reality cave were also important to the co-researchers.

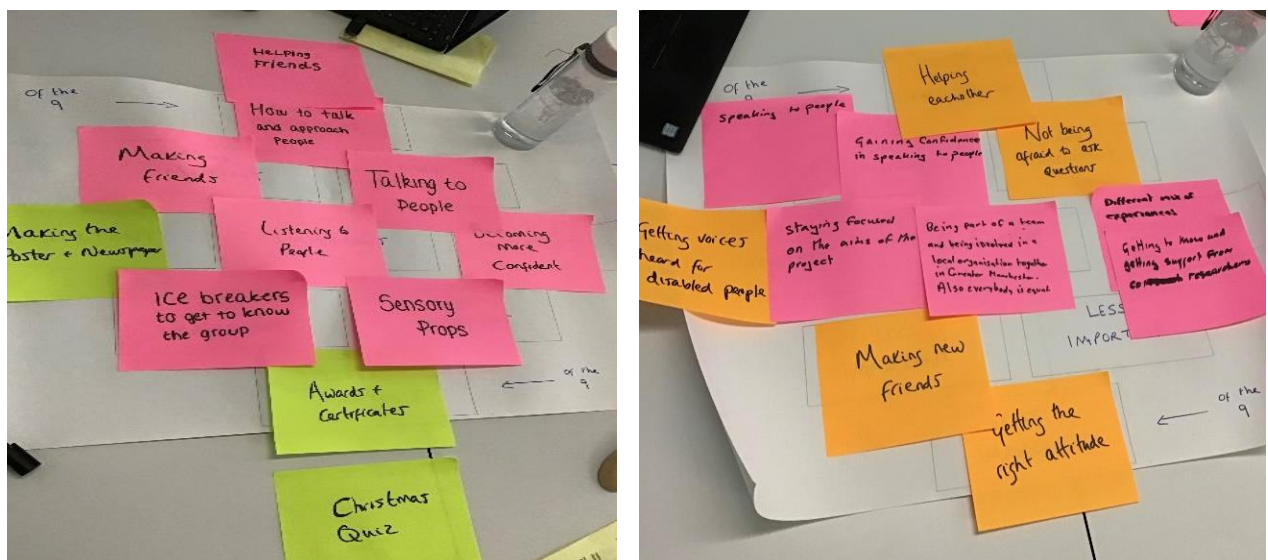
The co-researchers also talked about how the project has enabled them develop personally to become more confident, to learn new skills such as how to approach people, how to talk to people, how to listen to people and how to speak out for disabled people.

### Have you made friends with anyone in the group?

As this was a top priority at the pre-project Diamond 9 discussion, post-project focus group participants were asked about friendships they had made in the group. Unfortunately, no one had made a friendship with anyone else in the group that had extended to outside the group. One participant did join one of the other community groups from the team that he had not previously known about, so some relationships and friendships may still be developing.

Participants said that they would like to see each other outside of the group. When asked why people had not met up outside of the group, the answers mainly focussed around transport and travel.

*"I couldn't get out here on my own."*



**Figure Three: Post-Project Diamond Nine – What were the most important aspects of the project to you?**

## Limitations of the Evaluation

The author of this evaluation report gradually become more involved in the GM GOLD project and attended most of the monthly team meetings. While developing a relationship with the co-researchers was beneficial for the post project focus groups, the objectivity required for an independent evaluation was not as intended.

## Conclusions

Pre-project, the team of co-researchers were keen to be involved in the GM GOLD project and had aspirations for becoming researchers and developing research skills. The main motivations for wanting to be a co-researcher were personal and social: the opportunity to make new friends, talking to people, sharing their own experiences and becoming more confident.

Post-project the co-researchers provided evidence that their involvement in the GM GOLD project had aligned with Involve (2018) principles. The most significant way in which participants felt their involvement in the project had had an impact on them was by increasing their confidence, enabling their ability to speak up and share power. The increased confidence had come from learning new skills, and from feeling valued and the camaraderie of taking part in a team project.

The Involve (2018) guidance recommends a clarity over roles and responsibilities in order to unlock peoples' potential. The co-researchers did lack clarity about the role of a co-researcher and discussed group rather than individual roles. As stated in the Introduction, the GM GOLD project was ambitious in the involvement of 15 co-researchers and although this large number of co-researchers brings with it the strength of a diverse group in terms of experience, it also brings challenges in terms of support that would be required to facilitate the assignment of specific individual roles.

The social, relationship-building aspects of the project were important to the co-researchers. There was considerable discussion around the co-researchers being amongst new friends. Unfortunately, these friendships were yet to develop to the extent that the co-researchers connected outside of project team meetings. However, there were signs that these relationships were still developing and may in time lead to firmer friendships.

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# Appendix 1

## Focus Group Schedule

My name is Sue Caton. As you know, you are all co-researchers on the GM GOLD project. My job on the GM GOLD project is to find out what being a co-researcher is like for you. So I want to find out what you think it is going to be like, what you hope it is going to be like and then when the project is nearly finished, I will ask you to come and talk to me again to find out what it was actually like. We would like to record the focus groups so that we can make sure to remember what people have said. When we tell other people about what it has been like to be co-researchers we won't say who said what....no names will be used.

## Explanation of the process

Ask the group if anyone has participated in a focus group before. A focus group is a relaxed discussion designed to find out YOUR thoughts. I'm not here to tell you things – I want to know what YOU think. There are no right or wrong answers. You can disagree with each other, and you can change your mind. It is good if you talk to each other as we go along but please can I ask that you try to speak one at a time.

I think this should take less than an hour. Feel free to help yourself to teas and biscuits at any time and if anyone needs to pop out to the loo or anything that's also fine. Ask the group if there are **any questions** before we get started.

Before we start I need to ask you to fill in a consent form. This is one of these sheets that we can read through together. You can tick the boxes to say that you agree to take part and then sign your name on it.

### \*\*\*consent forms\*\*\*

At this point the **digital recorder is turned on.**

- So, first question, can I ask you how you found out about the GM GOLD project?
- Did any of you know each other before you started with GM GOLD?
- So, can you tell me....what is a co-researcher?
- What do you want to do while you are a co-researcher? What jobs do you think you'd like to do? (speaking to people, social media, collecting data, helping with data analysis, writing, sharing the research and its findings??)
- Why did you decide to become a co-researcher?

- We'd like to know what you want to get out of being a co-researcher. To do this we are going to do a card sorting activity! But don't worry, it's not hard! What we are going to do is have a chat about all the things you hope will happen because you've been a co-researcher on the project. To start with we will write them on these cards. Then once we've finished with our ideas, we will put them in order of how important we, as a group, think they are.

So, now we have them on the cards we need to whittle them down to nine cards and I want you to discuss amongst yourselves how to arrange them as follows in the form of a diamond:

Can you talk me through how you decided how to rank them?

That's wonderful, and that brings us to the end of the questions I had planned to ask you about. Does anyone have anything they want to add to the discussion at all? If not, thank you for taking part.

# Appendix 2

## Focus Group Schedule

As you know, you are all co-researchers on the GM GOLD project. One of my jobs on the GM GOLD project has been to find what being a co-researcher is like for you. Back in November 2018 when GM GOLD first started you had a conversation with me about what you thought it was going to be like and what you hoped it would be like. We put all the ideas down on post it notes and made a diamond to show what we thought was the most and least important things. So, now that the project is near the end, I want to talk again about what it was actually like to be a co-researcher. I want to record the focus groups so that we can make sure to remember what people have said. When we tell other people about what it has been like to be co-researchers we won't say who said what....no names will be used.

## Explanation of the process

To remind you about last time, a focus group is a relaxed discussion designed to find out YOUR thoughts. I'm not here to tell you things – I want to know what YOU think. There are no right or wrong answers. It is good if you talk to each other as we go along but please can I ask that you try to speak one at a time. I think this should take less than an hour. Feel free to move around if you need to and if anyone needs to pop out to the loo or anything that's also fine.

Ask the group if there are **any questions** before we get started. Before we start I need to ask you to fill in a consent form. This is one of these sheets that we can read through together. You can tick the boxes to say that you agree to take part and then sign your name on it.

### \*\*\*consent forms\*\*\*

At this point the **digital recorder is turned on.**

- 1) So, can you tell me.. what is the GM GOLD project? What was the project for?
- 2) What is a co-researcher?
- 3) As a co-researcher what have you been doing? ('including all skills - making decisions, speaking to people, social media, collecting data, helping with data analysis, writing, sharing and promoting the research and its findings??)
- 4) One of the things research that involves people with learning disabilities as co-researchers wants to do is to share the power - share the decision making. Have you felt that you had power? In what way? Have you made any of the decisions? What decisions?
- 5) Have you felt like an equal member of the team? Have you felt that your voice was heard?

- 6) What things have been helpful in helping you to do the research
- 7) Has there been anything you think has been difficult?
- 8) Has there been anything that you have not enjoyed doing?
- 9) Diamond Nine – What has been important to you about being a co-researcher on this project?

Go back to original Diamond 9 photo. This was what you said you wanted to get out of being a co-researcher.

- What do you think about these ideas now?
- Do you think you have made new friends? Has everyone got along well? Do you think you will carry on seeing the new people you have met?
- What do you hope will happen to the research team next?

That's wonderful, and that brings us to the end of the questions I had planned to ask you about. Does anyone have anything they want to add to the discussion at all? If not, thank you for taking part.