

# Expert Critique Workshop

Table 1

<b>Researcher</b>	<p>Okay yeah. So, you wanna think about, err if kind of a younger relative wanted to speak to you and was using Ticket to Talk to build up a profile about yourselves, what do you think is useful about the app? What do you think would be useful about the app in encouraging conversation? Then we'll think about what would you change, what do you think is okay as it is, but could be made a lot better about it. And, what do you think is not useful at all, something we should just get rid of? So, keep something, change something, and get rid of something. So, we're gonna do this for about 40 minutes and then have a re-group.</p> <p>Okay so when you log in you get a list of people you want to talk to. These could be older relatives or friends, if we're thinking it's a younger person using the app. Then, you select one. So, when you're in there you've got Tickets, inspirations, conversations. There is also some useful information in there as well. So, these are articles about a hobby your older relative might enjoy, or it could be advice on err dealing with a relative that has dementia. Erm, kind of who you've got there, people you can talk to, and you can change as well. Erm, yeah, so I will leave you with that. If these come up, you can just dismiss them. They just tell you kind of what each section does.</p>
<b>P1</b>	Okay so you want us to, actually add something to this, or write it down here?
<b>Researcher</b>	<b>You can play with it, you can just look through it, or you can just think of how you would use it. It's just here if you want to have a play.</b>
<b>P1</b>	Okay
<b>P2</b>	What, what, you want us to jot down what we want to be added on to it?
<b>Researcher</b>	I want you to write down what you want to keep, what you wanna change, and what you wanna get rid of. And we're all gonna regroup and come up with our big ones.
<b>P1</b>	Okay
<b>Researcher</b>	So, is that all good? If you have any questions just give me a shout.
<b>P1</b>	Right, right, yep yep. Let's have a play.
<b>P3</b>	So, to use tickets we press this one yeah? So, try to add tickets, what is the protocol. Is that a picture you think?
<b>P1</b>	A picture yeah.
<b>P3</b>	Do you think a person would remember this? Do you think the person with dementia would remember this?
<b>P1</b>	That's hard to say, because... It's not very personal, is it?
<b>P3</b>	So, it's all pictures then? All photographs? It's all pictures, images.
<b>P1</b>	Hmm...
<b>P3</b>	I can tell you something, my mother has dementia.
<b>P1</b>	Okay.

P2	Hmm.
P3	But it's not very advanced, but she has dementia. So, I find that when I visit her she really can't talk very much about any subject. She forgets. She remembers the past but she doesn't really remember even the news when she was watching it all the time. She can't tell me what the latest headlines are. She can't even remember what the headlines are, and she used to get personal and really angry about this, and really angry about that, but she can remember absolutely nothing. So, what I said to her, I sit with her and we go to my Facebook, and look at the people on there. That really entertains her. That's all I do, although, I'm not a Facebook person. I just I just read other people's posts, so I sit with her, we go over it. So, this is this, this is that, "Oh! That's nice.", "Oh look here is a recipe.", "Oh! That's nice!". That's interesting.
P1	Okay, not the people on it, not photos of other people?
P3	Family? No, it's just looking at a little screen, you can see all the little things moving around, music, dancing, yeah.
P1	Yeah, I think music and things are important.
P3	Sometimes a clip. But she can't keep her attention for very long.
P2	My father had dementia, and every time you went to see him you've got the same story everytime.
P1	Yes, yes.
P3	I get the same stories.
P1	What I was wondering is your -
P3	"Have you seen these ladies?" I've got to tell don't do it.
P1	I did wonder when you were saying she would watch the news but she couldn't tell you anything about it. But, do you think that was because she didn't understand it or remember it? Or, the communication?
P3	No, she's watching Arabic news. I have an Arabic station on for her.
P1	Is it, is it that she can't communicate it or? I mean, do you think she understands it?
P3	No, she can't remember, I test her. I've seen she's seen the news, and I say, "Have you heard about this?". And she'll tell me a very very funny story, we're Palestinian originally, over there, "Today I saw on the news, Jesus's grave, and they opened the door, and put baby Jesus in there". I don't know why, why, she is stuck on this item. I just can't understand this. And any other news, the fire at Gren – previously she would have cried when she saw it happening. No retention.
P2	Cragside, which is a department at the Freeman hospital, for the dementia place, in the middle of [?] square. They have three [?], different places for them like Saltwell park and places like that, Gateshead town centre, and they go out there, it helps.
P1	It does help that sort of thing.
P3	But, it's the past they will remember, this kind of thing, they will enjoy it, looking back, yes.
P1	Yeah looking back.
P3	But I definitely think it should be more than just memories, this app. You

	know, because I know from my mother, we talk about my family, other family members, because they are connected to me. Okay, she takes a bit of an interest, but not very much.
<b>P2</b>	If they're not going to what you want to do is add [?] to it, that's what you've got to do.
<b>P3</b>	Because then they would be more interested, that's it, full stop. Whatever makes them trigger. Each person has different triggers.
<b>P1</b>	Have you tried things, you know like um, drawing things, even colouring?
<b>P3</b>	She probably would sit and do it. She doesn't have the patience. I think she would love this you know. Actually, sometimes you can play with them -
<b>P1</b>	So would she like, rather than the necessary things on the app, just things, so she can press and just go through them.
<b>P2</b>	Things that they can do, you know, play with the things, flashing around, you know.
<b>P1</b>	One of the things coming up when you're saying tickets is you can be lead into questioning all the time. That's really not helpful. When you say "Can you remember?", that's bad, you know, because they don't. Um, so that you know, I think - Its' similar but if they can't remember, they feel bad. I listened to an expert recently saying this. We tend to say do you remember this or do you remember that? And they can't. It's not helpful.
<b>P2</b>	[?] ...you take them along to the meeting, and they sing the songs, but they don't remember. You would remember sort of thing.
<b>P1</b>	Do you think this sort of thing is more about, erm, us rather than the person with dementia? That it's the family that can't cope?
<b>P2</b>	They can't communicate, they're trying to get -
<b>P1</b>	The person maybe quite happy to be the way they are, they might not be aware but okay. Whereas we're assisting, we're trying -
<b>P2</b>	We're trying to -
<b>P1</b>	Yes, maybe that's for our benefit rather than their benefit, because we feel, we need to -
<b>P2</b>	Yeah, for the family, for the children.
<b>P1</b>	You did actually start with that, for the children.  For younger children, I think the kind of thing you were talking about, you know that program that's been on.
<b>P2</b>	I haven't seen it.
<b>P1</b>	I've read about it, I haven't actually seen it, but it seemed to be the fact that the children just wanted to play. And here is this old man who can hardly walk without his stick, he was lying down on the floor pretending to be a lion. He was loving it. So, being involved in their games maybe better for their imagination?
<b>Researcher</b>	<b>How is it going?</b>
<b>P1</b>	Erm, it's a difficult one, we were just speaking of experiences of this lady's mother who has dementia, and um, just saying how she's not holding anything in her head, and showing photographs doesn't even - this is mostly about showing things, and it doesn't really work.

P2	My father had dementia, and you went to see him every week, and we were saying you'd go round and round and he'd tell you the same things that he told you before.
Researcher	<b>Okay.</b>
P2	That was his news you know?
P1	But we had previously been talking about, there was a program on the other night, which neither of us saw, I had read about it, where they were introducing young children to very elderly people with dementia.
Researcher	<b>Oh, okay.</b>
P1	And, it was amazing success because the children just got involved in playing their games, they behaved naturally.
P3	They weren't trying hard.
P1	Did you see it?
P3	No but I -
P1	No, no but er, one of the instances was I think there was a man over 90, with difficulties with a stick and didn't really do anything, he was suddenly lying down on the floor and pretending to be a Lion! He was about to roar! You know, able to do that, involved in their imagination, rather than them trying to remember things. Younger children that's okay, it's so natural, but maybe you can follow on from that.
P3	I've seen something like that, it's a new thing with older people and the younger people. I think it's an excellent idea.
P1	Yes it is, they have more patience with each other than perhaps the age groups closer. Erm, but maybe again, there's something, do you think with your mother could, maybe a car or something they would snap? Do you think she would be able to do that?
P3	No I don't think -
P1	No no -
P3	Her attention span is very short, that's the problem.
P1	So, if the attention span is short.
P2	If we stimulate her, we might get a long attention span.
P1	Yes, yes.
P3	I don't think so, I think it all depends on your background you know. If you did this when you were younger maybe.
P2	You need to find out what maybe she enjoyed when she was younger, and places she's been to.
P1	Which is what this apps all about isn't it? The tickets are finding out about their background, sports maybe, a football match?
Researcher	<b>Anything you can get in there. It's quite an open source of media, so you've got sound clips, pictures, and videos. So, you can capture those things in there maybe? That's what I was thinking when I was developing it. Shall we put something down, shall we think about – Let's go with what we would change first.</b>
P2	Well you can't really change anything because each dementia person has different symptoms. There is no sort of, here you've got dementia so they've all got the same sort of dementia. Some can remember music, some can

	remember photos.
<b>Researcher</b>	<b>Yeah.</b>
<b>P1</b>	Well I was saying um, I do believe that maybe it's not a good thing to continually ask them questions, about things that they can't remember.
<b>Researcher</b>	Yeah, shall we write this down? Do you want to write it down?
<b>P1</b>	Do you want to do it because I'm going to go shortly?
<b>Researcher</b>	<b>Okay cool. So, shall we think about that, so asking questions about things we can't remember.</b>
<b>P3</b>	So, I will repeat what I was just telling [?]. I would say that, talking about my mother, when I go visit her and there isn't much to talk about because she doesn't really remember and she doesn't really. I tell her things, I tell her things, I tell her my problems, and she just listens. She was one of the most caring persons. So, I sit with her, I sit next to her, and I open my Facebook account, okay, and she gets very entertained, but not about families, although I will bring up family messages. "Oh, this is this person.", " <i>Oh really, what has he done?</i> ", and then that's about it, that's about all she wants to know. Then I move on to a dish which, how should I put, a recipe I want to do. She'll look at that, " <i>Oh, that's nice! That's interesting.</i> ", and then there will be a clip, a dance, or something, she'll look at it but that's about it. So, so hopping around, interests this family, yes. We're Palestinian originally, I give her a few pictures, looking at this, "Oh here is your home town.", okay, that's really quite interesting for her. Here is your home town, here is this, um but not for very long.
<b>P1</b>	Maybe, maybe then, young people, which is what this is about isn't it. Maybe young people meeting an older person and actually taking something like an iPad, and even showing them a video of themselves dancing or interacting with other young people, it might be something that just like.
<b>P3</b>	I mean the profile is good, because you can ring a bell, but it isn't everything. You know, the person's background, their history, is not the only thing, not the total conversation. I noticed in your app, it's all about the person's history, but it should be more than that.
<b>P1</b>	It should be more impersonal than that.
<b>P3</b>	They talk about current affairs, you know, you tell them why don't you try. Yes, press this button and see what happens. And draw, and wanting to draw, some apps you can have art, and they can actually take part. And on a big piece like that one, the bigger the equipment the better.
<b>P1</b>	Yeah, yeah, and they can actually enjoy doing it, and knowing that their bringing up things might actually help.
<b>P3</b>	Not just sitting back.
<b>P1</b>	Yeah yeah, I think so. If you think, a lot of that, a lot of the things we've talked about is like being a child again, where the whole world is new to them. It's new experiences, they don't realise it's not new experiences, but it's new to them. So, they can enjoy them, just like a child.
<b>P3</b>	And they don't really need to be prompted to talk, because she will talk when prompted. Sometimes you have to explore a bit to find out what she wants to talk about. A young person will not have the patience to explore.
<b>P2</b>	I think before when I used to see my dad, it'd be every week, and I'd tell him

	what had happened, he couldn't think beyond that.
<b>P1</b>	Yes yes, no no.
<b>P3</b>	But then er, what you can do is present an issue. You can say look you know, I can't do this, what do you suggest, rather than just here is your history, no. I'm trying very hard to put a curtain on this, you know something like this, and then they say why don't you do this. They must not be treated as people who don't have any opinion, at all, no, like they don't know what's going on or how to do things. They still do. So, I think you have to also allow them to be involved in your problems. You know, I'm trying to put a leg on a chair, I can't think you know. I do this with my mother, and sometimes she comes up with these incredible ideas out of the blue.
<b>P1</b>	Does she do that with cooking?
<b>P3</b>	Yeah cooking, I say im going to be making this dish. Oh, if you want to do that you must do this, and I say oh yeah can I do this, no you do this and you do that. She doesn't do any cooking anymore, but she likes to...
<b>P1</b>	That's right!
<b>P3</b>	So, let them give advice, let them think that they can give advice -
<b>P2</b>	I mean 30-40 years ago, my wife, she'd get fed up with him and say "I'm not bloody going, he keeps saying what he already said to me.". But, nowadays, if we knew what we know now then, he used to be a navy officer, I could have had photographs of his ships, something like that, but you never thought of that you know. The only thing that you could talk about was the news that he had, the last time that he won at bingo, at the bingo place.
	[...]
<b>P1</b>	So, you're saying involve?
<b>P3</b>	Yes.
<b>P2</b>	If you could get in touch with their best friends, use that? Get in contact and use that?
<b>P3</b>	If they are still alive. I think definitely bring them in. Let them, let them participate. Let them think, let them express an opinion on things. How do you cook, how do you build this? Tell them about the political issues. Talk to them as if they were normal, not someone with dementia. It can be very hard sometimes because it all seems very random.
<b>P2</b>	They're all treated equal, as if there is one rule that works for this person and that person. There in that section there or that section there. I remember as a boy I used to play football for the YMCA, and I'd go and play Stannington. We went to play, and all these people had dementia, and we would be playing football, and they would be standing 3 deep around the pitch. And they just stood there, and they never said anything, they just stood there. I always remember because there was one fella and he used to go and we would be playing football and he would go walking along the outside, going "Morning Echo! Morning Echo!". He must have been selling papers before he got... I'll always remember that, most peculiar! Today they're all just hidden from society more or less.
<b>P3</b>	Well it used to be like that, but now I think it's different you know. They're

	not sick people.
<b>P1</b>	I think erm, what I was saying. I don't know if you've found this at all? Do you use music at all?
<b>P3</b>	Yeah, music is good.
<b>P1</b>	I used to teach exercise to older people, and some of them would have dementia. They couldn't remember to come to class, they had to be brought. Once music started they started to remember the exercises. I found that it was a like a concentration device, it wasn't just the exercises, they all remembered little things, maybe even just each other from the class.
<b>P3</b>	So, should we put add music?
<b>P2</b>	They should call some of their friends and get them to go occasionally.
<b>P3</b>	I think we should put add music.
<b>P1</b>	It's not necessarily a piece of music, I always just thought it was the rhythm. And doing mechanical things, like clapping their hands and moving in time to the music.
<b>P2</b>	I knew a senior nurse at ?, and every time she come she brought us a domino board that had been made, and put the holes in. I mean, some of them weren't in lines sort of thing, the domino board, they would do things like that you know. They might have had a carpentry background or something like that you know. Helped to bring some of these round.
<b>P3</b>	This is about young people talking to old people.
<b>P1</b>	Yeah it is.
<b>P3</b>	I mean definitely let the young people share their, their, let the young people share their problems.
<b>P1</b>	Just letting them tell their problems would be helpful for them.
<b>P3</b>	They can ask advice, and make them talk, "I have an exam.", "Oh don't worry", it makes them react. Stimulation yes. So, this app from what I saw, it's all about the person you're talking to. We don't know, what is the age of the people you are talking to.
<b>P1</b>	I presume when they're saying young people, they're talking about teenagers, maybe 15-25, that's what I had in my mind. They might be interested in new music, then they might enjoy it as much as anything.
<b>P3</b>	I wonder if they can do things like the film the person and show them the film. If they can take a picture then and there, they can take a video, if the app can capture it. No?
<b>P2</b>	I mean you can stand them in front of a mirror and get the same effect I suppose?
<b>P3</b>	I think another thing this app can do is err, you say bring your friends in, maybe communicate with their friends through err, Skype.
<b>P2</b>	I don't think that works if err if you can't see their faces.
<b>P3</b>	You can see their faces on Skype. So, you can help them do that.
<b>P2</b>	This is what I'm saying, if they can see their friends they can maybe communicate with them.

P3	We can't really say we can take anything away from the app, what he's got there is a good starting point with historical pictures, but it's not everything. It's a bit basic, it can quickly finish, end. Here's your father, here is your sister. There is nothing else to talk about. But definitely they should be able to participate themselves, touch the screen, and err, so the app should be interactive.
P3	He's focussing on the app, isn't he? Can you go beyond the app, start off with a conversation?
Researcher 2	<b>No no definitely, it can be definitely something you can use to start a conversation.</b>
P3	Then you can go beyond, say let's go and do a jigsaw puzzle.
P4	I think it has to take into account that it is a condition that deteriorates, that the what you start with isn't going to be the same, so the memory goes, very soon, they'll be much more limited in scope. That has to be understood by the younger generation. Also, it's variable, some days there will be more response than others.
P3	Are these young people going to be guided?
P4	A warning, be prepared, there are no set rules on this. Some days this might happen, some days might be better than others.
P2	Really, my children should be collecting photographs of me in case I later need them, then they can say "Oh, do you remember this?" You can have a think when you're active and able to do things you know.
P4	Apparently, I understand music to be really quite important.
P4	So, I think on this app, a quick guide for the younger person about what to expect with dementia is rather important. So, do we put that down? A simple guide to stages of dementia, what to look out for, what to be prepared for. Perhaps that is better?
P2	Rather than adding music, the ability to add music in the background while they are sharing photos with their friends. We need a guide to the stages of dementia, what to prepare for.
P4	It's very important to note that's it's a variable, one day it's like this and another it's something else.
P4	Did you want to say something about not just about the past? Get them to say something interesting about the person that's calling them. I had this thing at school, or whatever, and see if there is a reaction, if not, move to another subject. Just try something other than the past.
Researcher	<b>So, I as a younger person, could record a video of myself doing something, something like that?</b>
P2	It would depend on the dementia, if you had photographs of children they used to know as kids, that might stimulate it a bit.
P4	The other thing is, if you had a previous conversation the chances are that would not be recalled, so you know, you are starting afresh. It's fine for the person making the call, but the dementia subject will not recall, it won't be useful for them. It might be useful to the person making the call.
P2	I have an ex-service colleague, who was invalided out, and his wife had a stroke 6 years ago, had dementia and that. He was in a wheel chair, he has to operate the wheel chair behind when he goes out. He's stressed up to



	here, they've had her in 5 different homes, and none of them will take her, she'll just burst out in horrible languages and start screaming.
<b>P4</b>	So, he needs something to destress.
<b>P3</b>	He has a carer that comes 3 times a week so he can play walking football. They come to their service. If he wants to go shopping he goes at half past 2 in the morning when he knows she's sleeping. Go to the supermarket at half 2, he has a hell of a life.
<b>P3</b>	We were saying to researcher 2, that the app can maybe just be the start of the conversation. If it starts the nice rapport between the two, maybe it can lead to something else, let's go play a puzzle. It shouldn't be seen as the end all, not to be caught up.
<b>P3</b>	What kind of ages are you thinking of for using this app?
<b>Researcher</b>	<b>Around 12 and up.</b>
<b>P3</b>	12? Actually 12 and are up are quite good because you can't control them. They just want to talk and fiddle around, and that in itself is entertaining. It's probably better than a more controlled older person. More loose and fluid. More natural, it should be really natural, rather than er..., that's how I think.
<b>P4</b>	If they've got a pet, they should ask about the pet. That's often a fairly important focal point. That's a good conversational thing. If the child has a pet, it's again a good conversation point, having a video or having a picture.
<b>P2</b>	They say there is a care home that allows you to take dogs and cats in, it stimulates everybody. They have it in the lounge, dog comes up waving his head and that.