Better Together: Enhancing Technology through User Engagement and Inclusion

Transcript from the 2017 Accessibility Conference

Jennifer Krul, Emmetros Ltd.

For more information, contact:

Email: jennifer.krul@emmetros.com

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Welcome, everyone. I will introduce Jennifer.

JENNIFER KRUL:
I am excited to talk about user engagement. I am a product designer. I engage people and include them in design and develop into products we create. I work for a small company. We have a specific goal. That goal is to make life better in a small way for people living with cognitive impairments, specifically early onset dementia.

To do that, we create software. Our first product is Memory Sparks 1. We provide software, a digital memory aid, that allows people to live more independently, capture information and recall information that matters to them. Like people who are blind or low vision, need glasses to see, memory a tell people with cognitive impairment, memory loss, particularly, to remember.

I won't get into the nitty-gritty around what our product does. If you're interested in learning more, I can share that information after.

For the rest of the story, I will focus on why we created this product and choose to engage people as part of… And how we do that as part about design and development.

You might be thinking, why dementia? Why are we choosing to focus on creating products for people living with dementia or memory loss?

Here is why. An estimated 47 million people worldwide are living with dementia. By 2050, that number is expected to rise to a staggering 135 million. By the age of 80, there is a highly likely one in two will be diagnosed with dementia.

If you look around the room, the person next to you or yourself, so you might be thinking you don't know much about it, you might be wondering what that means for you. What will it mean for you if you are diagnosed with dementia?

I will give you a quick overview. Some of you are probably very familiar. Maybe you have had family members. Others might be less familiar with what this means.

Dementia is an umbrella term for a set of symptoms caused by disorders affecting the brain. The most commonly known and diagnosed is Alzheimer's. There are several others. People living with it may experience symptoms such as memory loss, difficulty with thinking, problem solving, language, remembering, recalling words. They more also experience changes in mood or behaviour and be disorientated easily or not recognise where they are, so somebody who is in a situation where it is a familiar place, it could be someplace they have been 100,000 times before and suddenly they can't recognise where they are.

It might be they are at a cottage or at home. Suddenly they can't find the bathroom. They don't know where it is. Difficulties with place.

We don't often think about this, but some with dementia experience physical symptoms. One care provider I spoke to was telling me about how her mother, in the mid stages of dementia, was having a hard time making a fork and a knife work. She was having difficulty with that. We don't often think of that, but that is something that we as designers and developers need to consider as part of our work with people with dementia.

Dementia is progressive. That means the symptoms gradually get worse as more brain cells are damaged and eventually die. Example, person in the early stages might have difficulty finding words, so it takes longer for them to retrieve that word they are looking for.

It is in their filing system. The pathway is not there. It might mean people have difficulty remembering tasks, appointments, things like that, more so than the rest of us. They may also have the quality remembering something somebody told them 10 minutes ago. It is really that short-term memory part.

In the mid stages, the person will need more help with activities of daily living, so things like managing their life, their everyday activities, remembering to do certain things, things are on safety, so remembering to turn the stove off, that kind of thing. Then, in the late stages, probably the stage most of us think about, if we have experience caring for a person with dementia, where a person loses their ability to communicate verbally, has a lot of physical symptoms, is usually in long-term care and needs help with all activities and daily living.

As those of you touched by dementia will know, being a person with dementia and living with one has a lot of challenges. A diagnosis of Alzheimer's disease or other dementia can take a tremendous financial or emotional toll. Primary caregivers will experience caregiver stress and fatigue. The person with dementia themselves feels overwhelmed often and stressed by this disease that'll change them over time, so not just a disease that needs acceptance in the moment, it will keep changing, so that is challenging and they may feel they are being a burden on the family members and they don't want… They are feeling guilty about that increased reliance on others and don't want to be a burden.

I believe we can make life better, even in a small way. By we, I mean the work we do, working on software for people with dementia, but also all of us in this room. Anybody working on products, information products, websites, technology is even thinking about, so right now we don't think about people with dementia. We think people with dementia don't use technology.

To kind of plant that seed of another group of people that bears thinking about.

This question comes up a lot for me – do people with dementia use technology? Do we even need to care about how our technology is designed? The answer is yes, people with dementia use technology, and that number is growing. I have talked to several people living with dementia, and they use technology for kinds of things – communicating, the same things we do – FaceTime, texting. I have talked to people who use calendars and note keeping apps, fun things with a technology – playing games, watching Netflix, things like ancestry.com, these kind of things.

Using technology in the same ways we are using technology. Over the time we will see that use of technology amongst people living with dementia increase, so if you think about the next generation of people diagnosed with Alzheimer's disease or another dementia, they are baby-boom is. If you think about the baby boomers in your life and think about how they use technology, they have iPads, smartphones, smartwatches.

A diagnosis of dementia doesn't mean suddenly will toss your technology out the window. In fact, I think the opposite is true in that the people we are seeing now with early-onset dementia are actually out there, looking for solutions, they want things to help them live well, maintain their independence. Over time, we will see the use of technology will be an important piece of living well with dementia.

Recently I spoke with a woman diagnosed with early-onset dementia, and I asked her how her use of technology, mobile technology in particular – are used in iPad and a smart phone and a watch and a smartwatch – and asked her how her use of technology had changed since being diagnosed with dementia. She said that technology prior to her diagnosis, she thought was useful. She has since become dependent on it. She cannot imagine her life without it. It also do the things she needs to do everyday.

She is still working, still going to yoga classes, to the movies with her partner on Friday. This is the generation of people we need to think about going forward.

The trick for us – and I don't know how many of the designers or are involved with projects – but I think the trick is to figure out what we can do to fill that gap, what can we do to make sure we have things that better meet the needs of people dementia. There is no checklist. You won't hear me talk about (unknown term). The only way to find out whether your technology is useful

on cognitive impairment generally, is to ask them, sit down with them and ask them, talk to them, figure out what they need, walk-through designs with them, figure out if they meet their expectations.

There are no checklists. There is nothing to say yes, check, check, check, this is compliant, this will meet the needs of people living with dementia or cognitive impairment generally.

Alright. That brings me to my favourite topic – engagement and inclusion.

We hear a lot about - or some anyway – about inclusion of people with physical disability and people with cognitive disability and impairment. I believe people with cognitive impairment – in my case particularly – people with dementia – should have a say.

The reason people aren't often included is that they are often marginalised, and there is a prevailing assumption they are incapable of communicating what their perspectives, needs, wants and therefore unable to make a meaningful contribution. We need to change that.

People with dementia in particular have voices. Most – a growing number – want their voices to be heard. There is a growing movement, so the keynote speaker was talking about people with disabilities no longer hiding themselves away, and in terms of stigma and so on, other was applicable to this group living with dementia. I think probably a stigma around people living with dementia and changing that lag behind other discussions around inclusion.

There is a growing movement in the dementia community of people advocating for themselves that they want to be heard, so people living with dementia advocating, advocates, advocacy groups. There is also a group called the Dementia Action Alliance. As I was making up the notes for this talk, I looked at the notes. The description reads as follows, "Baby-boom is a younger generation of people living with dementia are changing the culture of dementia globally."

This sounds familiar. We have been hearing similar things. They are speaking out about the need for a better understanding of Living With Dementia and speaking out about the need to be included.

What does this mean for us and how do we go about doing this? When you think about how we start engaging people living with dementia or cognitive impairment generally, this is an engagement model that we have come up with and I will talk a little about each thing we do

and maybe you can take a little nugget away and use it in your own practice.

We have four different ways of dealing this. The first is through interviews. We generally do a meet and greet with them first, so we have a person with dementia and usually wishy the care partner to be part of that, so if they have a spouse or child that is their primary care partner, we would invite them to do an interview with us. In that interview, we try to get to know them and allow them to get to know us. It is designed so people can feel comfortable and understand a little bit about what we do. We will ask them about the use of mobile technology, so that is one thing we are interested in learning – how people living with dementia are using technology.

We will ask them a little bit about how they live well with dementia, so what strategies they use, what their experiences are like, what are the challenges they face and some of the things they have put in place to try to help them?

This approach of having the care partner there and the person with dementia themselves as part of the interview works really well and helps everybody to feel comfortable. Then we ask if they would like to move on to helping us out with other things. One of the other things we ask people to help us with is usability studies. I don't know how many are familiar with that.

We work with a person one-on-one and usually work with a person with dementia themselves, alone. We show them what we are doing, show them designs of our software and ask them to tell us a little about what they are thinking, what they make of it, whether it meets their expectations, what were they expecting versus what they're seeing, that kind of thing. We walk through it with them and ask their thoughts. We are clear during the studies that we are not there to test them, we are there to test the product and we want to learn from them and their experience.

The third way we engage people is through product testing. Product testing – we ask people with dementia to try using our app for about 2 to 3 weeks. What is great about this approach is we can give them time to process and play with the app in their own time. For people living with dementia, it is difficult to be shown something and offer their thoughts on it without having time to think about it, so we offer an opportunity for them to play around with them in their own time and ask them to take notes on what they are seeing and doing. Those notes can be done, so we try to be flexible around that, too. Some people record their thoughts in an audio recording of typing or writing is difficult.

Others will write down notes about what they're doing and how they are feeling about what they are doing. This has been really great. We have had good feedback from taking this approach. If people don't have an iPad, which not all our product testers do, we provide them with one or use during that period. It is on loan.

The fourth piece is advising. This is a fun thing. We have people who are on call for us, so if we have a question about something we are doing, and this applies to anything we are doing, so we have people who advise us on various things, including conference proposal submissions. I have had people with dementia review my conference proposals to make sure the language I am using is good. I have had people review my usability study protocols, my guides. I have had them reviewed so next time I talk to somebody, can I make it clear, better?

We have people interested in providing feedback on our sales playbook. And also for product design. Once I have talked with people, and if people are interested in continuing with helping us with our work, we can engage them. "We are creating this design. Would you like to provide feedback?"

I don't how many are from tech companies, but typically how these studies work is you call up and ask for participants with certain criteria. They come in, you pay them and you never see them again. This way, with the group, we can maintain longer-term relationships and get to know people are little bit, which is nice.

What we learning? Two things, two key things we have learned is recruiting people is hard. I'm hoping it will get easier over time as more start to advocate for themselves. It is tricky. It is not like product testing where you call people and become innovative again. It takes time and effort. Recruitment is relationship building. Building rapport, not only with a person with dementia and their care partner, but also with organisations for people with dementia or made up of people with dementia. The relationship you have with those organisations is important because no organisation will connect you with people with cognitive impairment unless they think you are a good person and know what you're doing and can do your work in an ethical way.

The most important thing is the how we do things matters. So not just how we get the feedback, but to get the feedback in a way that is respectful and meaningful to the people we are working with. Part of that, one of the interesting things we are doing and this idea of the catalyst for inclusion is we have partnered with the University of Waterloo and the Mary

Alzheimer's and Research Programs. They asked people working with us about their experience working with us. All the data collected will be used to create best practices for working with people with dementia and engaging them in technology project.

The idea that other people can do this, too, and we want to provide resources to help them do it well.

Here are my top five things about engagement, especially when you're working with people with dementia, although I think most would apply to people with cognitive impairment generally. Remember who the expert is.

Early on, when I started this work, I met with a friend who had experience doing research working with people who are blind or have low vision. I asked for advice on how to go about working with people with disabilities. She said to be humble and maintain a learner's mindset. I have taken her advice to heart and try to remember I don't have dementia, I'm not a care partner for a person with dementia, I don't know what the experience of having dementia is like, so I need the people I am working with to help me understand that experience. I am not the expert. They are. They are the ones with the lived experience. That was a useful piece of advice.

The second thing is, being warm, kind and empathetic – being a good human being and listener and making sure people feel what they are saying is being heard and it is valued.

Sometimes when working with people with dementia, or their care partners, you hear things that are hard. Being able to stop what you're doing and listening to what they say, even if you're busy, let them talk. That is OK. Be flexible and roll with it. When working with people with dementia, you never really know what you will get. We have tried to build in a lot of flexibility into our usability experience practices. For example, location of how we do our research. We are flexible about where we meet people. Often we will meet them in their homes if that is where they are comfortable. Sometimes they come to our office or sometimes they meet at a neutral location, so a memory clinic or something like that. Sometimes we meet over the phone.

An interesting thing is we have met with several people through Zoom, a Videoconferencing Tool. It is a conference advisory group that came up with it.

The other thing about flexibility and time, we let people know, even if we're on their doorstep, if it is not a good day, if they are having a bad day – and this happens with people living with dementia – one day grey, next day terrible, it is OK. They can tell us, "Bad day. Come back another day." Building in a lot of flexibility around that. Roll with it. If you go into an interview with 100 things you want to talk about or product features you want to test and you only get a few, it is OK. Just roll with it and be grateful for the feedback you have got.

Keep it simple. Plain language, speaking clearly. I have found it helpful to ask one question at a time. Sometimes, as you may have already guessed, I have a tendency to speak quickly, so to slow down, ask one question time, and also I find it helpful to ask more specific questions, like, "What do you make of that font size?" Abstract questions can be challenging for people living with dementia.

Show respect and gratitude. This is probably the most important one. Earlier this year, a colleague and I attended a hack-a-thon for people living with dementia. We were talking with a dementia advocate from Scotland and we were telling her about what we did. She whips out her purse and brochure. It was called core principles for involving people with dementia in research. One of the key points in the brochure was respect, including respecting people's time and the notion their time is as important as our time.

There is maybe a tendency for us to think of a person who is retired or does not have a lot on their plate. They have time, they can do this. One thing I try to keep in mind is that our summary spends with me, that might be the only… If they spend that hour doing the cognitive processing required to do the thing they are doing, that might make them done for the rest of the day. So even if they have time in a general sense, I still try to respect that they are giving me something, they might be giving up their whole day. It is a big day. It is important to be grateful for the time people give.

I want you to take two seconds to think about this, about what it feels like to be included, like thinking of a time when you felt included, that you felt somebody has heard what you have said, and what that felt like. If you think about, maybe it was warm, fuzzy, maybe it was a hug, maybe it felt comforting to have people understand what you are going through. Any other thoughts? Anybody have anything about what it feels like to be included? The feeling?

JENNIFER:
Somebody else might feel relaxed and confident. If you think about a person living with dementia, your abilities are declining everyday. That is hard, right? If you can feel like you have

a voice and are contributing to something, boy, that feels good! Just to give you a picture of what somebody looks like, this is our friend Gerard. We have is permission to share his photo pretty much everywhere we go. Gerard is one of our very dear favourites, a dear friend. He has participated in many different ways – an interviewee, tester, advises us from time to time.

This is a real person, personally uses technology, and is really glad to talk about his opinion, to provide feedback. He is grateful people are asking him.

Why engage people? There are the emotional benefits. Organisationally, there are benefits to businesses and organisations, at the least of which is, by gathering feedback, you can create a better, more useful tool.

This is important not only for people or organisations for profit, but also not-for-profit. If you spend money having something created for not-for-profit or yourself, you want to make sure what you're creating is useful and will provide what people need.

The only reason, only way to find out whether your product or tool is meeting people's needs is to ask. There is no checklist.

Informing product roadmaps. Recently we worked on a feature list for the next generations of our product. I had a big list. I thought that would be good. I spent time talking to people living with dementia and the list has changed. It is useful, valuable because now we know where to spend our time and our money - on features that matter to people and make a difference.

This is a quote from Marybeth Whiten, the chair of the Ontario Advisory Group. She has been working on the research product. Her perspective and reason for being involved in the project is she really feels her first and most important object of developing technical solutions for people with cognitive impairment is to include us in the development. It doesn't matter whether you're creating something specifically with dementia, which likely not many of you are. But even just to think about, if you are creating something designed for people with a high senior population, say, for example, even thinking about the population of people living with dementia…

I want to end by saying, if I leave you with one thing today, I really want it to be this – people with cognitive impairments, including dementia, are people, people experiencing challenges, but who have something valuable to contribute. On our journey, we have had opportunity to

meet wonderful people and we are grateful for the chance to get to know them.

At our company, we are not medical experts, not scientists. We can't develop a cure or delay the development of the disease. We are not trained social workers or people who can provide post Alzheimer's care and support. We can help in some small way to help people with dementia be more independent and speak for themselves.

OK. I'm done.

(Applause)

Any question? Lots.

SPEAKER:
(inaudible)

JENNIFER:
The question is around adversity. People with dementia have different challenges and how that plays out in terms of the design of a product. We have started with a product designed a little more specifically for people with early to mid-stage dementia and for people with memory loss. Over time, as we learn more about how people are using technology and how things shift over time through data analytics, we can see how things will need to change and shift as people's journey changes, so targeting that specific slice and building on that and creating changes and multilayer features to the product over time to accommodate other challenges.

SPEAKER:
What are some of your apps?

JENNIFER:
Speaker aids, allowing people to add information about their lives, what is important to them. It is designed to be easy-to-use and also to track health information. If someone is going to a doctor's appointment, maybe they can speak more independently. They have a personal health history available. What tends to happen, even in the early stages, is a person with dementia will go to a medical appointment and the conversation will be between a medical professional and the care partner.

So having a tool that summary can say, "I remember I had these surgeries," That is there. And then we have almost a whiteboard in the app that allows people to add information about their day. That is a common physical strategy that people use – a white board. People will say things like they went out to 2 PM or that somebody is coming to get them at 3 PM. One of the tools people using today in the physical sense is that. It is being adapted for digital.

SPEAKER:
(inaudible) I'm wondering if you are aware of initiatives, developing technology for the greater population, so you can walk into facility and anyone can use the digital screens? And where I am coming from (inaudible) and we are implementing solutions at hospitals. So we don't know what the solution is and we would like to be able to speak to somebody who is working on one.

JENNIFER:
The question is around checklists and if anyone is working on to contribute guidelines to #wickegg. They're trying to figure out what works and doesn't work for people with cognitive impairment. That's probably the biggest initiative going on that I know about. It is a cognitive accessibility working group.

SPEAKER:
I'm interested with regard to people with brain injuries.

JENNIFER:
The question is around whether we have given consideration to things involving other cognitive impairments. We don't want to be too broad in our focus. We have had many questions and people coming to us and saying that something would work for people with Parkinson's and brain injury. That is something we are potentially exploring down the road. Our focus is on dementia, but the products we are creating, we are not being exclusive. Anyone can use them. We have created a particular target.

SPEAKER:
(inaudible)

JENNIFER:
Yes, on the App Store. If anyone is interested, they can follow up later.

SPEAKER:
(inaudible) living with dementia. (inaudible)

JENNIFER:

The question is around whether people remember to use the tool. That is an issue for some people, but often people will carry a notebook, so the idea with adding something that can be used on an iPad or iPhone is they are bringing those things for other purposes anyway. If I look at people who are early-onset now, they have those things with them all the time. Over time, they may start to forget to bring them with them. In the early stages, they are remembering to bring those things along.

They are creating their own solutions, which is really interesting. Pulling different apps and creating their own solutions, which is fun to see.

SPEAKER:

Thank you for such an interesting session!

(Applause)