**Workshop 3**

R: alright everybody thank you for coming. So this is the third workshop that we’ve done.

[apologies for not attending last 2 sessions]

So I think the main thing to come out of the discussion from the last meeting was the fact that although there’s lots of information available from PUK, it’s a fantastic resource and they have lots of information about different things. But it’s very easy to access if you’re on the internet and you know what you’re looking for, but if you’re newly diagnosed with PD and you don’t really know that much information in the first place, don’t have anybody to ask, aren’t online then actually it’s not that easy to access that information. And one of the things that came up very strongly was the fact that these PUK meetings are an excellent resource for specifically newly diagnosed people to come and find out information, and even people who’ve had PD for years to find out new information by sharing experiences.

Ra: Can I just say something? Talking about new experiences when you first hear about the PD, i went to a few different doctors and they couldn’t see anything whrong with us and then i went to local doctor, eventually come across us, and he says...he was a neurology person, and he knew straight away i had PD just by looking at us....shaking back and forth...that was it, within 2 minutes he diagnosed it. He just loked at us and said “you’ve got PD” and i was really down...i didn’t take anybody with us, I drove from Newcastle and my mind was just going “PD”. I thought that was the end of the world. Because PD to me was just somebody that was just one minute...it was so rapid. But that was years ago, i’ve had it for 9-10 years now and gradually...it has started going downhill...but that initial contact was bad. Just telling somebody “you’ve got PD”.

R: and did you get any information?

Ra: No! The doctor had nay there. He just says “you’ve got PD”. I could have drove myself, the way my mind was, i could have drove into the river, something like that. And i thought i was young! Do you know everybody what I mean?

H: oh yeah absolutely

R: and so then how did you get involved with the PUK meetings?

Ra: I just met a fella on the street and he was telling us of this thing that he went to and that’s how i got to know.

R: and were you open to coming to the meetings? What was the main reason that you wanted to come?

Ra: well for my wife aswell because she had nobody to talk to, it was all my problem

R: so just for the support

A: same thing happened to me in Cumbria aswell actually. Said I had PD but they didn’t have anything for you so I had to move back to the NE. He said “I can’t do anything for you, sorry” so i moved back to the NE where I knew where the help was. It’s been brilliant since i come back here like.

R: it’s an encellent service

Ra: people need to be educated. Before i went to the doctor i needed somebody with me to take their time, say “you’ll be alright, it’ll not kill you”. I thought it was the end of my life

R: well that’s it.

Ra: even if he’s telling you that afterwards it doesn’t sink in. All you’ve heard is “you’ve got PD” you can’t hear the rest of the conversation. Especially if you’re by yourself

R: well one of the other things we talked about last time as well was that even when you do get this information from PUk, these leaflets and things like that, that a lot of the time they have medical jargon and things in them and don’t really tell from the experience of someone who’s gone through it, it’s more from the medical professionals.

D: that’s right

[Ha arrives]

R: so those were the main things we talked about the last month really and as I said, the main thing that came up time and time again was around people who were newly diagnosed. The main stuff was around sharing iformation and making sure that information was available to everybody, because there’s people missing out. So what i’d like to do today is start thinking about some of the ways that we might help that sharing of information. And we talked about a couple of different sharing pathways, i suppose we could call it, between yourselves and someone else within the same group; so between H and L for example. you sharing your experiences so that you can gather knowledge between the members of the group. Sharing information between this group and another group. And then sharing information to people who are newly diagnosed and don’t have any support system in place. So there were couple of different things. So what i’ve tried to do is take that into account in the different scenarios i sent you and have a little think about....don’t get bogged down with the technology for now...it’s just around thinking about how we could support that sharing of information in different ways. There are not necessarily what we’ll do as a project...some of them are particularly tricky for different reasons. We’re going to talk them through and see what’s feasible.

So the first one was about anybody with PD finding out information about research, which was something that was important to you J, and specific issues to do with PD. So that kind of...a couple of people said that they would have liked in the meetings to have more information about PD itslef

[R reads out first scenario- Radio show]

D: how would that be funded?

R: that’s a good question. It’s all hypothetical at the moment.

H: so would this be local? Like a local station or would you try to have it national? Or have it very local like a hospital radio?

R: well what do you think would be best?

H: well I can’t see the big BBCs taking something like that on, because why would they choose PD when there’s so many other groups? I think it’s a fantastic idea. I think it’s a bit utopian...

Ra: what about the hospital? Wansbeck hospital?

H: yes, that’s what I said, hospital radio that might be the answer mighten it?

Ra: I don’t know how you would find it like, it would be a lot of work

H: well if enough people were interested you’d make it your business wouldn’t you, for something like this, to find out where it was and how to access it

R: so what are the positives of that idea?

H: well it would reach everybody couldn’t it? Because most people, let’s face it, may not have access to a computer but most people will have access somehow to a radio

Ra: especially for this group. You could run it

R: any other positives?

H: well the fact that it’s a two way thing, i think that’s really interesting it’s not just you being told something

Ra: yeas, you can ask questions

H: you have the opportunity to question, have your own questions or question what’s being said, or ring in for something that hasn’t been mentioned. That’s an opportunity isn’t it, if you’ve just found out

Ra: that would have helped me

R: so it’s important to kind of have a two way interaction

D: absolutely, it’s a great idea

R: so if there’s no more positives, what are the negatives than?

J: I think one of the negatives is that the staff at the hospitals don’t know what PD is about. I was in hospital a few weeks back at the falls clinic for the elderly and when i got in the immediate thing they did was unpack my case and fasten us to the bed. Because i was at risk of falling they didn’t want me to fall, everytime I tried to stand up they said “J you can’t do that, you’ll fall”. But what was the point in that, i was in hospital for a week, exactly a week and I was at the end of my bloody tether.

Ha: so if there was a radio show, you would ring in and tell them that experience

J: yeah

Ra: Wansbeck was is?

J: aye

Ra: that’s terrible i think. I would panic

J: ever nurse, male and female, every time i stood up “J sit down”. It was damn terrible, it’s done nothing, not a damn thing. It stopped us falling. I just couldn’t see the point, it was a waste of time

Ra: it’s just going to affect your recovery time

J: well it does, it affects everything

H: you have to be very careful with the radio because it’s got to be someone who knows what their talking about, who has a good Parkinson’s background. At the moment when the NHS is suffering how could you justify someon on the PD team spending time on that....but you can’t just have a volunteer because you can’t give the wrong information. This is very important, it’s a very important health condition and you’ve got to have the right information. You’re problem is actually getting someone isn’t it, who has the the proper background

Ra: the NHS have had to dilute their staff by having a senior one and then youve got the next teir and the bottom teir

A: care workers

J: another thing that happened to me, the staff have no idea about the timing of medication. It’s so important. They just don’t understand, i was getting my medication an hour later

R: it’s a big campaign now isn’t it?

J: I had to call a special meetin on the Saturday morning mainly about medication, and it didn’t go down too well but I got them to understand

R: so anything else? What would we need to make this work

Ra: you need somebody qualified as you say

H: you need some money

D: money yeah. Did they get it to work in India where it came from?

R: yes, they could call in to the radio show and listen to it, they could call in and leave a quaetion. So if we were to implement this idea who would it affect

H: well it would effect everybody you would want to reach because at the moment, you’re ok if you come to the meetin ang you’ve paid your £4 to PUK and you have access to the information if you want it. But there must be a heck of a lot of other people around who don’t do tha, haven’t joined. They would, if there was enough publicity...this is one of the problems, reaching out to everybody. And it’s such an easy thing to do, just to switch on your radio

Ha: you can see very old people switchin on their radio and listening in, i couldn’t see them picking up the phone.

R: so you think people might listen but not contribute?

Ha: yeah

R: so you need a way to encourage peope to contribute questions?

J: that’s right yeah, I think that’s important. I think you want to encourage people to come to meetings like this too, I mean there are several people in the area that have been diagnosed but they refuse to come out

A: there’s a fella next to me, hes got Parkinson’s, i tried to get him to come...

R: so do you think if you told him something like the radio show...

A: he just doesn’t seem interested at all

R: someone mentioned a little earlier about the staff don’t know about PD so maybe it would help them too to listen to some of the radio shows. Ok, does anyone else have anything to say about that one?

D: it’s a really good idea you know, if you could get the experts to back it. There’s this tremendous demand as you said H, and there’s a lot of different charities any way, the situation is we’re dealing with lots of other major illnesses in society.

L: you need the professionals to run it

R: so the next one was, this one might be a bit controversial...

[R reads next scenario- rating Parkinson’s friendly places on the appmovement app]

So users of the application, who have the application on their phone....does everyone know what an application is first?

J: mobile phones tend to get confused with something else

R: are you aware of what an application is? No? Ok, so an application is like a bit of software that you can download to your phones that helps you do something specific with your phone. So, the camera on your phone is an app, the maps (GPS) is an app. You can also make those apps a little more complex. So for this example i’m talking about, you can use the maps and add things to it. So users of the app can select a location in the community (a coffee shop, swimming pool, even a PUk meeting) and give a rating on how comfortable they felt in this place. so people could share their experiences, like freezing, issues with eating, sitching off and how they were treated, to help other PwP to identify places that are particularly PD friendly or unfriendly. So in this sense you would switch on your mobile, open the app and you would be able to see lots of little pins [shows example] in lots of locations. So you could say “i’m going to try this cafe in town, ill see if anyone has given it a rating” you click on that and you can see what other people have experienced in this place and this could help you decide whether or not you’d go there.

D: it’s like tripadvisor

R: exactly, it’s like tripadvisor for PD. So, any positives with this ideas?

L: people could abuse it, they could take you to court

R: so you think if you put something about a shop they could sue you?

L: yes

R: so, that would put you off using it?

L: yes

Ha: if you could persuade tripadvisor to add a feature so they could make it specific to different groups, you could have one for people with heart problems or diabetics or whatever. So there would be general tripadvisor and there would be general subsections of it

D: yes, the structure’s there already so if you could get them to do something it would be easy

R: [explains appmovement]

H: it’s very easy to use [tripadvisor], I mean you just click on the icon and you have the results but for some people who are not particularly comfortable with IT, using things like apps is not so simple.

R: do you all have smartphones?

J: I have an iPad

Ha: My phone’s so old fashioned it’s steam driven

D: I think mine’s the same

Ha: I use a PC

R: so do you use tripadvisor on the computer?

H: this would probably go down very very well at the young person’s meetings, you could see them using something like this. The difference between these groups, where people are at work, compared to ours is their attitudes to technology....they are virtually attached to their phones. It’s different with an older age group.

R: so are there any positives to this, don’t get bogged down by the mobile phone, just think of the way of sharing information.

H: Holidays. That would be good wouldn’t it. People who’ve been away on holiday, to say where they’ve been and how it was, more than local coffee bars. Imagine, PUK people say don’t go to so and so...

R: well you never know, it’s about opening up a space to talk about these things. And what about the thing about sharing your experiences in that sense, about places in the community.

L: i think that’s a good idea

R: and how do you do that at the minute?

A: just tell people when they come in

Ha: word of mouth

R: so I suppose this is a little like word of mouth but for people you don’t know.

Who do you think this idea would affect if it were to be implemented? Could you see yourself using it?

Jw: yes, I would, I think especially with wheelchairs

L: if i had the technology I might

H: i think people would use it just out of interest anyway, because its so easy, you just click on the app and find out what’s going on and which places are good and not

A: to see whih places are suitable for wheelchairs

R: so if we took away the phones completely and just said, somewhere there would be a map and there was a way you could add information, so say we had a map here and people added their ratings on postit notes for example? would you accept someone’s anonymous rating? You (L) said you would feel a bit awkward about writing something, what if you heard...

Ha: well tripadvisor itself gets abused with people writing false positives, false negatives, so you can’t necessarily trust them

L: I wouldn’t trust anonymous no

Jw: I think if someone recommended somewhere (a friend) we would try it

D: it’s tricky because I haven’t got the type of technology really that would work with this

R: what if it was a text message or a newsletter?

D: A text message yeah, again I think the point that Ha makes, it’s anonymous , you don’t know who...so i would be a bit cautious

R: So you would want it to be within your network of people

[moves on to number 3- reads scenario about text Qs to professionals and answers displayed in the GP office/ PD clinic on the TV display]

H: I think what we were talking about was what you get in GPs offices now, you get information videos about different things, that’s where that came from. But yes, I mean in a PD waiting room, if the questions are coming up that people ahve asked and you’re getting the answers from a professional, i think that’s a good ideas yes.

R: so what’s good about that idea?#

J: well, we’re getting the facts from the people that matter

D: yeah, it’s specific as well isn’t it

J: I mean the waiting rooms you’re usually sitting reading books and papers, nothing to do with why you’re there

Ha: what would be better real questions or hypothetical questions designed by the people who are providing the answers?

H: it says text your questions to a specific number

Ha: I’m just wondering if an alternative, instead of that, would be to have false questions in a sense. Then people could choose

H: yeah, I suppose you’ve got a choice but it’s a good way if people have got queries and most people have to get it answered and aired in public. Most people will share those. If the professionals are providing the questions that haven’t had the condition, they look at it differently

R: I suppose in the middle you could display FAQs

H: but then still have the choice to text in

R: so i suppose you would have to have your question answered in the space of time that you’re in the waiting room, that’s something to think about. Any other positives?

H: because most people will go to the PD clinic at some point it gives everybody the opportunity to ask what they want.

R: if we think about this being anonymous again, are there things that you might like to ask that you normally don’t in your meetings with your PD nurse or do you feel comfortable enough doing that?

J: i think it depends on the nurse?

R: would you prefer if your name was displayed with your question or just a question?

L: Just a question. If it’s anonymous you need to check it before it goes out [to be displayed], you need to watch

R: so someone needs to moderate?

Any other negatives?

J: i think one of the negatives would be a point i made before that some nursing staff and doctors don’t have a clue about PD. It’s important that the questions that are asked are positive questions and the person must have some ideas of the answers

Ha: otherwise you could get answers from people that are not only wrong but dangerously wrong...take 5 times the dose or whatever

H: the time factor, it’s ok if....you don’t want to be hanging around the waiting room withing for your answer

D: there can be quite long gaps as well between visits

R: ad who would this idea affect then?

L: anybody really at the clinic. I mean I’ve had PD for a long time but I still sometimes want to ask a question

H: it could be useful even for just getting some practical advice sometimes that you wouldn’t ask a professional usually. Just little things that make life a bit easier, i can’t think offhand but you know what I mean, that you wouldn’t ask Dr. W

J: why not?

H: well little practical things i don’t think, well maybe you would

J: well i think PD is so impratant, theres so few people that know about it and it’s important that...

H: you’re absolutely right J. I suppose things that you could buy that might make things easier for eating or drinking for example, that kind of thing

L: i think it should be more open to everyone

R: like having it in the community?

L: well like putting it on the internet

[session comes to a close]