Audio File Name: Expert 1 - Critique

Date: 14/08/2017

Comments:

Duration: 17:24

KEY:

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

I: = Interviewer (Interviewer in bold)

R: = Respondent.

I: So, yeah, what do you think?

R: I think it's a great idea. Um in terms of ways of connecting people, it is that kind of needs lead like I'm talking about, that kind of needs lead, finding out what's important to the person. But I really like the idea of actually it giving you a framework of this is how old somebody was. And almost like what were the main events of that year. You know, what were the main news stories, what were the, as you say, what were the main, what were the most popular singers. It is a way of connecting with somebody's history. The only thing that I said to you is I would be a little bit tentative about is that informed consent, that there would have to be um, because to keep information and to share that, if you were just using it for yourself, as a granddaughter then I don't see a problem with it. But if you're then sharing it with professionals and more that professionals and then sharing it with you, there'd be ethical restrictions around that. So. it would, I mean, it's certainly not, it's not something that you can, that is insurmountable by any means.

I think it will just be around establishing. In the same way that you would, when you go and work with somebody anyway and family members and staff in a care home where they share information, there would be an assessment of the person's capacity to consent to what you're doing. Whether it's in their best interests that it goes ahead, you know, there'll be those kind of assessments and policies and procedures in place anyway just for just general information about the person. So, it needn't be anything be anything massive on top of that, I don't think but it will certainly be something if particularly, I mean, I

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wouldn't be able to share information about a patient with a	
family member without their consent unless some kind of	
extenuating circumstances, you know, unless they didn't	
have capacity but actually it was hugely in their best	
interests. But it's a very, very kind of tricky line. And you	
have to be very careful.	
Um if it's just information with family members and stuff	
then I don't see, there's no real difference from picking up	
the phone and saying, "Oh, I had a chat to dad about this	
today," or something. But if you're just, I think, that can be	
sorted. I think by and large the technology, something like	
that is a fabulous idea because it not only gets you to share	
that, what's helpful and what works across family members	
but I like the idea of those prompts of connecting. And it	
might be those things that come up aren't what the person	
was interested in at all but at least they tell you. Might be,	
"Oh, that was rubbish." Or, "He was awful, he couldn't stay	
the notice." But you know, it's conversation, isn't it?	
I: Yeah, exactly. Yeah. And then you built off that, I	
guess, and find out different things.	
R: Yeah. Don't ask them about whoever. [Laughter].	
I: Yeah, definitely. What about the prompts	
themselves and the kind of content that that kind of,	
that you'd produce if you're using them. So, the, er	
sorry, the er the prompts are quite generic um and	
when I was designing them um deliberately made a	
decision to try and get things that might not have any	
negative connotations for people. So, for instance,	
talking about schools, it's quite difficult you know,	
because I'm like the bully at school and that kind of	
thing. How do you feel about that kind of design choice	
or should it just be kind of everything in there and not	
worry if something was negative or something?	
R: It's difficult, isn't it? Because different things will	
touch a nerve with different people. Um so, again it's	
difficult to have like a formula for things to say and not to	
say because for some people, school might have been the	
most positive time in their life but as you say, it might be the	
most traumatic. Um I don't know, I don't know whether just	
the use of open questions and again, I use the word	
curious but you can't go far wrong if you come from that	
position where you go, "Ah, you know." So, if I want to find	
out somebody's history, I'll often ask, "Who was at home	
when you were younger?" Um, "What did you do when you	
left school?" You know, just those kinds of things.	
And often conversation just goes from that. Um so, I	
suppose again, it's just not making any assumptions on	
asking about somebody's school specifically like a specific	
question, just more like, "Oh, how old were you when you	
left school?" Um or, "What did you do after that?" You	

know, just those kinds of things rather than, "What was	
school like for you?" Does that make sense? So, it's more	
just like an open question around who was at home um,	
"What were your friendships like as a kid?" You know, I	
don't know, those kinds of things.	
I: Yeah. I can see what you mean. So, especially	
about what actually happened to them, kind of.	
what did you used to like to do in your spare time when you	
were a kid? Those more kind of generic, open questions, I	
think, would be helpful. Um because people will talk about	
it.	
I: Yes. Okay, yeah, so that's good, take that into	
consideration. Um the other thing I was going to ask as	
well, so we talked about a lot about kind of memory	
boxes and life story boxes er and this kind of thing. So,	
I think there's quite a large overlap between that and	
tickets still I think in a lot of ways. But I was wondering	
kind of how you think technology like this would work	
in a family er wherein a family member had a diagnosis	
of dementia. Because um thinking like the (unclear	
0:06:16.2) like 60 of your family care, give it um.	
R: That did cross my mind. That did cross my mind. I: Yeah. So, I think that might be quite tricky. And	
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a physical photograph or a memory box or cassette or	
something. Um it's helpful for some people but that's all	
right, that's okay. You can't be expected to cope with that	
something that suits everybody. It's impossible.	
I: Yeah, exactly. It's never going to work.	
[Laughter].	
R: But I don't think that then makes it unusable, I think	
almost the opposite. Um it's again just finding out which	
families it suits.	
I: Yeah, okay. Okay. Er so I'm wondering if um a	
person with dementia had a profile about them on [s.l	
Tickets Talk 0:08:43.9], they couldn't log in and see	
that profile themselves. There's no option for them to	
do that. They can only like log in through someone	
else's account and see their profile. What do you think	
about that kind of to some choice?	
R: Again, it goes, it comes back down to capacity to	
consent. So, it's whether or not the person knows you've	
got this information, whether they have the capacity to	
understand why you've got that information in a way that	
you have, whether it's more harmful for them to know that	
than to not know that. So, it'd be very much a clinical	
judgement that would have to be around where somebody	
is in the illness and the people working with that person.	
Um I mean, in terms of freedom of information, that might	
give you, I don't know whether that would give you any um	
pointers or framework in terms of what the legalities are of	
that because people should be able to access the	
information that if something's about them. Um but there	
are limitations to that like especially working in mental	
health, there are times when we get information that would	
be harmful for the person to know. And so, that's kind of	
kept, that's like an aside, you know, that's like an exception.	
It might be something similar, I don't know. But again,	
depending on what you're sharing, if it's just stuff about	
somebody's life, there shouldn't be (unclear 0:10:14.0)	
there shouldn't be a problem with them seeing it. It's about	
them.	
So, if somebody had loads of information about me, I'd	
want to see it. [Laughter]. So, I don't know. Again, I don't	
know about the whole legal side of it from that point of view.	
Um that would be something that you could you know, iron	
out. But again, it would probably be on an individual basis.	
The details of it, I mean, there would have to be like the	
information sharing policy that's kind of low. If somebody	
wants to contact us and wants to see what I've written	
about them, they have the legal right to do so and I have to	
disclose that. It's how it's set up in terms of the framework.	
Is it something for the staff? Is it something for family?	
Who's it for? And that'll dictate what needs to be thought	
This sicial. This that it diotate what hoods to be thought	

about in more detail, I think.	
I: Yeah, okay. Yeah, because this is the primary	
design for the family to use and then there was an	
option to kind of add like a professional carrier to it if	
someone was to transition into a care home. So, then	
they could see that. So, it's kind of like the life story	
box in a way that could bring that with them, that their	
profile would go with them. Um yeah. But then I	
suppose you could do that and you know, because a	
bit tricky I guess if they could see it or not. Yeah. Okay.	
Um other than your experiences of like working with	
families before, how effective do you think something	
like this would be at kind of helping like those families	
talk to each other and like spot conversation, do you	
think that kind of thing would work like could you see	
it, what kind of setting would you see it in?	
R: I think, and I think again particularly it might be	
helpful for families who don't live close together you know	
to kind of have that, that connection, that shared	
connection with the family member would be really useful	
for families that aren't, you know, because more and more	
families live further apart really and rely on things like	
Skype and things to communicate and it might just be	
another form of communication around you know, I've seen	
granddad today and sort of talked about. Um in the same	
way that you might put something on messenger or	
something, you know, it's er, so I think it'd be positive	
really. But also, I just think more in terms of as you go to	
visit the person, it'll give you that more kind of shared	
experience with the family around what helps and what	
doesn't help and this is the kind of things I used to talk	
about, I don't mention that. Um which again creates	
conversation, brings people together. So, yeah.	
I: Okay. Is there anything you want to add to I	
don't know.	
R: Not really. I think more about my colleagues who	
work in the positive behaviour support service which is like	
the, it used to be called the challenging behaviour service.	
So, that's a service specifically that tends to go mainly into	
care homes when people are presenting with the behaviour	
that other people find challenging. So, they go on and do	
the whole formulation of understanding a person's views.	
Anyway, you're coming to the end of your master's this	
month as of tomorrow, isn't it?	
I: (Unclear 0:13:36.6). [Laughter].	
R: Um but you know, if you're thinking of kind of	
practicalities and advice about rolling something like this	
out, you know, beyond deadline there's somebody that you	
know, I can put you in touch with. It'd be helpful to have a	
conversation about.	

I: Yeah. He's publicly available in the app store so	
you can download it as well. So, it is kind of out there	
already. Um but yeah. But just trying to think of ways in	
which it can kind of be improved. So, it's just to kind of	
help a bit further. Um yeah. I think those are kind of the	
main issues that I've kind of had troubles with. But	
yeah, I mean, if there's any other criticisms you want to	
add to it?	
R: No, no, not at all. If I think of anything, if I've got any	
more feedback, I'll drop you a line. No, I think it's really	
positive. I think anything we can, it's kind of promoting that	
needs-lead person-centred view of things and trying to get	
rid of those assumptions that we all have because they	
create barriers and just figuring out where the person is and	
what's important to them and you can't go far wrong. But	
that's hard to do, I can say that from a, you know, I still get	
stuck and I'm professionally trained, you know, so it is hard,	
it is hard, it's really hard. And depending on what type of	
dementia somebody has as well, their presentation can	
fluctuate hugely. It's like going and thinking, "Oh well	
(unclear 0:15:00.0) today."	
So, yeah, it's hard, it's hard for people to know. Um and I	
think something like that almost like normalises it a little bit	
in things we're actually using, the kinds of things that might	
be helpful. I wonder whether there's any um option of	
having almost like if you're struggling or almost like	
signposting to other services for ideas, you know, people	
like Age UK are really helpful and they do some great	
information leaflets around dementia and understanding different types of dementia and the kinds of difficulties that	
• •	
might come with that. So, I don't know whether on the app,	
it'd be useful to have just signposting if you want more	
information or if you're still struggling to know what to say	
or— I: Yeah. That's what I was thinking about in the, I	
was talking about the articles before and you could add	
(unclear 0:15:51.5) information there. That could be	
prepopulated with little things like that or there could	
be a separate section or something like that as well.	
R: Yeah. Just signposting for um, because sometimes	
I was working with a family whereby the lady was caring for	
the mum who had a dementia but it was quite a fluctuating	
presentation but actually the daughter has a learning	
disability. Um so she struggles to understand why her	
mum's doing what she's doing. And actually, I went online	
and the Alzheimer's and Dementia Society have a fantastic	
leaflet for people with learning disabilities. So, it breaks it	
be useful maybe for younger children or, and I didn't know	
down into kind of pictures and really kind of short sentences, really digestible information that again, would be useful maybe for younger children or, and I didn't know	

about that, I was just kind of thinking, "How am I going to, how am I going to work with this lady to try and help her understand what's going on. And just went on the website and there's all this stuff. So, um there's loads out there and I think most people don't know. I mean, I didn't know. So, even just like the odd signpost of if you're struggling, if you want to know more information or if you're struggling to, if it	
would be helpful to have somebody talk to, you know, those	
kind of signposts really. I think that will be useful.	
I: That could be good, yeah.	
R: Um yeah. But if I think of anything else, I can just	
drop you a line but I know, it's like when you're coming to	
final stage, you just want to write the thing up and get it	
done.	
I: Yeah, I know.	

[End of Recording]