**South East Northumberland Parkinson’s UK Participatory Research**

Transcript of “3.WAV”

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**INTRO TO SESSION**

**00:00:00**

R: [Hands over to J]

J: [Introduces idea behind project]

R: [R explains the project changed a bit as we are no longer focusing on Google Glass]

**WHAT IS A RESEARCHER ACTIVITY**

**00:05:11**

R: [R introduces the what is a researcher activity. The cut-out researcher is names “Skinny”. Key questions; what is a researcher?; what do they do?]

**00:07:35**

[noise – impossible to hear most]

**FEEDBACK FROM ACTIVITY 1**

**00:23:00**

R: [introduces the summary section]

R: So we had a lot of discussion around the type of ummm person the researcher might be actually. So inquisitive, open minded, interested, able to relate to people, good background knowledge, good communications. Empathy. Know what its like from the inside out.

And then we talked about some of the problems of drawing conclusions from data, so some of the practicalities of research and what actually the process is. We have recruitment, collecting and analyzing data, obtaining funding, getting results, publicizing the results, because you need to justify the spending that comes through, when we had we might publicize through personal websites, group sessions like these, publications, conferences so that we can inform other professionals. We talked about how it was important to do this not just nationally but internationally. To make sure that other researchers in the area know what’s going on.

Then we actually talked about how important it is to let participants know who have taken part in the research what the results are. Which is something I am very bad at doing, and sometimes I am very bad at doing it. But sometimes the results come year down the line, which makes it tough for everyone involved doesn’t it.

J: Shall I do mine, now? I guess we started off a little bit differently. So the first thing we talked about was how a researcher might try to find solutions or find cures. And we talked about how researchers in general should aim to make peoples lives better. Then we talked about some of the more high level things a researcher might be doing. So on this was looking at things that haven’t been looked at before. Being aware of existing knowledge.

And we had a discussion about how doing that might be really difficult because people might doing things at the same time in different parts of the world but they might be doing similar things. How easy is it to be aware of all this sort of stuff that is going on? We also talked about how a researchers role might be to translate things that are very speculative or conjecture into something that is testable or a hypothesis. We also talked about some of the practical things as well, so like obtaining data, you have collect data, we talked about analyzing data. And also things like how would you, what is it you actually do to obtain data, so things like do you run experiments, you might do surveys, we didn’t talk about it but I think this discussion overlaps with what you were saying about recruitment, and analysis and things like that.

And we also talked about, a little bit about how a lot of researchers often have to define boundaries because they need to know what they are looking at, and really need to know what they are not looking at even more. We talked particularly about Parkinson’s as well, and how there is a challenge when you try to study a particular condition when it is very dynamic and changes a lot, and umm, it experienced very differently by different people. Is that representative?

M: So we talked about collecting and analyzing data, and ummm yeah getting funding for projects, asking questions, broadening the knowledge. We also talked about the present situation of research. In the case of Parkinson’s we talked about research helping people understand more about the disease, provide information for the carers, and ummm the researcher to have the right knowledge and the project. I think basically that’s it.

**DOCUMENTATION DISCUSSION**

**00:28:50**

R: (explaining and asking how the group would like the sessions documented and reported back on)

M1: If you go away and write a summary, then at least it will get done, and it would be a way of capturing. I have a feeling that there might be times when we are doing, I don’t know whether you would call this brainstorming where we think we’ve got some ideas if we leave it for a while then they’re actually gone and we haven’t got ideas. It’s disappeared. Even if it’s not, in inverted commas, “accurate”, it wouldn’t matter. Because they would be a statement of where we were.

R: Ok, so what we’ll decide to do then is to share anything that we write up and summarise and reflect on from each session, umm but on the understanding that if you would like to add something to it or change something that it is open for you to add things to. OK? Right, good decision!

M2: Can I say one thing, there’s one point I’d like to say. And I though it’d be done well before this. We’ve been going some years, and I expected when we first started this group up that we would have someone come and talk to us about Parkinson’s. But it doesn’t happen very often. We don’t very often talk ourselves about Parkinson’s. These meetings are once a month, and uh, it is important because it is knowledge and we talk about subjects but I think what is very important because we’re all here because of Parkinson’s, is that what’s good for me might good for someone else. Why don’t one of us, maybe one every two month give a 15 minute talk.

M1: It’s interesting and I had similar thoughts today. I didn’t get a, crowded with so much to do, I meant to have a quick word with people for the news letter to invite some contributions to things that maybe, nothing, one end is a cure sort of thing the other is how do I get up in the morning without falling over, things that people might have found or problems that they have that they could share that we could help each other. I just thought of that in the car on the way over.

M2: I think it’s important. I think it’s important we all get together and share. There’s no this I get involved in Parkinson’s, this is how I treated myself, although the treatment might not be, or the exercise or whatever, although it may not be appropriate for that people at leats they get to know about things. I was just telling… sorry, what’s your name again?

M: Melina.

M2: Melina?

M: Melina.

M2: I had the computer on last week, uh, a week ago, no, a fortnight ago. And I picked up umm something about the Parkinson’s from ummm a project they are doing in America. It’s called BX. But no one has seemed to have heard about it. I mentioned it to me Parkinson’s nurse, she mentioned to the doctor. Never heard of it. It’s an exercise going on in America but we don’t seem to get to know what’s going on. And their projects being developed in another part of the world that affects Parkinson’s. And this BX, it’s meant to be as close to a cure as you possibly can get for the time being. But it’s in America.

Group: Hmmm.

M2: It could take a couple of years. But at least people are coming out with their experiences with this new drug over in America. But why, why on earth has it got to be left to one of us to get on the Internet and find out what going on. [inaudible]. Michael J Fox. People that’s in the know. What’s happening?

M1: isn’t part of the problem that its so vast, because as Parkinson’s members of Parkinson’s UK we get the research as a publication which summarises quite a lot of what presumingly what the editorial panel thinks is significant progress. In fact is it called progress, I cant remember what it’s …

?: It is called progress

M1: Progress. And, out of. Just. An area that is absolutely vast that would be one of the explanations why, why its not happened in terms of something that you’ve found that, umm, other people don’t know about. It’s also interesting that we, we credit people with being experts and assume that everybody knows everything but nobody knows everything about anything.

Group: Yes. That’s true.

J: So it sounds like something around information sharing. But it sounds like more than just sharing it here, maybe…

M3: Sharing experiences as well isn’t it, really.

Group: Yeah, yeah.

M2: You know twice a year we go on a day trip somewhere in another part of the country. That’s fine. But we’re not dealing with the problem that we’ve got. The problem that is being able to understand Parkinson’s. We have experiences. I think its important we’re able to talk about them. This sort of thing. And compare notes.

M3: I agree with you. It’s something that uh I’ve thought about before. And before I joined I thought this was a forum for sort of exchanging experiences if you like. But it doesn’t turn out to be that way really. You know we’ve had some good speakers, like today was brilliant. Ummm, but it doesn’t relate to what we’ve got.

M2: I think there’s something we mostly know. I think it was, the priest and that, it was good to have him talk about those things, but does it fit.

M1: But that’s not many of us.

F1: But Jack …

M1: We’re involved in this because we’re interested and there are two, three, four, five, six, seven, out of how many? So it’s something you and I are interested in but not everybody comes here is interested in and maybe they get something else and so…

F1: jack that’s what I was gonna say. You’re interested in that and David is you know as Harry said but a lot of people who come Jack they come, they want the company and they want the social side, the social side is important. So, you know, and there have been occasions where they have been able to share and talk about certain things about their Parkinson’s, and I think it’s trying to get… what it is you’ve got such diverse interests and backgrounds in the group, ages etc, I mean its trying at some point something for everybody at some point in your program isn’t it.

M2: I think, I agree with you, it’s impossible to get everybody, all the ideas. It’s just a .. me telling you. And I’ve got Parkinson’s. This is how I ease my Parkinson’s. And I think it’s important that we keep doing… you know, every time we get a UK magazine, it’s always “keep moving”.

M1: And, and I suppose. In respect of things, it’s a kind of research in that there’s a group of people in the room and we exchange information. Where there’s experience is something we’ve learned from, for example, the exercise and we’ve experienced types of benefits that we tell other people and we’ve gathered the data because we’ve done it and we’re spreading our conclusions as to what we’ve come to and its not very formal but it would be a possible early stage to research project or whatever. And it’s a benefit we get from coming here I guess.

M2: Well I don’t disagree with the social side of it, aspect of it, as you say. Just we don’t talk about Parkinson’s.

F1: I don’t know how you’d formalize it though. I don’t know how you’d formalize that.

M2: I think it’s just a matter, of, of just experience.

J: It’s an interesting challenge isn’t it because I imagine maybe, and this is a complete assumption from me, some people would come to a group and session like this, and although everyone has this shared label I guess of Parkinson’s but maybe some people come here maybe not to think about that to much.

Group: Hmm, yeah. Yeah. Hmmm.

J: Maybe to just enjoy being with people? So it’s an interesting tension point because some people might come here for very different reasons.

F1: Yes, yes that’s right.

M3: Yes it’s the social side isn’t it.

F1: I think that’s right. Anyway, sorry we’ve gone off.

R: No, it’s very interesting.

J: It sounds like the starting point of a project there.

F1: Well I was just going to say, was going to say to Roisin; there you are!

**EXPERIENCES OF RESEARCH ACTIVITY**

**00:39:20**

R: Well I was just thinking that! OK. So just for the second activity, and we will keep it very brief because I’m aware we’re running out of time, we want to think a little bit more about the question “what is research?”. We’ve thought about it in the context of a researcher and what a researcher does, but just to begin thinking about it. If we can think about some of the places that research happens. There’s lots of different places where research can happen. And then maybe think about some of the research yourselves have taken part in that have taken part in those places. Just sharing some experiences of taking part in research really.

So, who has a project they would like to talk about?

M4: Falls?

R: The falls one?

M4: Mmm.

R: And where did that take place?

M4: In the, mmm, hospital.

R: In the hospital. Mmm. Ok. And it was one around falls?

M4: It was a project, a project wasn’t it?

F2: Yes a project. It went over 6 weeks.

R: Was it an exercise?

M2: It was to try and get people to walk without falling.

R: OK.

M2: And I think the main thing, was they were trying to convince people with Parkinson’s that consistently fall, to try and prevent them falling, or at least reduce the number of falls. Ummm.

R: So what did you do when you went three times a week for six weeks?

M2: Just these special exercises. Umm walk a full, walk the whole length of the space. Walk from that end to that end and walk in a semi-circle. They let you go, maybe, 100 meters without any assistance.

R: OK, so you were building up as you went along.

M2: Building up yes.

M5: Because confidence is an issue, confidence you know getting confidence back. I would certainly identify with that as well. Yeah.

M2: In fact the guy that’s in charge is coming to give us a talk on this project.

R: Ah, excellent.

M2: It’s quite good.

R: OK.

M2: Before then I could only walk so far without anyone to help me.

J: So how did you come into contact, how were you invited to take part?

M2: Well, err, it was one of the Parkinson’s nurses.

J: The Parkinson’s nurses?

M2: Yep, aye. I quite enjoyed it. It was only two or three hours or so.

R: Right. Does anybody else have any experiences of research that’s taken place in the hospital?

M1: Yes oh well. Part of it was in the hospital. I’m trying to remember the name of the doctor who’s running it. It was a series of 12 week exercises three times a week in a gym, and the, the aim of the inquiry was to see if exercise could increase the lung capacity of people suffering from Parkinson’s.

R: Ah, I know who you’re talking about. Was is ???

M1: ???, yes.

R: Ok, lung function.

M1: And umm the only feedback I’ve had from ??? is that for the group as a whole it did increase by four percent but what the variation was I don’t know, ummm… but it gave me motivation to carry on. Which I’ve done ever since.

R: So you’ve had a positive benefit from that since it was carried on.

M1: Yes which might be different from the one that was being measured in the study or not even the name of the study. But that mental wellbeing is felt by it, as much as anything else.

J: So I guess you never received individual feedback?

M1: Being promised it. But it hasn’t happened yet.

F1: It’s an important thing isn’t it. Feedback. The importance of feedback.

J: I guess its really important when you’re doing health related work where people are individually measuring you but researchers only ever report on the group. They don’t tend to report on specific people. But I guess you really want to know actually “has that helped me?”.

M1: Gallons of blood being taken, before and after the exercise. So obviously things being measured other than lung function. So.

R: So what about… I know diaries are a pain but I suppose in a way if you’re keeping a diary and you’re monitoring yourself you’ve some idea as it goes on if you’re improving or not.

M3: That could all sort of come under the term managing. Managing Parkinson’s, managing whatever. You know. It’s a general term which is somethimg you find from experience, and ffro yourself, not necessarily from other people. That’s why I said I thougt there may be more of a forum, for that.

R: For managing yourself, yeah. Have you ever done any research before?

M3: No, no. I’ve looked at books and leaflets and things, you know, we’ve talked to a lot of people about things. Umm. We’ve never done anything that was eh conclusive I don’t think. It’s been down to the clinicians who decided that. You know, it’s a big gap in terms of months, you know, before you see one or the other. Really. You see the Parkinson’s nurse before but that’s not a regular thing you’re not seeing them every week.

J: So I was just wondering if anyone here has taken part in research that happened at the University? At our university or anything like that? Or has it always being at the hospital?

M3: I don’t know..

F3: I’ve done some at the University.

J: Is that what you were mentioning earlier Carole?

F3: Yes.

J: OK. So is it worth us putting down… University. And what was that project about?

F3: About, mmm, I think it was about dementia. It did tell me afterwards that I didn’t have dementia.

J: Oh so you got feedback on that.

F3: It was to do with some quiz on his computer. He came to my house and it took about two to three hours. And then I was supposed to go back and do some more but they didn’t want to do the next lot because I’ve got metal (something) and I was on morphine.

M3: But its not the morphine it was the metal.

F3: Because I’ve got metal (something) they wont take it.

M3: Because they wanted to do an MRI scan.

R: Ah, I see. So you were excluded from the study in the end.

M3: But the um research as really from the psychiatrist people at the University, you know, they were doing it from their angle. Umm, as part of a doctorship as well really.

R: Yep.

F3: Well I thought I was getting Alzheimer’s. So I went to see him after these tests he said you’ve not got Alzheimer’s.

R: Ah good. So was that for you, in a sense, you were able to be seen by psychiatry a bit quicker?

F3: Probably.

R: Because it takes quite a long time to get an appointment with psychiatry doesn’t it.

M3: yeah, yeah.

J: So what motivated you to take part in that study? How did you find out about the study? Was it through your doctor?

M3: I think it was through the clinician that was in charge of sort of, the man who looked after Parkinson’s people and elderly people in general. And I think he must have put the names forward or something, I don’t know.

F3: I cant remember now…

J: So that was quite interesting because although some of the research took place at the University, although you were never able to do it, it was an example of the researcher coming to your home. And I guess asking you to do some activities.

F3: I got to that stage, and the stage was at the University.

J: At the University yes. So has anyone else had experiences where they have taken part in studies where they’ve been asked to do things at home?

M4: Yeah I was in the drooling.

J: In the drooling? Yes, you can say whatever you like about that one! So the drooling one, let’s talk through that one.

M4: Aye yes, I was checking on how many times a day I drool and my daughter’s asked to watch how many times. She’s watching me. \***laughter**\* And it was good, because I’ve learned to swallow now.

R: You still wonder how many times you swallow?

J: Ah, ok, so it’s had a positive impact.

R: Do you remember the main thing?

M4: I’ve still got my watch yes.

R: You’ve still got your watch?

M4: Yes. I also got this little medallion thing from speech therapy.

R: Ahhhh right ok. But it beeps though.

M4: Oh yes it beeps, yes.

R: the watch is better isn’t it.

M4: Mm yes.

J: So what did you have to do for that study? Was it quite long that one?

R: It was ten to twelve weeks.

M4: Ahh, yes. Ah. I had this thing on me and it pings to tell me to swallow. It vibrates didn’t it, it vibrates.

R: It did.

M4: Which was very helpful I found. I had it in my bedroom from first thing in the morning, I put it on. And every time it pings I knew to swallow.

J: And did you have to write down anything?

M4: Yes, yes. I had to take a note every hour. Every hour of the day.

J: Oh, blimey.

R: Just one hour a day.

J: Oh, just one hour a day. Ok. So that was a diary? And I suppose every now and then you had a wonderful researcher come and visit you?

M4: Oh yes, I cant remember her name…!

J: And how long was the study for?

R: About twelve weeks. Ten to twelve weeks.

J: That’s quite long isn’t it. I suppose these are quite short weren’t they, there or four weeks. I dunno how long was the lung exercise?

M1: Twelve weeks.

J: Oh, ok, twelve weeks as well.

R: But that one involved you going to the hospital, didn’t it?

M1: Yes.

J: And then the Google Glass project, Harry, do you want to talk through that o ne. You did it tice actually, didn’t you?

M1 Yes. Well, to some it up, I found it absolutely fascinating. Umm, I had quite a few difficulties with it but probably no more difficulties than I would have had with a complicated phone. Because I would have and difficulties with that. Ummm, also saw it had the potential if it worked a little bit better, and some times there is a very thin line between something being working well enough to be successful and not. It could absolutely become indispensible or appear to be indispensible because of all the things it potentially could do, and one of the things that wasn’t in the exercise but I put it on and I said “where am I” and the map came up on top of the screen and a dot and “I’m there, I’m there”. And I thought that was absolutely fantastic. Umm, for somebody who’s walked a lot and gets lost and things like that it was…

J: hmm, yep. So was that was quite a different type of research wasn’t it, it was very, umm, was it quite flexible for you?

M1: Yeah, yes. I felt a little bit sorry for Roisin in that it must have been incredibly difficult to analyse, because I don’t know how, quite how, not difficult to record but to bring it together. Obviously as an individual I had no experience of the experiences of other people in the sample. But I’m trying to put myself in your shoes, how would I bring this together, and interpret it and present it, would seem to be quite a difficult thing to do.

J: So, I suppose we could put this as… open… ended. And I guess how would you comp[are the types of stuff you did there, compared to these types of research, Do they contrast quite differently

M1: Yes, ummm. The Google Glass, ahm, there didn’t seem to be… we’re going t try it out, we’re going to see what peoples experiences were, and the difficulties and benefits from doing it. The hospital based one was much more formal in the sense that there was an experimental group to do the exercise, a control group that wouldn’t do the exercise, measure the lung capacity at the beginning and the end. Sort of classical clinical trial. And, obviously there was other things being measured as well otherwise, it wasn’t just lung capacity and I wasn’t sure what they all were. But much more formal. Now it may well be that at an earlier stage the sort of conjecture thing was, umm, well, in Parkinson’s people die because they get pneumonia because of lung capacity, lungs don’t work too well, what might make lungs work better, it might be exercise. We’ve got to look around the literature, there’s no data, well lets get some for Parkinson’s people. Now I know I am making assumptions about what might have gone on.

M3: But the Google Glass is more of a product development type of thing really isn’t it. Whereas the other is, is not a product development.

M1: Getting the Google Glass is not, presuming, when you were starting out, you weren’t sure, you were quite open minded, hence open ended, where it would eventually lead. Whereas the hospital based one, either presuming it is someone doing a stats test that either it would make a significant difference or it wouldn’t. And it’s sort of black and white, and I’m not sure if it would be as black and white as I have put it. Whereas the Google Glass, was ah exploratory. Could research end up in lots and lots of different research projects coming out of that.

R: Exactly, certainly thinking about what research projects could come out of it, and I suppose that’s the model that this one is taken as well that we’re doing now. We’re looking to see what could come out of it.

It’s interesting to see that, actually, there’s three here that are sort of technology related. So the one that you were involved in carol was a computer based test, as well.

F3: Yes. Things were coming on from a screen.

R: And then of course the watch was a technology, and these were a technology. Then these are more exercise-based things. OK. Again, we’re out of time.

M2: Can I just mention one more thing. I find it very difficult when I go to the nurse and I have to tell them how much medication I need to be taking for ourselves. If I’m at the end of my medication, and they say “what are you suggesting”. Three tablets a day, four tablets a day. And I find it very difficult to be able to understand. I can understand why the nurse is asking for our opinion but having to give her advice on what we should be taking. I find it sort of confusing.

J: So would you expect them to be able to tell you?

M2: Well I mean they must have plenty of experience because they’re in the ob, they could compare my medication with Harry’s. Harry’s just told me he’s starting a course at half seven on CR, and nine o’clock at night. I would put it on at 10 o’clock and 4 o’clock in the morning.

J: Do you find it quite difficult to say how much you should have?

M2: Well I do. I mean there’s times when me medication does me good and there’s times when it doesn’t do any good at all. Just to give an example, (inaudible).

F1: Was that doctor woods decision, or someone else’s decision?

M2: It was doctor woods who put me on it.

F1: Right, he said that.

M2: I felt I was having too many tablets. And the nurse took me off them. Gradually of course. I’m no worse than when I was on them.

M1: I wonder Jack whether a partial explanation for that is that up to an extent prescribing for Parkinson’s is a bit of a black art. Partly because the research shows that we’re more different. It’s not like maybe such and such a condition you need a certain dose of penicillin to cure such and such an infection. And this is the dose you would get and this is how you would take it. For us, maybe we cant be sure when there are things like that. Before when I was on my very first medication at all I was given some literature and I was allowed to decided and I’ve never had that experience before. Here’s the data, this drug got this advantage but it’s got this disadvantage and this has got that and you choose. But not everybody would like that I don’t think.

M2: I just cant understand why, I was on all of these tablets, and then because they thought I was on too many tablets they just took me off them. We’re just experimenting with ourselves.

M1: Yes.

**CONTROL, POWER & GAIN ACTIVITY**

**01:01:55**

R: Ok, so what we’re going to do, for this very last super quick one is have a little think about the research project you have taken part in. Peter I didn’t ask you if you’ve ever done any research?

M5: No I haven’t.

R: You haven’t?

M5: No.

R: So, you can use this one as your example..! **laughter**

For anyone who does not have Parkinson’s, but is aware of the research that goes on we would also like to hear your perspectives on how much control that you felt you had throughout the process. How much power you had. And how much gain you got from it, so what do you feel that you gained from the research. It’s very open to interpretation.

F2: When you say power, other than agreeing to participate or not participating, where else would the power come in?

R: Yes, so, perhaps the power to leave the study once you’ve already agreed to taking part. How to make a difference to the study at any point. Power to step out from doing something you don’t want to do but still participate. Power to say no, is a good one. To say “no not like that”.

F3: The problem is when you’ve got one or two things wrong with you, you don’t know what’s causing what.

M5: Yes that’s true.

F3: I’ve got Parkinson’s, Arthritis, Osteoporosis and I don’t know from the medication I’ve got what I’m taking for what.

F1: Yeah, just keep taking the pills!

M5: Just keep taking the tablets.

M3: I know what its for.

F2: Gain, or no gain. Oh oodles of gain. I don’t think it made any difference to my life whatsoever. I haven’t drooled since (laughter). To be fair Dorris, that no gain at all is because it was specifically to do with something else. That was just the name of the game.

J: Do you think you had quite a lot of power?

F2: because I had to do a little bit of diary as well, and I could have said I’m not doing my part, I could have walked away. That’s why I was asking what power meant. I could say, I could play or I don’t want to play. That’s why I was asking what the definition of power was. That was my only input really. And I made the tea!

J: So Harry you said for the exercise project you didn’t have much control?

M1: No.

J: But you got a lot from it.

M1: Yes.

F1: I just have to tell you as a, diverting a little bit. But it had a huge impact on our family this when Harry did those three months beacsue um on December the 30th my daughter had her first baby, down in the Midlands, no family. And, err, that was December the 30th. And in the January, for three months, Harry started three days a week the research project. So we were up and down and up and down the M1 because she had a very very very bad time and umm we had to be there. So how on earth Harry… he should have had a medal for doing this. He said he committed himself to it at the beginning and he was going to see it through but it had the most incredible effect on the family. We were worried out of our minds for Kate because she’d had such a terrible birth. And he was driving up and down to Newcastle for these three days… it was a very difficult time for you, wasn’t it?

Anyway, I just thought…

J: That’s really important to hear!

F1: because sometimes these research projects can impact on the rest of the family or on other people.

J: That was something we were aware of with the Glass project as well, that the projects can become very intensive, even more so than the researchers imagine.

F1: You know, sometimes projects can impact on other family members.

J: Maybe we should capture that next to the control here…

F1: I think I just wanted to say it. I just wanted to get it off my chest!

M1: It’s made me realize how long ago that was now. It was two and a half…

F1: It was two and a half.

M1: And I’ve not stopped since. I still go three times a week.

F1: But if you can see the difference it makes with Harry, you can tell. When he gets back you can tell he’s been to the gym. His mood’s better, just different, and physically better.