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START AUDIO

Facilitator: ____[0:00:05] if we could all just kind of fill out this saying a little bit about what our personal experience of dementia were, and perhaps even what we do differently or what we would tell ourselves now that you'd might've found useful when you first had contact with someone with dementia, when you first found out about what it might mean.

So if you spend five minutes just thinking about this, complete it, and when everyone's done just put your pen down, or something like that, just so I know. Then we're just going to quickly go round and share those, is that okay?

Then I have to get my thinking cap on.

Suran: [It's draw the doodle ____ 0:00:43].

Facilitator: Draw the doodle? Just continue, you don't have to be an artist for this I promise you.

Anna: I've already drawn myself accidentally with two chins, so don't worry guys, I've set the bar nice and low. (Laughter)

Facilitator: I'll draw how I think I look.

Anna: Yes, try and turn it into a smile.

Facilitator: Psychologists would have a field-day with this.

Suran: I've done a stickman.
[Completing forms 0:01:06-0:03:04].

Facilitator: Oh I've just realised that I've misspelt dementia, oh dear. You see if I hadn't noted that no one would've noticed it.

Nadia: Misspelt or is it just a simple typo?

Facilitator: Oh it's a typo, there's a missing 'n'. I wouldn't fit in the box if I added the 'n' so...
[Completing forms 0:03:27-0:05:07]

Anna: Yes, I've made myself look a bit chubby, I tried to draw a pair of earrings and it backfired.

Facilitator: I thought if I made it sketchier and scratchy it makes it look more artistic but really it's just covering up my flaws.

Anna: You look a bit like the butch uncle of, what's he called, not Uncle Ben, Mr Ben.

Facilitator: Mr Ben?

Anna: Do you know the one who used to go in the cupboard and then have adventures dressed up in different clothes?

Roisin: I know who you're talking about, mixed with Edward Scissor Hands.

Anna: Yes. (Laughter)

Facilitator: I'm getting more the Edward Scissor Hands than, potentially, the weird butch uncle of Mr Ben.

So how are we doing?

Suran: I've kind of stopped because I'm stuck.

Nadia: I don't really know what to write.

Facilitator: You don't know what to write?

Nadia: No, because I haven't really had a lot of experience with dementia.

Facilitator: But I suppose, what was your..? Would it be easier to hear what other people say and then think about what sort of things might inspire you?

Nadia: Yes.

Facilitator: Alright, okay, let's do that. Who would like to go first? Who's happy to share theirs?

Kate: I will.

Facilitator: Brilliant, I was going to offer someone then who was probably from this table, so you beat us to it.

Kate: I'll just say what I've written because otherwise I'll go on for ages.

Facilitator: There's nothing wrong with that.

Kate: My grandfather has dementia and now has days where he doesn't remember much at all, including things like how to eat, but he has some better days as well. By this stage I find it quite heart-breaking to visit him because I just feel so bad for

how confused he is. So it makes it a lot harder because there are very few ways in which we can connect anymore.

Am I reading my advice to myself as well? I've just said, 'Be patient, make sure the person with dementia feels supported and loved. There's no real need to correct mistakes.'

Facilitator: That's really great, thanks for sharing that with us [Kate]. What I'll do is I'll chuck this on the door for the time being, of course everyone is very welcome to ____ [0:07:32] with them at the end.

Who would like to go next? How about one of you folks?

Anna: I can go.

Facilitator: Go on then Anna.

Anna: So my experience is actually only through friends who've got family members, so it's pretty limited and second-hand. But I think I'd tell my younger self to not be afraid, to try and be kind and to try and be understanding.

Facilitator: Thank you. What about one of you folks, would you like to go? One of you experts?

Sam: My great-grandma had it and we saw it deteriorate over five years before she died so it was quite upsetting. But I would tell my younger self to not get frustrated and tell my family

members not to get frustrated either because it's horrible to see everyone getting frustrated with her.

Facilitator: Did you say getting frustrated with her?

Sam: Yes.

Facilitator: Okay, I can definitely empathise with that a huge amount.
Do you want to go Roisin?

Roisin: So I'd like to explain my doodle first, which is just a stickman but I did draw a cat, so there you go. (Laughter)

Facilitator: The cat?

Roisin: I have cat so she's just my cat.

So my grandfather had Alzheimer's but I was at uni whenever he was... Well, he was diagnosed before I went away to university, and then I went away to university so I kind of saw him every, maybe, six to eight months. So obviously each time that I came back he was progressively worse and worse.

But my dad was his fulltime carer so obviously I heard a lot of the information about how he was doing and stuff through my dad. I think I probably lived a lot of experience through what my dad was going through. I know that he was very frustrated and had a lot of issues.

I would say one of the things that I found when I went to visit him is that he would always light up whenever we talked about things in the past. So I would say to learn about the person's past and then use this to support conversation because it's really hard to have a conversation with somebody with dementia, especially if you're frustrated or you don't really know what to talk to them about.

Facilitator: Thank you very much. I'll add that to the wall. Now, who would like to go next? One of you lovely folks on the table here?

Leanne: Well I've got personal experience through me nanna having it, who's now in a care home because the family members who were close to her couldn't really cope with what was going on. I think, to be honest, it was undiagnosed in my mum as well before she died. So I've kind of had two lots of experiences with that.

I think for me it would just be being supportive and patient with family members. I've got a lot of care background so it would be to try and get them to see it from a carer's point of view really.

Facilitator: Thank you for that. I think there are a lot of things coming up already. Sometimes it depends on your age but it's not always necessarily about helping the person with dementia or talking to that person but it's actually all the other people around them, sometimes that's the most challenging thing.

Nadia or Suran, would either of you like to go?

Suran: [Let's just drive past the picture because I look drunk].

Facilitator: Beautiful.

Kate: We won't hold it against you.

Facilitator: You haven't seen mine yet.

Suran: Well believe me it's... I look like, I don't know, ____ [0:11:38].

Well my grandad suffers with Alzheimer's. There was the language barrier anyway so I wasn't as close as I should've been but I felt... Then the way my experience links into what advice I'd give myself is not to be afraid of the person because of the illness because I did see how it affected my other family members and I was a little bit scared. So don't be afraid of him just because of the illness that he's got.

Facilitator: See the person and not the illness.

Suran: I know it's Alzheimer's disease but I didn't want to say disease because it sounds a bit contagious. Illness sounds a little bit less, I don't know, sounds a little bit better than disease.

Kate: Yes, that's interesting.

Facilitator: There's a whole thing around trying not to talk about dementia in general as a disease, or even as a condition, and instead just- Sometimes it's hard to avoid that but sometimes, like what you're getting at there, it stops you seeing them as a human being, as a person, as someone with experiences. Don't use the 'p word' the 'patient' word, that's often an important thing to know.

So, I'll share mine now. You can see my famous picture of the hunch Mr Ben or whatever it was, or the large Mr Ben, the chubby Mr Ben.

It's really funny actually because I often think of myself as a researcher doing stuff with dementia but I do have a personal connection with it as well. So my grandma, who passed away this summer, had dementia for 10 years. I suppose a little bit like how some people have said my real connection with dementia was mostly through my mum being her live-in carer. I suppose most of my experience, because they lived quite far away in the Midlands, was often hearing my mum moan about my grandma and the problems that she was having.

So to think about what advice I'd give my younger self about dementia, I didn't really understand. I knew it was a thing at the time but I didn't really understand anything about it. But also I didn't really appreciate that you can just talk about most things or anything with someone with dementia, actually I could sit down and talk to my grandma about virtually anything that was in the room. Sometimes things would be remembered, which you think, "I don't really remember that happening when I was doing such and such with you when I was younger" but actually sometimes that's fine, it's probably fact and it's probably memories to them and that's all that matters.

Not to avoid talking, which I think is probably what I did an awful lot of the time. I suppose also help other people in my family understand the condition a little bit as well, because they're often the ones who got most frustrated with my grandma, so that's me.

I'll put that up on the wall as well. Now, what do you think? Have you made any more connections with yourself now? Any other things? I guess it is what you would tell your younger self that you're struggling with or...?

Nadia: Just both really because, I don't know, I've got a friend whose grandma had dementia and it was really bad, but I didn't really speak to him about that very much so I don't know much about it.

Facilitator: Would he speak to you about it very much or..?

Nadia: He did once but not a lot.

Facilitator: So what are you trying to get out of workshops like this, is it to try and find out more about it?

Nadia: Yes, mainly.

Facilitator: What sort of things would be most useful for you?

Nadia: I don't know.

Facilitator: Shall we put it on the place holder for the time being? We're still going to stick you up on the wall.

Suran: You've got an interesting stickman anyway. (Laughter)

Facilitator: There you go you see, look at that, it can go against the other beautiful stickmen.

Anna: We were talking when we were waiting at the Metro, I think though perhaps your interest in performance, character and things like that could be quite interesting. What you've not mentioned is that you've got an incredible memory, so was it you who said you could memorise two pages in 10 minutes?

Nadia: Yes, something like that.

Anna: So it's almost like you're the polar opposites. So sometimes you just have to use what you know, so you're almost like our memory expert in the room because you've got a ridiculous brain. Actually that could be interesting in thinking about...

Facilitator: Also in terms of performance are you interested in- By performances do you mean theatre and art performance?

Nadia: Yes.

Facilitator: There's a whole area of dementia research around the arts and performance and how that helps people evoke certain types of memories. So sometimes moving around, listening to certain types of music, doing certain types of dances or movements actually helps you recollect certain things from your past which can often be quite therapeutic, well to be honest with you, to carers as well as people that have actually got dementia as well. So there maybe something there, maybe something that seems to relate.

That was good. So the point of that really was to just get a sense of where everyone's kind of coming from in the room. I think that's been really helpful. It's been really helpful for me anyway so thank you very much for sharing that.

This activity will look quite familiar to you two guys, sorry about this. But kind of pretend that you can't remember what happened, and even if you did just see where it goes this time. So those who were at the very first workshop we did do you remember that at the end everyone came up with what they thought was the most important take home from the workshop, which we then started to relate to an agenda, like a manifesto for DemYouth? So these were what we thought were the really important things for the project to do going forward. Thinking a little bit about how many younger people perhaps don't know an awful lot about dementia and perhaps they need to find out some more information.

Each of those 12 points everyone made I have stuck onto cards. What I actually did was I transcribed as well... Leanne and Suran, you might find your bits on here. I know Sam and

Nadia's are there somewhere as well. You found them last time I think, didn't you?

Sam: Yes.

Facilitator: Yes, see if that comes up again.

So on the back we've got little quotes which relate to each of these points which I've summarised on the front. Each of them are about things that we think should be important for a project like this to do.

What I'd like to do is if we can put ourselves into little groups. How will I play this? I think we'll probably have to have two and a three, obviously, clearly, with myself, Roisin and maybe Anna, would you like to sit in one of these or are you..?

Anna: I'll just go wherever.

Facilitator: You'll just go wherever.

So perhaps... What shall we do? This is it, I was thinking we'd maybe have four or six, I never even planned for odd numbers. How about we have Leanne and Kate, do you want to come over here onto this table with Nadia, do you want to come over here as well?

Then we've got Sam, Suran and Roisin. Do you want to go over there?

Roisin: Yes.

Anna: Are you going to go in this group then, so shall I go in that group that's got slightly less people?

Facilitator: Oh, you can do if you like, you're moving around.

Anna: Then we'll have equal groups. Not that I'm escaping from you or anything.

Facilitator: I was going to say... [Oh, are you alright? This isn't gymnastics 0:20:07].

Okay. So you might want to group yourself around so that you can all look through and pass around these cards. I'm course expecting Sam-

Anna: Does anyone want any juice whilst I'm up?

Sam: What juice is there?

Anna: There is orange or apple and mango?

Facilitator: Or water.

Anna: Or still water.

Sam: Orange please.

Facilitator: Are you going to get to the point where you're going to be making a cocktail again?

Sam: Maybe, it was really good last time.

Anna: Do you want it half and half?

Sam: Go on then, we'll do it half and half.

Anna: All serious decisions.

Facilitator: Actually Kate, do you want to come and move around here so we're all a bit clustered around? Do you want to have this chair there?

Kate: Thank you.

Suran: You always make such nice things.

Facilitator: They're not nice things really, it's just nice paper that covers up [the holes in the floors 0:20:53].

So do you want to just pass these round the group and then just talk through them a little bit? Flick through them, read some of them and read what's on the back. Speak among yourselves. Sam and Nadia, you're more than welcome to just pretend, once again, that you haven't done this before or you can just ask questions in relation to them.

Nadia: I remember there was quite an extensive debate last time.

Facilitator: There was an extensive debate.

Kate: Were we involved in creating these as well?

Leanne: Yes, was it that first one?

Anna: Yes, it was a while ago so it would probably feel a-

Facilitator: It was a long time ago. So this is a way to get back up to speed, I guess, on the things that we were taking about last time.

Anna: So these are the main things that people said they would like in the future. [Silence/shuffling 0:21:41-0:21:53]

Nadia: So the most important thing isn't it, the manifesto? Do you want us to come up with three?

Facilitator: I wasn't going to go there; you're getting ahead of me there Nadia.

Nadia: Oh sorry.

Facilitator: But that's fine, we can go with that.

The idea of this activity, to let the ball out of the bag here, is you've got to choose three to take forward to the next activity. So what you think the three most important agenda points are, or manifesto points, I keep changing the way of talking about these things.

Nadia: I don't know what anyone thinks about those two but signposting someone, does that come under one bracket, I don't know how you feel about that? Just from reading this one, on the back there and the phrasing, it would just be someone who knew what was going on. So maybe signposting and better information about someone who knows...?

Leanne: Yes, you'd need to start off somewhere and then signpost them to information. That's the main thing really.

Kate: It's difficult because things are linked aren't they, but if there is education about it from a young age...

Leanne: It also depends on if that one someone's there who, from a young person point of view, someone who's there to inform the young person or inform the old person? Do you help the young person or help the old person? Do you give them comfort and support or do you support the old person?

Kate: Yes, there are almost two whole brackets of care that are needed, or support.

Leanne: There are two different strands of that there, but I don't know. That might make it easier to narrow it down as well, I don't know.

Kate: Yes, kind of like have a tree.

Leanne: Yes, if we think we're going from an old person perspective there and a young person, I don't know.

Kate: I guess I would feel like this would be, for me, an important one.

Nadia: Which one's that?

Kate: Just 'We need more interaction between young people and people with dementia' and ideas for-

Leanne: Oh right, what's it say on the back? 'Get young people more involved in workshops or if they know someone with dementia getting more involved with the care package maybe so they can understand it a lot more and they can help a family member out or other people affected out.' Basically just helping with activities or taking them out during social activities just so that they can have interactions with them. It might not be on a day to day basis.

Facilitator: Yes, that was one of the longest ones.

Leanne: I suppose that helps as well because you can feel quite alone if you've got dementia.

Nadia: I think I remember that one actually.

Leanne: Was that yours? (Laughter)

Facilitator: So when you think about interaction what do you mean? What's in that that's so important?

Kate: I think that in society in general we've got a lot of lonely and isolated people, and dementia is one of the things that can make that worse. I would hate to feel regret. I think one of the difficult things is that obviously a lot of people who are suffering with dementia are a number of years off the end of their life and if you're a young person struggling to get your head round that by the time you've understood and got ideas

about how you could relate to them in a helpful way it might be too late. You might feel a massive amount of regret about that because you just wanted your grandparents to know that you loved them but you didn't know how to convey that.

I think for them the best way for you to convey that you love them is to interact with them because it combats that loneliness and that boredom. Even if you can't remember from one day to the next whether someone's visited you, when someone actually was there or when you were on the phone or when you did get a letter it lifts that person's spirits. They can probably carry the feeling of that forwards even if they can't remember it. So they might not be able to say, "I spoke to my granddaughter about this" but actually in that day it made it a lot more bearable and they had those feelings.

Leanne: I can link it to that heading because it's all well and great having it out there because it's all well and great having it all out there but it's not-

Kate: I also think the young person has that memory as well to take with them for the rest of their life. So in terms of relating to people with dementia, you know, I think the crux of it is interaction isn't it? I can think philosophically all I like about how well my grandads last few years were, or not, or what was happening or what developments in medication there were, and all sorts of things around dementia, but if I hadn't actually spoken to him and gone on that journey with him then he would've been alone in it and I've not really participated in it.

Facilitator: Yes, I think that makes complete sense.

Kate: I don't know, but...

Facilitator: No, that's very well put. You convinced me. (Laughter)
Excellent.

Kate: But how you would do that I don't know. I think it might be worth having ideas.

Facilitator: Yes, it's almost like how do you encourage people to make those connections and interactions more maybe?

Kate: Yes, so I suppose it's a bit like addressing fears, so it's partly education and partly inspiration and ideas about something that works well with someone's dementia because obviously there are things that wouldn't work so well. What was it somebody said about getting knowledge about that person's past so that you do know how to have a conversation with them because that's what they're likely to still be able to remember.

So if the app had somewhere where you could tap for inspiration and it's got different levels of things that you can do with someone who's got dementia... Obviously that will vary depending on how far along they are, but, you know, if you're at a loss then you've got something like, "Write them a letter about something you've done in the past" or, "Ask them a question about something that they studied at uni because they'll probably still remember that", or something like that.

Facilitator: Like lots of little prompts for [Crosstalk 0:29:16]. Hold that idea, I'll come back to that later. It's very related to something we talked about last week actually.

We've missed all your conversation sorry, have you been prioritising stuff, sorry, in our absence?

Leanne: We're sort of grouping things at the minute I think, getting carried away with how we can youth-proof it.

Facilitator: Youth-proof it, yeah.

Leanne: I hate that phrase.

Facilitator: Youth-proof it, is that actually a phrase, I've never heard it?

Leanne: It's one which my local council, my local authority, used a lot and still do.

Facilitator: Really?

Leanne: Youth-proofing, it's like when you've got a report and then you've got to youth-proof it so young people will read it ____[0:29:58].

Facilitator: Young people speak or more simple language or something?

Leanne: Yes, they've got a big book and you turn it into bullet points.

Facilitator: So without using the word youth-proof how could we do something that's not like that but more interesting? Were you picking up on a particular point?

Leanne: There was one we picked up, was it that one or that one? I think they both went together.

Nadia: Like making a cartoon or a game to mix the information together really.

Facilitator: So making it a bit richer?

Leanne: Yes, it's kind of like what MyMaths does at school, like making maths fun.

Nadia: It is like making it fun and educational at the same time. It depends on the target age, like I was saying as well.

Leanne: If we're targeting early, like pre-teens, then you want something slightly more fun, whereas if it's a slightly older age when you reach your teenage years into younger adulthood you don't want to be playing a silly little game, well you did but

you want something a little bit more advanced or you'd think,
"This is for kids."

Facilitator: So do you think that one should be up there with the
interaction one, which we seem to have put up here?

Nadia: I think it's different. I think the interaction is different to making
it youth-friendly. That's about the information you provide isn't
it and that's about actually interacting. I think this falls into that,
if you know more about it the interaction will come. I know for
me, I'm just a young person maybe, my main one was getting
rid of being afraid of the illness.

Kate: Do you think being educated about it or having something like
that would've been what helped you to be less afraid?

Nadia: Yes.

Kate: I think sometimes it's almost like a stigma isn't it? If you undo
myths...

Nadia: It's just when you hear that they have a violent outburst or
something or they don't remember who you are then you think,
"Oh shit."

Leanne: A lot of young people when they see something bad they focus
on that bad thing and think that person's going to be like that

all the time. I had it with me mum and I thought she was going to be like that all the time. But when you get passed that initial barrier they're back to the person you used to know and what they used to be like.

Nadia: My grandad wasn't allowed; it was a little bit less developed where he was from. He wasn't really allowed around the younger kids because he wouldn't know how to treat them because you've got to be very delicate with the younger child and he'd pick them up and swing them about and it's not safe. So if he was around the kids there would always be someone older there with him. When you've got your granddad and his grandkids you want them to have that relationship.

Leanne: It's like the lack of trust in that person really isn't it? You know they're not a violent person but it's trying to [Crosstalk 0:33:17].

Nadia: So he was never alone but at the same time he was because he wasn't allowed to be alone. So there is almost that balance. He'd walk off to the shop, because we had a family shop and he'd always go down because it would still be his, but obviously my uncles took it over. He'd always just randomly go off and you'd be like, "Where's he gone?" You'd find him down the shop and he'd come back with a load of sweets for the kids so it was always good. He'd be like, "Do you want a sweet?" I'd be like, "It's tea soon, no."

Facilitator: So do we think there are any of those on there that rather than thinking about the three we want to choose are there any that

you think are probably not so important? It's really difficult, you can look at that and think every idea is an idea that someone's suggested at some point but let's not worry about that too much. Are there any ones which you think are less important for us to take forward?

Leanne: Well they're together. We need to start leaving younger people out and [considering ____ 0:34:22]. So that's getting one together if you think about.

Nadia: What's that? 'We need ways to communicate with and between those that are affected.' Is that not interaction? Not just focusing on communicating with the person with dementia but also communicating with the other people that are affected?

'So having strategies to communicate with them better, better approach to dementia within the whole space or...'

Kate: It's a different kind of interaction isn't it? It's like a support network interaction rather than the direct interaction between...

Nadia: 'Signposting them to networks.'

Kate: It's difficult to pull anything out and be like, "Oh no that's not important" because...

- Nadia: General awareness... I think that's an overriding theme, we need better general awareness of what dementia is. So whether that's through, sort of, signposting people to support networks or better, sort of, information. I think that's the overriding theme. I don't know what it says on the back?
- Kate: One of the problems we discussed was better education. You don't get much apart from the R Charity having a 15 advert to deal with it. So we think we need better basic awareness about dementia and everything because you can't just go, "They've got dementia" because that ends up as a stereotype. It needs to be more sensitive.
- Nadia: So that's maybe about what all this is.
- Kate: So it's about education as well.
- Nadia: Like making people understand.
- Kate: Yes, so information that's young people friendly is also the same as educating people and signposting them.
- Nadia: 'Being with people that have dementia', that's about communication I think. 'New ways of being with people, it would be good if there was someone there all the time.'
- Facilitator: Oh God, that's a long quote.

Kate: Yes.

Nadia: We thought of like a robot companion, a robot that would be a resident and could almost read their minds and understand what is going on with them. They'd interact with the robot and you interact with the robot. So like Facetiming.

Kate: So is that one about educating young people as well or getting information out?

Nadia: I think that's something to do with communication. We need ways to communicate between ____ [0:36:49].

Kate: So if we feel these fours are roughly the same?

Nadia: Yes, it's all about putting the information out there.

Kate: Shall we pick one that we feel sums it up the most and then discard the others?

Leanne: That one's another communication one to read.

Facilitator: You see for me it's [Crosstalk 0:37:03] to see how people make sense of an activity. You've done it differently to how they did it last time.

Nadia: 'We need advice on the best attitude to have when interacting with people with dementia.' Is that communication or is that information? Or is that a bit of both?

Kate: Sorry, can I just..? Yes, I think again it is educating someone on how to communicate isn't it?

Nadia: Yes.

Kate: Which is one of the main parts of how you...

Leanne: Basic advice on how to go forward really isn't it?

Nadia: It's like when you're dealing with a kid as well. How do you deal with a child? Do you talk down to them or do you talk to them like they're just a normal person? Just change your language slightly, don't use overcomplicated words or profanities.

Kate: Yes, you don't necessarily say it all really loud and really slowly. That can be helpful but...

Nadia: Yes, it's like when you're talking to someone who speaks a different language, don't talk to them like they're dumb and don't sound patronising.

Facilitator: Can I just say that in five minutes we need to have chosen three to take forward, not to push you too much.

Nadia: Well we've bunched them together and I think what you're saying about the overriding...

Facilitator: So do you guys have the idea that you might take one from each group that you think's important?

Kate: Yes, I think so because we don't want to...

Facilitator: That makes sense.

Nadia: So we know which ones the groups are, shall we put the-

Kate: I'd pick this one out of these two because although it's interesting to hear their opinions it's actually involving them...

Nadia: Yes, if you're going to get them involved and not leave them out then you're going to listen to their opinions.

Kate: So if we have that one as one that's chosen.

I guess I've already that out of those ones I'd pick that one but I'm not saying that we should. I just think that that overall sums it up, that we need interaction between young people and people with dementia.

Leanne: I think that one would be a good one to add on because you do need-

Nadia: Unless there's that one?

Is that not in that one? If you interact with young people and people with dementia?

Leanne: Yes, that would be under-

Kate: I guess, I don't know, I guess we're working generally towards more interaction between young people and that's what the app is going to, hopefully, help people to do. But it needs to address educating people and find ways to involve them.

So I suppose I'd say this is about having the family around, not saying, "We'll protect the children and keep them out of it" but actually, "Yes, your grandad's starting to forget things but when he's a bit cross it's mostly because he's frustrated because he can't remember. It doesn't mean he doesn't love you." Doing that involvement thing, "Do you want to come to your grandads?" and not, "I'll just go and leave the kids behind."

But then that is more that if you, as a young person, want to interact with your grandad what could you do, what helpful ideas might there be? Does that make sense?

Nadia: Yes.

Kate: Then we need to pick something about getting the information out and educating them, and reducing myths, stigma and fear, which is one that you said.

Nadia: There is something about that staying just between the young and people with dementia.

Facilitator: So we've got these two at the moment: 'Need to stop leaving people out and get them more involved' and 'Need more interaction.' So did you decide that these were, kind of, similar or different enough?

Kate: Yes. I think that one was from one group, that one was from another group, and we're still going to choose one from this, which was... Obviously there are elements of interaction between all of them.

Facilitator: What do you think Leanne?

Leanne: Looking at ways of connecting information so that young people would engage with it, a lot of people have got a

negative point of view on how people with dementia should act and how they actually are.

Nadia: So it's all about reducing stigma?

Leanne: Yes because a lot of people... With the violence side of it and stuff like that, I don't want to be horrible but a lot of people because they don't understand it they think that that person is always going to be like that.

Nadia: So what stereotypes? If you've got an image of a stereotype you think that everyone's going to be like that.

Leanne: It's basically just trying to give them information that proves that that isn't always going to the case.

Facilitator: Do you mean looking at more positive stories?

Leanne: I think so yes. Basically just looking at what that person really is and what they've been through in the past and things like that. If you can see what's in the past you can really...

Nadia: Look past the illness and see the person.

Leanne: Yes, you basically need to be able to have all that information to see the person and not the illness. It's the same with all

disabilities really, it's a case of seeing the person and not what's wrong with them.

Facilitator: So do we want to choose that one for the next one then, does that one capture that one?

Kate: Yes, I think it definitely captures that. There are good elements to all of these but I think that one is good. I don't know, what do you think?

Nadia: Yes, probably for the manifesto of what we're trying to achieve here. I think a lot of them will come regardless, you'd think about the main things you want to achieve and some of these are just like sub-points. I don't know if I'm thinking more overarching, maybe umbrella points and then you've got...

Facilitator: We've got: 'We need to stop leaving younger people out and getting more involved. We need more interaction between young people and people with dementia. We need ways of connecting information that young people will engage with and not paint a negative picture.' That sounds great, and a very, very worthy set of points for us to focus on.

Is there anything from the others that you think we might be losing which these don't capture that's quite important, or do you reckon these are the really important ones and it's all good? We can always return to these later.

Kate: I think this one's not quite covered which is interlinking with the networks around, so the family. I don't any of those really encapsulate this, which is when there are all these people who are affected by someone or some people with dementia. If you've got one person caring for someone day in and day out they're likely to get frustrated. If they're doing that alone they don't feel like they've got a support network. It's difficult and having communication between others who are also affected, whether it's other people in the same family or connected with people in the locality who care for someone with dementia, or whatever. I don't think that's quite included in those three.

Facilitator: Do you think it's important enough to try and move one of the other one's out if there are two the same?

Kate: I don't think it could, I wouldn't swap one of them for it because I think it's a slightly separate, although obviously very linked, issue, depending on how well I've understood what it is you want to achieve with the app. But it's specifically young people connecting with people who have dementia and that's what the app wants to help people with then that's almost like a side effect issue, that there are strains when you do that and how to cope with them.

Facilitator: But in a way, I guess, that could be giving people more information couldn't it?

Kate: Yes, it could be. So as long as they're getting the information that includes information about how to cope as well as information about what dementia is.

Facilitator: Particularly if you're talking about more interaction between people it might be to get more interaction you need to help the carers and help young people, maybe? What do you two think? Obviously that's important but do you think that's important in terms of these or do you think this might be covered in some way by this if we interpret them quite loosely?

Nadia: I'd say the top two are very interlinked in my view. That's just my view though. I think maybe those two are similar in the way I'm interpreting them.

Facilitator: I mean we could put those two together and put this one in, what do you think Leanne?

Leanne: Reading them again the top two do seem pretty similar. But then I think [they're all important 0:47:26] and that is part of the communication and connecting the information because you don't need that support on the side as well to help the carers and all the other people who are trying to understand.

Facilitator: So shall I make a judgment call here, shall we collapse those two together but keep them in because they're so similar. I think a few of you have mentioned that now. Then put these three in? It's like 3.5 manifesto points. Is that a good compromise?

Kate: Yes.

Facilitator: Good. Let's discard all of the others. Let's not throw them away but put them to the side. Let's see how this group are doing. [No group conversation 0:48:20-0:49:14].

There we go. (Applause) Well done, brilliant, we made it. It's not an easy task because it's almost like you're saying all these things aren't important.

Roisin: Well they're all important, that's it.

Facilitator: They're all important but it's just about prioritising what we think are the most important things going forward. Awesome. So the next bit is each group needs to share what we they selected with each other. Does this group want to come over to this table for the timing and bring a few more chairs over. I'll move the chairs over.

Anna: How many do we need all together? Eight?

Facilitator: So we cheated a bit over here anyway.

Anna: Did you, what?

Facilitator: There was a bit of a cheat going on.

Roisin: Did you have more of them?

Facilitator: Well there was a little bit of a...

So let's place our three things together, so those are your three.

Roisin: Shall I switch this recorder off?

Facilitator: You might as well leave it on for the time being.

So there's one overlapping between them. Again same and Nadia'll not be surprised by this next component. Now what we need to do in the next 10 minutes, I'm going to put a 10 minute limit on this bit of the activity, we need to try and decide which of these six, there's actually five in total but that's okay, which of these six we think are the most important to take forward to the next activity.

Does someone from each group want to quickly say why they were chosen?

Kate: Are these ones ours?

Facilitator: Yes, those ones are yours, this one can be passed on.

Kate: Shall we do one each?

Suran: So we've got, 'We need ways to communicate information that isn't just text and helps people to try out tips and strategies.'

We chose is because we recognised that there might be a better way to communicate what dementia does, the symptoms of it, how it can affect the person and how it can affect the person around them, and having a more physical way of learning about it. We even talked about in schools and teaching classes about dementia, how you would just have a normal conversation and how it wouldn't be much different from a conversation with anyone else.

Facilitator: Was that the one that says 'Engaging'? Was it, 'We need ways to communicate that aren't just text'? So what do you think, 'Not just text' means? Did you guys talk about that at all in your group?

Roisin: Not really (Laughter) because we really talked about every single one in quite a lot of depth. We went through and grouped everything together into similar things, and then that's how we selected our important things. So we talked about the general themes that came out.

Although I'm looking at this and I'm thinking that something that isn't just text...

Facilitator: It could be like a cartoon or a game, all sorts of things.

Roisin: It could be role play. We talked a lot how a lot of times just learning information isn't quite enough so getting out there and actually having some level of experience... We likened it to learning about first aid in school and then actually doing first aid on somebody, it's a different experience.

- Facilitator: Does one of the folks from the other group want to share one of theirs that they chose? Who would like to go first? Go on Leanne, you go first.
- Leanne: 'Need ways of connecting with information that young people would engage with and not paint a negative picture.' It was basically giving them the information so they wouldn't see that person how somebody else has described them, and to get information about how that person was and how they still are but with that little bit of extra difference really. It was just trying to paint a positive picture about who they are.
- Facilitator: That was because there was a sense that sometimes there are a lot of negative stereotypes around dementia, or rumours about how aggressive people might be and how that might be a misunderstanding through their experience.
- Roisin: We actually talked about that quite a lot as well didn't we? About how we should be seeing the person as an actual person and not just the condition. I think Nadia's description of what she would tell her younger self is the thing that we took forward into our discussions, it was great.
- Anna: Our next one was, 'We need ways to communicate with and between others that are affect.' So that was drawing on the fact that for a lot of people it wasn't just about their relationship to the person who's developed the condition but it was about

relating to family who are around that person. So that's why we felt that was a good one.

Facilitator: Did we have that one as well?

Nadia: We did.

Anna: Ah, Yahtzee.

Kate: Yes, so we had that one as well, partly because we were saying that if there's one person who's caring for someone with dementia, or the main person who's looking after them or connecting with them, they could probably get very stressed or frustrated themselves. So feeling like there's support, either within the family or with other people who are in the same position could hopefully alleviate that and/or inform them on how to deal with it and how to cope.

Facilitator: Sam, do you want to share your one?

Sam: We thought that we needed more information that was younger person friendly because at the moment, from all of our experience, there isn't that information out there. If we targeted the younger person then it'll be easy reading for an adult so that we could address ____ [0:56:37] but primarily address the younger people and get friendly information to them.

Anna: You were saying about raising awareness weren't you [in people's minds 0:56:50].

Sam: Yes, like planting a seed when they're in school classes or something like that.

Facilitator: So we were talking about youth-proofing a little bit, and not in a very positive way. What is younger person unfriendly material? We talk about young person friendly but what's unfriendly for a young person?

Nadia: Text.

Facilitator: Just text?

Nadia: Like if you've got a big text no young person's going to go and read a chunk of essay, as much as they say they will no one will.

Sam: You could have it in a pocket guide. (Laughter)

Facilitator: Here we go... I thought we'd got you out of the pocket guide in our last session.

Nadia, do you want to share the last one that we had? This is where we cheated a bit wasn't it? Do you want to explain why we cheated as well?

Nadia: Because they're very, they link in together and we couldn't decide which one outweighed the other so we kind of linked them. 'We need to stop leaving younger people out and getting them more involved. We need more interaction between the young people and people with dementia.' I think the main point we took was that we took it more from a perspective of what Kate said where instead of saying, "I'm off to see grandad" and then leave the kids behind, say, "Do you want to come and see grandad?" So having more interaction.

I think, was it this one? I'm trying to remember but it's gone out of my mind.

Anna: What do you think it is that would make parents want to leave their children behind?

Leanne: It comes back to the negative picture and the stereotype, that you don't want your kids to witness them being violent or anything like that, but that's not that person.

Anna: Trying to protect them?

Nadia: Yes.

Facilitator: Do you think sometimes there's the lack of trust of the child as well as the older person?

Nadia: I know that's my personal experience, that I've seen a lack of trust leaving young kids with my grandad anyway. So there was a lack of trust in his ability when, especially if it's grandparent and grandchild, you want to be able to let them have that bond, sometimes it's closer than parent and child. But when there's a lack of trust from a parent or another relative then the illness has taken away that bond and that's slightly more detrimental than the illness sometimes.

Kate: That comes back to one point that we said that about, I can't remember which one it was, the one where it's all around people and where if the parents are more confident in responding to the condition then they'd be more confident in supporting younger people.

Facilitator: Sometimes it's not actually about making stuff young person friendly but maybe just adult/child friendly, like your parents are something like that.

That's brilliant, that was great. We've done really well so far; I say we but I've done nothing so far apart from make some cards.

Anna: They're very beautiful though.

Facilitator: They're wonderful, exactly, see how straight cut they are as well. Absolutely fantastic. I hadn't even brought that to everyone's attention.

Now what we need to do is, sadly, come up with a way of turning these five to six into three to take forward to the next bit.

Anna: I'm going to do the first easy thing and take out that.

Nadia: Don't say that.

Facilitator: See, now it is just five although it's more like five-and-a-half still.

Anna: That's me done.

Facilitator: So the way we want to do this is you might want to group some together if you think they're doing the same thing and then we could recombine them, or we could actually put two together and think, "Actually this is saying something slightly different" or we could rewrite them. But in the next couple of minutes let's see if we can choose three to take forward and then we're going to start a very simple design activity.

Nadia: Can I pick on something which we picked up on with regards to the ways in which you communicate? We did overarching themes of what we wanted to achieve, whatever we were going to produce, this, will feed into something like this, this or this.

Kate: In some ways those are in a similar category because-

Anna: Do you want to come round this side so you can see them better?

Kate: One is connecting information with younger people that's not negative, one's just more information that is young people friendly, and this again is similar. I don't know, in my mind those three are quite similar. I don't know if anyone else feels that or if I've completely misunderstood them?

Nadia: That's the way we took it.

Kate: I don't know how you would pick.

Nadia: It depends what you want to achieve.

Kate: Maybe come back to it then. What about this versus that?
[Silence 1:02:35-1:02:55].

Facilitator: So do you think all those three are definitely saying something quite similar, in which case should we think of-?

Kate: Remove two of them or make a sentence that combines the lot of them.

Facilitator: Yes, you could do that. It would be a very long sentence.

Anna: What are the bits that are different? So what does one have that another one doesn't have?

Kate: I think this one is an overarching statement, 'We need more information that is young person friendly', that's kind of what all of these are saying, except this one adds in the element of for it not being a negative picture to counteract that negativity, and this one focuses on the complex nature of how communication can be and what's most effective. So we could put, "We need more effective information... Effective communication of information that is young person friendly and that's not negative."

Anna: Do you want a piece of scrap paper?

Kate: I don't know what I just said now. (Laughter)

Facilitator: 'We need more information that is young people friendly and not negative' is that what you said?

Kate: Yes, and effectively communicated. I guess that's what this is saying, that it's not just text but that it's done effectively in a way that works.

Facilitator: What do the rest of you guys think about that?

Sam: I agree. (Laughter)

Suran: Are these guys out? Such swift decision making.

Nadia: There is a little arrow.

Kate: 'Need more effectively communicated information that is young person friendly and not negative', great. It's not the most beautiful sentence but-

Nadia: Can someone cross out the 'er' on the end of younger?

Facilitator: So does that mean we've got three? Fantastic.

Roisin: Yes, if that still counts as one.

Facilitator: Easy. That still counts as one. Should we rewrite one of these ones to make sure that makes sense as well? [Silence 1:05:04-1:05:15]

Kate: I think this one I relate to more as young adult whereas I would relate that more to children. So now I don't need my parents to hold me by the hand to take me to interact with my grandad,

but when I'm eight my dad's possibly making that decision for me. That's why those two are different but both important so I don't know how you would then put them both in one sentence.

Anna: So it sounds like something that's age appropriate doesn't it but that sounds really jargonny.

Kate: I feel like this one essentially sums up the whole app in a way, that we want interaction between young people and people with dementia. This is one of the elements of making that happen because sometimes parents are taking that decision away from children.

Anna: So is that our cheat, is that our heading and they're our three bullet points? Are we allowed that John?

Kate: I don't know if what I'm saying makes sense.

Facilitator: Maybe that's the heading of what the app should be doing and then...

Anna: It's like that what it needs to do and that's how it's going to do it. I'm upside down so I can't tell.

Facilitator: Or should it be doing, 'We need to stop leaving young people out...' and I know you said that might be for younger younger

people. I hate this young people and this older people thing, does that mean I'm old?

Nadia: I don't think it's just young people, I think that there's a generational thing where you've got the grandkids, the parents and the grandparents. I think sometimes if you type in young people maybe the parents will see them as the grandkids, so the parents will make the decisions and the young people don't really get a say. I think I'm touching on what you're experiencing as well and what you're saying. Who made your decisions?

Leanne: It's just everybody making the decisions for you because you're a younger person. But you need to have that sense of being able to stand on your own two feet and make a decision for yourself.

Facilitator: So in that case, are we happy with that then? Is that what we think it should be doing? I'm just going to make a judgement call and say, "Let's keep it and let's do it." I like to be so participatory and democratic but I'm going to be authoritarian here and be like, "No, that's what we're going to stick with."

That's fantastic. That's great. So we'll move on to the next activity now, which we'll do around the big table still. What we've been doing here, I guess, is trying to think about what we think the priorities should be for the project going forward. Now when we do design work, again this requires a little bit of drawing I'm afraid Nadia, I know you're not a fan of that, stickmen are absolutely fine, and again this is an activity that

you two have done before so I'm sorry about that but I'm always interested if you come up with different things.

What I'd quite like to do is think, "How can we translate those points into a human being, into a person?" So obviously the idea with this project is we're going to create an app of some description, which should be for a young person and to help them understand issues to do with dementia, a little bit like the things that we talked about there.

In design often when we're making things sometimes it's quite difficult for us to think about making something without having an idea of who we're making it for. So one of the really simple things that we sometimes do in a design process is we come up with these things called personas. These are some examples of a range of different personas that we have say. So you can see that sometimes a persona might be very simple, it might be a little sketch or doodle. But it's basically a fictional character or fictional person and it says a little bit about who they are, what sorts of things are important to them, what sorts of things they find valuable, what would they like to get out of life and things like that.

So what I'd like us to do is just spend a couple of minutes silently working on our own and then share back to everyone, and come up with a persona of who we think should be using the DemYouth application. Who would that person be? Where would they live? What would they do? What's important to them? What sort of situation do they find themselves in?

What I'd like you to do is think back to these points that we've said are very important and think about, "Who are the specific types of people that we think these types of issues would be important to?" You might want to think about your own personal experiences here as well.

So I will hand out a persona sheet for everyone and no one gets away with it on this activity. There we go.

Kate: Is there a toilet somewhere?

Leanne: Yes, I was just going to ask that actually.

Roisin: I'll show you.

Anna: So are there things that you've noticed which are different to last time or does it feel very similar, obviously the exercises are similar but in terms of the points that are being raised or the focus?

Sam: Quite different I think.

Anna: Yes.

Facilitator: Why do you think that is?

Sam: I can't remember what the three points were that we picked, I don't think any of those were.

Facilitator: I can tell you they are completely different, I've checked.

Anna: It'd be interesting, I suppose, for you thinking about what you can remember from last time. It's interesting that it's quite different.

Nadia: I think we took it on a different spin, especially with the girls. I was working with Nate and he went very much from a technical perspective whereas these were more hands on. So it was very different of me being in the group anyway.

Anna: Yes, because I suppose for Nate he is a designer isn't he so that's his...?

Nadia: Yes, I mean he does have experience and he did think about that, but he was thinking very much more about the practicalities. Whereas, especially Leanne, was thinking more about the experience and who it's going to affect whereas Nate was more about how it's going to affect. So it's good, it's more of a positive actually because he ____[1:12:22].

Anna: Yes, that's really true.

Facilitator: It's always different when you hear it coming from someone who's lived through that and breathed through it, isn't it? Sometimes I think the problem is designers, and I say that as a designer, you come along and think you can just solve a problem and do it like that.

Nadia: That lip balm smells lovely, sorry, totally off topic. It smells really nice.

Anna: [Are you just doing it separate 1:12:52]?

Nadia: Yes, cold weather does.

Facilitator: Has everyone got a card to get back? Good.

Kate: Oh no, do you get trapped if you go for a wee?

Roisin: You get trapped, yes.

Facilitator: Is there another typo? I've misspelt dementia again but in a different way.

Suran: Dementa.

Nadia: Like from Harry Potter.

Leanne: It's Dementor not Dementa.

Nadia: Sorry, I thought I'd just throw in a Harry Potter joke as well. ____[1:13:34].

Facilitator: I should do one of these shouldn't I?

Anna: You see, you said no one was escaping.

Facilitator: I seem to have lost a sheet.

Anna: I thought you said, "I seem to have lost my shoes."

Facilitator: Well that does happen quite regularly. ____[1:13:53] that's missing.

Roisin: I'm sorry, it is just going to look like me as a stickman.

[Silence/Filling in forms 1:14:05-1:14:36]

Facilitator: I have another card as well in case anyone wants to go to the bathroom.

Nadia: Are you hiding your photo there?

Anna: Is it bad?

Roisin: It's not very good, it's my first year of uni.

Anna: They still use the same one? Do you look like a child in the picture?

Roisin: I look exactly the same just with a lot more blusher on (Laughter) and with a rather smug look on my face.

Suran: That's at 18?

Roisin: Ten years okay.

Facilitator: Have you been 10 years at Newcastle?

Nadia: I look blonde in it.

Roisin: Mhm, maybe I was 19.

Nadia: I look blonde in my university photo because of the lighting, I definitely wasn't blonde.

Anna: My friends say that I look like a startled rabbit in mine, because you're not allowed to smile in your passport photos so I was like... (Laughter) I just look a little bit like I've done something naughty.

Nadia: Passport photos are never good.

Roisin: I know.

Sam: My passport photo's not that bad.

Nadia: I wasn't thinking about yours.

Sam: Whose?

[Silence 1:15:43-1:16:22]

Facilitator: Are you alright Kate?

Kate: Yes, I just find it quite difficult because I feel like it should be accessible to... I feel like I'm being really limiting by being specific because...

Facilitator: Welcome to the horrible world of personas. (Laughter) There's actually a big problem with them because they make you think of this as one person, so they're useful because of that but you also then realise that, actually, there's a lot of diversity in the world.

Kate: Yes. I don't know. I think it's difficult because you think you might be busy, you might be in fulltime work, you might be

seven and just going to school, you might be home-schooled, you might be a punk or you might be a chav. I don't know. (Laughter) But all of these people-

Facilitator: You could put it all down.

Anna: Yes, you can do an age bracket. I thought I was being hilarious by calling my person Chris Topher or Chris Tine, because I was like, "It could be a boy or a girl..."

Roisin: Or gender neutral.

Anna: Or gender neutral, yes, you're exactly right.

Facilitator: So they're happy? That's one thing you can decide on.

Kate: I've decided that they're capable of happiness but they might not be happy all the time, they just where when this picture was taken. It's clearly a photograph. (Laughter) Oh no, I've just accidentally given them a third eye. (Laughter)

[Silence/Writing 1:18:10-1:18:52]

Facilitator: All done Sam? [Sam the 1:18:56] official persona writer. You'll get a job as an experienced designer.

Sam: I didn't do very much detail though.

Facilitator: I'm sure the detail is in how you talk about it, not to put you under any pressure.

Suran: Molly is rocking a crop top. She is pulling that off.

Roisin: She's got a really, really long neck.

Suran: She does. It was hidden in her hair, I hadn't noticed.

Anna: Maybe she's a ballet dancer, they tend to have...

Nadia: Quite a long neck.

Suran: That's what I was just thinking as I looked in the mirror, maybe it's me. I can't rock a crop top though.

Leanne: She looked a bit like a witch though, that's why I put the clothes on her. She had a really pointy nose and...

Anna: To de-witch her. Again, I tried to do gender neutral hair, which means that my person's either got a bad bowl cut or some terrible curtains. I've not made it either way. It's too short to be one and it's too short to be another.

[Silence/Writing 1:20:08-1:20:32]

Facilitator: You don't need to complete everything if you're struggling. I probably could've said that right at the beginning couldn't I? This is one of those things where there are no rights or wrongs, that's what I always tell my students and then they get their assignment marks back. (Laughter)

Nadia: Yes, my lecturers used to say that, "There's no right or wrong answer" and then they give you a [Crosstalk 1:21:03]. No right or wrong answer, okay.

Suran: Is it just how good you are of persuading people of your answer? You did law didn't you, so it's all about being able to argue that black is white or... I based this knowledge on having watched 'Suits' so I ultimately think that being a lawyer is having an empty envelope and going, "Yes, that's emails." That's just what they do isn't it, that's being a lawyer?

Nadia: That's the practical side, the academic side is...

Suran: You have to memorise all the precedent don't you, and all the different Acts and things?

Nadia: They say you're supposed to.

Anna: I thought I'd like to be a lawyer and did my work experience, when I was 16, as a lawyer but I went to go and watch a trial in the courts in Hull. I came out at the end of the day and they were like, "We nearly had the police out for you, you were supposed to go back to the office" and I was like, "Nobody told me." So it wasn't the best experience.

Nadia: Courts are the best part of it.

Anna: Yes, it was fascinating. A man had smashed another man through a sheet of glass in a pub, so they were being...

Nadia: One of the best ones I saw was a guy who'd decided to play cowboys and Indians with his seven year old and a nine inch kitchen knife, using it as a tomahawk. He had a nine inch knife and was playing cowboys and Indians.

Roisin: Is this a child and a child?

Nadia: No, it was a father and son.

Roisin: The father stabbed the son?

Nadia: No he was just messing about with it and drinking in the street I think, it was a magistrates so it was very minor.

Roisin: Was it an old father and an old son? A child?

Anna: You were saying they were six or seven weren't they?

Nadia: It was like a seven year old son I think; the father was 25.

Roisin: Oh dear.

Nadia: It was an interesting one. It's even more interesting hearing the solicitors talk about the case before.

Roisin: Oh really?

Nadia: It's the best part about it.

Roisin: So you're quite articulate, I just bumble on. I talk in front of people all the time and I'm just, "Bhm-bhm..." I just mumble on.

Facilitator: I'm the same, a bit of verbal diarrhoea.

Nadia: I get it all the time.

Facilitator: Shall we start sharing some of these then? Who would like to go first and say what they've put down? Do forget there's no, "Is this a good persona? Is it a bad persona?" that doesn't really matter at all. In that case I'm going to pick on Roisin first, share yours.

Roisin: So, 'My name's Sarah. I live in Newcastle and I'm 18. In a typical day I go to uni, socialise with my friends and study for my exams. I'm very, very busy but I also find time to talk to my mum on the phone.'

'I've got an interest in dementia for two reasons: firstly, I want to be a doctor; and my granny has dementia, she lives in Durham. I try and visit her but it's really hard because I'm so busy and I find it difficult to talk to her.'

'I like to spend my free time with my friends going to the cinema and going out...' This is just basically describing me when I was 18. (Laughter)

'My dreams for the future right now are to graduate and then travel. I use my mobile phone and a laptop, I don't really use anything else technology wise. In terms of helping I'd really like to help my mum with my gran but I feel a bit helpless. I feel like I'm old enough to take on some responsibility and do this but I don't know how to do it because I feel nervous and scared.'

Facilitator: Excellent, fantastic, thank you for that, that was Sarah. Shall we hear from Molly now Suran?

Suran: Molly from Newcastle, she's aged 14. A typical day is school and dance, so that links into the ballet dancer.

Anna: Had you written that already?

Suran: Yes.

Anna: I knew it from the neck. (Laughter)

Suran: Interest in dementia because her grandma has it. Spends her free time dancing and going shopping. Her dream for the future is to own a dance studio. She'd like to help with looking after and talking to her grandma on a daily basis. Technologies used – phone, laptop and a tablet.

Facilitator: So to ask a little bit more about Molly, do you think a challenge Molly has is that she doesn't have many opportunities to help with her grandma, is that what you're trying to get at there?

Suran: Yes.

Facilitator: Interesting. What about you Sam?

Sam: Well I did Harriet, she is 12 and from Newcastle. Her typical day is generally school, unless she's on holidays, and then horse-riding. She has an interest because her grandma has it. She likes to spend her free time with friends and horse-riding. Her dreams of the future are split between being a lawyer and

a bus driver. She would like help with grandma because she doesn't know how to react when she's asking her mum who she is. She uses everything that's Apple for technology.

Facilitator: So iPhone? iWatch?

Sam: Yes, she's a real Apple worm. (Laughter)

Nadia: Have you just done yourself in female form?

Facilitator: It's alright, you should see the amount of Apple machines around here. People's ears are burning.

Sam: I have an iPhone, just in case anyone was wondering if I was having a dig at them.

Facilitator: Kate, can we have yours?

Kate: Yes. My person has no body or hair or nose but they have a big heart, it's just invisible. They're name is Jen Y. They live everywhere in the UK and they are aged between 11 and 25.

A typical day is school/work, talking to family, having [fun 1:27:36], just playing games and sleeping. They're interested because someone in the family has started to forget things a lot and they are worried about them and how they can help.

They spend their free time reading, climbing, drinking tea, eating cake, socialising, playing with Barbies, playing football and going to rock concerts. In the future they would like to save the world, be content and be alive.

They would like to help with how to be a good grandchild and friend. They use a laptop and a smartphone.

Facilitator: Fantastic, thank you. Leanne, can we pick on you or do you still want to work on yours for another moment or two?

Leanne: I'm alright at the minute, I'm just stuck on help, but I can discuss the rest of it.

Facilitator: Yes, go on.

Leanne: I called her Lauren, she's from Gateshead and she's 19. Her typical day is either school or university, going to work, seeing friends and family, and working on her exams.

Her interest would be through personal interest and family experiences. She likes to spend her free time with trips to the cinema, friends, shopping and eating out. Dreams for the future – to work with younger people. Technologies – phone and laptop.

That's all I've got. I'm stuck with the other one.

Facilitator: Do you think there's anything in terms of the difficulties? We can come back in a moment, but in terms of the sorts of things

we were talking about earlier where you might find any connections. So maybe some of the experiences you were talking about and some of the manifesto points we picked up? We can come back in a moment.

Leanne: My mind's just gone blank to be honest.

Facilitator: That's alright, no problem. Nadia?

Nadia: I've got Billy, he's from Durham and he's 13. In his typical day he goes to school, goes to dancing, he either has a kick about with his grandad or he likes to play sports with his friends.

He's got an interest because grandma's got it and she sometimes forgets who grandad is. He likes to spend his free time dancing, playing football and chilling with his friends. His dreams are just to be happy.

He would like help with how to help grandma and grandad interact again because he misses going out with both of them together because he likes being a family. I've also got a quote, "Mummy's upset about granny because..." He's upset because whenever his mum's around granny she gets upset.

Technology he uses – he's got a PS4, or any other console but an Xbox, and he uses his iPad quite frequently. Yes, that was a dig at Xbox. (Laughter)

Suran: I feel like that's maybe a modern day Billy Elliot.

Nadia: Absolutely. It's a slightly better drawing though.

Anna: [Crosstalk 1:30:59].

Facilitator: I feel really offended, not only am I an Apple owner but I also have an Xbox. (Laughter) What have I done to pick on you?

Nadia: I said iPad, so Apple's good it's just Xbox, it's Playstation versus Xbox.

Facilitator: Let's hear your one then Anna?

Anna: 'So my name is Chris, I'm from Newcastle/Gateshead', so I guess he'd live in the river, but I felt like I wanted to represent both.

Facilitator: Underneath the bridge.

Anna: 'I'm 15. My typical day would be school, sports clubs depending on what night it is, homework, TV and chatting to my friends online. I'm interested in dementia because one of my family has got it and I see the effect it's having on my parents.'

'My technology is my phone and computer. I would like help with my grandparents, and also to be able to talk openly with my family because we know it's there but no one talks about it.'

My dreams for the future are a good job, a family of my own and my own house. I would like to spend my free time with my friends playing sports or on my computer/smartphone.' That's it.

Facilitator: That's it, fantastic. Leanne, did you put some stuff down in the end because you were scribbling?

Leanne: Yes. I put for help it's basically getting more support and advice through the correct services, which does link to what we were mentioning before about the communication and interaction.

Facilitator: Brilliant. So it's interesting how a lot of stuff is about finding out information, I suppose, in relation to someone who's starting to get dementia. I suppose I have a question about where people would go to find that information now, and would people think about looking for advice somewhere?

Kate: Google?

Anna: Yes, what happens if you Google, "My grandparent's got dementia, what should I do?" Shall I find out? I'll get back to you. (Laughter)

Facilitator: Is Google the first place a lot of people would go these days?

Nadia: Yes.

Facilitator: I know it sounds obvious but I've been trying to search for information on Google sometimes and you're trying to figure out what the right word is to say.

Leanne: Before you end up on something completely irrelevant.

Facilitator: Yes.

Roisin: Sometimes I Google things like, "What's that girl with the red top in that ad's name?" and it will literally bring it up. "Who's that girl in that ad with the car and the red top on?"

Nadia: Google is good if someone else has searched it before you, if no one else is thinking the same thing you'll not get anything.

Kate: Sometimes you're just trying so many different types of, "How else can I word this?" but maybe the information's just not there and that's why it's not bringing it up.

Roisin: I suppose the thing about looking for something like dementia is that you would get... I suppose if you Googled a question like, "My grandmother's got dementia" that might bring up something other people have talked about, like in blogs and things like that.

Anna: So the first post is an interview between two people and there's also a link to a podcast, so I guess you could listen to it but it still is, I don't know if you can see, a page. It's still a lot of text. There are a few hits, mainly from Alzheimer's.org.uk, so that's the Alzheimer's Society, they are case studies but they're long written, which is what we were saying.

Roisin: Do most people use their phones to find things on Google or do you use your laptops?

Nadia: Whatever's to hand I would say.

Kate: It really depends. If I was working on a project I would definitely be using my laptop but if I'm just out and about and something has randomly occurred to me then it's my phone.

Roisin: I suppose that also affects it, if you're going to be reading a lot of information trying to read it off a tiny screen on your phone.

Nadia: [You do have a 1:35:03] mobile friendly app or mobile friendly text.

Sam: [___ so Siri can talk to you about it 1:35:12].

Suran: Have you tried asking Siri?

Sam: If you hold that in, press speak and then put your headphones on...

Suran: It reads the website to you?

Roisin: Oh, that's quite useful to know. What if you ask Siri what dementia is?

Facilitator: Let's pause that. So we need to figure out how to make Google better around this stuff, and Siri differently needs to be better.

We've only got a few minutes left but I'd like to make sure everyone gets a chance to think about- We started a bit late this time so we're a bit behind where we were when we did it last time... To start thinking about app designs specifically.

Can I split the groups up again a little bit, so can I have Suran, Kate and Nadia, would you like to go over there onto that table? It's an opportunity to grab some more food, drink and whatever. Also you might want to take your personas with you, in fact there's no might, you definitely do want to take your personas with you.

Roisin: Shall I go with this table?

Facilitator: Why not? Sam, Leanne with Anna, do you want to stay on this table? Now on each table you've got a little pack and these

should be the same cards each, if you just want to have a quick look through those?

First of all I'd like you to choose one persona on your table to do a little bit of a design activity for, so think about creating something for that specific person. Those cards that are in front of you are actually loads of different examples of types of applications that already exist and things that apps do. Then what I'd like you to do is, when you've chosen which person you're going to design for, first of all talk among yourself and then I'd like you to select three of the applications which you think might be useful and stick them on the sheet in front of you.

So I guess, in a way what we're trying to do here is combine apps together.

Nadia: Does anyone want a drink whilst I'm up?

Sam: No thank you.

[No group conversation 1:35:12-1:37:55]

Facilitator: You can combine characters.

[No group conversation 1:37:58-1:38:10]

So one question I have is which of you two wants to have their persona done for this activity? What are you thinking?

Leanne: Use that one.

Sam: Use which one?

Leanne: Use this one if you want.

Anna: So Lauren, how can we help you?

What are the options of things that we've got?

Facilitator: So talk through those a little bit. I guess the question is with these one is, are there any of those that don't make any sense? Are there any apps there that you think, "What's that going on about? That seems like junk. How is that relevant?"

Sam: I wish my persona was an old person now.

Anna: An old person? How come?

Sam: I think that's who the app should be designed for.

Anna: Okay, so the boot's on the other foot? So it's to help the grandparent, for want of a better word, initiate contact with the young person?

Sam: Yes.

Anna: That's interesting because we've been thinking about it very much from the young person's side.

Facilitator: Why do you think that?

Sam: Because then they've got something to relate to constantly instead of just when somebody's visiting them.

Facilitator: How do you think they could relate to a phone or to a thing, is that better or worse than relating to a person?

Sam: [I know it's not ____ 1:40:04].

Facilitator: But in mean in general, do you know what I mean? Would they be contacting people through the thing?

Sam: Yes. I think they'd just get used to the iPad if you get it in the early stages and perhaps not in the later stages.

Facilitator: Maybe let's park that for the moment, let's just park that and focus on the young person's side of things. It's not to say that isn't relevant but it might be a slightly different project Sam (Laughter), but I think it's a really valuable point because sometimes, I guess, the person with dementia is a little bit forgotten.

- Anna: So I suppose it might be thinking about how this enables young people to be in more constant contact.
- Sam: Perhaps the young people and the old person could use the app.
- Anna: Yes, so it's almost like a meeting point. Or even if it was just a prompt because I know I mean to ring people with a massive frequency and often weeks can go by and I don't think it's been very long. So even if it was just a little alert to remind the young person.
- So what was your question, were you asking if some of them do or don't make sense?
- Facilitator: Yes, so are there any that particularly jump out at you as relevant to this particular character? So there are things here that Lauren has issues with to do with more support and advice, connecting to information and stuff about how to interact as a family as well.
- Leanne: I've picked them out straight away, obviously being a young people because young people use a lot of media. So obviously you can use Twitter and social media on Facebook where you can get some advice and support off other people who are in a similar situation and you can both get each other through and come out with a positive outcome.

- Anna: So that would be young people who share the same kinds of challenges giving each other advice on what's worked well or what hasn't worked.
- Do you think that would be just for young people, what about the wider family?
- Leanne: Wider family can do it as well because obviously a lot of people nowadays use social media and it's not just centred around young people.
- Anna: Do you think they're two separate things, so is there one where it's just young people talking to young people and one where it's young people talking to their family, or do you think it can all be in together?
- Leanne: I think it can all be in together really because everybody who's in that situation is facing the same sort of barrier, so it would be a good idea for both parents, younger people and, if necessary, the older generation as well to put their input in.
- Facilitator: So do you think that would be around having conversations with each other? So who would be connecting with who through these types of things?
- Leanne: Like with the Facebook it's connecting with a wide variety of people, not just your family and close friends it's, like I say, a wide variety of people. ____[1:43:47] it's more focused to one person and asking general advice.

Facilitator: Do you think these things are the same type of thing? So if you had an app would you combine all these things together or would you have these things as separate areas of a specific app?

Leanne: I think it would all be linked together because, basically, you are talking to other people.

Facilitator: So would you put them together do you mean, like that?

Leanne: Yes, because you're basically doing the same thing with all three, you're talking to others or a family member or anything like that.

Facilitator: That's cheating.

Sam: I'd pick three completely different ones.

Anna: Okay, let's hear them.

Facilitator: Okay, let's hear it then.

Sam: Right, I think [my approach is completely the wrong angle 1:44:45].

Anna: There's no right or wrong, that was John's mantra. (Laughter)

Sam: My mind-set is firmly on an app for the older person.

Facilitator: Oh okay.

Anna: But then we can think about how we incorporate that into something can't we?

Sam: So the user person, the 19 year old, I'm the young person who would share this app, and you would personalise the app. Your community radio would have songs on from the older person's prime of life so they're always happy when they're playing music. So it's not the modern day music that they won't be able to relate to but something that they were able to relate to.

Anna: Would that also be for the young people to listen to to familiarise themselves with songs from the older person's era?

Sam: Yes. Then I've got [pinning listing] and sharing so that the photos and memories of the older person will be at the young person's dispense so that they can stimulate because [they've always got the information ____ 1:45:44]. So they can then stimulate a conversation with them and find out even more about their grandma/grandpa or mother or father.

Then other people's stories, which may be a bit patronising I guess, but it helps people with dementia link up and be able to go on trips out with an organisation like Carers Together or something which could be organised by the younger person.

So I would combine all three into one that you'd both have access to.

Facilitator: So who would be using this then?

Sam: Both of them.

Facilitator: Both of them, okay. But it would look a bit different depending on...?

Sam: You could have any of these you wanted, whichever was more relevant to the person, it would be completely personalised. Then you could perhaps have a log-in.

Facilitator: What I really like is the community radio and the pinning listing and sharing thing, they're quite...

Anna: That could form the content I felt like. So sometimes you could intersperse stories from their own life, it might be song, song, song, story, song, but the story might be someone reminding them of a story. I don't know.

Sam: Or triggering them to be able to tell you the story, you know, even though you might've heard it several times.

Facilitator: So can almost imagine making a radio station for a specific person, a bit like a Spotify list where you can make your own random thing to connect stuff. But then you maybe find out what works and what doesn't work between the family and that's shared. Also it becomes something to talk to people about.

Sam: Everyone's got family photos haven't they, so you could then-

Anna: Scan them in.

Sam: Yes, digitalise them so you've always got access to them.

Anna: Yes.

Facilitator: You could use them in a conversation with someone, like reminiscence?

Sam: Yes, you could say, "Who's that?" if it's a family photo, because normally they can tell you who's who. I was hearing from one of our employees where he went to see his grandma with his dad, so that was his grandma's son, and she said, "Where's Joe, I haven't seen him for months?" but that was her son. But because he was older...

- Anna: She didn't recognise him because he wasn't the age that her brain was at. It's interesting I think because the three you've chosen are much more about the interaction, which was important in the earlier chat, and the ones you've chosen Leanne are much more about information. The two of them complement each other quite nicely because one's about sharing with the wider community of people who might have the same experiences, where as yours is much more focused around the family unit. So I do think the two...
- Sam: Yes, but if you just had the dementia app and you clicked on it and all these would come up. Then you could click on the radio if you wanted to listen to the songs or if you wanted to look at the photos or you could click on other people's stories. Then you could add as many as you wanted, or as little as you wanted.
- Facilitator: I didn't quite understand the other people's stories bit, do you want to just explain that to me again?
- Sam: I've done some work with the organisation Carers Together where they group people in the community that have dementia or any other disease or illness and then they take them out on days out. It's completely free. Say you went on a coach trip to Beamish or something then you could link your accounts to one another so you could communicate with each other. If you catch them in earlier stages then they'll communicate with them all the time and try and organise more events so they aren't by themselves all the time.

Facilitator: How does that relate to the stories bit? So would you be sharing what they liked doing, what would that bit be doing?

Sam: Well they'd learn other people's stories first hand wouldn't they, on the trips out or wherever they're going, and then perhaps they could relate to that. I'm not sure.

Facilitator: Okay, so you're talking about making connections with other people?

Sam: Yes.

Facilitator: Oh I get you completely, yes.

Sam: Are you sure, did I explain it?

Facilitator: Yes, sort of, I think I do. Leanne, have you found anything else of interest over here, or anything else you think's rubbish?

Leanne: I'm thinking about the photos and stuff, whereas people talk on social media and it's another way of making friends. So if you take pictures of something you like doing and there are a couple of other people that like it as well then you can get on and be friendly then you're making friends out of something that people maybe don't see as positively as others. It's a way

of making friends, through social media, with people who are in the same situation and doing something that you both enjoy.

I was looking at the one but that's kind of similar to all those over there and which could come under that one.

Facilitator: So what would that one be? How would you incorporate that one then?

Leanne: That's basically like talking on social media as well. That's basically seeing somebody and understanding a lot more than you can on social media. That's more like getting into the friendly situation where you're gaining friends out of social media and the situation.

Facilitator: I don't want to over interpret what you're saying here so tell me if I'm wrong, I'm very happy to be told I'm wrong. Here are you saying that really this doesn't seem to be too much to do with the asking for support or anything like that, this is kind of like a side effect of it, or this is something where you'd rather share some things with people and it not always be able the support, or maybe this is a way with connecting with people before you start talking about support?

Leanne: It would be a way of connecting as well but it is linked to interacting as a family. If your family are on social media as well they can get a bit more depth about what you like and what you don't like and then you can come together and do something that you all like, and involve the person that has

dementia as well. So it's kind of doing it as friends with other people on social media or involving the family a lot more.

Facilitator: So does that relate with some of this stuff here? I'm starting to wonder actually whether these apps are..?

Anna: Instagram and Flickr?

Facilitator: Basically you take a photo... I've probably made something very simple as complicated as I could. (Laughter)

Anna: I think there's something nice about all of it. For example, say if an older person has an opportunity to listen to music or engage with particular photos so that the parents or grandchildren, so the next generation down, can see what they're looking. So they can see what they've been listening to or see what they've been looking at so when they see them they can be asking about-

Sam: You could set that up for them so they don't have to do anything. Perhaps the profile could be split into two so that you've a sufferers profile and a carers profile, then the information could all be on the carers side at their disposal whereas the sufferer wouldn't get to see that.

Anna: You wouldn't want it to be overwhelming for them would you? You'd want them to just have what they can...

Leanne: I think the radio would, kind of, work well with the photographs because if a family with dementia sees a certain photograph or hears a certain song they can go to their family and discuss their point of view on stuff. The family could take that and think, "We can do an activity that involves you because you like a certain thing", or something like that, "Or we can take you out to a certain restaurant" or something like that from seeing the picture.

In a way it's like reliving the good memories that they are remembering.

Anna: Yes. Are you going to get yours stuck down.

Facilitator: So shall we stick these down?

Anna: We need to name it.

Facilitator: Let's see if we can give that a name. I'm seeing these two are kind of one and the same in some respects, but I'm very happy for you to take ownership over your own apps and you can brand them and name them, whatever you want. If you want to give your app a name and then also say a little bit about how this helps the character out, so how does this help out Lauren? Just so that I have, as well as the recording, a little bit of a reminder of what you thought was most important on the app.

For you Sam that might be more about how it might help family or help the grandparents.

Leanne: ____[1:55:18].

Anna: I'm going to the toilet.

Facilitator: Yes, it's just by the lifts.

[No group conversation 1:55:27-1:56:59]

How are you folks doing? We're 10 minutes over the home time.

Roisin: Oh really?

Facilitator: Yes. We just need to wrap up. I love people talking, sorry...

Roisin: Okay, has everybody gone?

Facilitator: No, Anna's just gone to the bathroom. So as I say, if you could think about a way of capturing what you think the three most... I don't know whether you've got to that point where you've chosen three?

Roisin: So we've picked three important ones, so we actually have four.

Facilitator: Try and put them together.

Roisin: So these two are quite similar, should we take one of these?

Facilitator: Of course we've done some cheating over here as well.

Roisin: So what would our app be? It has a way to get information about the person and the places that you've been together, experiences that you've had.

Katie: Yes, a memory book.

Facilitator: Now you're picking up everything aren't you?

Roisin: So are you a teacher?

Nadia: No [Crosstalk] who can't spell herself.

Suran: I can't spell; I'll make loads of [Crosstalk 1:58:17].

Roisin: But we also said that this needs to be a conversation.

Facilitator: I've given them the hurry up.

Katie: Sorry.

Facilitator: Oh sorry, I didn't mean that in a bad way. (Laughter) There's no rush but there is a rush.

Katie: Sorry, I'm just going to nip off and phone a taxi. Is it 89 City Road?

Facilitator: Sanderford.

Anna: What have you named yours?

Sam: I didn't know what to name it.

Anna: 'Don't forget your head.' It's tricky, naming stuff's really hard. I've sat in lots of different situations where we're like, "We need to name this project" and it's hard.

Facilitator: You could just cheat and call it DemYouth.

Anna: But my friend, who likes to think he's a gangster, was like, "You can't be throwing words like 'dem' around if you don't know how to use it.'

Facilitator: ____, fantastic, thanks.

Leanne: I just cheated and took that one off you.

Facilitator: [Pointing out I misspelt 1:59:30]-

Roisin: Oh no, I didn't do that.

Facilitator: I don't mind. It's okay Roisin, I'm used to your...

So before we go, because we should all wrap up and go. Are you cold Anna, I'm really hot?

Anna: Yes, I think I'm a little bit poorly.

Facilitator: Oh no.

Anna: Don't come too close to me.

Facilitator: Blimey. I've just come out of two weeks of being really ill so I'm just going to stand right over there.

Anna: Stand right at the other side of the room then.

Facilitator: Really super quickly, because I know people are going to have to make a move. Can we just quickly share each of our app designs with everyone else so everyone can hear them? Over here we made two, which I see more related than I think Sam and Leanne do, but I'm happy with that, I'm fine with difference, and we've got one over there. Do you want to share yours first of all? Who wants to do this?

Katie: I don't mind. I wasn't really focused then right at the end.

Roisin: I tell you what, I'll do it then. So we called our app 'Memory Box'. We liked the pinning and sharing ideas first of all, but we were more interested in the pinning of experiences and collecting experiences that you've had with gran, that Billy had with gran. So if they went and did something together he could then go and back and show her that this had been happening.

We wanted to have a tracking option so that gran could maybe wear a wrist watch and we could see where she was. But we thought about this very carefully and we said that this needed to be a conversation in the early stages, where you'd actually talk to the person about that. That was from the girls' experience of wandering and how scary that is.

Facilitator: We did an interesting project a few years ago where we looked at those tracking things. If you frame it as safe walking or safe wandering, rather than just... It's weird.

Nadia: Safe walking not stalking. (Laughter)

Facilitator: Yes.

Anna: I like how it rhymed.

Roisin: So let's call it safe walking. Then the final one that we thought was very, very important, and we went back and back and back and forth about this on lots of different topics, was having peer support where you could actually post questions and there was an option to be anonymous if you wanted to be or have a profile where you could link with other people.

Facilitator: Fantastic, well done that group. Thanks Sam, it's just going to be applauding you I'm afraid.

Leanne, do you want to share your one? It's just worth saying, we had Lauren as a character we were designing for.

Leanne: I've basically taken the hanging out with others and three lots of social media so you can talk with other people, talk with your family, and get a bigger support network. Take a snap or two is taking photos of stuff that you like to do, that your family like to do or that others like to do and just making new friendships.

It's basically getting support and advice from various different sources that can help you understand each situation a bit better, building the relationships between families and creating activities where you can involve somebody with dementia and plus your family can understand how the person with dementia is, and create new friendships.

Facilitator: I think quite an important thing from that one as well is if you look at it we cheated a bit and it's got all the social media things all wound together. I think the point with that is that actually those are the places where people are already chatting and talking. So I guess there is a thing about actually making use of those things and those places where people are already talking to other people. That was something that we were talking about wasn't it?

Brilliant. Sam, do you want to just [Crosstalk 2:03:27]?

Sam: My app was called 'You'd forget your head' because that's something that my mum used to say to me when I used to forget things in my early days, which I still do now but she doesn't say that anymore for some reason. Never mind...

So mine was focused on the sufferer and Lauren. They would both get the same profile, apart from Lauren's will have more information packed into it about dementia and what not. The three things that I picked were other people's stories...

I've done some work with an organisation called Carers Together who take people out for the day who wouldn't get to go out. Then they could link up with their own 'You'd forget your head' profile so that they can always be in contact with one another and it's someone familiar with them and not a stranger.

Then I put pinning listing and sharing because everyone's got family photos and if you talk to people and show people with dementia old family photos they can often name people that you wouldn't have a clue who they were and tell you a whole story about them as well. So I think that's really important.

I think that the community radio's really important as well, and to personalise it for the sufferer so that they can listen to music from the prime of their lives which they absolutely adored listening to. Then it keeps them happy all the time, which is what should be the immediate focus on any sufferer in my opinion.

Facilitator: Great. What is interesting about that is if you actually started off with community radio when you came up with it and then you worked backwards. Initially it was designing something for the person with dementia, which could then be actually given content by the family and the family could share tips.

Sam: Yes, I didn't say that. Any of these could be added into the personal profile so that you'd click on the app and then my immediate three would come up, but then you could add as many or take as many away, whichever the person would prefer.

Facilitator: Great, fantastic. (Applause) Well done Sam, everyone else jumps in. That was more of a round of applause for absolutely everyone, thank you very much for your input. Sorry we've gone massively over. If you've got people who are relying on you being at home and they're worried about where you are then tell them that John's bad at time keeping and they can write a letter of complaint to me.

Thank you very much, particularly, as well for Sam and Nadia because they were here last time and this time they were helping chip along and direct the discussion. It went in a

different direction from where we were last time, which is good.
The ideas were completely different. I think there are.

Anna: Do you feel a more emotional attachment to one or the other,
last time or this time?

Sam: This time obviously. I can't really remember to be honest.

Facilitator: This is the Sam who can't remember last time, that's the
problem.

Nadia: I would say last time was ____[2:06:23] but this time was
more... I think for a very practical side last time whereas this
time we were looking more at the condition and looking at it
more in a way which took away the practicality almost. I think it
was very different but good different.

I know for me that Nate, as a designer, led the conversation
and he was looking at practicality and how we could do it,
which is all good but this time it is a little bit more-

Anna: It'll be interesting to see how-

Nadia: How it's going to come out, yes.

Sam: ____[2:07:09].

Facilitator: Quite how we're going to do that I don't know, that will be the conversation for the next workshop when we host that.

Just to say thank you very much for your time today. We'll be in touch about progress going forward. The idea is that maybe we're going to try and run one of these workshops again with the same format with another group or another couple of people anyway. Getting people to give up their time can be quite difficult so we're not quite sure whether that's going to happen.

But we'll be in touch primarily through Anna and via the Facebook page. Then either way we're going to do some ways of making sense of the conversations this time, the conversations last time and share that back with you all when we have something proper to give back to you. Hopefully the next step will be some proper tangible ideas for what we're going to build at the end of the project.

Nadia: What's the timescale for this project?

Facilitator: So the timescale was that we were meant to be wrapping it up round about January/February time whereas now it seems like we're likely to build something starting from January/February time. So we've probably got until mid-way next year until we have a thing that's ready to go up on app stores and whatever.

There still seems to be a little bit of debate as to whether an app is the right thing or whether it should be an online resource, of some description, which has other things that people can use. Ideally it would be an app but then we could only build an app for one operating system, for the time being

anyway. So we'd have to decide whether you're an Android or an Apple person, or an Xbox or a Playstation person.

Yes, but mid next year hopefully it will all be done. So there will be something tangible coming your way, I promise, I absolutely promise.

So yes, thank you very much and dismissed. If there's any paperwork that needs to be filled out.

Anna: I realised that even though [I won't be able to tell actually how much it is 2:09:06] I'll speak to Caroline on Thursday, I still need you to write and sign. So what I'll do is I'll fill in the number and I'll drop you a text on Thursday so you know how much when I've double checked.

Sam: I don't know whether it's been paid in.

Anna: Did Jamie take your details?

Sam: I don't think he did.

Anna: I think it would be hard for him to have paid you.

Sam: ____[2:09:30].

Anna: So what I'll do is I'll double check whether Jamie has paid anything because it was a while ago now, and also I'll double check-

Sam: I don't think he did.

Anna: I'll double check how we're paying it and so I'll just drop you a text. But it will probably, because it's quite a long journey, a reasonable amount of money.

Sam: I can't remember what he said it was. He did tell me. I think he said per mile but originally on the first meeting I got told it would be a round figure but then at the next meeting that didn't happen.

Anna: So how many times have you actually driven through?

Sam: For the Gateshead one twice.

Anna: So it's actually like six returns then isn't it? So is it 60 miles there and back or is it 60 miles one way?

Sam: 60- Yes.

Anna: So actually you'd get it like that.

Sam: I think it's 60 miles, you'd have to check.

Anna: I'll double check but you've basically done that journey there and back six times.

Sam: But the first time was to Gateshead though.

Anna: Yes, but it's reasonably similar. I'll be able to work that out. I'll drop you a text on Thursday.

Sam: Was it Gateshead? Where was the first one? It was on the-

Nadia: [Felon 2:10:33].

Sam: Yes, it was near the metro station, well there are loads of metro stations aren't there?

Nadia: It was near Felon, it was the old offices for Design Works.

Sam: Is that Gateshead?

Nadia: Yes.

Anna: What I'll do is I'll tell Caroline how many miles you've done, she's the office manager. I'll find out how much we can reimburse you. I remember there was a girl who lived in Hexham, so obviously she was doing quite long journeys. I can't remember what they worked out but-

Nadia: Is it mileage or time?

Sam: They took my vehicle details but I've had three different vehicles.

Anna: You don't need the vehicles it's just how much you've driven.

Sam: Oh right, okay.

Anna: I'll text you on Thursday.

Sam: Right, that'll do.

Anna: Are you alright for your taxi?

Katie: Yes.

Sam: Do we need to take out cups and wash them or should we just leave them?

Suran: Do you want us to help wash cups or anything Anna?

Anna: Thank you so much.

Roisin: No problem at all.

Suran: Do we go back this way down the stairs?

Sam: Can I quickly go to the loo?

Anna: Yes, I'll be in touch.

Sam: Thank you.

END AUDIO

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