

File: stammerapp1.1 WAV

Duration: 1:31:51

Date: 24/08/2016

Typist: Facilitator2e Mackie

START AUDIO

[Background conversation 00:00 – 00:05]

Facilitator1: Okey-doke. So just to start off with, we've kinda had a little bit of an introduction already, haven't we, Male1, I think? So more for you, really, as I kinda said: I have a background in speech and language therapy, but have been working in this field for quite a while now. Mainly I've been looking at research around Parkinson's but I've always had a focus on speech and language therapy.

And this project we're doing today has... So, about 18 months ago, we worked with the Royal College of Speech and Language Therapists and they asked us to help them to develop some technologies that would support them in their everyday practice, I suppose. And two of the areas that they came up with for us to look at: one was dementia and the other was stammering. And the reason that they highlighted these as important areas is because they're really underrepresented in speech therapy, as I'm sure you'll know yourselves.

So... But actually what we found is there's a lot of therapists that have stammerers on their caseloads, actually. And we actually had two or three very, very, very large and diverse workshops. Normally we like to have workshops that are about 6 to 8 people- 6 to 8, not 68- and there was closer to 68. Well, there was about 18, 19 people, so very, very big workshops. But it just shows the amount of people who are actually working with people who stammer.

And one of the most interesting things, definitely, for me, from that workshop, was we were trying to find out from them what their practice actually was; what they actually do with people who stammer, and we didn't get even remotely a cohesive answer from anybody. So what we kinda learned was that the practice around it is extremely different depending on therapists, depending on the individual who's coming in for the speech therapy, some do group work, some do individual work, but it's all very, very different and the ways that they kind of look at the outcomes of therapy as well is very different depending on the people.

So we did kind of mock-up an application and some ideas based on those workshops but what we really thought was kinda lacking was any level of

input whatsoever from people who stammer, which really is the most important thing. If it's the user, the person who's supposed to be using the technology, then we really need input from them. And when Facilitator2e- I won't say I did the lit review because it was Facilitator2e. So when we looked over the literature review- i.e. when Facilitator2e did it and showed it to me- what we found was there's only a very small amount of published work about applications to support people who stammer, but- of those examples- there is nobody who's worked with people who stammer in the process, which is interesting because, you know, they should be the first people really you go to.

Do you wanna have a little chat about what you've been doing while you've been here?

Facilitator2e

Okay. I'm a librarian by profession, but I'm very into the research side of it and that's what brought me into this department and I came in for an internship for people with disabilities. And they found out that I had a stammer and were like: "Right, well we have this project, how about it?" So I got put on that. And since then, as Facilitator1 said, I've done a lot of reading around it. I've learnt a lot about the different aspects of it and stuff. More than I knew before.

I have been involved with the national charities for a while. I've been involved with the BSA since I was younger and I'm currently the vice-chair of the Scottish Stammering Network as well. So since I've arrived I've approached it very more from the point of view of the person who stammers rather than the speech and language therapy side, and very much more on the peer-support network side of things. And it's made quite a good combination because we've been able to look at it from both angles, which has been very, very handy.

Facilitator1

Yeah, it's been great.

Facilitator2e

And what I have also done while I've been here: I attended the World Congress for People who Stutter in Atlanta and I took a survey out there and I asked a bunch of people questions about what they would like to see represented in an application for people who stammer, what sorts of situations might they want to practice and stuff like that. And then after the conference I posted a copy of that online as well and gathered a few more responses [inaudible 05:35]. And yeah, that gave us a lot of interesting ideas about what people might want to see in a mobile application, however it also demonstrated how broad a field it is. It's such a complex thing. Everybody stammers in their own way, everybody deals with the stammer in their own way, people find different situations hard and stuff like that. And that really came across in the survey results, I think. It was a very broad

range. The purpose of these workshops now is to narrow the focus a little bit and pick out the points which are the most important from that. But yeah.

Facilitator1 Excellent. So I dunno if you would like to introduce yourselves a little bit, so we...?

Male2 Yeah. Can do. [pause] Do you wanna go first?

Male1 Do you wanna go first or would you like me to go first?

Male2 I'm easy.

Male1 Okay. [pause] I'll go first. I never speak first at work.

[laughter]

Facilitator1 Well, here's a supportive environment for you to do that.

Male1 Okay, right. My name's Male1. I'm 43 years old and I work at the James Cook University Hospital as an audiotypist, which is behind the scenes, doing the... Dictating out patient clinics for a couple of departments. At the moment we're doing a lot of diabetes and respiratory, but in the past though we've done gastroenterology, paediatrics, dermatology. I've been in this post now... It'll be 4 years this November. And before that I worked in the hospital's Intensive Care Unit admin office. And then before that I worked in the hospital's stroke admin office. In my spare time, I do enjoy socialising and going to the cinema a lot.

Facilitator1 Okay. Great. Thank you. Right, Male2?

Male2 Hi. Yeah, well, I'm Male2. I'm the Regional Community Fundraiser for the Royal British Legion, which means I spent a lot of time speaking to volunteers and corporates and trying to get them to give me lots and lots of money for the British Legion. Been doing that now just over a year. Before that, I did my Masters in International Development and Education and

before that I qualified as a teacher. In my spare time, I like to go out and play football and go out for a few drinks now and then.

Facilitator1 Excellent. Thank you very much. Okay, so what we thought... Shall I do the first activity, you can do the next one?

Facilitator2e Yeah. That's fine.

Facilitator1 Okay. So what we thought would be kind of a little bit of an ice-breaker and to help us understand a little bit more about how you experience stammering, I wondered if you could tell us a little bit about maybe some of the situations where either you're having anxiety around your stammering or where it's particularly difficult or where you might need help in any way possible, I suppose.

Male1 Asking for train tickets.

Facilitator1 Right.

Male1 Right. Oh, up until a few years ago, I used to still have a post-it note in my hand at the train station.

Facilitator1 Right. Oh, really?

Male1 Yeah, I was that bad. It was only- just train tickets. Right. And so I would attempt to ask, but if it never- If I got really blocked, or if it was just too much, I used to just go back with the post-it note.

Facilitator1 Right. So you had a workaround for that already with the post-it note.

Male1 Yeah, but still. It was avoidance, though.

Facilitator1 Yeah. Yeah. Okay. And what do you think might have helped you in that situation to...? Is there anything that would've helped? I mean, I know you used the post-it note.

Male1 I don't know. I mean, maybe just trying to keep calm.

Facilitator1 Okay.

Male1 Yeah, but maybe just train tickets.

Facilitator1 Yeah. Alright. Did it happen for any other type of tickets, like the bus or...?

Male1 I get a weekly bus ticket. So I have to go to the bus station though for that. And since I've been doing it now for literally years, the woman knows what I'm there for anyway.

Facilitator1 Okay.

Male1 So I can still ask her and that, you know, but she already knows. But sometimes, when I don't get to the bus station, I have to ask for a ticket from the driver. I do still have a post-it note in my hand, and sometimes it works though and sometimes I have to show him the ticket, you know, the post-it note. So I think it's just asking for tickets sometimes.

Facilitator1 Yeah. Okay. Okay. Interesting.

Male2 I think generally if I'm either tired or anxious or stressed then it comes out a lot more than it does, and that could be in any situation. So, you know, so it could be if I've had a really long day at work or if I haven't had much sleep and I'm tired, then it comes out then. On the phone. I think it comes out more on the phone than it does in person, and that might be because on the phone you're purely using your voice and that is it, whereas face-to-face you've got the body language and the person's there and you see them and it's... But that might be linking into the fact that, on the phone, you can be more nervous.

Facilitator1 Yeah. Okay. Interesting. Alright. I think these are things that have actually come up as well quite a bit in the- these exact things, actually, have come up in the previous work as well. Okay. Is there any place that you get advice about your stammer? Currently?

| | |
|---------------|--|
| Facilitator2e | Change colours for this. |
| Male2 | Not really. I ask you now and then, but no, generally not. I keep an eye out online and see what's going on if I'm bored and I just wanna have a quick wee look, but generally not, no. |
| Facilitator1 | Okay. So online? |
| Facilitator2e | Online. So where would you go online? What sort of sources would you-? |
| Male2 | I just generally Google up-to-date news on stammering. If, you know, now and then it perks my interest, I'm like: "Okay, what's going on? Is there anything new?" But friends. I go to friends. That's... Would be it. |
| Facilitator1 | Yeah. Okay. And what type of- What type of advice are you getting from friends? |
| Male2 | Generally try and relax and think about what I'm gonna say before I say it. |
| Facilitator1 | Okay. |
| Facilitator2e | That's not always helpful for me, though, sort of thing. I sometimes find that the more I think about what I'm gonna say, the more likely I am to stammer on it. |
| Male2 | Yeah. I know. It's- I would agree with that, but generally it's- It's... When you approach friends, I mean, it may not be so much getting the advice from friends but it's more- Well, it's more the fact that you're engaging with people who you socialise with and you can relax. |
| Facilitator1 | So does it kind of boost your confidence to be around friends who are able to listen to you, I suppose, in a way? |
| Male2 | Yeah. |

Facilitator1 If you're having a particularly bad time, I mean.

Male2 Yeah.

Facilitator1 Okay. Anything from you? Is there anywhere you seek advice from?

Male1 No, not really. I mean, if I was particularly stuck, I think I would either Google the BSA, or if I have a job interview coming up I'd Google sort of like 'stammer advice for job interviews'.

Facilitator1 So you look for specific advice about things?

Male1 Yeah.

Facilitator1 Okay. Okay. And can I just ask about...? I think we've kind of done...all that.

Male2 Erm... Sorry. I think with the advice though, quite a bit, because I've had private therapy before, the past when I was younger, you know. And I spent thousands and thousands of pounds. There's a lot of information techniques that I still use from that and the advice I get from that.

Facilitator1 Okay. So you revisit some of your-? And actually, we were talking about this before as well, weren't we?

Male1 Yeah. Yeah.

Male2 And I've definitely found that private was a lot better than anything you can get on the NHS.

Facilitator2e Well, yeah. I think often you can, with private, you're more willing- You're more likely to get a specialist in the area, whereas NHS you might just get a speech and language therapist in general, rather than someone who's specifically stammering.

Facilitator1 Just double-checking timing. Alright. And we're way ahead of schedule. We might finish a little bit early. Okay. I think, obviously, when there's less people, the conversations take a lot less time so... Facilitator2e, do you want to add anything?

Facilitator2e Well, erm... What? To either of the points?

Facilitator1 Yeah.

Facilitator2e Erm... I think... One of my hardest situations is reading aloud. If you hand me a book or a sheet of paper and someone says: "Read that out." Can't do it.

Male2 Yes, I'll agree with that. When I have to do presentations for work, I very, very, very rarely take notes with me. I will have cue cards on me, with just some very basic points, but I will never take a script. It's because it's that idea of, when I'm doing a presentation, I know what I want to say and it doesn't matter in what order what I say it. You know, and I can kinda change bits of it and I can kinda just wing it, essentially, because I know what I'm talking about and the other people doesn't know what I'm talking about because obviously I'm the expert in what I do at work so if I miss things out, so what? And if I don't want to say something, then fine.

Facilitator1 Interesting. So does that take some of the pressure away from-? Well, if you have the notes- Kinda, as you said, if you have the notes there, then you feel like you have to cover everything and not having them takes the-

Male2 It's that balance between having notes and having a script. So if you have cue cards with a few points on, like if I'm telling a story of, say, someone who we've helped and I'll have maybe a couple of dates on and how we've helped them, like say with their injury for instance. But, apart from that, the rest is just entirely up to me, how I fill the blanks.

Facilitator2e Yes. And I find that's something which is different for different people. For example, I did an open day once and I was doing a speech and I showed up with just a short list of bullet points- the key things I wanted to cover- and that's all I had. The other girl who was doing it, who also stammered, had written out her whole speech on an iPad and the only way she was going to get through it semi-fluently was if she read it word-for-word off the iPad

sort of thing. Whereas, had I done that, it would've taken me half an hour to get through a five minute speech. So it's- Yeah, it is different for different people.

Male2 Yeah. I mean- Sorry, I mean, when I'm reading to my nephews, then I do tend to stammer with those books sometimes, which is...

Facilitator2e Yeah, I think it's the idea of you can't change the wording, you can't swap stuff around, you can't reorder stuff. If it's written, you have to read it as it's written. You can't substitute and restructure, that sort of thing. So that's always been one of my bugbears. But yeah, in terms of the rest, I agree with that.

Facilitator1 You wouldn't have anything to add to this?

Facilitator2e Maybe a support group.

Facilitator1 A support group?

Facilitator2e Yeah. It does kind of factor into the BSA. However I'm talking...

Facilitator1 A physical support group?

Facilitator2e Physical support group, yeah.

Male2 When I did my course, when I went private, part of the after-course care was we had a list of contacts and we actually had a mentor. And for the first, I think it was three months, we had to call them once a week to speak to them. And then, after that- Then, within a month, we had to call six people off that list to have a chat with.

Facilitator1 Ah, interesting.

Male2 And then I had just a list of people and you could just pick up the phone to them and just ring them.

Facilitator1 So that's kind of interesting in terms of having a support network around you of people who are kind of like-minded or it's almost like a safe-

Male2 Yeah, it was. And then what they had is, it wasn't a rank system but they had the coaches and the owners at the top and you had your buddies there. Then had the more experienced people and obviously the further down you get the less experienced they were. So it was always good to know who you could call. So, if you were having a bad day, you could pick up the phone to one of them- it didn't matter who it was- and just speak to them.

Facilitator1 Interesting. Male1, do you have anything else to add to the conversation?

Male1 I get really stressed as well having to phone restaurants and book a table. I find, and this is ridiculous, I have a really great housemate and he's a really big help, but if I'm phoning up somewhere I still need to go into a room by myself to phone up that place. I'm sorry. Y'know, I'm- That's really extreme. I'm okay, though, doing it that way. Though, I have to physically take myself somewhere quiet, though, to do it. And if I leave it, it can become like a monkey on my back, so I try to get it done straight away or as soon as possible.

Male2 Do you find that-? See, because I do that with work as well. So like if I have to phone a volunteer and there's a bit of noise and people talking or joking around in the office then I'll walk out the room and I'll walk down the corridor to where it's quiet, because the noise can be distracting and when you're distracted then you stammer more.

Male1 Right.

Male2 I dunno. That's something I thought. It's...

Male1 I'm fine with background noise, though. I think I'm just very self-conscious. And I'm more self-conscious in that situation than when I use the phone at work, when I pick up the phone at work so it's like... I don't know. It just feels different for me to do that and I'm definitely more self-conscious about my stammer when I have to phone up a restaurant.

| | |
|---------------|--|
| Facilitator1 | Is it because someone's listening to you on other- listening to you perform while you call up the restaurant? |
| Male1 | Possibly. I think, as well, I do find it a tricky situation, anyway. So I do try to phone a place rather than just pop in and book a table face-to-face. Just to expand that comfort zone a little bit. I'd feel it was a bit of a cop-out if I was to go in in person and book a table, if that makes sense. |
| Facilitator1 | No, definitely. You're kind of- You're pushing your boundaries as much as possible. I think that's quite a positive attitude actually, really, to be honest. |
| Facilitator2e | Yeah. At least you do do it, you don't try to pass it off to someone else. You still- Because, you know, a lot of people would give the phone to their flatmate and be like: "Please can you phone for me?", whereas you're still doing it. And you're maybe taking yourself off somewhere else while you do it, but you're still doing it, which is great. |
| Facilitator1 | Yeah. |
| Male1 | Okay. Thank you for that. |
| Facilitator1 | Excellent. Okay. Well, if no-one else has anything else to add to this one, I think we'll push forward with the next activity. |
| Facilitator2e | Although, one quick question before we do move on: Have either of you ever used any kind of technology to help with your stammer before? Like have you ever used an app or used a metronome or something like that? I remember I had one speech therapist, and she gave me a metronome and she was like: "Try to talk to the beat of the metronome." And then she sped it up and said: "Try to talk to the beat of the metronome." |
| Facilitator1 | Oh, really? |
| Facilitator2e | And as a result I ended up talking like this and it sounded really unnatural. And especially, a Scottish accent, we talk so fast. Trying to slow us down doesn't work. |

| | |
|---------------|--|
| Male2 | That's like being a Geordie. |
| Facilitator2e | But yeah, that was the only thing I'd really tried up until a certain point. How about you? |
| Male1 | No, never. |
| Male2 | No. |
| Facilitator2e | Okay, so this is a new territory. |
| Facilitator1 | Definitely new territory. Excellent. Facilitator2e, do you want to explain what we're doing in this one? I'll just push on with these. |
| Facilitator2e | Yes. Okay. So what we're going to do here is... We've gone through the transcripts of the workshops we did with the SLTs and we've looked at the survey results, and from that we've pulled a few ideas of things which people might be interested in seeing in a mobile application for people who stammer. From this we've made these statements and there's about forty of them so there's quite a lot of different- |
| Facilitator1 | You might be better coming round here. Sorry. |
| Facilitator2e | Oh. No, no. – of different statements. And what we would like to do together is look through them and think which ones are important to you two, but also which ones do think are important in the grand scheme of stammering as well, and which ones do you think are maybe more specialised. And we're going to try to pick out the most important ones, which will hopefully be included in the final- I'm really sorry, I cut these out earlier. |
| Facilitator1 | It's taking a very long time. |
| Facilitator2e | There's quite a few of them. So yeah, these are things, which we'll then try to include in the final application if people like the ideas. And also, if there's anything you can't see there, which you would like to get out of a mobile |

application, we have a few blank ones as well, so you can add your thoughts to this massive list.

Facilitator1 And there we go. So forty is the right thing. So, what we were thinking because there's so many...

Facilitator2e Originally you were all going to have our own little things each, but because there's this many we decided we would combine and do it together.

Facilitator1 So if you would like to put a dot on, or a cross or a mark or whatever you want, on the ones that you feel apply to you, and then we'll start to take some of the things away.

Male2 How many?

Facilitator1 You can have as many as you want.

Facilitator2e As many dots as you want.

Facilitator1 And then we're gonna pick the top three. This may be some time. Do you mind if I take a photo of the back of your heads?

[laughter]

Facilitator1 From kinda like [unaudible 26.44], if that makes sense.

Facilitator2e We're gonna get the table in. It's not literally just the back of your heads.

Male1 Sorry, Facilitator2e. Thank you for explaining.

Facilitator2e Yeah, she's not just gonna stand behind you like: 'Click'. Also, if there's anything you want me to clarify, like what it means, then just let me know. Some of them have just been pulled out of the other stuff.

Male2 That one there, what-? Can you clarify that one a bit more?

Facilitator2e What 'constructive feedback' would be? It would be stuff like posture, like if someone notices that maybe your shoulders are up here. It wouldn't be stuff- It's kind of letting people know things which might make it easier for them and kind of... suggestions of that stuff. So maybe: "If you work on your posture, it might help you" or "If you keep eye contact, it might be good." That sort of thing.

Male2 Okay. Thank you.

Facilitator1 I keep getting told off for not taking pictures in workshops by John.

Facilitator2e Oh, alright.

[silence 28:06 – 28:21]

[laughter]

Facilitator2e On the recording, there's just gonna be: 'Bonk'.

Facilitator1 It's alright. It means we'll be able to cut a big section out.

[silence 28:33 – 29:32]

Facilitator1 Okay?

Facilitator2e Yeah?

Male2 I think there was some there which would be useful to some people. I don't mean me, personally, but I think there were definitely some for some people. Because obviously with stammering there's obviously a massive degree of spectrum it can be. And I think there's some there that definitely will be helpful for some people.

| | |
|---------------|---|
| Facilitator1 | Have you marked them off? |
| Male2 | No. |
| Facilitator1 | Do you wanna mark them off in a different colour? |
| Facilitator2e | Do you wanna mark on them blue? |
| Facilitator1 | Do you think Male1, as well? |
| Male1 | Yeah. I think 'small talk', 'practise when making calls'. |
| | [silence 30:06 – 30:37] |
| Facilitator1 | So anything else that you'd wanna add that other people might find useful? |
| Male1 | Oh, I think maybe that one. Yeah. |
| Facilitator1 | Okay. |
| Male2 | That one. Sorry. |
| Facilitator1 | Delayed auditory feedback. Okay. |
| Facilitator2e | Yeah. That's always fun. Have either of you actually tried delayed auditory? It's so weird. It's so odd. |
| Male2 | No. I think it would be really useful but I don't know if I would like it because of that. |
| Facilitator2e | It's so distracting. |

| | |
|---------------|--|
| Male2 | Yeah. That's- |
| Facilitator1 | Okay. |
| Facilitator2e | Do you know what delayed auditory feedback is, sorry? Just to make sure. |
| Male1 | Isn't it when you wear earpieces and they have continuous background noise? |
| Facilitator2e | Yeah, it can be that, or it can be your voice played back to you at a slower pace and that sort of thing. There's a couple of different types. One of them is like a masking noise and another one is- |
| Male2 | Was I red or green? |
| Facilitator2e | You were green, I think. Yeah. It can be masking noise or it can just be your own voice played at a delay and that then forces you to slow down. It's forcing you alter your speech through a noise in your ear. It's interesting but it's odd. It kind of makes you talk a bit strangely sometimes. |
| Male2 | I think you're probably end up best being [inadudible 32:08] |
| Facilitator1 | Facilitator2e, did you have any that you wanted to pick out? Your favourite ones? Because you've been looking at them for weeks. |
| Facilitator2e | I know. |
| Facilitator1 | Even if they're the same ones |
| | [silence 32:20 – 32:30] |
| Facilitator1 | So one of the things that I find actually quite interesting is when we talked through the issues of the phone as being quite a big one, but nobody's |

selected that they would wanna practise making phone calls, so why...? I'm just wondering why.

Male1 I get to use the phone literally every day at work. Picking it up and making phone calls to other departments. So I use the workplace as my main place for making phone calls.

Facilitator1 Okay. Alright, okay.

Male1 If that makes sense.

Facilitator1 That does make sense, yeah. It does make sense.

Male2 I spend a lot of time on the phone because of job and also personal use as well, so...

Facilitator1 Okay. Alright. No, excellent. That's great. So is it more, then, the situation, I suppose, for... Sorry. Is it more the specific situation like booking a table or ringing a... What do you call...?

Male2 A volunteer?

Facilitator1 Not a volunteer. A call centre or something. Like for your broadband or whatever else.

Male2 I think because each phone call is always different, I don't know if I'm gonna stammer until I'm in the phone call. Generally, [inaudible 34:02] if I'm introducing myself [inaudible 34:03] I have to, every time.

Facilitator1 Okay. It's interesting, because it's the first thing I would've gone for. I would've been like: "Let's have a way for people to practise making phone calls" but actually it's not really that important. That's very interesting. Okay.

Male2 I think when you get excited as well then I tend to stammer as well sometimes.

Facilitator2e Yeah, any kind of high emotion I think affects it.

Facilitator1 Okay.

Male2 That's an interesting one.

Facilitator2e Yeah.

Facilitator1 Do you think that's for somebody else?

Male1 I...

Facilitator2e For some people-? Yeah, where's the blue pen?

Facilitator1 Or what? 'I would like to stammer openly', you pointed to. What do you think?

Male2 I...

Facilitator2e Why do you think it's interesting?

Male2 I think if you stammer and you're out in public, which 99% of people are gonna have to be, you can't hide it. It's as simple as that. You physically cannot hide it. So, rather than having to be reminded to stammer openly, I think it's more about getting confidence to embrace it and to accept it. Even if you don't like it. You know, because I'm sure that everyone doesn't like having a stammer, to be honest, and if there was a magic cure then I think most people would take it, but I think getting reminded on to stammer openly might just add more pressure to somebody than it's worth. Because they get this app on their phone and go "Warning: Remember to stammer openly". It's just adding that extra pressure, so I think it's more about having the confidence to speak.

Facilitator1 Okay. And we've got the confidence here.

| | |
|---------------|--|
| Facilitator2e | I think that probably depends on the person. |
| Male1 | On stammering openly, I find that if I openly disclose my stammer to somebody then after that I can go on to have a fluent conversation with them. It's just odd how it works for me. |
| Facilitator1 | Oh, okay. |
| Facilitator2e | I find that. Kind of like advertising your stammer. You can, then- It kind of takes the pressure off. |
| Facilitator1 | So is that an interesting one that we wanna to keep? With the blue? Possibly for other people? |
| Facilitator2e | What? The stammer openly one? |
| Male1 | Yeah, that's- |
| Facilitator1 | Yeah, because we seem to have two... I understand what you mean, Male2. It's interesting to you, but maybe not in that format that you're thinking. |
| Male2 | Yeah, I mean, it's like I tell people that I have a stammer and I even make jokes about having a stammer but... |
| Facilitator1 | Male1, you're getting rid of all the- You're getting rid of, like, half the things. |
| Male1 | Oh, am I? Sorry. |
| Facilitator2e | Well, yeah. To me, advertising and stammering openly... aren't always the same thing. You can- Stammering openly could just be trying not to use avoidance techniques, sort of thing, whereas advertising is when you openly say 'I have a stammer. If you'd like to give me a bit more time that would be..'. . |

| | |
|---------------|---|
| Male2 | Yeah. |
| Facilitator1 | Okay. So let's edit that slightly. |
| Facilitator2e | Yeah. |
| Facilitator1 | So these are not solid things, that's one thing that we wanna say. Is there anything-? Does anyone have anything that they'd like to add? Write down and add? |
| Facilitator2e | We have some blank ones somewhere. |
| Male2 | Maybe sharing stories. |
| Facilitator1 | Sharing stories. |
| Facilitator2e | Oh, like: "I would like to share my experiences"? |
| Male2 | Yeah, like maybe... I dunno. Like best tips and tactics or something like that might be interesting. |
| Facilitator1 | Sharing stories. |
| | [silence 37:41 – 37:47] |
| Male1 | Can you read my writing? |
| Facilitator1 | Yeah, it's fine. |
| Male1 | I'm writing very quickly. I would like to practise presentation skills. |

| | |
|---------------------------|---|
| Facilitator1 | Excellent. |
| Facilitator2e | Ah, okay. Yes. |
| Facilitator1 | Okay, and I'll just put... |
| Facilitator2e | Yeah, presentation skills comes up a lot in support groups and stuff. |
| Facilitator1 | Okay... We've got... |
| Facilitator2e Male1's. | If you maybe wanna put your green dots on yours. I'll add a cross to |
| Male2 | Can you read that, Facilitator1? |
| Facilitator1 | 'Sharing stories on forum', 'Sharing tips and techniques on forum'. Excellent. Okay. Right, now, we didn't 100% think this through, how this might actually look. Okey-dokey. |
| Facilitator2e | How should we...? |
| Facilitator1 | We've got... Let's put the ones in the middle. |
| Facilitator2e | Both, yeah. And me. I'll put the ones that are just me all the way up here. |
| Facilitator1 | Male2... Everybody. This one's right on the top. So... What we would like to do is... |
| Facilitator2e | These ones... |
| Facilitator1 | And these. Okay. So I know you've got your own ones. I'd like you to pick your top three. So what are the-? I think, were these ones-? I think- I've done them the wrong way round, sorry, guys. So these ones are Male1's. |

These ones were Male2's. Obviously everyone's put their dots on these ones and Facilitator2e's got hers. So, just for you, what are the three most important things you would like to do to support your speech?

Male2 That one.

Facilitator2e Okay.

Facilitator1 We've got stickers.

Facilitator2e Oh, yes. That's what the stickers are for. 'I want to be able to reduce how much I stammer.'

Facilitator1 Okay... So this one... Top.

Male2 That one.

Facilitator1 Okay.

Male2 At least I think they're linked together so if they can track their stress levels and if you find that you've got more stress and you stammer more, then if you can reduce your stress then you might be able to reduce your stammer.

Facilitator1 Great.

Male2 And that one. Because, again, I think they all link in together, so if you can monitor your speech and monitor your stress then it's...

Facilitator1 Okay. And Male1? What do you...?

Male1 I like 'Practise for the job interviews', the 'practical demonstrations' and the 'testing yourself in real-life situations'.

| | |
|---------------|---|
| Facilitator1 | Okey-doke. Did you have any different ones, Facilitator2e? |
| Facilitator2e | Erm... I'm... I would say a 'peer-support group'. |
| Facilitator1 | You can have the same ones also. |
| Facilitator2e | Yeah. Let's see... Sorry, just taking another wee glance over. |
| Facilitator1 | I've taken over your activity, sorry. |
| Facilitator2e | No, that's fine. |
| Facilitator1 | This is Facilitator2e's facilitated activity and I'm just like: 'Ma ma.' It does happen occasionally. |
| Facilitator2e | 'Develop speaking skills' and 'Sharing stories'. |
| Facilitator1 | Okay. Right. So, we can do another round. Okay. Now, we need to pick the top three out of them all. So let's- If people want to make a case, I suppose, for their options and then see whether you agree or not, I suppose, on the ones that you'd like to- So maybe in this task, rather than thinking about just you, think about a wider group of people. So how do you, for example, think that the Glaswegian BSA support group- I don't even know if there is a Glaswegian BSA... |
| Facilitator2e | There's an SSN support group. |
| Facilitator1 | But basically people that you don't know, for example. What do you think would be their-? Aligning with your own interests. And what do you think would be more beneficial to a wider group of people? |
| Male2 | I would like to put the case forward for that one. 'I want to be able to reduce how much I stammer'. Because, ultimately, when you learn new techniques, or new skills, or how to address situations, y'know, whether you use tools or techniques. The ultimate aim is to reduce down how much you stammer and I think there's no getting away from that. And if there's ways that you can |

do it, then that would be a good thing, because that encompasses a broad range of things, including tips and techniques or medicine if that came out.

Facilitator1 Does anyone have any disagreements to that statement?

Male1 I wouldn't say reduce my stammer better. I'd say manage my stammer better.

Facilitator1 Okay.

Facilitator2e Yeah, I'm more on that. For me, it's not so much reducing my stammer as becoming more comfortable with it, meaning- even if I do stammer- I'm not completely panicking and thinking that I've completely messed up a situation just because I've stammered. It's more like managing my own expectations of the stammer rather than reducing the 'percentage of syllables stuttered', sort of thing. It's less clinical. But, at the same time, acceptance of your stammer can lead to a reduction in stammering. So they can be connected in that way.

Male2 If you learn how to manage your stammer, then surely by de facto you are going to reduce it because you're learning how to cope with it. And even if that is accepting the situations that you know you're going to stammer, so you prepare for it regarding the situation, then you're still going to reduce it.

Facilitator1 Okay. So shall we revise this one a little bit? Rather than the main aim being reduction, being more about understanding and managing?

Male2 Yes.

Facilitator1 Okay?

Male2 I would- Yeah. Yeah, well, I said that.

Facilitator1 Is that-? Yeah? Is that what people are thinking?

Facilitator2e Yeah.

Male1 Yeah, that's better.

Male2 Yeah. I think once you know how to manage it, you then reduce it.

Male1 Yeah. Yeah.

Male2 So my way would be manage-slash-reduce, to kind of encompass that idea of...

Facilitator2e Reduce-slash-manage my stammer more effectively.

Male2. Yeah, I'll agree with that.

Facilitator1 Okay. So when you talk about managing your stammer, do you still consider it a way of reducing your stammer at some point or is it much more around the...?

Facilitator2e Personally, that's not my end goal. If it happens, great, but that's not what I'm aiming for myself.

Facilitator1 It's quite interesting because I think in the survey results and actually in a lot of the BSA literature and whatever else, there's kinda almost polarised opinions of stammering. One being: 'We need to find a way to cure it, to get rid of it' and the other is: 'No, other people need to be more accepting of my stammer. This is just the way that I talk.' So there's two very polarised views. Which is- It's quite interesting.

Male2 That's interesting because, I dunno if other people agree, but my view is that people have to accept it, y'know, because it is what it is and I accept that I've got it. But, by all means, I want them to find a cure. I think they should find a cure. And you know, if there was trials for a cure, I would put my hand straight up and go: "Yes." Straight away. No questions asked. Unless, obviously, I'm gonna, like, lose a limb.

 [laughter]

Facilitator2e Yeah, you get perfect speech but you lose a leg.

Facilitator1 Take an arm.

Male2 Yeah, but it's, y'know, it's like: Yes, people have to be understanding, but I think, at the same time: Yes, if there's a way to reduce it and knock it down by 20-30%, then yeah, do it, by all means. Unless I lose a limb.

Facilitator1 Okay. Does anybody else wanna add to that?

Male1 I just feel that I'm always gonna stammer, and that's okay, but I think that the most important thing for me is, like, what I do with my stammer, rather than have it totally go. I don't think that I'd- I don't know what life would be like for me without having a stammer. I've had it for so long.

Facilitator2e Well, yeah, it's like the whole thing that I find, people always ask one of two questions of people who stammer. It's either: "Do you wish you hadn't been born with a stammer?" or "If you were offered a magic pill right now which cured your stammer would you take it?" And, normally, if I was offered something right now, no side effects, it would cure it, I would seriously think about taking it. However, if somebody said: "You could go back in time and not have a stammer", no way would I take that, because it's very much made me who I am today. I don't know who I would be without it. It's kinda formed my character. It's formed the decisions I've made in life, the places I've been I wouldn't have been without it, so it's quite...

Male2 That's interesting.

Facilitator2e Why? Would you go back and not have it?

Male2 Yeah, I would. If I had the chance now. I accept I've got it and there is a fair chance that I'm gonna have it for the rest of my life. You know, which is part and parcel of it. But if I had a chance not to have a stammer? Then yeah. Definitely. Then I would I would quite happily get rid of it right now. And if I could go back twenty-odd years and not have it, then yeah.

Facilitator2e Well, yeah, as a teenager I might have had a different opinion, but now- as an adult- I'm like: "No, I don't think I would." I do know other people who are like you, though. They would just go back and just get rid of it and re-do their life without it.

Male2 So a perfect example was when I came back from working in America, back in 2008. One of my friends was studying audiology there and she'd heard about two drugs that they were testing back in 2008 that they thought was going to have a great effect on stammering, didn't in the end. But then they linked me to these two drugs and I kept reading up on it and keeping track, but eventually I think the drug trials just flopped so they couldn't do it. But straightaway when I saw that might have a promise, then yes, I did get a little bit excited thinking you know what it is, if there's a drug then yeah, I will take it. And if there was a drug available 20-30 years ago then yes, I would take it to get rid of it.

Facilitator2e Well, if there was a drug, I would think about taking it but I would also look at the side effects and look at, like, if it dulls my senses, if it makes me kinda... If it affected me in any other way, then I would seriously think about not taking it.

Male2 Yeah, okay. Well, yes, so I agree that there's that trade-off.

Facilitator2e Yes, because it might be that you don't stammer because it makes you completely void of anything. So there's no emotion to make you stammer. And that, I wouldn't be up for that. I quite like having intonations and stuff. It's like there is a Russian speech technique which is if you talk with no intonation at all and slow yourself down and talk like a robot, sort of thing. And you're fluent, but it's not worth the trade-off, in my opinion. But there are some people who do that and do that quite happily. And they're fluent and they like that.

Male2 I wouldn't want to do that. Being a Geordie, it's sometimes...

Facilitator2e It's so much effort.

Facilitator1 It's all very interesting from an outsider's perspective, I must admit. Just the differences in opinion. It's all very interesting.

Facilitator2e Yeah, it's very divided even within.

Facilitator1 Does anyone have another one that they would like to advocate for that they think would be useful to lots of different people?

Male1 I think the stress levels ones because as we've already identified in this first exercise here, some situations are more stressful. And I think that everybody though is different. So I think that a mobile application, if it could be individual for each person, and to maybe make a list of possibly their most stressful situations and stuff, I think it might be helpful. It would be very individual, because obviously, for me, calling up a restaurant is a lot more stressful for me than picking up the phone at work. And then for somebody else that might be vice-versa, total opposite.

Facilitator2e Yeah, I'm the opposite.

Facilitator1 Oh, alright. Okay.

Facilitator2e I'm the opposite, because whenever I pick up the phone in work, I'm representing that workplace. And that, to me, is added pressure. If I'm phoning a restaurant, I'm just representing myself. If I embarrass myself, yes, it's embarrassing, but I can get over it. Whereas if I disgrace the organisation, I know I'm not, but if I stammer and disgrace the organisation, it's so much more pressure for me. So I always felt a lot more nervous about using the phone at work, because I'm not representing me, I'm representing the council I work for. If I pick up the phone here, I'm representing the lab, sort of thing.

Facilitator1 Okay. Anybody have any thoughts about why that shouldn't be involved, included or something which could be, should be put in instead?

Male2 No. I think it's brilliant, because the data that you could pull off that for purposes of research and looking at how you could develop new techniques or just that- Sorry, there's me thinking about research, but the amount of data that you could pull off situations there would be amazing. And it could prove invaluable to... whether it's your doctor, or your speech therapist, or a researcher, or yourself. Yes.

| | |
|---------------|---|
| Facilitator1 | Okay, so we're gonna include the stress levels, but it will have to be personalised for each person. Depending on the situation. |
| Facilitator2e | Yes. I don't think we can absolutely say that everybody gets stressed in this situation and stuff like that. |
| Facilitator1 | So we're sucking diesel, as they say. Male2, you're doing well here, with your greens. Anybody else wanna advocate for a last one? |
| Facilitator2e | Well, I'm slightly biased, so... I'm very much in favour of peer-support and coming together and I think the sharing stories thing does also factor into this. It's the case of having people who you can turn to, you can hear their stories, and you can reassure yourself you're not alone in it. Listen to other people's stories and hear what they've gone through and make friends who also stammer who you can turn to if you're having a bad day, and share techniques and everything. And I think it's a great thing. I have had so much more help off of this sort of thing as opposed to speech and language therapy. No offence. |
| Facilitator1 | None taken. |
| Facilitator2e | But yeah, just having people who I could turn to who are- To talk to in a safe space, a judgement free zone. Where I can say anything, admit to being scared of stuff, admit to this and that. Yeah, I find it to be invaluable. |
| Male2 | I'll agree with that. But... |
| Facilitator2e | No, go for it. |
| Male2 | I think being able to monitor your own speech is invaluable because, obviously, the whole point is 'look at how much the app can support and help you' and being able to monitor where you're having your ups, where you're having downs with your speech would be important so you could look at how to address those situations. But I'm torn. But I am torn between those two and I would love to see them both in, to be perfectly honest. |
| Facilitator2e | So would I. |

Facilitator1 One thing I was gonna say is Facilitator2e, you made a very good point when you said "Well, this one is linked to this one". So is there anything-? Any other qualities that we could- Because actually, I think this monitoring actually links to this one about managing your speech, in a way.

Facilitator2e Well, yeah, you can monitor and manage your speech.

Male2 Yeah.

Facilitator1 So I mean it could be that this actually feeds into this one. Does that make sense?

 [general assent]

Facilitator1 Are there any of the other qualities?

Male2 I would say... Oh, where is it? Things like the techniques and practising can come off your peers, because you know you might find someone who has the exact same issue as you and they might be able to suggest something. Either like picture everybody naked or something but you know it's that sort of thing which links into this.

Facilitator1 Okay. Is this the kind of thing you had in mind?

Male1 I think that is one is an umbrella term for maybe that, that and that, right, in my personal view. So that covers those three for me quite specifically.

Male2 Those two, I agree with, yes. That one to an extent, because to develop your speaking skills. That's such a broad topic and such a...

Facilitator2e It is. No, I do agree, it's a broad topic. However, I however I've known people who have joined a peer support group and, through being there, they've gone from not speaking in any meetings to joining in in every meeting, so there can be development. I know that speaking skills is a broad

term, because it can just mean speaking at all or it can mean public speaking or it can mean... Yeah.

Facilitator1 Yeah. I mean, in a lot of ways, it could actually be that as well, couldn't it?

Male2 Yeah, but again, that could make...

Male1 Well. Right. If this is at the top and this can maybe lead down to this. And then from these two, then we get the speaking skills.

Facilitator2e Oh, yeah. From the techniques and the stories?

Male1 Which can go into job interviews, which can go into real-life situations. Sorry.

Facilitator1 Excellent.

Male2 No, I see it. I would just maybe put that over there.

Male1 Yeah. Sorry.

Facilitator2e What, more as an offshoot sort of thing?

Male2 Yeah, more there, because then that can link in to other things, because that isn't purely just that. That is more... kind of... Let's say... if you go to a speech therapist who says: "What about practising this tip?" That hasn't come from a peer support group. That came from a speech therapist. Or if I go online and I read an academic paper which has trialled a technique out, that hasn't come from a peer-support group, but it might be a way to develop your speaking skills. So yes, I agree that fits with that, but I also think that doesn't fall just under that. That's kind of like...

Facilitator2e It could come from that, but it could also come from over here?

Male2 Yeah.

Male1 Yes, please.

Facilitator1 So, one of the things I wanted to ask here was... Practical. 'I want to be practical demonstrations'. I want to...

Facilitator2e I think that's a typo on my part. I apologise.

Facilitator1 Have practical demonstrations-

Facilitator2e Yeah. Probably 'have'.

Facilitator1 -of tasks and/or techniques.

Facilitator2e Yeah. That was one of Patrick's things from the survey.

Facilitator1 So what do you think it means in terms of practical demonstrations?

Male1 It could be techniques which you've learnt either from private speech therapy, the Starfish, the McGuire or the NHS, or any other source of help to the individual themselves.

Facilitator1 Right, so the people in the support group would be able to give demon- How would they? How would they do that? Would they do that just from typing or...?

Male2 That's interesting that you actually mentioned McGuire, because that's the course that I've done.

Facilitator2e Oh, have you done McGuire?

Facilitator1 Oh, we were talking about it for a long time.

Male2 Yes, the McGuire. So what you have to do for the McGuire is- One of the techniques that they used to do- I mean, it's been years since I've done it. But within a time period you would have to go up to random people and engage, either it could just be asking for the time or asking for directions. And then at the end of the... I think it's five days, they go to a public place. So I did mine in London in Speaker's Corner in Hyde Park where all the politicians go. Put a crate down; you stand on top of the crate and go: "Hi, my name's Male2r and I stammer" and then you talk for, like, five minutes, two minutes.

Facilitator2e Oh, okay. I did wonder earlier when you were talking about the whole phone tree thing. I was thinking: 'The McGuire Programme has that.' That would be why.

Male2 Yes, I was- I don't know if I still am, but I was the youngest person ever to do it. It was all adults and me.

Facilitator1 And do you think it helped you?

Male2 Yeah. Definitely. The help that I got from the NHS was absolutely useless, to be perfectly honest. I learnt more going that course for the McGuire course than I did.

Facilitator2e And did you feel like that was because it run by other people who stammer as opposed to being run by speech therapists who haven't necessarily been through the condition for themselves? Or do you think that it just happened to be by people who stammer and that wasn't why it was useful?

Male2 I think... I know I'm...

Facilitator2e Sorry, that's a bit of a leading question.

Male2 No, it's not. I understand what- I wouldn't like to say, because the McGuire course worked for me, especially if you saw me the video of me when I was little compared to how I was after the McGuire, but I'm fully aware that it wouldn't work for other people as well. And I remember going to a conference and there were lots of different possible ones that you could

choose from. Just because it works for one person, you know. I might just be lucky that I went on a course that helped, but it may not help you, for instance, compared to, say, the other ones out there. Because obviously different courses, different techniques, different views.

Facilitator2e I've heard different stories, yeah.

Facilitator1 Okay. I'm gonna have to move everybody on from this discussion, although very interesting, because even though we started off slow, or started off fast, sorry, we've talked a lot about lots of different things for a very long period of time. So, what I think we'll do is... I mean, we've definitely got this as one of our key features and we've agreed that this is an overarching one for these.

Facilitator2e So that the managing one is also overarching those two.

Facilitator1 So let's say 'monitor and manage'. We want to be able to- Shall we make this-?

Male2 Reduce-stroke-manage.

Facilitator1 Monitor and manage.

Male2 Yeah.

Facilitator1 Okay. Yeah, is that okay?

Facilitator2e Yep.

Facilitator1 So 'I'd like to be part of a peer-support group for people who stammer to practise skills'. To practise skills? To practise speech skills?

Facilitator2e To practise skills-

Male2 And to share stories.

Facilitator2e -and learn from others?

Male2 Yeah. 'Learn from others' is a good one.

Facilitator1 Okay. Skills and learn from others. Alright, so that's our three. What I'd like to do is have a little think, unless you'd like to facilitate, Facilitator2e?

Facilitator2e It depends on what you're about to say.

Facilitator1 Okay, then. So what we'll do is just take each one in turn, and we'll have a think about how we might be able to use a mobile phone application to support this quality. So this one is: "I want to be able to reduce, monitor and manage my stammer effectively." So imagine this is something that we have a million pounds to make and it can be anything in the entire world that you want it to be, even if it seems completely unrealistic.

Male2 I think... Because I thought about this actually a little bit, and I thought what would be quite good is if you- Let's just take, for instance, going to purchase train tickets, for instance, a thing that's already used. It would be good if there was an option to select you purchased train tickets or something. 'Tickets'. And then you have a set of four or five questions giving it a star rating one out of five and then you have a bit of room to type text in, if that- So, like-

Facilitator1 Is this rating the interaction that you've had with the-?

Male2 Yeah, so like rating the interaction and how you feel. So-

Facilitator1 Oh, your interaction? You mean-

Male2 Yeah.

Facilitator1 Oh, I understand. So reflecting on...

| | |
|---------------|--|
| Facilitator2e | Reflecting on how it went, sort of thing? |
| Male2 | Yeah. |
| Male1 | Okay. Is this after you've bought the tickets, Male2? |
| Male2 | Yes. So, for instance, one of the questions could be: 'Out of five, how did you feel before you went?' Okay? And the next question could be: 'How did you feel during or after?' Again, one to five. And afterwards you could have a couple of questions or you could have just an open text box where you could type your thoughts, feelings, you know. Even if it's like: "Aah, that was the worst experience I've ever had." Fine. It's there. It's logged. And then obviously if you were then going to go to a support group or whatever, then- Or if you have a partner, like a buddy type system, then you could share it and they can see. |
| Facilitator1 | Okay. So you would reflect on the interaction and then maybe share that with somebody else? |
| Male2 | If you want to, yes. You don't have to, but that's just an option. |
| Facilitator1 | And how might that improve your... either understanding of your stammer or how you can manage it better? |
| Male2 | Because you might find that if you go to book train tickets at six o'clock in the afternoon after you've been at work all day, it's worse than it is if you were to do it at, say, ten o'clock in the morning before you go to work. |
| Facilitator1 | Okay. |
| Male1 | I used to book it at ten o'clock in the morning. [laughter] |

| | |
|---------------|---|
| Male1 | Sorry. I really did. |
| Male2 | Sorry. |
| Male1 | Self-reflection's really good. |
| Facilitator2e | I'm always really interested in how you felt before versus how you felt during or after because, quite often, how you feel before... You maybe had predictions about what you think's gonna happen, then you come out the other end and you're like: "Well, okay, the world didn't explode. I thought it was gonna." But, you know, you find it's not been as bad a lot of the time. Quite often you're like: "I'm gonna stammer on every word" or "I'm not gonna get it out; they're gonna be like 'What? What? What?'" But that doesn't- Yeah, it quite often doesn't happen as you think it's going to happen. |
| Facilitator1 | So what type of things, then, do you think you're going to want to reflect on? Because you've mentioned a couple of different things there, like the perceived experience versus the actual experience. |
| Male2 | Yeah. And also maybe how- Also, whether they do want to do this or not, maybe how did the other person interact with you? You know, were they patient? Were they a bit of a dick? Sorry for swearing on the- |
| | [laughter] |
| Male2 | You know, because it's, y'know. And did they end your sentence? Because, if someone finishes your sentence, which I absolutely hate, then afterwards you might feel a lot worse because someone has finished your sentence compared to if you've managed to do it yourself. |
| Facilitator2e | Yeah, or when you're trying to say something and they try to guess and they get it wrong. And you're like: "Well, now we're just taking longer because you're making incorrect guesses at me." |
| Male2 | Yeah. |

Facilitator1 So I suppose, if the interaction was negative, how would you turn that round to a positive learning experience?

Male2 Go for a pint.

[laughter]

Facilitator1 But you mentioned sharing? Is that something you would-? I'm just trying to think in my head how-

Male2 I think for some people, yes, it would be. I would talk to my friends. If I had a really bad day, then yes, I would pick up the phone, even if they don't know that I've had a bad day specifically with stammering. I would pick up my friends just to have a chat with them just to...

Facilitator1 Yeah.

Male2 Yeah.

Facilitator2e I think it's kind of reassurance, if you have a bad day, that there's still people you can talk to and it's fine. And it's not a bad experience to talk to them. It's kinda reassuring yourself that not every communication experience is going to be bad.

Male2 Yeah.

Facilitator1 Okay. Do you want to add...?

Male1 If I was to be doing this, right, I would be rating myself on my fluency, on my eye contact, maybe my rate of speech, whether or not I substituted words consciously. And, good or bad, I would go over it for self-reflection. Because I'm thinking of it like: If it's a bad one, that doesn't mean that they're all gonna be bad. But then if it's a good one, it doesn't also mean that they're all gonna be great as well. So I think that each of them just needs to be individual reflection. But I think overall, though, it is useful because either way you know that you can do it and that you can get through it as well.

And I would also be making a note of before, just for me personally, how I physically felt before like do I have a pounding heart or a dry throat. And how I felt afterwards as well, because sometimes the effects of that situation, it's not just on your speech. There's other effects as well.

Male2 And what about, maybe-? Again, this is gonna be- What about actually recording the conversation?

Facilitator2e That has come up before. That came up in the SLT workshops.

Male2 It's whether- Personally, I wouldn't because I hate listening to my own voice, especially if I stammer, but it could be- Again, that could be really good for be able to monitor and say whether- It's again looking for specific words or sounds that you stammer on.

Facilitator1 Yeah. So, again, as a source of self-reflection, listening back?

Male2 Yeah. That's all I've got for that.

Facilitator1 No, I think that came up really strongly in the therapists' workshop, actually. Anything else to add to that one?

Male1 When I was in my speech therapy course, my therapist spoke about having a toolkit. It could be a mental list or it could be an actual physical list. So maybe putting into the application a toolbox, such as intercostal breathing, McGuire techniques, Starfish techniques, desensitisation, mindfulness, slow breathing, any positive thoughts and positive sayings and such.

Facilitator1 Okay. Affirmations, are all they called?

Male1 Sorry?

Facilitator1 Affirmations?

Male1 Affirmations, yes. That's it, yeah. Yeah.

| | |
|---------------|--|
| Male2 | That would be quite good, that, actually. |
| Facilitator1 | So that could be quite interesting as something you could do linked in with the rating, actually. So if you have a particularly bad rating then, even if it's a bad experience, then you get a little affirmation to say exactly what you said: "They're not all gonna be this bad. It might have been bad today but they're not all gonna be bad. What could you learn from this experience?" or something. |
| Male2 | That would be interesting, especially if you tried to use one of the toolkit techniques in the situation. And if you tried it three times, and three times it didn't work, then you might be like: "Okay, that's not working for me, try something else". |
| Facilitator1 | Try something else. Yeah, okay. That's interesting. So they're kinda techniques for helping to manage your stammer. Where would you get those from? |
| Male1 | I think personal experience and from your training course. Online research. But, again, every toolkit is going to be different for every individual person. |
| Facilitator1 | Ah... |
| Male1 | I'll have things which will work for me which won't work for Male2, and vice versa as well with Male2 and me. |
| Facilitator1 | Interesting. So you create your own toolkit? |
| Male1 | Yes. Absolutely. |
| Facilitator1 | That's very interesting. |
| Facilitator2e | That's something that quite often comes out. Techniques. It's often not quite so much that somebody's following a very strict technique. It's more like that you've heard different things. You hear someone talking about a |

technique and you're like: "Oh, that sounds quite interesting. I'll give that a try." And then you'll kind of cherry-pick from here and there and be like: "I'll give that a try... Oh, that works..."

Male2 They do that on the McGuire course, actually. So you learn the basics of costal breathing, but then if you know you're gonna stammer- So like if you're gonna stammer on an 's', you will purposefully stammer on an 's'. So you'll go 'sssssugar'. Or you can replace the word with something else. So, like, they give you different techniques that you can try and you can pick from. So the McGuire course does pull bits in from that.

Facilitator1 Okay. Excellent. That was actually very, very interesting. Does anyone else have anything else to add to that? Though somewhat quickly, as we're running out of time. No? Okay. Let's go onto the next one.

Facilitator2e I'll try to use more of this side of the page on this.

Facilitator1 Okay, so I want to be able to track- Tracking stress levels. So how could we do that with the application?

Male2 I think we briefly touched on that before. Where you have a situation, you've got a star rating, you've got the questions, and you've got a chance to- Obviously, then. Could it also maybe link into some other health things that are already out there or getting developed? For things like if you know you're going to be booking train tickets so it picks up your heart rate, for instance.

Facilitator1 Okay, so like biometrics?

Male2 Yeah, so like bio- So you could mix it up with biometrics and actual... like, your own personal views. Because you might have found it really stressful mentally, doing it, but according to your biometrics you might be completely chilled out, you know.

Facilitator1 Okay. So like your heart rate. We did say blue-sky, didn't we? So it could be anything. So like your heart rate, your... You could measure your sweat glands?

| | |
|---------------|---|
| Male2 | Sweat. Yeah. |
| Male1 | Physical sensations. |
| Facilitator1 | Okay, we also said self-report or reflection. Anything else about tracking stress? |
| Male1 | Oh, yeah. Perhaps... Again, individual though to each person, but maybe your top three most stressful situations, such as picking up the phone, going for tickets, speaking to new people. Again, it'll be different for everyone else. |
| Facilitator1 | Like identifying your stressors and then learning to manage around it? That's quite interesting. |
| Male2 | I mean, rather than going for situations, you could even go as broad as times of day, as well. So maybe it's not specific situations, but if it's first thing in the morning and I'm still half asleep then that's going to- Speaking to people when I'm worse because my brain's still waking up. Or by the time it hits eleven o'clock, twelve o'clock, one o'clock, two o'clock, well, then I'm then hungry. So, yeah. So it's interesting to see whether times of day reflect. But, then again, you could compare that to the seasons, which again I dunno if that'll make any different whatsoever, but wintertime when it's obviously darker and colder. That might make a difference compared to summer. |
| Facilitator2e | What, whether it's like SAD? |
| Facilitator1 | Just one more thing that we have on here was... |
| Male2 | The times of day. |
| Facilitator1 | The times of day and... |
| Facilitator2e | I've got that. |

| | |
|---------------|---|
| Facilitator1 | NHS or... Sorry, what did you say already? Methods that are already available around managing stress. |
| Facilitator2e | Okay. |
| Facilitator1 | Tips and strategies for managing stress. |
| | [silence 01:19:02 – 01:19:16] |
| Facilitator1 | Okay. Last one, unless anyone has anything else to add? Sorry, I'm not moving you on. I'm thinking we should maybe rethink our- It's very useful to do the practise workshop because- |
| Facilitator2e | Yeah, it lets us know which bits take a bit more time for discussion. |
| Facilitator1 | Okay. Final one is about the peer-support group. So being part of the peer-support group. How might we facilitate links to a peer-support group through an application? |
| Male2 | For the peer-support group, I don't think it would have to be people who stammer. |
| Facilitator1 | Okay. |
| Male2 | So I think it could be... Let's just take my friends here, who are obviously based here, some of them. You could have anonymous- You could have an app that's, like, anonymous. So if you're out in a situation... Let's just say you're out for having a meal or you're out having a couple of drinks, they could rate you. And I don't mean that in a bad way, but- You know, and it can stay anonymous. Especially if you ask someone to do it, then that might give you some thoughts for self-reflection and how you feel. |
| Facilitator1 | Okay. |
| Male2 | Just a thought. |

| | |
|---------------|--|
| Male1 | Partners, as well. |
| Facilitator1 | Partners? |
| Male1 | Partners and parents. |
| Facilitator1 | What do you guys think about the rating? |
| Facilitator2e | What kind of thing would you want to be rated on? Would it be fluency? Would it be overall communication? Would it be avoidance things, like they picked up on avoidance techniques? Again, I think it would be a very individual thing. It would differ from person to person but... |
| Male2 | It would. I think it would be very generalised- how you interact with your friends. Because I think, when it comes to people like your partner or your friends know you better than anybody? So, y'know, they might see you stressed and know that you stammer more. You could find that rating out. So one of them could be 'How stressed did you think you were?' and if you stammer more- |
| Facilitator1 | Oh, okay, so it doesn't have to be anything to do with the stammer even? It could just be like... the situations around it? |
| Male2 | Yeah. So it could be: 'Was the person stressed?' and give them 5 because they were- because they looked like they wanted- y'know, because they were completely stressed. 'Did they stammer?' And they got 4. But then the next week, you might find: 'Okay, 1.' They were chilled out. 'Oh, so I had 1 for stammer.' And, again, they could reflect on certain situations they might notice that we can't, about when we stammer more. |
| Facilitator1 | So would this be when you're actually co- when you're located with the person, like if you're going to the cinema with somebody and then they rate you on your speech? |
| Male2 | Yeah, sort of, but that's sounds very like... I don't mean to sound like they're being judgemental of you but... |

| | |
|---------------|--|
| Facilitator2e | I've gotta say, personally, if I'm out with a friend and they're listening to my stammer rather to than what I'm saying, I would get a bit annoyed. |
| Male2 | Yes. Okay. Okay. The way I'm trying to put it across is that they weren't listening to your stammer but they were looking at you generally, though. So if you were out with a friend and you saw that they were maybe a bit down, you would ask: 'Are they alright?' and try to support them through that, y'know? |
| Facilitator2e | Okay, so it's just like a general 'I notice you're a bit worried, we're standing in a queue at a coffee counter, you seem a bit worried' kind of thing? |
| Male2 | Yes. It's that kind of general... |
| Facilitator1 | Anything to add, Male1, about support groups? |
| Male1 | If they also meet all together physically, though, all the dates, times and places of the meeting or any forthcoming meeting or any forthcoming events as well. |
| Facilitator1 | Okay, so sharing a lot more of the wider community based stuff that's going on near you? Where you can meet up with people who have a stammer? |
| Male2 | Would you also like-? Like you mentioned also, the thing to do with purchasing tickets. Would you like to have somebody maybe sharing tips or stories with you about how they might've booked tickets? |
| Male1 | Yes. Yes. |
| Male2 | Yeah, so like stories and tips on a forum or you could maybe do an instant chat type thing across each other. |
| Male1 | Maybe a forum with a question of the day or something. Or a thread. |

Male2 Yeah. Yeah.

Facilitator1 Okay, so you could pose a question. Would this be an anonymous forum or people that you know?

Male1 I mean, it could be either/or maybe.

Male2 Yeah.

Facilitator2e It could be up to you whether you want to show your username or not.

Facilitator1 Oh, so you could have a public or private...?

Male2 Yeah, and within the app, you could have groups, like on What'sApp for instance you've got chats. You know, like group chats. Like that principle but on the forum, though.

Facilitator1 Okay, so it'd be like... It's almost like, say, putting something on Twitter, for example, and you might ask a question on Twitter and hashtag something and everyone comments on it and gives you a response? But you don't necessarily know who they are. Or if you do- If you're part of a Facebook group that's like a big group but you don't necessarily know everybody.

Male2 Yeah, and obviously you know if you, say, have two thousand people have the app, you might have your own small group within that of, say, forty people and you might post just for them.

Facilitator1 Okay, so you're building kinda specialised networks of people. So for example, it might be like covert stammerers or...

Male2 Yeah. What a name.

Facilitator1 Covert. That's what it's called.

| | |
|---------------|--|
| Facilitator2e | Yeah. |
| Male2 | Really? |
| Facilitator1 | Covert stammering's where... You know that thing you were talking about as a strategy of replacing one word with another? That's called covert stammering. |
| Male2 | Oh. Oh. I didn't know that. |
| Facilitator2e | The official name is covert stammering, yeah. |
| Male2 | I never knew that. I thought you were just making, like, a really cool name for a forum. |
| Facilitator1 | No, no. Not necessarily a technique, though. We tend to suggest that people actually do speech therapy because it like builds up and up and up and up and up, and the stress and anxiety levels around covert stammering is really quite... |
| Male2 | Really? |
| Facilitator2e | Yeah, because a lot of people just avoid talking completely or avoid situations where they might need to speak. |
| Male2 | Okay. |
| Facilitator2e | Or some people substitute so- words so much that their sentences come out and they don't make any sense because they've swapped out so many words. Bruce Willis sometimes, if you watch his interviews, you can see him doing it. And you're like: |
| Male2 | Yeah. |

| | |
|---------------|---|
| Facilitator1 | Bruce Willis? |
| Facilitator2e | Bruce Willis has a stammer. |
| Facilitator1 | Really? |
| Facilitator2e | Yeah. He's a big covert stammerer. |
| Facilitator1 | I didn't know that... |
| Male1 | I didn't know about Bruce Willis. |
| Male2 | Me, neither. |
| Facilitator2e | Yeah, Bruce Willis, Samuel L. Jackson, Emily Blunt- |
| Male2 | Really? |
| Facilitator1 | Really? |
| Male1 | Emily Blunt, I knew, yeah. |
| Facilitator1 | Really? |
| Male1 | Yeah, a few people have, yeah. |
| Facilitator1 | Oh, wow. So are they-? |
| Facilitator2e | Ed Sheeran. |
| Facilitator1 | Ed Sheeran? |

| | |
|---------------|--|
| Male1 | Charles Dance, I believe, as well. |
| Male2 | Gareth Gates. |
| Facilitator2e | Oh, I didn't know- |
| Male1 | Charles Dance. |
| Facilitator2e | I didn't know Charles Dance. I did know Gareth Gates. I didn't know Charles Dance. |
| Facilitator1 | Okay, so are they all covert stammerers or are they just resolved stammerers? |
| Facilitator2e | Well, not all of them- They've kinda worked out techniques to get through it, I think. |
| Male2 | What would be interesting, which I think would like into this, when I was at school, I used to have music lessons and sing. That used to help a lot. Which is just a thought. |
| Facilitator1 | Okay, so it's like melodic intonation therapy, I suppose. If you teach... Melodic intonation is one of the ways of- Do you know when you're spacing, using your metronome, but then you kind of talk like-? |
| Facilitator2e | Switching up the rhythm. |
| Facilitator1 | Yeah, you would look at, say, a set of sentences that you use all the time. If it was a question then it would go up at the end, so you'd be like: "Would you like a cup of tea?" And you start of doing that, then you would bring it into more natural intonation. "Would you like a cup of tea? Would you like a cup of tea?" |
| Male2 | Yeah, because I've never seen someone stammer when they sing. |

| | |
|---------------|--|
| Facilitator2e | Well, it's a proven thing that we don't. |
| Male1 | I don't stammer when I sing, or when I'm in a works chorus. And what I do at work, which is so helpful on the phone, my opening, it's very generic, right, and that's almost like singing. I just say: "Typing pool. How can I help you? Michael speaking." And I hardly ever, ever stammer on that. |
| Facilitator2e | Because of the rhythm, yeah. |
| Facilitator1 | Yeah. |
| Male1 | It's like, yeah... It's really useful for me. |
| Male2 | Well, that's the answer. Just get everyone to start singing and people would never know that they stammered. |
| Facilitator2e | Well, yeah, if only we lived in a musical. Life would be so much easier. |
| Male1 | Gareth Gates, remember him? Came second. |
| Facilitator2e | Neil Young, as well. |
| Facilitator1 | Well, Facilitator2e, you're a font of knowledge but this line is talking is... |
| Facilitator2e | Yes. |
| Facilitator1 | ...eating up... Okay. So, I think that's also really- Because that type of strategy that you've built up is also really- It's something that could potentially be really useful for- I mean, even if you were thinking about an interview situation or doing small talk, having some kind of practise line that you say all the time could potentially be- |
| Male2 | Go for jobs in musicals. |

| | |
|---------------|---|
| Facilitator1 | Yeah. |
| Male2 | Then you'd be fine. |
| Facilitator1 | "I am Male2! How are ya? Great! Hire me, please!" No. And that's on the recording... |
| Facilitator2e | I know someone who stammers who actually works on Broadway in New York and he's just like: "I just sing all the time. It's fine." |
| Facilitator1 | That's very interesting. Okay, does anybody have anything else to add to that? |
| Male1 | Maybe a contact name of your buddies or your local speech therapy department as well? Individual though to your area, as well. |
| Facilitator1 | Okay, so signposting? |
| Male2 | That idea of doing a buddy-buddy system did actually work really well when I used to be in therapy. It was very- You would have a coach and also two or three buddies. It was interesting to have the difference between the coach and the buddy. |
| Facilitator2e | And it would be possible just for people to say their location so you could get it narrowed down to just people who are also in their area and you could talk to people close by and stuff like that. |
| Male2 | Not too close, though, because I don't want a person turning up at work. |
| Facilitator2e | Well, yeah, obviously not pin-pointing the street you're on. |
| Male2 | [inaudible 01:31:10] person that stammers! |

Facilitator2e

But yeah, you could just do a kind of Newcastle thread and Edinburgh thread and stuff.

Facilitator1

Excellent. Okay. I think we've got loads and loads of ideas to take forward and I'm already starting to maybe rethink the way we're doing our other workshop. So maybe presenting some of the- Because there's so many ideas here. Maybe we'll present these as a kind of design realisation? So put a scenario out and say, for example, 'Male2 is going to book some train tickets. He opens up his applications. He rates-'

END AUDIO