File: DemYouth-2-001_cut.wav

Duration: 1:38:01

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Typist: 715

START AUDIO

John:

...when they are recording and some light up when they are not recording. So I have to double-check and things. Yes, it is really good, good design that.

So what I would like to give each of you guys is a batch of cards. Now these cards should look a little bit familiar to you because, I know [at 0:00:17] the end of the workshop last time we went round and worked in little groups and came up with what we thought were really important points. Which kind of then turned into a little bit of almost like an agenda or manifesto for the DemYouth Project.

So on each of these we have on the front whatever it is that you put pretty much on those little whiteboards in those workshops; and on the rear is what you said to us about what that represents. So if you are thinking when you read, 'we need more interaction between the young and people with dementia' that is actually quite good isn't it. On there it says 'get young people more involved in workshops or if they know someone with dementia get more involved with their care package maybe' and it then goes on so-forth.

So, what I would like to do is just to sit down in your groups and just flick through those very quickly and just familiarise yourself with what is there. And talk between yourselves and your pairs and Jamie and I, I guess, can chip in as well. Just about what you think each of these mean.

So this is just a refresher on some of the things that we did on the end of the last workshop. Does that sound alright?

Nadia:

____[0:01:33] between others that ask for it not just for [Crosstalk] person with dementia but also communicate people that are effective. So have instructions to communicate with them better so that they can better approach dementia with the knowledge base around them.

Nate:

I would say that is important because...

Female 1:

So it is not just trying to... Because you may have one person who can communicate really well but if others can't communicate then it is reliant on that one person to do it all.

Nate:

Exactly and dementia doesn't just affect the person with it, it affects their whole social circle, their whole family, their whole world. So everyone needs to be made more aware I think and everyone is...

Female 1:

It affects their living just if they have got any interactions like medical professionals, banking, shops. Someone was saying that they work in a shop and they thought that someone had dementia like a customer. Nate:

I think it was one shop in... Where was I? I was in Darlington, I went to a training day, a Champion's Training Day with Arts and Sound Society and Paul was saying something as simple as a black doormat can scare someone with dementia because they might think it is a hole because dementia doesn't just affect the mind it affects obviously your sight, your dexterity so. I think everyone needs to be made a little bit more aware.

[Crosstalk 0:03:02-0:03:06]

Jamie: So in terms of communications between others that are

affected would you say it is not just between someone with

dementia and ..?

Nadia: And like the primary carer, it effects the whole family and...

Jamie: So it could be communication between different carers with

different practitioners.

Nate: Well just from the experience I have had, social care and the

healthcare sectors don't communicate enough because they just hand off the person. Say, "Oh, right, you've got dementia;

go to the memory clinic, go to, you know... Go to this scheme

that's running and see..." Some people I have seen that is it.

For a GP they are under a tremendous pressure anyway so for

them to take that extra time out of their day, to take that extra

care is something which there is no incentive to do so I don't

think. But it is just they don't have time to do it and they are

under a lot of stress and obviously with the NHS is like at the moment and you are not hitting targets then you are phased.

So I think it is important to understand not just the users - and so the person with dementia, their family - but obviously the healthcare and the problems that the healthcare people are facing and the problems that the social care people are [Crosstalk 0:04:33].

Nadia:

It is nothing personal. Sometimes it is not always, it is one assigned. They have got different patients don't they so they have got to manage different patients. And obviously, dementia, it is not a disease it is an illness where it is different around every person. Not everyone is the same. We might have similar types of dementia but...

Nate:

It can affect people completely different I think. Just that there itself is important to get across to people, you know, when you mentioned dementia to somebody doesn't know they are probably going to say, "Oh, they don't remember anything." Although someone's memory could be fine but if they are affected by a different form of dementia, it is their movement or their sight or...

Nadia:

Yes, like forget how to... Because you can forget like basic things like walking...

Nate:

Yes, when to go to the toilet. People don't understand that it affects all of these things.

Nadia:

It is not just like speech or memory which are the main two but there are different forms.

Jamie:

Yes, well they are the most obvious ones that you will probably see first aren't they?

Okay so do you think this is important?

Nadia:

Absolutely.

Nate:

Yes, communication I think is sort of the underlying theme for the whole project I would say with...

Nadia:

Yes, I think there should be, like I don't know just a thought I have just before I forget but for the App if there is something like... Make it a multi App where if you are a primary carer, if you are just here say to see your granddad or your grandma and you are just a grandchild. So you just want to like...

[Crosstalk 0:06:13-0:06:18]

Nate:

I like that because everyone is affected differently so I think...

Nadia:

Yes because there is no point in having just a generic App you want something like so if you are a carer you want something that is going to help you. If you are just going to visit a relative with dementia you want to know some advice on how to speak

or deal with the relative. Not even if it is just coping, it is just a bit more of an awareness App or something whereas there is an awareness and then there is coping strategies.

Sort of, like, just take on what the NHS are trying to do but make it better.

Nate: Or make it more personal.

Nadia: Yes.

Nate: It is very hard [Crosstalk 0:06:56] myself.

Nadia: I like, was it your group's idea that you [Crosstalk] and I am

thinking maybe like if there is like... You know the Paperclip you get on Microsoft Office, if there is like a little Dementia Friend and the Dementia Friend says, "So what's going on?" Or even if you can do it like a Siri thing, you can speak to the

Dementia Friend and they speak back to you.

So you have got a person there. It is not an App it is a person

in an App form. I don't know how far technology can go?

Nate: That was it.

Nadia: Was that one?

Nate:

So we need a way of connecting with information that young people would engage with and not paint a negative picture. Or you just mentioned text there and then you mentioned Siri. So using your voice to interact with the App.

Obviously that would be a lot more expensive whereas ____[0:07:47] I would have thought.

Nadia:

Yes, it would be expensive.

Nate:

However, that is something that we definitely need to consider. The fact that some people are not happy to [Crosstalk]. Some people aren't happy to speak about it. Some people don't want to listen but everyone learns differently, everyone interacts differently.

I know, me personally, I love to do stuff whereas some people love to read.

Nadia:

Like there are active learners, kinaesthetic learners things like that.

Nate:

So I think that is important when you are thinking about the interaction with the App that if you are not a strong leader or if you are not a strong...

Nadia:

If you are thinking about young people. If you are talking – I don't know how young we are talking here – are we talking young people as in, sort of the, ___[0:08:29] so like 11 to 19 or are we talking younger?

It is 11 to 25 is sort of the...

Nadia:

So 11 to 25.

Nate:

But even then, the reading proficiency in an 11 year old and a 25 year old could be completely different. And even some 25 year olds might not be able to read as well as a 16 year old. So I think having a way to present the information through different media would only benefit people.

Because I love reading but sometimes I just want to pop my headphones in and watch a video about something sort of thing.

John:

Also, you were talking about Siri which almost makes it more accessible if somebody is blind but they have got a mobile phone and they can activate it with voice. Could they not access the App [Crosstalk 0:09:14].

Nadia:

Or even if they want some information fast like how long... It is quicker to speak something than it is to type it out. I bet typing this out it took five minutes but we have just read it in five seconds, example there you go.

I don't know, like if you want something quick, you want some advice like you are visiting, I don't know... I have got ____[0:09:39] use so if you use it for day to day use you know say you have visited a relative or you care for a relative and

you need some advice and you say, "What can I do in this situation?"

[Crosstalk 0:09:50-0:09:55]

Nadia:

And even better signposting for sources of information [Crosstalk]. Because you can surf the web and that can have quite a benefit but often would be useful to have other ways of finding information you could do with some other support. And have that available to you rather than you have to search for something that might be relevant.

So that again going back to this sort of accessibility.

Nate:

I think one thing from sort of this [Crosstalk 0:10:28] is I have realised that there is so much out there. There is some good information out there, there is good advice, there is good stuff but it is so overwhelming for someone in that situation.

Nadia:

I think we need to get everything. I think we are going to have to do a lot of work if we are developing this and get everything that is out there and condense it.

Nate:

Or not necessarily condense because that would be a lot of work. If you could just have it, so like literally you are signposting, you are saying, "Actually you've said to us this is what's important to you. Here is some basic information for more [Crosstalk 0:11:05]. Here's some good stuff."

Because a lot of people will find out about dementia when they have dementia themselves. The first thing some people will do is jump on Google and Google isn't accurate. There is a lot of research on there that is medically accurate and whatever but a lot might get lost in...

Nadia:

A lot of people, yes, because people pay to get their stuff.

John:

So are you talking about like a filter system where you would maybe signup on the App with a profile and you would say, "I am 12 years old my grandparent has dementia." And then it would then filter the information that was relevant to that first. Is that kind of..?

Nadia:

No, I do think that is an idea because that makes it more personal as well, if you sign up to the App as well. Because then one, you can monitor for like MI purposes you can monitor how many people are using the App; because you could have it run in a database.

If, maybe there was also... I don't know could it be linked to like a Helpline and then that, if they sign up to our App could we... Because there is Dementia Champions...

Nate:

Dementia Champions and Alzheimer's Society do a lot.

Nadia:

Maybe have some sort of linked to that so if they needed any extra additional help they could ring up the Helpline and then they could say, "Oh I'm signed up to the App, here's my detail."

They could bring up the details of the case, like a case study and they can help them that way. That is confidentiality and things like that.

Nate:

The only problem with that is in setting up a database they need protection and all of those things. But I felt a system similar to like what Netflix does, as soon as you get the App what do you have to do? You pick three films or three TV series or whatever that you are interested in. If you could have a platform of accessing all this information where you signed up and maybe you know about the finances and it is more to do with the social side of things and maybe it is about the generic understanding of dementia that you need to focus on. You could [Crosstalk 0:13:03] that way.

Or whereas some people might have an understanding of the condition, might have an understanding of the social care but may need help on the medical side and the finance side. So I think being able to cater to someone's needs is definite. It should be a definite feature or a definite factor in that.

Nadia:

Yes.

Nate:

We need ways to communicate with an between others that are reflective not just focussing on communicating with a person with dementia but also communicating with other people that are affected. So having strategies to communicate with them better so that they can better approach dementia within the whole space around them.

I think that goes up there doesn't it?

Nadia:

I think that goes, I think they are all interlinking to be honest. I think we all had very similar ideas.

Nate:

Yes, there are definitely similar themes isn't there?

Nadia:

Yes.

Nate:

We need advice on the best attitude to have when interacting with people with people.

Nadia:

That is something, I wanted to mention stereotype. What I was going to mention is dare I mention the word Youth Proofing because I know I have done a lot of work and like when you are youth proofing reports and things and a report which is sent out to professionals and then you are having to take that and put it into youth friendly form. I was like, dare I say that word because I know it is feared?

John:

I think that is possibly a really good idea. There is a lot of information out there that academics or medical researchers might have been putting out there but can young people relate to that?

Nadia:

I mean you don't want to patronise or stereotype young people and say that is it but...

Nate:

Well it is not only that but it is just the tone of the conversation to academics which released the paper are going to have a completely different conversation than 2 15 year olds in the park.

Nadia:

Absolutely.

Nate:

So I think having the information there is important but definitely how you communicate that with them. Something I learnt very quickly was working with the people in a care home I had to change drastically from when I was speaking to the healthcare professionals who worked there.

But language is something which is huge.

Nadia:

This one is on about how you interact with a person with dementia so it feels like they are having a normal conversation. So I think it is like conversation tools and [Crosstalk 0:15:34].

Nate:

But then what about interactions without any words, you know, people will be able to recognise actions, gestures, body language. What is it 50% of...

Ann:

It is 70.

Nate:

Is it 70% of...

Ann:	Communications
Nate:	Yes, so focussing on that.
Ann:	I probably should have tried to send that to you non verbally shouldn't I?
John:	Now that we have kind of touched those and remember a little bit about what was in the pack from last time. I would like to bring everyone together again so do you guys want to come over here away from the pizza temporarily.
	That is a fun table because there. That is the fun table. When you have done the hard work you can go back to the fun table so there are no distractions.
	Ann do you need to
Ann:	I need to scoot. Do you want to take this chair Simon?
Jamie:	Thank you, that is great.
Ann:	But lovely to meet you. I am sorry I can't be here for longer

But lovely to meet you. I am sorry I can't be here for longer and I will look forward to meeting you all again soon. Jamie will get me back up to speed on what happens but enjoy the rest

of your evening.

Nadia: Bye.

Bye.

[Crosstalk 0:16:35-0:16:38]

Jamie:

So did we manage to read through all of these?

Nadia:

We did.

Jamie:

Because I think I talk too much. I think I distracted these two.

Nate:

Well the last four, we need to stop leaving younger people out and get them involved. We need to consider young people's opinions and we need personalised guides that are easily to hand, easy to handout to find more about what to do which were points we mentioned.

Nadia:

Yes.

John:

So what we need to do because we have got 12 like manifesto points here which are all useful. How was your discussion, by the way, guys? Was it good?

Nate:

It was good, it was good. I mean we spoke about some of the points whilst speaking about some of the other points.

So, quite a few of them I think have got some overlaps haven't

they?

Nadia:

Pretty much so.

John:

What we need to do is we need to narrow these 12 points down to 3.

Nadia:

I think one of the main points which we kept coming across was about communications and effective communication whether it is communicating with the patient or whether it is... I don't know whether patient is the right word or whether it is communicating like so for the young person to understand what is already out there.

Because I think communication is like a broad one which covers a lot, because there is a lot out there but is it effective and can young people understand it and access it?

John:

So do you think some of these are specifically about communication then? Shall we make a little pile of ones which are communication?

Nadia:

That one says communication.

That one actually has communication in the title. So do these two – sorry Nate, did you put that there – do these two go together. Is that what you were saying?

Nate:

Well that is communicating yes, making it more user-friendly.

Jamie:

Because Nadia mentioned there youth proofing and making information outside there more accessible.

John:

Okay, excellent.

Nadia:

That is more interaction with young people and people with dementia, it is a bit different. It is interaction not communication. Ways of connecting with information that young people would engage with and ___[0:18:45].

I think that was the one about their character. I think that was the...

[Silence 0:18:50-0:18:56]

Nadia:

I think that was what you discussed last time.

Nate:

I think the whole theme of the project is obviously to do with communication so it is... Male:

Difficult to separate.

Nadia:

Yes.

John:

We can dive into that a bit deeper in a minute. So was there any kind of themes or issues coming out do you think of any of these ones that are left over that you thought were important or do you think communication was the biggest issue?

Nate:

I think general awareness was a point because obviously dementia just affects not just the person it affects the families, the social circles, it affects everyone.

Nadia:

I think also general awareness came across, it was a broad illness. It is not just someone is being a bit forgetful like in their speech or in their memory. It is also like the way they are forgetting actions.

John:

Does awareness relate to communication at all or do you reckon that is something completely different?

Nadia:

No, I think that is different, I would say. But I think the way you communication awareness, I think it can link in but I think it is separate. I think awareness of... There is awareness of what is out there and the help and then there is awareness of what dementia is. I don't know...

There are two different things there. There is helping people just be more sensitive to it generally sort of knowing this is a thing that people might be experiencing it. Then there is actually... I guess this big cluster of stuff here is maybe more practical stuff; this is how you communicate. Is that right?

Jamie:

Simon and Emily did you have any other themes that you came across when you were looking at them?

Emily:

Yes, we were basically talking about communication as well weren't we?

Simon:

Yes.

Emily:

How to sort of communicate effectively with the person who has got dementia so you can actually have like a meaningful conversation, yes. That is basically what we were talking about.

Jamie:

So meaningful conversations, yes.

Nate:

One thing we mentioned was the fact that a lot of communication isn't verbal and that someone can respond without words. And you could still have these conversations or an interaction without the use of words.

So I mean one exercise the care home I visited used were flash cards so if the person could gesture at what it was or get

their words out they would be able to put a card down. They were very simple; it was like a picture of a toilet if they needed to go for a toilet break or a picture of a drink, a glass of water or whatever.

So there is other ways of communicating without speaking and I think it is important not to just focus on conversations straightaway. I think it is important to understand how we can communicate with someone in general, so, you know, through different media. We mentioned different media the fact that sometimes you don't want to read a load of text sometimes you just want to watch a video or listen to an audio book or whatever. And I think because everyone is so different you just need to make sure it is accessible, like what you said, just make sure it is accessible for all these people to opt in and opt out when they need it; rather than make a big point of, "Yes this happens and make sure you get it and read it all..."

I think the purpose of this App is there to support and it is almost like a goto as if like if you were writing an essay and you needed a word you would look in a dictionary. If you are living with somebody with dementia or working with someone, this is a way you could quickly just...

Nadia: Of if someone has just been diagnosed and you don't know

how to cope with it.

Emily: Yes.

Nate: Yes, exactly.

Nadia:

Like what you were saying about a filter system, like membership. So that would be quite...

Nate:

And the good thing about that is you could build a community then as well. So if you signed up to it and you become part of it then you could, you feel like you belong to something.

I think that is why the Alzheimer's Society, Dementia Friend Scheme is doing so well because you are part of a community. It is not just, "Here's your badge." You are part of this scheme, now you are part of this community, you know, you have a sense of belonging, a sense of ownership. I am doing this, I am important.

And I think that is vital especially with people with mental illnesses. Especially with dementia where people can lose a lot of who they are to still give them something to be proud of. I think that is nice, yes.

John:

And that relates a lot to what you were saying earlier as well Sam about your kind of pocket guide idea which you [Crosstalk 0:23:36]. It is a great idea. The fact that it is a quick reference thing that people can kind of dip into and dip out of.

Great, right, so what I am going to do, so this bunch of stuff here, what was that about?

Nate:

This is just engaging.

John:

Is that engaging? So because this is meant to be about communication, the biggest theme is about communication.

These things are very important – obviously – I am going to put them here for the time being. So let's focus on this little group of themes we have here.

So, what we need to do now is get these down to three and that might be because some of these already have overlaps within themselves that it kind of gives us a focus point for thinking about what we think might be the most beneficial to people. And it might be that we really struggle to narrow it down anymore than we have done already but let's try, let's see what we can do.

[Silence 0:24:42-0:24:47]

Nadia:

I don't know if anyone agrees but I would say that those two maybe, got to get that personalised and ___[0:24:53] with the way that is going to engage people. If it is personalised it is going to be more positive isn't it?

Emily:

Yes.

Nate:

And in that case we don't need that one because that is talking about really connecting with young people and places.

Nadia:

Yes. Signpost the sources of information – maybe then get rid of that because it is personalised again signposting the sources of information. Right, so if you are personalising on what you need then that will link into that, I don't know?

Emily:	Yes.
Simon:	Yes, I would say that is fair.
John:	Were you going to say something Emily?
Emily:	No, I was just agreeing with what Nadia was saying.
Nadia:	We need ways to communicate information that isn't just text; again that is personalised and looking at ways, that is similar.
Nate:	It is a little different isn't it? Because personalising would be the topic of the content whereas [Crosstalk 0:25:48]?
Nadia:	Kind of give information that young people would engage with and not we need ways of communication that isn't just text and help people; tried tips and strategies. I would say these link very closely together.
Emily:	Yes because if you don't want to paint a negative picture I guess you could do that by having loads of text.

So I would say those are very close together; almost overlapping.

Nadia:

Nate:

I think with that one you are going to face a lot of barriers. We need ways of being with people with dementia when we can't physically be there.

Emily:

Yes, that was like when we were talking about the robot or something.

Nadia:

What am I thinking is Facetime but...

Simon:

That was the companion idea, yes that was the blue-sky idea, the crazy idea that Zara came up with.

Jamie:

Have you ever seen, I think it is called 'Be My Eyes' and it is an App for people who are blind and they take their phone and they speak and get the App up. And they hold their camera up in front of them and you have got these helpers who are at the other end and they are just sort of... "Oh someone needs help, press a button." And you see what their phone's camera is seeing and then they can hear through the microphone.

So they would say, "Am I going the right direction?" Or, "Is my kettle on? I can't see." Or, "What temperature does this package say my food needs to go on for?" And other people answer.

Nadia:

Ah right.

Emily:

That is good.

It is just a simple video connection really, isn't it?

Jamie:

Yes, it is just like a Skype call.

John:

Yes, yes exactly, yes. But you think of it very differently.

Jamie:

Yes.

John:

We did a project a few years ago where a lot of people could take a photo of something in front of them and then it used crowd sourcing. So workers online in some anonymous place tagged what they could see and then within 10 seconds the phone would say, "You clicked," or something like that; really elaborate. Because computers still aren't very good at that sort of [Crosstalk 0:27:43].

Nadia:

I guess how they linked, no they are different.

Nate:

We need ways to communicate with and between others that are effective.

Nadia:

So that is like creating a network maybe or...

Nate: Yes, what would you guys think, which one is more important

Yes.

to you Emily?

Emily:

Jamie: So what are the two that we are looking at?

Nate: We need ways of being with people with dementia when we

can't physically be there or we need ways to communicate with

and between others that are affected?

Nadia: That is creating a social network.

John: So this is not just focussing 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 so that we can better approach dementia within

the whole space around them.

Emily: I think that one is probably more important because then you

have got a support system for people with dementia. You don't feel like you are alone. Instead of just you being like a way to

be there when you are not there they can be with other people,

so I guess. See what I mean?

Nate: I think, yes. I agree with that. I agree, I think that one is more

important because as we mentioned dementia doesn't just

affect the person it affects the whole social circle, family, friends whatever so... I would say that is more important in this case, I think, because the whole App is to do with communicating and speaking to the right people and giving the right information to the right people, I would say that is more important.

Do you guys agree, disagree?

Jamie: Shall we do a show of hands?

Simon: I am completely torn between them both.

John: Why are you torn Simon?

> Well, I think that that one is ideal. I think that when you can't physically be there and they have got alternatives to do what, like you were saying with the blind people. Perhaps you could do something similar then you know that your family member is always safe and always can do what they want to do.

Whereas the other one is kind of not like that is it? It is kind of the opposite. The family are getting reassurance instead of the person that is ill getting the reassurance.

So we have got to figure out what the project... Do we want to help the family affected or do we want an App to help the person?

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Simon:

Nadia:

Simon:

Or both.

Nadia:

Or both.

Emily:

Yes perhaps we need to do both to be effective.

Nate:

I think, yes I think both of... By increasing the people around them, so awareness you would then reduce the risk of having to keep an eye on them when you are not there, I guess.

So if you knew how to behave and you knew say in a house that you couldn't leave certain things plugged in or you knew to lock certain doors or lock certain cupboards or whatever, or not lock them in some cases...

Simon:

The problem being with that though is how widespread is that going to be and is everyone, the families that are affected going to use it. And then if they don't then you would say, "That one takes priority." It might be that...

Nate:

I think...

Simon:

Because if you make this App and then how many people are affected by dementia? Is it 800,000 or something and then say 1 in 8 use it whereas if all 800,000 could have that App where you can't be there then that is going to be more effective than having 1 in 8 families reassured. Because then that is 700,000 people that will essentially be let down by us.

Nate:

But I think that as dementia gets worse when they would probably need an App to look after them the most, they are probably going to have someone there with them at that point, whether it is a live-in carer or whether it is a family who is their primary carer. I think past a certain point of, once your dementia reaches a certain point then you can no longer be left on your own.

I think it is more important about raising the awareness, you know, understanding of the condition so that you can then prepare for later down the line when that person cannot be alone or that person or understanding what is going to happen to that person.

Nadia: Can I ask what sort of limitations we do have with budget or

technology wise?

John: We won't be able to make a robot. That was maybe a bit too

[Crosstalk 0:32:14].

Nadia: Seeing that on the news the robots are coming in everywhere

aren't they?

John: Yes, there was one on the news actually the other day as well

which was specifically for a robot designed for social care and dementia care. It was pretty ghastly in the sense it was very

frightening actually. I am not sure I appreciate that.

I would say, I mean at the end of the day obviously in the space of this project we need to develop an App and that is going to have relatively limited [Crosstalk].

Nadia:

Or something with timescales and things if we are doing one where like...

John:

But we can, I mean for example video connection is quite easily possible. I guess you also have to think about realistically if for example a video connection connected a person with dementia with their family, how many people practically have data connections that could maybe do that? Or you need to be in wifi and things like that, so.

Nate:

One thing we, like my friend and I who were doing the placement we were talking about care homes. His dissertation was all to be about old people and technology and what affect that is going to have.

One case study he used was a care home. They had replaced all their old TVs with brand new TVs and it scared all the residents because they didn't recognise them. They weren't sure of what it was. So imagine if you have dementia and your phone starts going off and you answer it and there is someone there. Or it is a video call and you can't recognise them or recognise their voice or know what is going on, it could act as the opposite of what you want it to be; a traumatising experience for them rather than something which is going to help.

So I think, it is just... Yes, it is just understanding at what stage are we preparing this App for?

You can think of some really, some more sensitive things in that sort of space though where you can imagine a system where it is almost like a glove that someone wears and it gives you a gentle squeeze as if someone is holding your hand remotely or something like that rather than seeing their face on the screen. So you get the feeling someone is with you but then you will still have the problem that some people will think, "What's going on here?" You know, all of a sudden from nowhere.

Jamie:

Well there are those necklaces you can buy as well where when you touch them yours lights up but the person who has the other one of the pair, that also lights up. So then it is like a way of knowing that someone is thinking about you kind of thing.

Nadia:

I thought you meant the call for help ones, the panic buttons.

Jamie:

Oh no, no.

Nadia:

I know you can get the... When there is an old person or disabled person with needs.

John:

So with these ones then, so at the moment we have got... So this is a cluster of three that you think are pretty much the same. Is that right? Is that...

Nate:

That is these two I guess.

Nadia:

These two are the same and that is... They are closely together.

John:

Ah, okay brilliant. And you are just trying to decide which one of these two.

Simon:

I am still torn between them. I can understand what you are saying but I think when you can't physically be there if you could develop something that would prolong the dementia so that it didn't get to that serious stage until a lot later.

Like, I don't know, for instance, you could have a game of Sudoku on it or Crosswords or – I don't know. Make it adaptable for them for whatever they like doing so that they keep their brain stimulated instead of just doing nothing all day and waiting for the carer to arrive.

Jamie:

I guess we need to think who this App is for? Who is the audience? Because is it for someone with dementia or is it for someone who wants to find out about dementia?

Nadia:

Because I am feeling... I thought it was about the young people who are affected. And if it is the young people that are affected, it is this one because more young people that are affected are going to be effected by someone living with dementia. And that is what I thought the project was going to be about.

This is almost seamless. It is amazing. So on to the next, fourth part of the activity which is where we actually define who we think the user of the App is. It is like, that was just absolutely fantastic. Thank you Jamie.

Jamie:

You are welcome.

John:

So this is around a little bit... Because Nate is a designer so he might actually know some of this stuff. And I am a bit, I don't really like stuff. Have you done anything to do with personas before and...?

Nate:

Oh yes.

John:

Personas are just like the bread and butter of design work these days.

Nate:

Especially in user experience.

John:

Yes.

Jamie:

We did these on a bus to Cragside.

Nate:

Yes we did.

Jamie:

We did.

John:

So does everyone know what I am talking about when I say something like a persona?

Jamie:

I don't.

John:

Jamie, do you want to go ahead.

Jamie:

No I don't.

John:

Oh you don't know, oh you don't know.

Jamie:

I will be the person that says they don't.

John:

So I guess a real simple way. These are just some examples, clearly just a completely random different examples of what personas look like. They are kind of caricatures of specific imagined people which ideally are representative of real people who often when you are kind of designing things you try to think about who the user and the people who are going to be living with and using the thing that you are going to make is going to be.

And often that is quite a difficult thing to choose and to decide about. So quite often creating a persona about who you think

that person is ideally based on the fact that maybe you have talked to some of these people beforehand; referencing a conversation Nate and I were having earlier as well. It means actually that kind of helps figure out who you think you are creating your product or in this case your application form.

So on that note, I would like to split you up into pairs again. So Nate and Emily, Simon and Nadia. And I would like you to come up. So this is the interesting thing so normally what would happen in a design process is someone would give you the persona and you would design around that. Well in this case I actually need you to make it up. And I don't actually want you to make it up. I want you to think about who you think based upon the things we have just been talking about, what we think the main issues are that we need to address in this project. Who we think actually is the key user of this application?

And I think actually that then might mean we can go back to these and figure out which ones are the priorities. And then on the next bit we are going to do some very simple App design things as well.

Jamie: So I am going to need a pen.

John: Oh yes, I have got lots of pens. I have got the standard toolkit

of the designer...

Nate: Sharpeys.

John: The sharpeys. Do not put them too close to your nose.

Nadia:

The stuff that goes straight through the paper.

John:

They probably will. So don't worry about it, we have got cleaning implements. So if you want, if you want to work together in pairs or do it individually. It is completely down to you.

Nate:

I have got to leave in about 10 minutes sadly.

John:

So you can rip through loads of personas for us then as the designer and then kind of just leave us to make sense of it all.

Nate:

Well, I have probably got a load on my laptop from it. But I can help you if you want.

Emily:

Yes.

Jamie:

I can tell you about one because when I worked at Metro Radio, Metro Radio has its own brand persona and she is called Deborah. She is 33 years old, she has got 2 children. She likes current pop music but she also likes songs from the last 2 or 3 years. She is kind of into news but she doesn't remember all the facts, she is more interested in the headlines.

So that is Deborah and that is Metro Radio. So all their decisions are based around Deborah, is this something

Deborah would listen to? Is this something Deborah would want to hear about in the news?

Nate: Yes, from my projects we did like a project with Unilever all to

do with like washing dishes.

Nadia: See I have got an image of just a girl or guy about 15 their

grandparent have got dementia and on a typical day they go and visit their grandma but occasionally they forget who they

are.

John: Perfect.

Nadia: And they just don't know how to cope with it.

Simon: When we find the first one do we have to draw?

Nadia: That is what I am thinking.

John: You can do a stickman. You can do a stickman if you want.

Don't worry I was a train designer and I can't draw for toffee.

So I just write instead.

Nadia: Give us a computer, I can put something on Photoshop but I

can't draw with this hand.

Simon:	Don't worry.
John:	There is no pressure.
Nadia:	I don't know, can you think of the helping the older person with dementia?
Simon:	I was during that but throughout I have been thinking about the different age groups.
Nadia:	Was there any of the NTS Cadets?
Simon:	Yes.
Nadia:	Was there any at the NTS let you know that there was anyone with dementia?
Simon:	What do you mean?
Nadia:	Whether there any young carers for an elderly relative?
Simon:	We all got our Dementia Friend badges.

Nadia:	Really?

John: So would it be a Dementia Friend that you are designing this

for or could it be ..?

Simon: It could be couldn't it? But then it is the age then because

[Crosstalk 0:41:57].

John: And actually that could be anyone really couldn't it?

Simon: Yes, yes.

Emily: But then I think it should be something that the person with

dementia can use as well?

Nate: Well some research, I think there is a researcher at Newcastle

University, a pathologist she is chopping up a load of brains to figure out why, what causes dementia and what is it. And she

said that...

Jamie: Frustrated graphic designer.

John: Actually I only printed enough, I thought I had printed off 20 of

these. I might print off some more.

[Crosstalk 0:42:27-0:43:23]

Jamie: But this isn't about. Nadia: She is one of these really modest people I am guessing. Emily: Yes, I didn't mean it like that. You will do us the Mona Lisa. Jamie: [Crosstalk] John: This isn't about making pretty things this is about the content it is not about the pretty things. Nate: I am going to have to make up... John: No worries, thank for coming over. Nate: Yes. Let me how, what the rest of the... John: Will do and I will also let you know about the thing I mentioned earlier the hip funding or something. I am just going to print off the... I will show you out as well.

Nate:	Thank you. And could you just send me a message about when you are free[0:44:06].
Jamie:	Yes, studio in Gateshead.
Nate:	Oh it is more of a design centre.
Jamie:	Oh yes, whereabouts is it?
Nate:	Gateshead College.
Jamie:	Okay, yes.
Nate:	Next to it.
Jamie:	Is it just like the main campus?
Nate:	You know behind Auto Keys.
Jamie:	Just round there?
Nate:	Yes.

Jamie: Ah right, that is dead easy to get to. Yes, just bought a new bike as well. Nate: Jamie: Oh nice, nice. [Silence 0:44:37-0:44:43] We have lots of pizza. John: Nate: I might take a slice for the road. John: Yes, take a slice for the road. Nate: Thank you very much. There is still plenty of pizza, don't worry there will be more. John: There is still like an entire one.

[Silence 0:44:58-0:45:06]

John: I can use Nate's.

That is why I didn't draw nothing, get halfway through and... Nate: John: It is useful to know at least what I think I am doing. I took that photo from two miles away. Simon: You took a photo of a ten-year-old boy. Nadia: From two miles away. I can't draw. Simon: [Silence 0:45:30-0:45:44] Nate: Which way is? John: Ah yes I will show you out Nate. See you guys later on. Nate: Jamie: See you later Nate.

Emily:

Bye.

[Crosstalk	0:45:50-0:45:53]
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[Silence 0:45:55-0:46:02]

Jamie: I am scared to lift this bit of paper up and look at the table in

case I have...

Emily: No, mine hasn't done anything.

Jamie: Oh, that is alright.

Nadia: Oh, he has so much food to eat.

Jamie: I can thoroughly recommend the 333.

Simon: Right, okay.

Jamie: It is a taste sensation.

Simon: I am partial for a bit of change.

Jamie: Oh, I am not going to lie, it pretty much tastes overwhelmingly

of pineapple.

Right, I will put a little less pineapple. Simon: Jamie: I mean if you like pineapple that is... Simon: That does really. It is alright though isn't it? Jamie: Simon: Yes. They should sell that. Jamie: Simon: Bit of grenadine I mean you have got a mock cocktail. He is creating mock cocktails and someone put Tabasco in it. Nadia: Simon: See that is beautiful. Look at my attempt, I am getting nowhere. John:

It is just like a potato.

Nadia:

John:	You get a sense of where they are coming from in their life and
Nadia:	It is a bit confused.
Simon:	So it is grabbing its balls.
	[Silence 0:47:12-0:47:29]
Simon:	It is an ex famous politician's daughter.
Nadia:	Ex famous, why would he be ex famous?
	[Silence 0:47:36-0:48:25]
John:	Times like this I realise how little I know about the young. What would the young person want to do? Do people use Facebook anymore?
Nadia:	Yes.
Emily:	Yes.

A bit too much probably. It went down the other day.

Nadia:

Jamie: Ah, it went down for four hours and I didn't have a clue what to

do with myself, it was horrible.

Emily: I didn't even notice, I mean that is probably a good sign.

Jamie: It is probably a really good sign.

Emily: Yes, I had no idea.

Jamie: I was writing an article though and I had sent the interview

questions by Facebook so I was waiting for the answers back

and I was like, "Oh I've got a deadline."

Emily: Oh, that is annoying though.

Jamie: So I had to stay up until half three in the morning to get them

through.

John: About your dreams for the future? I asked some quite difficult

questions there didn't I?

Nadia: They are broad, very broad.

[Silence 0:49:13-0:49:20]

[Aside conversation 0:49:20-0:50:17]

[Silence 0:50:17-0:50:24]

Nadia: I was going to try and make my character metrosexual so you

can't tell; so it is not gender specific.

Jamie: There was a new phrase I heard the other day because they

were saying metrosexual as a term is kind of dying out and

now, what are they calling it? They are calling it Lumbersexual.

John: Lumbersexual.

Jamie: Lumbersexual and it is men who dress essentially like

lumberjacks. So massive beards, long hair, I can't explain

myself. But then like flannel shirts and...

John: I think that was a real thing. I remember in the mid to late '90s

there was a shop called Eddie Bower. I don't know if you

remember Eddie Bower Jamie?

Jamie: Oh yes.

John:	And Eddie Bower were just lumberjack shirts but like proper lumberjack shirts.
Jamie:	Yes. They were thick flannel like.
John:	Yes, yes.
Jamie:	Sturdy flannel.
John:	I actually did exercise wearing it. You would never want to get caught in the rain.
	[Silence 0:51:21-0:51:34]
Nadia:	Jamie is Neil still working at Youth Pocus?

Nadia:	He is, I was just wondering. I haven't heard from him in a
	while.

Jamie: Are you doing one of his projects?

He is.

Nadia: I was.

Jamie:

Jamie:

Oh right.

Nadia:

And I think it was him who originally contacted me.

Jamie:

Yes, oh, yes he is still there.

Nadia:

Yes but ____[0:51:51] I don't think.

John:

Shall we quickly go round and see what folk have said. Emily do you want to go first? After you lan, sorry it was very rude of me crunching away on the...

Jamie:

Shall I go first?

John:

Oh go on then Jamie, yes you can be brave.

Jamie:

Okay, so my name is Harry I live in Sunderland with my parents and I am 15 years old. During my typical day I go to school and after school I spend time with my grandparents while I wait for my mum and dad to get back home. I play videogames and use social media, talk to my friends.

I have got an interest in dementia because recently my grandfather has been diagnosed but my mum and dad haven't really explained anything to me. I like to spend time with my friends in my free time, talk on social media and I am an Instagram fiend; I actually put Instagram fiend.

My dreams for the future are to get good enough grades to get into college and study art. And I would like help with understanding a bit more about what dementia is and how I can help grandma. Technologies, I use internet enabled devices such as mobile phones, laptops, tablets.

And that is Harry.

John:

Well done, a brilliant, brilliant persona. Simon do you want to go next?

Simon:

Yes, okay. I am Billy, I am from Whitby and I am aged 10. And I spend my free time walking the dog, doing homework and I go to cubs or scouts – whichever one it is, I don't know. And my typical day is school, homework, cubs and I visit grandma and I have an interest in dementia because my grandma has dementia. And she doesn't often know who I am which is quite upsetting.

Sometimes when we go round with my mum she always says, "Who's that with you?" Which I always get upset about. And my dreams for the future I want to be either a postman or a bus driver, love the uniforms.

Jamie:

Oh it is that extra detail, I love the uniforms.

Simon:

And I would like help because my grandma has got dementia and I use my school iPad for technologies.

Jamie:

Great.

John:

Really good.

Nadia:

Done a little girl, I say little, she is 14. She is called Ophelia, she is from Newcastle and she likes chilling with other friends and performing. On a regular day when she is not in rehearsals, she would go and see her elderly relative after school and she has got an interest because she has got a grandparent with dementia.

I didn't want to be gender specific or anything I didn't want to stereotype, I just said grandparent. Often she would go round and the grandparent would have forgotten to complete menial tasks and on rare occasions forget who she was or who her family was.

Dreams for the future, she wants to be a performer. She wants help because she doesn't know how to react when... She finds it hard and she doesn't know how to fully react when a relative forgets who she is and also like how can she help with sort of coping strategies for remembering how to complete tasks. And what technologies do I use, well like all little kids these days they have iPhones or Blackberrys or phones you would generally associate with a well-off businessman - not bitter at all – I just go round with a Nokia 3310 I first got.

John:

I loved those phones.

Jamie:

Indestructible.

Nadia:

They were and they lasted. You didn't have to charge your phone every five minutes.

Jamie:

I look at my phone now and it breaks.

John:

Shall I read my one out then? Mine is a bit vague. I had more in my head than I think I put down on paper.

So I had Susie, not that you can tell the gender from the little stick person I put together. Susie is aged 15 from Gateshead, what is her typical day like? Well she would like to go to school and go to college but she actually didn't go to... It doesn't make sense does it? See this is thing when you write about a fake person the age doesn't make sense in terms of what I had in the rest of the story.

Suzie is 17, she is 17. She finished school a year ago – that is what I was going to say – she finished school a year ago but she would like to have gone to sixth form college but hasn't been able to. And why she has an interest in dementia it is because a family member, her gran, who she spent a lot of time with when she was younger has got a mode of dementia and she has to look after her and care for her for most of the time during the day whilst her parents are out earning money.

How does she spend her free time? She spends a lot of time on Facebook, plays a lot of games on crappy online cheap game websites. And she likes to go to town and see some of her old school friends as and when she has time but she isn't always able to do that. What are her dreams for the future?

She is not really thinking too much about the future right now but she would like a career in something which might mean going back to college at some point in the future.

What would she like help with? She would like to be better connected with her friends and also ask for some advice because there are some things around what her grandmother does and says that she doesn't quite understand. And what technologies does she use? Facebook, Xbox and she has a simple phone, a Nokia 3310; probably unlikely really but whatever the conversion of that is.

Jamie:

Cool.

Emily:

So mine is sort of two people, my persona. It is like a double persona; well it is not really but... Because what me and Nate were saying was how it would be good if the App could be for the person with dementia as well. And then especially towards like the later stages of dementia and like the way that you would sort of, well the way you would sort of communicate with the person becomes mostly how you communicate with the child anyway. So I think if it was something that could help a young, like a young child could probably help the person in the later stages as well. Like the way it was sort of designed.

Obviously, they would be looking at it for different things and maybe different sections of the App for different things but it could be used for both of them, like different purposes.

So we have Kevin and Susie, they both live in Sunderland. Kevin is 12 and Susie is 85. Kevin goes to school and they both like going for walks in the park and watching TV. Susie has just been diagnosed with dementia and so that is why they are both interested because Susie is Kevin's grandma.

Kevin likes playing the guitar, Susie used to like playing the guitar but now she has got quite bad arthritis in her fingers so she can't do that anymore. And Kevin wants to be in a band in the future and Susie just wants to understand more of what is going on with her and just be happy for the rest of her years I suppose.

And they both want help with understanding the disease and Susie doesn't use an awful lot of technology and Kevin uses his phone, TV, computer and everything.

John:

Great.

Jamie:

Brill.

John:

So there are a lot of like overlaps I think what we have done there. Did anything from the other people's stories really stick out to you? Anyone?

Nadia:

Like the crossover idea there, I think it is good. Crossover, you know they have got the similar interests so, perfect.

Emily:

Oh thanks.

Nadia:

I am just developing your story there. I think in the similar interests, they want to be able to do or maybe she has forgotten and stuff.

John:

I guess it is like finding those overlaps and commonalities and kind of almost connecting people with those similar overlaps.

Emily:

Yours sort of stood out for John. I mean I can't remember what your person was called, Susie, yes?

John:

Susie.

Emily:

But I felt really sorry for her really because she is not having the best time. I am presuming that the reason she couldn't go to college was partly to do with having to care for her gran or..? Yes, like that is really sad really especially if she is not sure what to do and she shouldn't really be in that position but, yes it is quite... It is not fair really.

Jamie:

It was interesting that your's John was the only one that had a young carer everybody else they had grandparents who had dementia and they would visit them every now and then.

Whereas in your case John this young person was the primary carer.

Emily:

Yes, they are the sort of people that we really need to try and help as well.

John:

The most common theme would be people who just have little touch points with their grandparent. That is kind of the most common like maybe the first point of experiencing dementia probably an awful lot of people have. Sorry mine was a little bit depressing, I didn't mean it to be [Crosstalk 1:01:15].

Emily:

No, no it is important.

Nadia:

I am sure there was someone last time who said that they had quite a big impact on their relatives and I can't remember... I don't know, if you remember someone, I think it was one of the girls said that she went and cared a lot for her, I think it was her late grandma.

John:

I can't remember her name but she struggles to come to these workshop because she is caring the whole time.

Nadia:

I don't know if that had an impact on your persona?

John:

Well it did, a little bit. I am sure it did.

Nadia:

I just remembered that when you said it.

John:

So coming back to our things when we said earlier then. See this is all; I have planned all these things you see. You need method in the madness.

Simon:

Were those two linked. I can't remember?

Nadia:

Yes.

John:

These were the two that were linked weren't they? So do we think there is much in the personas that we have kind of put together here and imagined which overlap? And are there things here which we need to maybe get rid of again because we don't think they are important; but going forward we need to..?

Nadia:

I think the personalised thing that is going to come if... We will keep mentioning this thing about making it a network and inputting your own sort of thing. I think the personalised isn't a main theme. I don't know how you all feel but I think that is a sort of, something which will be developed in whatever we do that you put in your situation and that is how you sort of...

Simon:

What was the answer to that one?

Nadia:

So like because I don't know... Me and Nate were discussing, we were discussing it initially like personalised, I think also you have touched upon it Jamie. That you put in all your information and it becomes a network, not just an App it is a

network. So it becomes a social networking App as opposed to just an information App.

So I think the personalised bit of it if we are going to do, if we maybe take on that sort of aspect of a network that is going to come automatically. So I don't think that is a big thing. I mean I think it is, it needs to be personalised because that is the way you are going to get the information that you need to help. But I think from what we have identified, the other three are more important there; the sort of key points.

And I think the personalised guide is going to come regardless of what we do. I don't think we are going to forget that. It is hard to explain what I am trying to say.

John:

No, I...

Emily:

No, yes I think I know what you mean because...

Nadia:

If we are looking for one to chuck.

Emily:

Yes, because it needs to be something that you can personalise it. That is not something we could do it is just something that we need to make available otherwise it is not going to work anyway, like it has got to be something that we can sort of...

Nadia:

Yes because at the minute there is loads of stuff out there anyway which isn't personalised and that is, well the reason we are doing this is because it is not working. We are going to

expand on what is already out there. And I think that is just the next step is to create a personalised thing. That is the whole part of the project.

Emily:

Yes, like we can't do the personalising part but we are just making something that can be.

Simon:

I think we could make the personalised part if we take for instance each and everyone's ideas there is like a widespread of age there isn't there? Like mine is 10 for instance then it goes up to 17. A 10 year old's understanding of an App is going to be more vague than a 17 year olds who is going to want more detail about it.

So if you were to make an App and then have different age groups within it then I think that the personalised bit is fundamental. I don't think... I think that even though I was arguing for it I think that one needs to go.

Nadia:

Get rid of like make it more about the...

Simon:

I think that is going to be too complicated.

Nadia:

Because by the looks of it apart from you, you have got your split personality there – that came out totally wrong – but it is all, like even yours it is someone who has got a relative and they want help how to interact.

So I think it is that one or that one. I think that is something which needs to be maybe further down the line or for a

different group. Because we are a young person group I am just thinking like a young person sort of thing. We are a youth group, I want to say representing young people and the majority of young people and what we have come up with with the personas is how are they affected by someone else who has dementia not them. So I think we need to like educate, personalise how to help them cope with the fact that they have got a relative or close family friend with dementia.

Simon:

Which reinforces that point about the different age groups.

Nadia:

Which reinforces that and then so I think that one is not. Because I don't think, as young people I think we understand young people more than we will understand elderly. Because they are our peers and I think also what we are thinking maybe to help an elderly person with dementia I think it is going to be too advanced, too complex, too expensive to even think about...

Simon:

I think this one needs to go as well?

Nadia:

I thought they were linked.

Simon:

Yes but we need to get them down to three so it is either that one or that one.

John:

We could combine them into a new one if you think they are [Crosstalk 1:06:55]. We need ways of connecting with the

information that young people will engage with and not paint a negative picture.

Emily:

But if...

Simon:

I think they are the same points aren't they?

Emily:

If it is something that people would engage with surely that is going to be something that is not just text anyway so does that one not cover that one anyway?

Simon:

Yes, they are very similar aren't they? But that is just more diverse about how it says it.

Nadia:

So which one are we getting rid of it?

Simon:

I would get rid of this one personally. But if you want to vote for it though, I think we will vote, I think would be fair. Which would you say Emily?

Emily:

I would say get rid of this one but I mean I don't know it doesn't really matter, just get rid of that one if you want.

Jamie:

Which one, do they say?

Nadia:

Look on the back, what does it say on the back.

Jamie:

So do you want to read the front of that one, then the back of that one.

Nadia:

We need ways to communicate information that isn't just text and helps people try out tips and strategies. We were thinking of different ways to communicate on the Apps, reading lots of information might be boring especially if it is long bits of texts. So we came up with an idea, a bit like a simulator where you might be put in a situation where, a bit like earlier with the omelette egg thing. You test out how to communicate with that person providing you with different trial strategies and things.

John:

Okay.

Emily:

Yes, that is it.

Simon:

That actually links in with that one doesn't it? Because that is like the different ages.

Nadia:

So like that one. I would, well what is that one?

Jamie:

This one says, we need ways of connecting with information that young people would engage with and not paint a negative picture.

Nadia:

Well this one is then linking in with personalisation; shall we

get rid of this one?

Emily:

Right, see what the back of that one says.

Jamie:

This one says we could create the greatest resource on the planet but unless a young-un wants to interact with it or is inspired to engage with it, they are not going to. So we thought a game or a cartoon where you form some sort of relationship with characters which helps showcase some of the situations they might find themselves in. Also in a cartoon you can use humour quite well, you could showcase situations in a humorous way almost a bit lighter.

It is a very serious condition but that doesn't mean you have to tell kids it is a very serious condition or that it is a downhill process.

Simon:

They are very similar aren't they?

Emily:

I don't know.

Simon:

Which one did you want? Did you want that one?

Emily:

I don't know, I think after reading them back I think I want that one more. Oh, I don't know they are only bits of paper.

John: Good critical point in the design process. Emily: Sorry Jamie: Is there anyway we can combine the two like John suggested? Emily: Yes. Jamie: Is it a case that we might need to take elements of both of them and then rewrite one? Nadia: We could do that I suppose if we are compromising. But I think also now reading the back of that one it is linking it at that. Simon: I think they are both the same. Both the same that you need different information to engage young people. Nadia: Well shall we change it and then just put that we need to find a way to not just communicate by it? Emily: What is the back of this one?

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So it is more than text really is the point here isn't it?

John:

Nadia:	It needs to be more than just literature that you read.
John:	Yes because it is not like someone is going to sit down and go through [Crosstalk 1:10:09] on the phone.
Nadia:	No, but why would you do that?
John:	So we could stick them both together. Shall we just stick them together for the time being?
Emily:	Yes just
	[Crosstalk]
lohn:	Great let's just stick them together. Prilliant so the last kind of

John: Great, let's just stick them together. Brilliant so the last kind of bit before we go we are going to start thinking a little bit about

types of technologies.

So...

[Aside conversation 1:10:57-1:11:40]

John: Okay so each of you has got a stack of cards and they all the

same so none of you should be missing out. And if you spread

them out you will kind of also show a little bit to Jamie who will gawp at it as well.

So I think there is quite a few in here and what each of these talk about are obviously they are kind of different Apps, types of Apps and things they just do. So what would be just nice just for I guess for a couple of minutes is to just kind of scan through these a little bit, just think about them.

And then it would be nice for us to start thinking about actually how do these - not necessarily the Apps themselves that are kind of displayed here – but the types of things these things do. How do they relate to the types of things that we have identified as the priorities?

So if you can start to think about how we might design something which mimics these things. Do I make sense?

John: Excellent.

Nadia: Is someone pushing the hash tag?

John: I don't think anyone is hash-tagging DemYouth at the moment. We should be. Actually I will take a photo because then...

Nadia: No, not of me.

John:

Just something, the melting of pizzas.

Nadia:

Project money well spent. That is important.

Jamie:

Just on an aside now, has anybody seen the use of periscope with regard to the Syrian Refugee Crisis?

Emily:

No.

Simon:

Periscope?

Jamie:

Absolutely amazing. Periscope, it is a way of sending a live broadcast from your mobile phone so that other people can see it. But it is only available for 24 hours after you have filmed it and then gone.

What this German journalist has been doing is he has been following the Syrian refugees from Syria through to Hungary, Austria and then through to Germany and he has been interviewing people live. And his idea is that it can't be edited so that it is pure journalism, you can't say, "Ah well you've put that slant on it," because you can see that he hasn't, it is live.

And it is a fascinating bit of technology.

Emily:

Yes that is a really good idea that.

John:

Facebook have got their own version of it as well now, I can't remember what they call it. But yes it is really great. I just love those kind of advertisement they do, they have in the balloons or... It is very evocative.

[Aside conversation 1:14:16-1:14:46]

John: So there is one thing that is important to say is if there is any of

these that you don't really know anything about or you don't recognise let me know. Because I didn't know about some of

these until I started making these so it is nothing to be

ashamed of.

Nadia: No, I have never heard of this before, it sounds quite...

Simon: I have never heard of [Mobster 1:15:07] actually.

Nadia: Is this anything like Craig's List or anything like that?

John: It is a little bit like that, yes. So Freecycle is, yes so you can

advertise stuff and people come round and collect stuff that

you just want to get rid of.

Simon: Like the sites on Facebook?

Nadia: Oh...

Simon: The Freepages or whatever they are called.

Nadia: Yes, I don't think that is...

Simon: Buy and Sell.

John:

Jamie:

Nadia: Unless you want to be buying and selling your own...

Simon: Shall we select three of them, is that... Are we just?

> For now it is just looking through it but you can select three of them. I guess it is useful to think how do they relate to some of these three things? So that might be three of them or you might want to choose a number of them to do with one of these kind of manifesto points that we have chosen.

[Silence 1:15:56-1:16:01]

Along the lines of there the sort of giving away site. There was one project I remember seeing it was on my... I think it was called Pay It Forward, you did like a good deed or bought

something for somebody else who needed it and then they would then do a kind act for somebody else. This idea of just

doing something nice for a stranger.

[Silence 1:16:23-1:16:31]

Nadia:

I have heard of like Youth Projects, I did one was the Youth Council when I was involved. We did a skills auction where it was really stereotypical but the Youth Councils we would teach say an elderly person to use a phone and they would teach us a skill like knitting. It was really stereotypical but it worked. And it was just a way like we were doing on a project on like raising awareness and I like linking old people, I don't know if, like, that is anything like what you were saying.

Jamie:

Oh yes, yes, definitely. That sort of free exchange of not services but like...

John:

Volunteering, giving up your time. Then there are schemes in there are as well where you can collect credits so that the more time you volunteer you kind of have a bank of credits and you can put that on your CV or things like that.

Jamie:

Be Inspired which we are signed up with by the way. So if you spend I think 10 hours on this project we can get you the Be Inspired Certificate which is pretty cool and there is a few cash recommends as well.

Emily:

Is there?

Nadia:

I have already done it. I did it with Youth Council. There was one for the younger ones as well I think because the Be Inspired is 13 plus isn't it?

Jamie:

Yes. But I think there is a form I might you need to fill out if you are interested in it but it is just like a – my name, I am okay like you track how much time I spend on this project.

Emily:

I did it when I was doing like NTS before so...

Jamie:

Right, okay, yes. Oh brill yes.

John:

So, how are we doing? Are there any of these that don't really make any sense? We would like to talk about.

Emily:

No.

John:

Then I guess in that case shall we start picking some up that relate to some of these. Well actually maybe just go through them and we go round in turns and talk about, oh this one I think is really interesting. I think this is interesting because of... It relates to this.

Who would like to go first? Has anyone seen anything they are particularly interested in?

Well I have narrowed some down. I have got some which I don't think is... What I think is realistic or I don't think it is really appropriate.

John:

No, we don't need realistic quite now, don't worry about a tool.

Nadia:

Visiting before your trip, I don't... Like I think sharing experiences because I have got down – which one is it? Other people's stories to me if it was visiting ____[1:18:55] it would be that but that is already there so that one is out of the question.

John:

So stories are basically the [Crosstalk]

Nadia:

Stream what you see – I don't think it is really necessary. Data protection as well, things like that. Community radio, I am not really sure that... Again, I don't think there are the resources to man that constantly. But what I was thinking is something where like if needed there was access to speak to someone like a link to call a call centre. I don't know if there is a facility available where you can ring someone up if you need any help which is why I select the Hang Out, though not maybe a social network thing maybe it is like... What was that? I don't know if it is Amazon or something? No, is it Amazon Fire or something?

It is the way like...

Jamie:

Yes, it is like talk to a live person.

Talk to a live person if you need... Instead of calling you ring them up. That is what I was thinking with that. ___[1:20:02] that is Snap Chat, I don't think again Snap Chat is appropriate.

Selling things, I don't really think that is... Tracking your data I don't really... Again and that is like no. Taking a snap or two, I don't think it would be appropriate but like Chat Instantly. I think, I have got Local Chatter and Chat Instantly like you could have like a feat' going on and then if you wanted to message someone personally then maybe providing if this is where it comes if there was a network so, you know, I have got private social network if you sign up. So other people can see, like you can share or whatever.

Because obviously like the likes of Facebook you can only share so much with so many people but you can have that. And then you can have the ability to chat on news feeds. And then if you want to message someone specifically about a specific issue like someone has got, mentioned something and you want some advice, you can message them. Obviously, it is nice to get professional opinion but then at the same time it can also be more beneficial to speak to your peers rather than just speaking to a medical professional. Because they are in the same position as you whereas medical professionals they are not, they are outside.

John:

So in this case you could kind of see what people are talking about or asking questions about nearby. And has anyone ever used Yik Yak?

Emily:

No.

No.

John:

It is weird, it is an interesting thing.

Simon:

Never heard of it.

John:

Yes, it is kind of curious.

Nadia:

Pinning, listening, sharing just links to that, personalised. You have got different areas of dementia as you have got memory loss, loss of like forgetting to do thing. You have got speech, you have got forgetting functions like writing or walking. So you could select... Nate said something about how Netflix when you sign up you click three films and then they give you suggested links and that can get annoying at times. But that sort of thing, he had a good point where it was coming from. So I will give him the credit for that.

John:

I guess it is a different tool but they are still trying to sell you more films to download. It is actually trying to [Crosstalk 1:22:22].

Nadia:

So he had a good point and I thought he should get the credit for that one.

John:

Don't worry it is on the recorders.

Emily:

Even just making lists and images of the things that you are interested in and if there are local people, well people who live in the same area who have dementia you can maybe meet up and talk about things maybe. Is that another way, sort of personalise it from that side as well?

Nadia:

Or even if there is like, I don't know, Meetup and like...

Simon:

I think I have thought about it a little bit differently. My idea was that so my three were Hanging out with Others, Community Radio and Pinning, Listing and Sharing.

Now my idea was that the person with dementia clicks on the App and then it brings up like a tree of different things that they can click on. Now Hanging out with Others would be like first time – I don't know if you have ever heard of Carers Together, people from all over the community that have dementia that go on a bus load to Beamish for a day out?

John:

Okay, yes I know.

Simon:

Once a month or whatever. But then this can be every day. It is not just once a month that you get to see Doris or... Does that make sense? So if you wanted to speak to Doris you would click on the App and the tree would come up or whatever then you would click Hanging out with Others and there is Doris just waiting for you.

And the Community Radio I think that, well the Community Radio and the photo thing I think that the foundation would be nothing and then your family members would add to it. So in the Community Radio they would put your favourite songs on what you liked listening to back in the day or your favourite disco song. Just something to keep them happy all day while they are by themselves.

And then it would be the same for the photos like old photos of family members, old places. And then that could escalate and then... For instance where I live it is a village called Stanghow then old photos of Stanghow that they could access or people that want to access Stanghow old photos could do that as well.

Does that make sense?

Emily: Yes, yes I think...

Jamie: So would you be using that as a way to then start a

conversation?

Simon: If they wanted to then they could click on the Hang out with

Others and then see their friends from Carers Together, if they

are in that or anyone, your family members or...

Jamie: Because I have seen the Northern Regional Film and

Television Archive they have got this DVD package and it has old footage of school dinners. It is people like in old school uniforms with the school dinners. But then it pauses and it has

got the conversation points and it is like, "What were your

school dinners like?" And it promotes a conversation about

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that certain area. So it invokes a memory and then asks a conversation. And it is something that you can both share in that conversation.

Sorry, I didn't know if you meant you would use it to then interact with them or whether it would just be putting it out there for the person to sort of remember themselves.

Nadia:

It would be good for early stages of dementia.

Simon:

I think it was to remember themselves. Because I was talking to someone today actually one of my colleagues and he said that when his grandma had dementia him and his father went to hospital where she was laid. And then they were showing her old photos and she said some things like, "Ah, there's Joey I haven't seen him for years." But that was my colleague's father who was set next to him.

So she didn't recognise him at an old stage but she recognised him like back in the day sort of thing.

John:

Yes, it is kind of a neat thing there because I guess in a way what you are doing there is you are moving back to thinking and designing for the person with dementia instead of the carer.

Simon:

Yes.

John:

But I am not sure you are actually because I think you can imagine an App like that where a young person is able to

almost curate... Because they might not know what their gran's favourite song was or an old photo. They can go round the home and snap some things or...

Simon:

Yes, it is similar to what you were saying it can stimulate a conversation if there are old photos on there.

Emily:

And it will be much easier for them to have a conversation, they talk about things that were interesting for their grandparents because it is... Yes.

John:

And you can sit there and replay [Crosstalk 1:26:41].

Simon:

Yes and the photos are there for the young people to start a conversation, to ask, "Who's that?" And even if it is every time "Who's that?" And then she goes through all the family and at least she is happy because someone is there talking to her and she is happy talking about it.

Emily:

Yes, about something they are interested in as well, yes.

Simon:

Yes.

Jamie:

What I quite like about that idea is that I think a lot of the times when it comes to dementia people see the illness and not the person. Whereas with what you have described there Simon you are almost building a profile of this person which won't get

lost. So it is, sort of, "This is who my grandma is," or "This is who my granddad is." And you are sort of building up, that won't be lost and you can sort of go, "Oh yes, they like this, they like that."

Emily:

Yes and it will be quite good for other people who will come into contact with them to look at it before they went to see them so that they could have things to talk about and it wouldn't be sort of difficult for them as well.

John:

Do you want to talk about your ones Emily? Did you have ones you wanted to pick out or..?

Emily:

I didn't really get the picking out stage to be honest but...

John:

Are there any that you really want to talk about? Any that spark your interest or have we kind of covered?

Emily:

Pretty much. I think this is important as well especially like having other people's...

John:

People's stories?

Emily:

Yes. I think that is important especially if you have just been diagnosed with dementia and you are a bit sort of what is this going to involve for me and for the carers as well? So they can

hear about other people who have already been through it and I think that is important.

Simon:

Just going on that then if you think that is important could you not have it on my tree idea?

Emily:

Yes, yes.

Simon:

You could have any of them on the tree idea but it would up to the family to put them on for the person, what they think will be best for the person that is suffering.

John:

So who do you think the other people will be in terms of the stories then? In this case, what will be useful coming back to these kind of agenda points? Will it be other carers or will it be other people that know that person?

Nadia:

I have got, I will say this before I forget the idea. I got the idea of something, sparked on from the persona which you had which was two and create a more personal. I have got an idea from like... And that is just coming to me. You have heard of the game Sims and other games that you create a person. You create a person but that person is the family member with dementia and then like what Simon was saying with putting all their interests, photos; you create this person and obviously you can link in to all the other things. And then that person, that is the persona and then sort of their family members, they can have their own but they can be like a friend. And they have their own personality but that is their mutual friend, so that is

the main... The person with dementia is the main one and then obviously each other persons like a friend of that person.

So it will remember who, you know it is sort of embedded there that it is... It will remember they are and who their friends are. So they have all got individual personalities but obviously that personality says, "Has anyone else got a phone?" That is like saying, "That's Bob with the dementia. You're Bob's son and like..."

Jamie:

Yes, I have now found.

Nadia:

Susie's the sister and obviously there is the different App and you have got Bob here and then socially they would be linked in sort of thing. I don't know, I am just coming out with random ideas.

John:

I am sort of following you; I am sort of following you.

Nadia:

It is hard. I am trying to connect everything there but I am trying to come up with, I don't know I am just coming up... Like I am jumping the gun a bit on my ideas and I am just trying to... It is kind of coming to me and I am just trying to get them out before I forget.

Simon:

I remember a strange idea about my tree. So...

Emily:

No, I like this tree.

Stranger than mine.

John:

So last time it was like the pamphlet and this time, now it is the tree.

Simon:

So each family member would have a different colour and then so say it is the 10 year old he is red, so he would click the red tree. And then there would be an ideal pocket guide. Then there would be information about that and then perhaps family related questions that the family set to be able to get the conversation started. So when he has finished with the iPad he will give it back and then give it back to the person and she will be green, then she will go back on green and hang out with Doris for the rest of the evening when no one was there.

And then perhaps the mum would be blue and she would have a different complete set pocket guide.

John:

Are these kind of... Are you thinking of the iPad filling in for someone being there, is that what you are saying Simon?

Simon:

The person would use the iPad like with the... I think they are the best three personally the Hang out with Others, Community Radio and then the photos so she or he could look through and listen to their favourite songs. But then when the young person comes they can have the iPad and then go on a different part of the tree.

Emily:

Isn't it like they have all got different profiles on the App kind of

thing? No?

John:

And would they be sat together with the iPad or would they

be..?

Simon:

Well I don't, sort of... They would be sat together with it, yes. Because when nobody is there they would have the iPad to listen to the radio, to hang out and go through the old

photographs.

Nadia:

But would they be able to access the other person? So like maybe if they wanted to look through the other people.

Simon:

Who like Doris?

Nadia:

Yes, Doris, dementia person.

Simon:

No but they should be friends from... Because we would hopefully get them involved with Carers Together, from that programme. So that then the stories around are taking place to share first hand instead of reading up about someone which could get a bit tedious I guess after a while.

John:

And also that might actually act as a reminder and so you can imagine if you sit down together and you use this to have a conversation starter or a little story it might then also be a

reference pointer for some people to get back into that conversation at a later date. If it is someone with more mild dementia or cognitive impairment or something like that.

Is that what sort of you..?

Simon: I think so, yes.

John: I am not trying to put words in your mouth.

Jamie: My understanding of the idea is that it is content curation; it is

putting together information like photos and videos.

Simon: Yes, so it is almost blank when you get it.

Jamie: Yes and then you fill that with content and correct me if I am

wrong but there would be different profiles that would have this

content curated to it?

Simon: Yes.

Jamie: And then the user could look at, say, this is my 12-year-old

granddaughter's profile. This is the stuff that they are into; here

are some pictures of us together. This is like our link, this is

our experience. Is that what you..?

Simon: I think so, yes. But then the 12 year old, was she 12, you just

said, I can't remember.

Jamie: Yes.

Simon: The person would be able to access it and then get an array of

information fit for a 12 year old.

Emily: Yes.

Jamie: Right, okay.

Simon: Does that make sense?

Jamie: Yes.

Nadia: Yes, so you are login as that person and then the App, so it

would be tailored to either Doris or the 12 year old.

Emily: So you have like different options when you are making the

profile like how old you are sort of thing and then you sort of

personalise it from that point. Is that ..?

Nadia: But you can also see the other people.

Simon:	Yes but it would be a branch off the person with dementia's profile.
Emily:	Yes.
Simon:	So they will get their profile to begin with, originally and then they would branch off with their family member. And then they would be able to login to access their information to get the conversation started. And then the person will be able to access them to have a look at their life together.
	Does that make sense?
Emily:	Yes.
Jamie:	Yes I think I get it.
Nadia:	I think that is how it is going to be.
John:	At that point I need to end the session because it is 8 o'clock nearly.

Right.

Jamie:

John:

Yes, they go home time. So actually as is always the case with these workshops we have probably got through around about two thirds of what I expected as the conversations have been so rich and interesting. It is always the positive aspect of doing these things.

Thanks a lot for coming this evening. Just to say what we are going to do is I am going to... Obviously there is a reason I record these things is because we don't always scribble things down. So I think there were lots of really interesting ideas that came at the end.

And I really liked the way you were combining things together to make new Apps almost which wasn't really the intention but I am going to make that like a thing I am going to do on purpose in the future.

[Crosstalk 1:35:51]

Nadia:

Yes, I was going to say is there a way to combine the Apps? To create a multi App almost?

John:

Yes, I mean how we would do it, we would have to... All of these Apps they do things which are fairly simple to do on phones so obviously in this project we want to create a new App, a bespoke thing but it can kind of take the things that these do and shove it into one App and make it more useful, this particular situation.

Simon:

Perhaps it doesn't have to be a tree and it can be a picture of them when they were younger, how old they think they are. Then they would want to click on it wouldn't they?

John:

Could it be a snowflake?

Simon:

If they wanted it to be a snowflake I am sure it could be that face when they download it.

Nadia:

I think your element of nature; like a tree, a nettle.

John:

Well what I will do, we will listen through the recordings, we will kind of capture the ideas and also if you have got anymore ideas that you haven't been able to say there is obviously the Facebook group as well where you can kind of shove it in there.

Probably what I will try and do is do some sketches of some of these ideas and put them on the Facebook group for some comments and suggestions and go, "You've not really listened properly John. You've not paid any attention at all. What was the point of you recording it? What's going on?"

And I think we are probably going to try and maybe see if we can run this with some other people as well maybe or someone like that to make sure some other people get a chance to chip in their ideas.

But was that interesting?

Simon:	Enjoyed it.
Nadia:	Yes.
John:	Good, I enjoyed it a huge amount.
Jamie:	I think there were some really good ideas at the end there. I think, yes.
John:	I tell you what there is something about having to make decisions about what the priorities are that really get you to think about, "Ah what are we doing here and why are we doing it?"
Emily:	Yes.
John:	Actually, how does this make a difference? Cool, fantastic. Did you want folks to do that impact thingimybobby thing?
Jamie:	Yes.
John:	Or was that something they can do afterwards?
Jamie:	Do you want to have a quick look through it now and if there

is...

END AUDIO

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