## Data attached to Work Package 4 of the Designing for Healthy Cognitive Ageing (DesHCA) Project

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## Data Archive Link and Reference

McCall, V; Rutherford, A (2024): Serious game data archive for the Designing for Healthy Cognitive Ageing (DesHCA) Project. Version 1. University of Stirling, Faculty of Social Sciences. Dataset. http://hdl.handle.net/11667/227

## Background

The Designing for Healthy Cognitive Ageing (DesHCA) aimed to test, understand, and identify facilitators and barriers for various stakeholders, including older people, in achieving cognitively sustainable housing, in both new-build and retrofit contexts.

The DesHCA project has developed a co-produced legacy tool called ‘Our House’ as part of its Work-Package 4, led by Professors McCall and Rutherford. The archived data attached to this work-package has been generated from 10 playtests of the serious game legacy tool that was developed. Our House is a serious game that was developed to generate research insights on how to deliver housing for older people that is cognitively sustainable and inclusive.

## Overview

This is the transcript from playtest session 6, which took place on the 21st of June 2023. The playtest comprised of 8 participants. This transcript has been fully anonymised, with all identifiable characteristics, including the participants’ names, removed, or replaced with pseudonyms.

I: But I want to hear from you now, you've heard from me enough. So, I guess, I want to capture what – we'll start here – what have you felt, you know, what's your feedback on this game? We have prompt questions, but tell us about your person, you know, and what's informed your decisions when building the house and adapting it? Has the game helped visualise your own home and future, and did the examples, the daily life changes help you understand aging better, you know, that big, intangible thing? So, I'm going to start with Eleanor.

R1: We had a moment where it was pretty clear that we were just going to try to find…and we were quite fortunate with our budgets…to have a kitchen that was usable, a bathroom that was usable, entry in and out of the house, and one room downstairs that he could sleep in. And that was it, that was about what our budget was to make it liveable, to eat, sleep, wash, enter. Everything else was too expensive, and out of our budget. So, it's making the house usable, in an absolutely minimum standards kind of way.

I: Uh-huh.

R1: So, you know, does that still feel like a home, or is it a place that you're surviving in.

I: Indeed, indeed. And I heard you both had conversations about what you would do future-proof, as well, I think. What would you have done with Derek if budget hadn't been an issue?

R1: Well, I think it's tricky with him, because he doesn't have a diagnosis, so we're not a hundred per cent sure. At least with a diagnosis, you might have a bit of a clearer idea about what, if there is going to be further deterioration, what that means for your body, and what, then, futureproofing you might need.

I: Uh-huh.

R1: Ideally, we would have a lift, he could have gone upstairs, or at least a stair-lift, you know. What else would we have done?

R2: I don't know, because a lot of the rooms or spaces were hard or challenging.

I: Yeah.

R2: And it's like, sometimes you just can't fix things.

I: So, if you adopted…

R2: And it doesn't matter how much money you've got; some things can't be fixed.

I: That’s right. So, some homes can't be adapted, and we know that is true. So, would you have had the rehousing conversation for Derek if it had been an option?

R1: Yeah, and I think he's got the financial means, it looks like, to do that. He's got family support, so he would have had some support in trying to, moving, his family aren't close by. So, potentially, he would have been okay moving to a different part of town.

I: Uh-huh.

R1: Because it didn’t say that he particularly had a community in his immediate neighbours.

R2: Yeah. I think I've just built Derek's whole life up. And I just find it, it's just a really hard thing to sit and talk about, abstractedly, when you have experienced this yourself in your own family, and it isn't a paper exercise, that’s quite hard.

I: Yeah, not an uncommon story, indeed. And I think, well this is what you're all here for, isn't it, to support people in these situations. So, yeah, the campaign goes on, so yeah. So, that’s Derek, and that’s, and he does get a diagnosis in the third, and he gets all the help he needs, in real life.

R1: Oh, very good.

R2: And he's had a tax rebate.

I: Yeah, yeah.

R1: Let's check in with Derek, we need to get back in touch, has this actually happened.

I: Well, I am happy, leaving Derek happy, because I know he's happy at the moment. So, yeah, in real life, these things do get sorted once the diagnosis has been given. But challenging, and I think the story there is, the challenge is before the right bits in the system align, very hard when you're in that limbo. And a lot of people feel they're in that limbo.

R2: Yeah. And that can go on for a very long time, as well.

R3: And it's getting longer as well, isn't it, so…

R4: What, do you mean the limbo awaiting diagnosis?

R3: The limbo waiting, yeah, people are waiting longer for appointments, so therefore they're probably in limbo for longer.

I: Uh-huh, that’s right. So, how's Joseph getting on, our bachelor, about town, living the life, no, yeah?

R5: Not very good, anymore.

I: No.

R5: He's got his formal diagnosis, so you'd think he'd be able to get a grant, but like you said, he's in…

I: He's private renting.

R5: …private rental. So, the chances are, he's not going to be able to live there.

I: Yeah.

R5: Which is very sad, we tried to do futureproofing, but the extent of the physical need was not affordable.

I: Yeah.

R5: And not possible.

R6: And I think we thought we future-proofed it, but his decline is, kind of, much worse than we predicted, and given his budget, it was quite limited, what he could do.

I: Uh-huh, yeah. So, what happened with Joseph, he was in a very pricey bit of town? So, if there was a re-homing conversation, he could have went to a cheaper area, and renting was a bit more flexible, as well, in regards to some of the options that was available in the town. So, yeah, what were your key decisions when changing the rooms, what was your priorities?

R5: I think it was trying to make sure that on both physical, and the cognitive side, that we were, kind of, almost matching where he was at, or going slightly above it.

I: Yeah.

R5: But we were only able to do that, kind of, at one point, whereas realistically, the physical one, we were saying, we were anticipating going up to five. It was just like, it was just too, too far.

I: Yeah, and not the ability in that time to future-proof ready for that.

R5: No. And the thing with his story is, there's no, kind of, he talks about nieces and nephews, but doesn't really say how nearby they are, and that concept of, if he does need to move, what support has he got available to him.

I: Yeah, yeah.

R6: It also said, because like, his life was really happy in number one, it felt, like he loved living in the centre of time, and all of the amenities, and social life that that presented to him. But by now, like, the last sentence here says that his speech has been affected, and that he's avoiding all his friends.

I: Yeah.

R6: And then, if he's going to move to another part of town, like it might be cheaper, and it would be better for him, but then obviously, it's like a big loss of identity, and the things that…so, yeah, I didn’t expect the picture to get, like, that bad for him, that quickly.

I: Yeah, yeah. And remember, these are stories from over time, you know, from over years and years. But that is interesting, and I think Joseph's story is about the social connections, and identities that are so important for healthy ageing. So, and how we maintain those when, and how do our homes, and our wider environments maintain them as well. We can do better, we can always do better, so good. And Joseph goes to the seaside, though, that was an aspiration. So, found a care home next to the seaside, and has an amazing view, so I just thought, you know.

R5: That’s really good.

I: Okay. Ben, how are we getting on? So, I think Ben thinks they won the game.

R3: He got 14 in the grant, I think.

I: Yeah, you were given a grant. Ben is an interesting story. What were your priorities?

R3: I don't think we actually got…

R4: Getting as much grant as possible.

R3: Sorry, say that again, I was thinking about the grant money.

R4: Our priority was the bathroom, that was where he had the biggest difficulties. And then we applied for the grants. But we managed to get 17 times our money, so we were very happy about that. And so far, we've it's future-proofed it, because the next problem we've had has been repairs.

I: But we didn’t let you widen the doors, that was deemed essential.

R3: No.

R4: No, it's true, you didn’t let us properly future proof.

R3: That was just something that the assessment said we needed. And, actually, we could have got away with just putting a handrail in, for like, that would have been fine. And that would have, well we still would have struggled to afford that. But you could imagine someone trying to stretch, and afford the one thing they can, rather than going for the grant because they don't know it exists, or it's hard to access.

I: Yeah. And people do do that, yeah, absolutely. But then, even handrails, you do need a little bit of expertise, about where it sits, and you know, how supportive that can be. Or if you don't need them at all, there are other options. But there's sometimes a default in regards to the list that comes out.

R3: And it's still well beyond our means, as well, so.

I: Yeah.

R6: And also, if you need the handrail now, sometimes DFG takes ages to come through. So, then you just go for that anyway, rather than waiting for the other things.

R4: Yeah, but actually, we thought we had installed everything, but then actually, it turns out we needed to pay 20 per cent of the means tested grant. So, actually, we couldn't do any of those things.

R3: Well, we could just do the handrail, yeah.

R4: We could just do the handrail.

R6: Oh.

I: That’s right.

R4: Then, we couldn't find contractors, so…

I: Oh, no.

R4: …now we've actually, it definitely wasn’t done.

I: So, Ben's story is actually a real individual who's an in-depth case study, in that report I mentioned earlier. And it's actually a little bit heartbreaking for Ben. So, Ben was looking for a diagnosis in 2017, he waited three years for an epilepsy diagnosis, is it Ben who's got the epilepsy, yeah?

R3: Yeah.

I: And then, once he had the diagnosis, he had to wait a long time, hurting himself, kind of, as it went along. Got the diagnosis. Then, they were in an area without care and repair. Or, I think there was Care and Repair available, but they didn’t, it was like a use the whole Care and Repair, but they didn’t want the ugly wet-room stall with the half, you know the one that looks really institutionalised sometimes. So, had said, I'll get my contractors, got three quotes for contractors, got the grant, a week before COVID hit. So, the grant was given, but the work couldn't commence. And then, after COVID, the work that was quoted went up, doubled in price.

So, because of the doubling of the price, the local authority asked them to re-quote from the contractors, and then the contractors that were initially available weren't available, had went into liquidation. And I'm really sorry about Ben, since 2017, still doesn't have any adaptations done to their home. So, yeah, so this is one of the most challenging ones we've seen so far, and still doesn't have it, so yeah.

R3: And from a position where, actually, his house was mostly fine…

I: Yeah.

R3: …how quickly it can, sort of, become more difficult.

I: Yeah, it was all on one level, some of the things were already, yeah. So, I think Ben is a little bit close to my heart, that one, and I still, kind of, check in to see if there's any progress. So, but they're okay, I would like to tell you that, they're okay at the moment. So, Susan, how are we, you were in a little bit more challenging situation, initially?

R7: Yeah, so at the beginning it felt like there were probably only one or two adaptations that were needed and then, you know, the house would be okay. Having said that, four out of the six cards were only one or two cognitive accessible level. So, actually it wasn’t really a good house for somebody who had a dementia diagnosis to be in. So, Susan quickly lost access to all of the house. And then I thought, well what if she was still in limbo at that point, about her diagnosis, and she was on a waiting list, so that would be even worse. At first, I thought that I hadn't applied for enough, kind of, small adaptations, like plus one, here and there. But actually, that wouldn’t have made much difference in the end, anyway, because the cognitive level got so bad, that actually, there was very little you could actually do to make it more accessible. And then, there was actually very little available on those boards in regards to lifestyle, or outside, kind of, the boundaries of home improvement.

I: Uh-huh.

R7: Which is, actually, pretty much what Susan needed more help with. She did have her daughter there, and there was, like, no suggestion that her daughter, kind of, struggled to look after her, or do, like, daily tasks, we didn’t have that information. But I would imagine it would be really difficult for her daughter in that situation. So, yeah, bad situation for both of them, really.

I: Yeah, absolutely. And I had one group come to me and say, can we have an adaptation to make the carer's life easier, as well. And although these are individuals, it is sometimes important to think of the household impact of supported housing. Because, often, what will make it easier for one, makes it easier for the other, and the joint benefit of that. But caring is one of the hardest jobs in the world, so yeah, absolutely, it's about that too. So, Susan was in a challenging situation, but I think what you were also negotiating throughout was, is the house, 40 years in here, do we stay, do we go, and that conversation around that. But you did Susan well, very well, although, yeah, hard situation for her daughter. Well done. Okay, Sean and Kerry were in a slightly more, better financial position.

R8: Yes, yes. So, it all started quite promising. They had, they moved back from abroad to live with her mum, and they had their own home, and everything, and it seemed like a nice village. But there was this concern about Kerry becoming quite forgetful. And I think, for me, this story, in the second part, is the story of her not really accepting that she's becoming forgetful. But then, she has, I think she has a fall, am I right?

R9: Uh-huh.

R8: She has a fall, and she breaks her arm. So, that accelerates, a bit, the time. And thankfully, Sean is there to help her with the daily tasks. And in this period of being in limbo, he's there to support her, which is very good. And then, it gets worse, of course, because he has a fall.

I: They need to stop travelling.

R8: They need to stop travelling. So, he has a fall, so he has more physical challenges. But then, she has come to accept the fact that she might have Alzheimer's. And she uses all these coping mechanisms to help her deal with that, and care for Sean when he needs it. I mean, I'm very curious what Sofia thinks, but for me, this was very interesting. Because you can see things are getting worse, but they have, they're deciding a life course. So, they’ve been, these are two people who have been professionals all their lives, so they have this mechanism to deal with these challenges. And at the end it says, they are dealing with this, with what came their way in terms of the physical and cognitive challenges, but they are still engaging with local projects. So, they're still out and about, and talking to people.

I: You can live well with dementia, yeah, a positive story.

R8: Yeah. So, I think it's really…and also, I mean, I'm sure there's a lot more stories that, you know, are here. But it seems that in this room they are the only couple that we're talking, and I think that also helps. And it helps that they both worked all their lives, and they have this, yeah. And I don't want to say, cushion, but yeah, it's not so, it doesn't feel like it's a freefall, you know, [inaudible 0:16:23].

I: Yeah, yeah. But that’s really insightful, because that is meant to trigger the fact that the spouse, in a spouse situation, we know that there's a lot of reliance on the spouse. And paid carers, like Susan's daughter, and things like that, that informal care environment, very important.

R8: Yeah, absolutely, absolutely. And it's interesting that the care falls on the man in this situation, because a lot of times, the care falls on the woman. But I guess they, you know, they compensate for one, yeah.

I: Did you want to add anything?

R9: Just, when we were thinking about our adaptations, because whole parts of the house became inaccessible for them, for Kerry. So, when we were thinking about adaptations, I think we went quite low-key at the beginning. And so, it was around things like, yeah, sort of, memory aids, and smoke detectors, so, because she kept burning food, and stuff like that.

I: And the tech conversation is a good one to have, as well, just the tech.

R9: Yeah. But then, yeah, but then it's quite interesting that, after her diagnosis, she seemed to be putting in place some of those strategies, and yeah, mechanisms.

I: More proactive?

R9: Yeah, exactly.

I: And they had the wealth to invest in their proactiveness, yeah.

R9: Yeah.

I: Interesting, uh-huh.

R9: Yeah. So, it felt, if you look in the third of the scenarios, the numbers are really poor. But the narrative is much more positive, as well. So, it's that difference between the actual, you know, those two things, is quite stark, I think.

I: Good. And that’s, kind of, what you're meant to see. Because Sean and Kelly had a little bit of a more active role in their own futureproofing. So, with Kerry's mother, diagnosing a bit of caring and experience around cognitive impairment, they were able to align with things to live well with dementia. So, it's not all bad.

R9: There was a period, which sounded awful, in denial.

I: Yeah, well yeah.

R9: Yeah, which is very natural, of course.

I: I think, very natural.

R9: Yeah.

I: And most people are still in denial, even with official diagnosis, and so on, it's a tricky challenge to people's identities. So, that’s brilliant. And I have actually taken five more minutes than I promised I would today. But I hope…is there anything else to add, though, if you don't mind the over time? But this was brilliant, and I'm hoping none of this was unfamiliar to people, especially if you're all focused on how we age better, and so on. But it's an interesting methodology.

R1: It would be interesting to add into this something about, because we talk about ageing and adaptations, but also about repairs and maintenance to people's homes. Like, if you then add another element, with the same budget constraints, potentially of, do you fix the damp in the room, or the leak, or do you make your property more secure, or do you do some of this stuff. There's lots of different elements that feed into the house, which you could, yeah, really see expanding slightly to, yeah…

I: Definitely.

R1: …more choices.

I: And you can see, it is more, it is flexible enough to, kind of, adjust that way, as well.

R1: Yeah.

R4: You could even add in, like an advice service, where you'd go, and then they would tell you what you need to do, and see what the person would have done, if they had an advice service, versus if they were just setting it up themselves.

R2: Or dodgy salesmen.

R1: Yeah, what happens when it goes wrong.

I: Yeah, or dodgy salesmen selling you inaccessible bathrooms, yeah. Yeah, so have you, so have the examples helped you, has the [inaudible 0:20:27] game helped you think through that future-proofing element of homes and, well not environments, we didn’t really explore environments, but homes themselves?

R5: It makes me think about my parents, now, yeah, and thinking, okay their house is not currently fit for ageing well.

I: Yeah, yeah.

R5: And that’s scary.

I: It is, it is.

R3: My parents, too, and my mum's year of decision keeps moving forward. She's like, I'm going to decide when I'm X age, no, and then you're like, oh do you remember when you said that.

R1: Did she actually brand it the year of decision?

R3: No.

R1: Oh, right.

R3: It's just what I was…the last idea was to build a loft in the – not a loft – a lift in the garage.

I: I was going to say, a loft, hmm, not the best futureproofing. I like that, I can see a marketing campaign now – the year of decision is now.

R1: Yeah, good one.

I: Good, excellent. Well, I will stop recording that, thank you for your insights.

**End of transcript**