

# Care and Connect: exploring dementia-friendliness through an online community commissioning platform

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## ABSTRACT

In this paper, we present ‘Care and Connect’, a mobile application created through the App Movement platform that aims to identify and rate public places (e.g., parks, shops, cafes) on their ‘dementia-friendliness’ – their suitability for people with dementia and their carers. Care and Connect saw significant support in its early stages on the online platform, yet failed to engage participants in its design phase and deployment. To unpack this, we contribute an account of its initial use in the community, and then describe findings from research engagements with carers and people with dementia. These workshops used Care and Connect to structure discussions of participants’ own experiences of dementia-friendliness, and uncovered themes of 1) trust, 2) exclusion versus inclusion, 3) duration and quality of time, and 4) empathy becoming action. Using this evidence, we advance an account of online community commissioning as a process which needs to understand not only the general issues ongoing in communities facing significant life challenges, but also the particularity of community members’ experiences.

## Author Keywords

Dementia; dementia care; community information systems; community commissioning; mobile applications.

## ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## INTRODUCTION

The value of living longer at home for people with dementia has long since been acknowledged [34]; however, despite a recent concerted effort within the HCI literature to enable people to live safer lives in their homes, little research has focused on how technology can help people to live more meaningful and connected lives in the particular context of local communities (as opposed to simply keeping

people safe at home). This is despite technology having become an important part of many grassroots communities, where it can be used to organise activities, inform and mobilise members into action, or stimulate discussion around current issues.

In this paper, we present ‘Care and Connect’, a location based review mobile application to support the dementia care community to find, rate and review dementia-friendly locations nearby. Care and Connect was commissioned by members of the dementia care community (one of whom is an author on this paper) using the App Movement platform [9], a community commissioning platform to collaboratively design and automatically generate community driven information resources. Care and Connect raised significant support in its early stages, yet did not engage many participants in its design phase, and uptake in the community was less than we envisaged. This is despite a significant amount of current community work driving the idea of dementia-friendly public places [21]. In this paper, we attempt to unpack why the first iteration of the app was not as successful as predicted, and use the app itself to provoke discussions among carers of people with dementia to help shed light on the technology and information needs of the community.

App Movement is a platform that “enables the promotion, collaborative design, and deployment of community-commissioned mobile applications” [9:26]. The platform allows group customization of a location-based reviewing app template, and given a certain level of support, culminates in an automated process through which the app is created and made available online. The success of some movements has been exceptional [9], and against a background of well-backed attempts by the UK Alzheimer’s Society to create ‘dementia-friendly communities’ [1], the platform and its resulting apps clearly have some promise in the grassroots coming together and mobilising of communities. The mixed response the Care and Connect app received tells us something about the difficulties concerning community commissioning (and other design activities) happening within communities, like dementia care, which are at best on the periphery of larger society, and often almost entirely invisible [23].

From our experience, engaging people with dementia and their carers in the design of technology can be a complex task which requires work beyond conventional methods of

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configuring participant and civic participation in more traditional commissioning and participatory design projects. This paper contributes, a) a series of findings surrounding the information and support needs of people with dementia and their carers pertaining to community-wide technologies, and b) a critical account of community commissioning processes (and other crowdsourcing techniques) which prefigure the scope of participation for community members facing serious challenges in their lives.

### **THE COMPLEXITY OF CONFIGURING DEMENTIA-FRIENDLY COMMUNITIES**

Dementia is a complex condition, and the term is used as an umbrella for a variety of symptoms which range from the cognitive to the interpersonal [28]. The cognitive and the social, emotional aspects of the condition cannot be considered as separate from one another [6, 33]. Although each person will experience dementia differently, an illuminating paper by Ryan, Bannister & Anas [28] examines the experience of people with dementia through personal writing, and emphasises several themes which concern a sense of a changing self: a loss of status as a competent social partner, a loss of social and familial, and difficult feelings in social situations. Given the progressive nature of the condition, receiving a diagnosis of dementia is often extremely difficult, both for the person themselves and their family [10, 28]. It is commonly regarded that “ageing in place”, i.e., staying at home for as long as possible, is preferable in dementia, but many people will find themselves living in care for at least a short amount of time during the course of the illness. Further contributing to this complicated experience is that people tend to ‘step back from dementia, because it’s too heavy’ [23], meaning that people with dementia can become isolated from the communities and networks in which they once participated.

Despite the cognitive decline associated with dementia, configuring the person with dementia as fundamentally disabled is not only disruptive to their sense of self [29]; it can contribute to faster decline in cases of excess disability – disability beyond that which can be usually expected as part of their already-existing condition [6]. Positioning people with dementia as somehow ‘lesser’ is something that we need to fight against, particularly as researchers and designers whose decisions impact upon the public configuration of dementia and the lives of people with dementia and their carers [18].

#### **Place, space and community in dementia**

Extant work in HCI and social gerontology has identified outside spaces and activities outside the home for people with dementia as under-researched – Brittain *et al* [5] describe how most work in the area has focused on the home and institutional space as the (physical) design space for those living with dementia as well as those caring for them. In the same paper, the authors describe three overarching attitudes towards the ‘outside’ – outside space as *frightening*, *therapeutic*, or *empowering*. Some of the

participants interviewed describe how simple technologies such as mobile phones allow them to navigate outside space safely and meaningfully, but how other technologies (such as GPS sensors and/or medical alert technologies) highlight the visibility of their condition in an uncomfortable way:

*“...it makes you feel like your freedom is taken away from you, and if somebody sees you have a card or something, they think well, I’m stupid you know. I mean if I don’t know where I am, I ask somebody, I will stop them and ask, I wouldn’t carry a card like that.”* [5:10]

Part of a systematic response to the challenge of helping people with dementia to live longer, more meaningful lives in their localities has been the ‘dementia-friendly community’ initiative [21]. Initially launched by the Alzheimer’s Society in the UK, the initiative seeks to sustain people with dementia living for longer within their communities – but also living meaningful and safe lives. The activities carried out by such communities differ, but typically consist primarily of training local community members in the symptoms of dementia – particularly local businesses, who will then ostensibly have a good understanding of how to interact with a customer with dementia in a sensitive way [35]. Despite these initiatives, the larger concept of ‘dementia-friendliness’ remains relatively undefined. Emphasising the multiplicity of experiences within dementia, Swaffer [30] describes the dementia-friendly communities approach as “... *obviously meritorious*,” before going on to write that “... *just like cancer, dementia is not a single entity and it can be expected to affect any of a person’s functions such as memory, language or understanding of space*” [30:713].

#### *The contribution of digital design within DFCs*

Relatively little research has focused on the value of HCI design and research specifically in outside or public spaces for people with dementia. There is a wealth of design research which seeks to help people with dementia live more comfortable lives within their homes and localities [2]. For example, issues concerning the remembering of faces encountered in going about one’s everyday life can be solved with prospective memory aids employed in wearables such as Google Glass [20], or life logging technologies can help people with dementia and their carers to recall their days to ensure that users have eaten enough and at appropriate times [17].

To assist in the navigation of outside space, some research has been dedicated to the use of GPS technologies used to track people with dementia to keep them in touch with family members in the event of their wandering and becoming lost [12]. However, a number of participants with dementia in these studies have described an unease with these technologies. Engaging in participatory research with people with dementia surrounding safe walking technologies, Holbø *et al* [15] describe several methodological and ethical concerns with carrying out this sort of research. These are distinguishing views of people

with dementia from those of their carers, a focus on strengths retained rather than abilities lost, a desire for control, experience of symptoms, routines and skills, empathy for caregivers, and supportive and unsupportive characteristics of the local environment.

What many of these studies do not deal with is a holistic approach to what it means for people with dementia to live longer, more meaningful and more connected lives in their communities – although sensitively designed GPS technologies may in fact become a part of sustaining people within these connected communities, the social infrastructure needed to maintain these relationships is not yet in place.

#### *Dementia and the potential for user participation in the creation of new technologies*

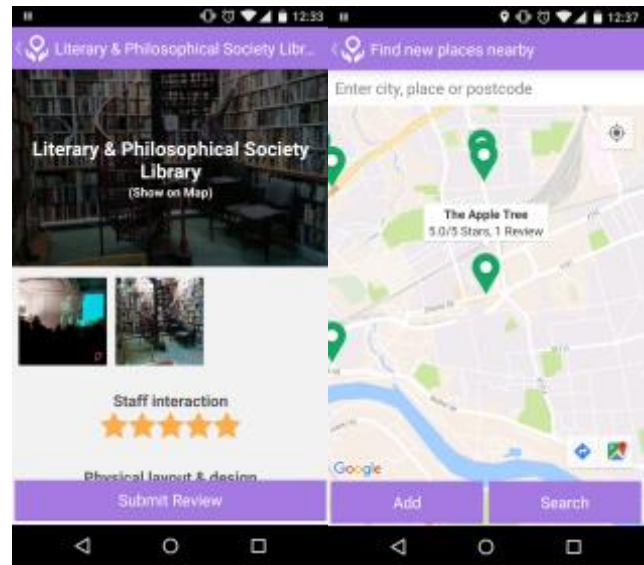
User participation in the co-creation of health and care service design has been indicated to provide effective and useful services which take into account the lived experience of their users from the ground up [8]. Taken together with the issue of stigma [23], the advantages of user participation in technology design and decision making points to a need for approaching technology design in a community context in which people with dementia and their carers are ensured a say in the matter and in which the final design both reflects their values and choices, and retains their voice.

Evidence suggests that modern information and communication technologies could meet some unmet needs of people with dementia and their carers [2, 22]. Beyond this, the participation of people with dementia and their carers in design, selection, and deployment has been found to be valuable, not least because of the need to understand the variety and complexity of experiences of living with dementia [3]. The current research challenge is not only technological; rather, it is about the participation of people with dementia, their carers and community in design and appropriation of assistive technologies, and in dialogically making meaning of the experience of living with assistive technology and dementia.

#### **Engaging people with dementia and their carers in DFCs**

It is against this background that Care and Connect was created through the App Movement platform in 2015 with the aim of facilitating the coming together of a community of carers – a group often reported to be seeking more peer and community support [10] – who could share among each other a host of local places and activities that in their experience have been enjoyable and enriching for the people that they care for. In this way, the app would not only support carers, enrich the lives of people with dementia, help to build a sense of community across disparate areas in the city, but also be a significant part of a bottom-up process which would help researchers and community groups understand what aspects of community places really were dementia-friendly.

In its initial commissioning phase, where the concept was proposed, Care and Connect was well supported (94 supporters in response to a target of 50) and advocated (25 comments, 30 share clicks and 97 organic shares)– however, it saw much reduced participation in the design phase (6 contributors) and low levels of engagement with the final app (61 venues, 36 reviews). This is after a significant amount of promotion by the creators at appropriate venues – i.e., travelling to carers’ groups, advocacy groups, and nursing homes.



**Figure 1: screenshots of Care and Connect in use**

#### **App Movement and Care & Connect**

The App Movement platform, described more fully by Garbett *et al* [9], has three stages; a **support phase**, a **design phase**, and a **launch phase**.

#### *Care and Connect*

Care and Connect is a location-based reviewing app which aims to map dementia-friendly places, which so far has been localized particularly around its launch area. The app is based around a navigable map which allows its users to pinpoint particular locations (or search for locations using text input), and then review them. Users are asked to rate the location on the following dimensions (out of five stars): staff interaction, physical layout and design, clarity of wayfinding, and atmosphere, ambiance, and calmness (these dimensions are the result of the contributions with most votes in the design phase). Reviewers can also leave a text review of the location, as well as attach a photo (see Figure 1, below). During the deployment of Care and Connect it is apparent that members typically contributed reviews at two peak times of day, early morning (8am) and midafternoon (2pm – 4pm). However, contributing behavior around venues sees members adding venues at three peak periods, early morning (6am), midafternoon (2pm) and late evening (11pm).

### Care and Connect: Usage Overview

The Care and Connect app has been available since May 2015 and currently has 254 installs (115 iOS, 99 Android), 76 reviews, 143 venues and 7 photos have been contributed by the community. Within the support phase, the campaign had 94 supporters, within a 30 day period, and at a time when the threshold was set to only 50 supporters. Within the design phase 6 supporters made a total number of 11 contributions (4 app names, 0 app icons, 3 color schemes, 4 rating options). The campaign saw a number of discussions within the support, and design phase with 25 comments being contributed throughout the campaign. Comparitively, Drone Zones, an app to find suitable flying locations has become more widely adopted with 33493 installs (6647 reviews, 10358 venues, 2212 photos) and was supported by 186 people within 30 days (threshold 50 supporters), with 58 submissions from 20 supporters in the design area.

### METHOD

Using the Care and Connect app as a tool to provoke conversation around dementia-friendliness and technology use, a series of workshops and one-off engagements with carers (and two participants with dementia) were undertaken in order to understand: a) what participants' experiences have been with public spaces, both 'dementia-friendly' and not, and b) their opinions and suggested revisions surrounding the Care and Connect app.

These engagements consisted of two workshops (12 participants in each), and six one-on-one engagements with carers who expressed a wish to be met alone. Most of our participants were carers with family members in the early to mid stages of dementia (20), although we also had two participants with dementia, six with family members in late stages of dementia, and two who were ex-carers, their family member having passed away.

We used printed postcards and guides to using the app to explain the ways in which we had been envisioning participants using the app (see figure 2). We also made the app available on several tablets which could be passed around the table to use during the discussion. After this, we lead with a series of open questions concerning dementia friendliness, before returning to the Care and Connect app in the final segment of the research engagement.

Qualitative data stemming from these workshops and one-on-one engagements was analysed using an inductive thematic analysis [4] in order to delineate five themes which a) uncover the gap between the "template" of dementia-friendliness which the app provided, and b) the particular information and support needs of communities of carers and people with dementia.

These workshops were carried out in two localities – one in the north of England and the other in the south of Ireland, both sites in which the app has been deployed or else is planned to be deployed. Ethical approval was granted from

two separate ethical review committees in both University College Cork as well from Newcastle University.



**Figure 2: we used printed and digital material in our workshops to stimulate discussion around Care & Connect**

### FINDINGS

Our analysis of qualitative data from research engagements with carers and people with dementia follows in four themes: 1) trust, 2) exclusion through inclusion, 3) time (duration and quality), and 4) empathy becoming action.

#### Themes from research engagements

##### Theme 1: Trust

Carers questioned the notion of 'dementia-friendliness' as being ill-defined, and had conflicting feelings on whether they would trust reviews left by other users of the Care and Connect app. Aoife, a carer for her mother, easily accepted the trustworthiness of the reviews based on an assumed common interest: "well you see it's like Trip Advisor really isn't it? So I mean who is going to go on this and not... you're going to go on this if you've an interest. So you would trust it". Meanwhile, other carers described how specific aspects of the app prompted more confidence than others – for example, Eliza had more faith in reviews left rather than the star rating which is described above:

*"I just wanted to say that the star rating is great, but actually I would always go to what someone has written, because...it's how someone speaks about a place that's interesting. So it's only got four stars, but actually it's - I'd bring my mum, because she loves it, good friendly staff, so it's that - people have written reviews."*

Others questioned the depth of the reviews left. Molly, who confessed that it would "never occur to [her] to look for a dementia friendly place. It would never occur for instance to go in and say, 'excuse me my husband has dementia, I value your help and working around this'", spoke positively about the app, but was disappointed that the reviews were so short and so general. She spoke about the possibility she saw of using the app as an educational tool, to allow people to learn about dementia:

*“I mean somebody who just puts on reviews as wonderful and staff are really friendly, okay that’s good, but somebody who can give a really in depth review can tell somebody like me what I could be looking for, what I could be expecting.”*

Despite a positive inclination towards an app which would help to pinpoint dementia-friendliness in the community, carers suggested that they would not use the app to inform outings with loved ones – at least not in the first instance. Mike, who described a suite of well thought-out activities he carried out with his parents (both of whom had or had had dementia), also spoke about the ways in which he would assess dementia-friendliness from his own perspective in the past:

*“If we were going to go to somewhere that I hadn’t been before, I would either have phoned them up to ask them about set-up, though I wouldn’t really feel particularly comfortable about doing that. I think nowadays, I’d use the web, the internet, to be honest. But that wasn’t as useful in those days. So I would actually, probably have paid a visit, myself. Just go out somewhere for a quick drink or something, just to scout the joint, you know? ... Then there’s no surprises when you go, because it can be stressful caring for somebody, dependent day by day and so you want to minimise any additional uncertainty or stress which might occur.”*

Although Mike described himself as a savvy web user and already employed a variety of techniques to ensure his mother’s safety and comfort when out in public, he was unsure about trusting Care and Connect enough to make initial forays out into public spaces (“Would we make a special trip to go? I don’t know if we would”). He spoke about the variability in experience as both someone with dementia and as a carer of someone with dementia – although he acknowledged that parameters such as staff interaction and calmness are important, there are “a million variations” within the seemingly clear-cut rating dimensions. Given that these rating options are reasonably broad they can fail to recognise some underlying nuances of those living with dementia, making transferability of these experiences difficult to place one’s trust within. As Mike indicates, there is a lot at stake when bringing a loved one with dementia out into public spaces, and the cost involved in doing so requires that these experiences are contextually relevant, reliable, and transferrable between community members.

Part of what is at stake when bringing a family member with dementia out in public is a move from ‘trusted spaces’ – the home – to outside spaces, which are often unknowable. And although our participants spoke highly of a culture that was coming around to understand dementia more completely (“people and society, I do feel are more accepting than maybe years back” – Marguerite), they were also worried about what this general attitude of dementia-friendliness might mean for the specific experience of them

and those they cared for. This is explored in more detail in our next theme.



**Figure 3: participants at a Care & Connect workshop**

### *Theme 2: Exclusion through inclusion*

Despite welcoming dementia-friendly initiatives, some carers were sceptical concerning the label of dementia-friendly and rejected the idea of an app which would only be for people with dementia. In one of the earliest workshops, carer Caroline described the label as “... another segregation,” going on to say, “if you call it a ‘Dementia-Friendly Cinema’... I think the ‘dementia-friendly’ shouldn’t have to be something where you put a big notice up. I mean my daughter has this salon, a beauty salon, that’s - it’s dementia-friendly because we do have a lot of people who have dementia.” Beyond this, in the same session, carer George indicated the exclusionary aspects of the app labelling some places: “I think, really, it’s better if it’s integrated into things. It’s okay letting people know that it’s really easy access and that they’re friendly, but without advertising it so other people don’t go, because you want them to meet everybody else.”

Initially, this hesitance to label places, activities and technologies as dementia-friendly may seem at odds with the first theme’s description of carers as being happy to see communities open up and accept dementia as a condition anyone can get. However, further exploration of this theme over workshops indicated a fear that labelling a place as ‘dementia-friendly’ would mean only a furthering of what has already historically been the case – the seclusion of people with dementia to ‘special places’ where they can be with people like themselves.

Carer Mike goes on to explain this in more detail:

*“You wouldn’t want to go past a restaurant or something and on the door it says, ‘We welcome people who have dementia.’ You know? And it doesn’t make the person feel that they are part of the community if there’s something there saying, ‘We know you’re different, but you’re welcome.’”*

In this way, pin-pointing places as dementia-friendly may be paradoxically turning people with their dementia and their carers off of engaging with such public spaces. Instead, carers tend to advocate a general ‘friendly community’ rather than a ‘dementia-friendly community’:

*“I believe that a lot of shops in Amble, particularly the Co-Op, I think the Co-Op probably were already dementia friendly because they were customer friendly. If the customer came in and wasn’t functioning very well the staff simply were lovely with them and just coped with that. I think that they were naturally dementia friendly.”* [Jo, carer]

Participants’ discomfort stemmed from declaring ‘dementia-friendliness’ in an activity, which then becomes defined by the activities that go on within – Gerald expressed an annoyance with local well-publicised ‘dementia-friendly’ cinema screenings, which included films such as *Mary Poppins* and *The Jungle Book*: “*basically, they’re all old films and, in some cases, they’re for children. They were made for children and have been previously screened for children. Does that mean that people with dementia are equated to children?*” However, many others welcomed the dementia-friendly cinema initiative, and an evaluation of the cinema screenings yielded some extremely positive feedback [36].

We need to be aware that, as with any community resource, an app like Care and Connect may become a site of conflict as identities of people with dementia and carers are negotiated within the activities that are ultimately promoted. Many of our carers broadly welcomed dementia-friendly initiatives as progressive, but were unhappy for what inclusion within these initiatives may mean for their loved ones. For instance, Jo, whose husband had received a diagnosis of early-onset Alzheimer’s at 48, described a tension between community-offered activities for ‘older’ people being uninteresting for her ‘young’ husband, and an unwillingness to bring him to more public places due to his changing behaviour.

*“It’s not that I was embarrassed. But I would be embarrassed for Keith if you know what I mean. Like, he was so giddy and he would be rocking in the chair and really, you know, it was... in a way it was sad to see because it wasn’t Keith, it wasn’t him, you know, and you would be trying to keep him calmer... you have to be aware of that out in a public shopping centre... You don’t want everyone looking at them. I tried to protect Keith from that. I was never embarrassed about bringing him out in the wheelchair and things, that never bothered me. But you don’t want people staring at him because he is being a bit loud and things like that.”*

Carers are caught in an in-between place, where emerging forms of media and technology are publicizing and normalizing dementia, which they welcomed – however, this opening up of a community did not yet soothe their

individual concerns about being in ‘public’ with their loved one’s dementia. Beyond that, their own experiences (as separate from being a carer) were often not addressed satisfactorily by the app itself.

### *Theme 3: Time: duration and quality*

Carers were reluctant to put total faith in an application which does not provide a high level of detail to plan a trip out with their loved ones, especially when comfort and time is at stake. For carer Mike, his trips out with his mother slowly began winding down as her condition progressed and her mobility deteriorated:

*“I don’t actually want to put her through continual stress. Because you think, like, the stress of getting into a car, the stress of then getting out the car, going out to places, back into the car, then out the car- that’s four different kinds of stressful situations ... Plus, the time it takes for her to eat food, now. If we went out for a meal, in terms of the quantity of the food, she’d probably be able to eat it, but it would take her three hours, probably, to do that.”*

Carers emphasised over the course of the workshops that the temporal aspect of experiences out in public with their loved ones was often excluded from notions of dementia-friendly activities or technologies. Organising trips out was difficult due to the time it took – as Mike describes above – but also the unpredictability and stress of ensuring the person with dementia is safe and comfortable greatly affected the aesthetic experience of time spent doing what were supposed to be pleasurable activities. Carer Aoife describes taking her mother out for tea in an upscale hotel, only to find that her mother locked herself into the bathroom and couldn’t unlock the stall from her side, meaning Aoife had to climb in and come to her aid. She also describes a situation where hours are added onto a supposedly enjoyable outing, attributing this partly to the stress of looking after her mother:

*“We got back to Fermoy, just hit Fermoy, and we realised my aunt had left her handbag in the Dunnes, so I had to turn around, my mother in the front going, “Where are we going? Where are we going?” The same questions over and over again. I almost said, “Would you shut up?” You know? So we had to go back up to Cork and they couldn’t find the handbag [...] We eventually got the handbag. But I knew my aunt who is so tuned in that the reason that she forgot her handbag was because of my mother, the pressure of it.”*

Throughout these workshops, carers express clear wishes to access spaces and activities for them and their loved ones that are aesthetically pleasing and meaningful. The dimension relating to ‘calmness’ on the app was validated over and over by carers who stress that they would never bring their loved ones to a busy or crowded place. However, time and again they also related stories of their own stress and disappointment when hoping for ‘quality time’ with their loved ones:

*"It's getting harder now because the thing is he doesn't really want to go out. He's not comfortable anywhere. And when he is here... I mean on Sunday - Monday, that beautiful day, I took him down to Kinsale and we sat outside the Bulman and it was beautifully hot. It was too hot. Too hot. So [I said], "Well, I love it. Take off your pullover then", because I was going to sit there. And he took off his pullover, but he was still too hot. But I still sat there anyway. I mean you can't have your life ruined by them."* [Carer, Stephanie]

Although Stephanie's words may seem harsh, they indicate an underlying frustration with the experience of caring in public spaces and attempts to balance that with her own self-concept and awareness of her own needs. Carers in public have to juggle many tasks – the safety and comfort of their loved ones often being prime – but given the affirmation of carers towards the 'calmness' dimension of the Care & Connect app, a truly dementia-friendly space would cater to the needs and wishes of carers as well. Part of those wishes was to provide a space not just for passive reviewing and knowledge sharing, but for empathy becoming action.

#### *Theme 4: Empathy becoming action*

Using the Care and Connect app to scaffold discussion around public spaces led many participants to identify particular locations or services which they deemed to be dementia-friendly. These were overwhelmingly places such as dementia cafés or recurring coffee mornings where carers, family members and people with dementia came together in a designated space. Asked about what makes these spaces so good, Kathy reflects:

*"I found it great, because you could bring the carer and the person that needs the care. You can both come and there are a lot of people ... it's a marvelous - it's just like this now. You're all sat and there's music and there's a hand massage or a neck massage and it's lovely and relaxing. And you meet the other people, same as yourself, you know. And people like - they're all having their own time to be together. And everybody gets to know each other, don't they?"*

Kathy connects being together with others 'same as yourself' as being particularly valuable for these sessions, and as in the above theme of *Time*, values the relaxing nature of the time spent together. In the same session, Marguerite reflects on the same cafe:

*"... there are separate tables of four or six and people sit down with anybody, with different people at a time and everyone is different, is at a different stage and they also would have maybe the district nurse come for 15, 20 minutes and tell you about help you can get, physical help and financial help and your rights and things like that."*

Not only are these spaces places to relax and empathise with others in similar situations, but they are also opportunities for carers to 'mobilise', learn about their

rights and affect change in their own situations. In this way, spaces like these see *empathy* becoming *action*. Even in the workshops we held where carers came together, conversation was occasionally derailed by the passing on of 'tips' – the best way to secure extra assistance in airports, rights to disabled parking spaces, special cards which quickly and discreetly informed others in public that the person they were dealing with had dementia.

Carers identified the potential for empathy to become action in other, non-specific places as well. Discussing the dimension of 'staff interaction' on the app, carer Aoife commented the following:

*"I noticed that if I'm out with my mother in Dunnes, and have gone for tea, I can't have her up with me and carry the tray. So you have to have somebody else ... maybe that they could get the tea, and I could walk down with her, or they could bring her down to the table."*

She went to draw a distinction between the app's dimensions of 'staff interaction' and 'staff assistance' – "staff interaction is different from staff helping you. You know, the interaction, saying, 'how are you?' That's fine, but would they still bring down the tray?". As described in the introduction, much of the focus in dementia-friendly community initiatives has been the training of local businesses to recognize the signs of dementia in potential customers – however, this prospective training occurs without actual contact with people with dementia, and therefore it is difficult to ascertain how these community members would react in similar circumstances. What carers seem to be describing in these instances is the need for a space where care for their loved ones is something that is shared among a group of likeminded others, at least for an hour or two; where they both can enjoy their time and learn about ways to change theirs and their loved ones' situations for the better.

## **DISCUSSION**

App Movement is a platform which empowers communities to create their own technology – and within this, it has a good track record of engaging communities of practice who have used the platform to share knowledge, and form and strengthen community ties in geographically-bounded areas [9]. However, what the above research shows is that when working with a community whose needs are complex and ever changing – "an ever-changing learning curve", as one carer acknowledges – a more critical perspective and open approach is required. In the case of dementia, its varied and progressive nature presents a continually changing landscape of opportunities and challenges in relation to both place and technology. The following section will discuss these findings in light of their implications for community commissioning processes, and more generally for digital design that seeks to work with people with dementia and their carers.

### Expanding on trust in online platforms for carers

Participants were overall positive about a resource that would list dementia-friendly places within a given locality, but found the lack of depth and specific information in the current Care and Connect dataset somewhat disappointing. They indicated that longer reviews and more targeted information would be welcome. This finding is similar to that of [32], who describe a series of research engagements surrounding the attitudes of older participants to Assistive Living Technologies and online discussions surrounding these technologies. Finding a similar level of distrust in their participant group, the authors suggest three modifications to online platforms which may work to increase trust – *contribution cues* that “act as prompts and suggestions for the type of language used and detail to add when posting content”, *legibility cues* - “simple prompts that are offered to a reader to promote their engagement with contributions and to offer questions to support them in reflecting on post content in relation to their own needs”, and enriched profiles and contributions that highlight the nuanced nature of varying conditions of each community member.

This final suggestion is one which is likely to be particularly useful in the context of the Care and Connect app, and in the commissioning process in general, given carers’ repetition of the importance of engaging with people whose situations are similar to their own (“*I think one of the problems would be, though, that it’s not going to necessarily be the same for everybody, so to speak... presumably, the dementia will affect people in different ways.*” - Mike). An enriched profile which detailed one’s own experiences as a carer or as a person with dementia may alleviate some of the issues surrounding reliability that currently exist.

### Representing place and time in digital technologies

Ways in which the Care and Connect application construe place and time were questioned by these deeper engagements with participants – as detailed above, participants described time as a worry, both in terms of the amount of time it takes to organise a public outing with the person they care for, as well as the fairly poor *quality* of time they experience as a carer in public, even doing ostensibly pleasurable or leisurely activities. Beyond this, some carers could not see themselves using the application while out in public with their loved ones – they are simply far too busy engaging with the person they care for to do this. They suggested that using the app in public would result in them leaving similarly short reviews.

It is worthwhile to note that the app did not prescribe a particular time or place for our users to leave reviews – in actuality, we anticipated that they would leave reviews in their ‘down time’ – i.e., in the morning or evening, and not during their busy outings in public. However, the spread of review data indicates that most reviews were left during the day (though at least some were using it in early morning or

late evening ‘down time’), and in our focus groups, participants assumed that leaving reviews while out and about was what was expected. Encouraging contributing behavior in a more suitable context, as part of either the planning behavior or as a post visit action, would offer more time to reflect upon the experience. This could be achieved through providing a bookmarking feature within Care and Connect that encourages carers to save locations they wish to visit and prompting carers later in the day to contribute their experiences.

Beyond this, carers suggested that the app or the reviews themselves might include more contextual data – it was no good that a particular cinema was very dementia-friendly if the journey there was arduous:

**Gillian:** *I think that's also an issue, because in Mahon Point [cinema in south of Ireland], for example, if they do dementia friendly projections it could be - or sensory friendly, I should say. But then Mahon Point is so - where the cinema is, is so hard to get to. [...]*

**Mary:** *By the time you're there you're already having troubles.*

Carers suggested that we include the option of ‘dementia-friendly journeys’ – with many carers reporting that they and their loved ones still used public transport very frequently, particularly in the wake of having driving licenses revoked due to dementia diagnoses, it is clear that they are already getting out and about and retaining at least some independence. Using digital technology to document and increase civic engagement and enjoyment of public services for people with dementia may be an option to include in the future, and this may be possible through App Movement.

### The complexity of inclusion in design

The themes of *exclusion through inclusion* and *empathy in action* may seem to conflict in certain ways – as may the welcoming of the app by almost all carers yet the hesitance of some of these same carers to attend places advertised as ‘dementia-friendly’. However, we argue that what this really points to is the complexity of *friendliness* – participants wanted people to empathise with them and their situations, but did not want to be felt sorry for or have places created for them which would segregate them and define them based on the activities that were provided (often without their inclusion or consent – e.g., dementia-friendly showings of children’s films).

This is a point which has been raised in HCI research before – Rogers & Marsden [26] describe how “*the tendency has been to develop technological solutions ... by providing for a lack of something. This could be technical (e.g., access to the Internet, computers, mobile airtime), a declining ability that comes with age (e.g., sight, looking after oneself, memory), or a physical or mental disability (e.g., autism, depression). While many projects have sensitively and successfully demonstrated how novel*



*technologies can support and enhance people's lives, some are fronted with a third-person perspective, asking questions such as, "What technology do they need?"* [26:10]. It can be difficult when confronted with a condition like dementia that is so often boiled down to a set of cognitive impairments, or a challenge like caring, where all we hear is that it is a 'burden', to not design technologies which simply plug these gaps.

### **Understanding the information needs of people with dementia and their carers**

Garbett *et al* [9] anticipated that the process of App Movement was not entirely suited to understanding the values and technological aspirations of people with dementia and their carers. However, there is evidence to indicate that carers and people with dementia alike can and do use technology to 'mobilise' community activity – the Carers UK forum, for example, is extremely well-populated and active, and serves as one of the foremost destinations on the web for carers of people with dementia to seek peer support and advice. Moreover, our participants described in numerous ways how they already use technologies in positive ways – i.e., using phones to keep in touch with their loved one when they are away from home. They also describe how they negotiate using technologies within their everyday lives which are unavoidable but make their lives harder: i.e., difficulties with moderating their loved ones' online purchases, using self-checkout in supermarkets and libraries, and self-service machines in banks. Although participants described difficulties with these machines, they did not avoid them, and also described how the services they supported were enriching to their loved ones and useful for them. We can imagine that using a mobile app like Care and Connect, or engaging in community commissioning processes like App Movement, can be similarly enriching given enough nuance.

It is clear that we need to work with people with dementia and their carers to understand how best they can be involved in community commissioning processes. Given our findings and an overall growth in use of technology by older generations, we suggest that the novelty of the community commissioning approach may provide a considerable stumbling block for users who are familiar with, for instance, Facebook and Twitter, but not with online platforms like Kickstarter. How to involve members of these communities in community commissioning processes in a more meaningful and comfortable way is an open question for the time being; however, our findings provide considerations of the sorts of values which this community prioritises, and may provide a good starting point for future work.

### **Participatory design and civic engagement**

App Movement does not position itself as an alternative to offline forms of participatory design – instead, its primary aim is to empower communities to commission their own technologies and engage in some design decisions around this. Ideally, this process engenders a series of community

conversations where the community comes to a negotiated solution or response to a community-identified issue. In the case of Care and Connect, it is worthwhile noting that the users who initially engendered the app idea were primarily academics and medical professionals. Although these individuals have a clear place within these communities, and have considerable experience with people with dementia, it is possible that an initial userbase of carers and people with dementia may have resulted in a differently-configured app and a more successful deployment, especially given the level of personal involvement and personal motivation such an initial user group might bring to the process.

It is also possible that App Movement, in its current early stage, is not yet nuanced enough to capture and then represent the experiences of people with dementia and their carers; instead, it may be worth turning our attention to different ways in which HCI researchers have attempted to do this in other studies. Wallace *et al* [34] describe a longitudinal engagement with a person with dementia and her family, wherein the use of probes were used to capture aspects of the felt history and lived experience of the family. These probes included objects like a self-tree hung with labels which helped structure participants' responses concerning their families and a wooden model home which participants used to describe the changing space of their home post-diagnosis of dementia. Incorporating more 'open' prompts and design tasks in an online system such as App Movement may be a useful addition to capture aspects of otherwise inaccessible or ineffable experience which could lend nuance to the overall process and ultimate design.

Does App Movement further a view of the person with dementia or their carer as a citizen and not just a consumer of technology? Care and Connect and App Movement fit well with Bartlett's [1] notion of citizenship as existing within the 'ordinary':

*Ordinary citizens – people who are not political – and 'mundane spaces of daily sociability', such as buses, parks, bars and cafes, can be regarded as spaces of political potential because they provide opportunities for 'subject positions to be experimented with and relations transformed' (Neveu, 2015, p. 147). [1:455]*

Mitchell *et al* [21] write that "people with dementia have the same rights as everyone else to be treated with dignity and respect, to lead independent, autonomous lives and to continue to be active citizens in society whose opinions are heard and acted upon" [21:2]. It may seem that expressing opinions and experiences surrounding local parks, cafes, and taxi services is a very small step on the ladder to 'active citizenship', but it is a step which has not been taken before. Future work could focus on how such technologies might incorporate more explicit expression and input by people with dementia – although our participants with

dementia reported being interested and comfortable in using the app, it is mostly used by carers at the moment.

#### **Moving forward: dementia and online commissioning**

Online community commissioning is an idea which holds a great deal of promise for the dementia care community – we can see that carers are ready to engage with technology when it makes sense in the context of their lives and when it ameliorates the lives of those they care for. Beyond that, governing charities such as the Alzheimer’s Society are increasingly turning to community-level initiatives (such as dementia-friendly communities), to increase service user participation in the design of services which matter to them.

However, the current layout of App Movement (and perhaps other community commissioning platforms) as well as the current iteration of Care and Connect is not yet nuanced enough to capture and represent aspects of the complicated experience of caring for someone with dementia or living with the condition itself. With this in mind, we offer the following lessons from our design engagements which we hope will help to direct future community-level technological work in dementia care.

**1. We should make room for a multiplicity of experiences within dementia.** Our participants indicated that the current iteration of the app was restrictive in its reliance on a starred rating system as well as in the lack of motivation for carers to input text and pictures. Beyond this, carers mentioned that, given the different ways in which dementia is experienced by families, that they would appreciate being able to know more of the history and experience of other users in order to place this information in context.

**2. We should consider different ways of representing and expressing experience.** We primarily worked with carers of people with dementia who themselves had no cognitive impairment; however, a truly inclusive design would also make room for people with dementia to use the app as well. However, the rigid star system and text review field is also perhaps lacking here – as dementia progresses, the ability to communicate verbally is often reduced. Both community commissioning platforms and ‘dementia-friendly’ apps may therefore consider how to utilize audio, video or other data in community design projects.

**3. We should emphasise design within caring relationships rather than for particular users.** While it is probably fair to assume that ensuring the comfort and safety of loved ones with dementia is high on the list of priorities for most carers, our engagements with carers indicate that their relationship with loved ones suffers when a particular activity does not take into account their values and preferences as well as those of the person with dementia. Community commissioning platforms should therefore consider the relational contexts where technology will be deployed.

**4. We have a certain set of responsibilities when it comes to representing our users’ lives through digital technologies.** Many carers mention a frustration at certain activities being labeled ‘dementia-friendly’ due to the inherent exclusion of other, ‘normal’ people within these activities. Labelling anything ‘dementia-friendly’ – including a piece of technology or a commissioning process – will come to define what dementia is or what the experience entails. In this way, designers and commissioners have a responsibility to represent users in a sensitive way which leaves room for them to claim and tell their own experiences.

**5. We should make room for forward motion.** Care and Connect, and indeed many location-based reviewing applications created through App Movement, are useful for communities to come together and share knowledge, there is no ready ‘back door’ for business owners, managers or city councils to respond to reviews, act on suggestions and engender change with the participation of the community. Our participants indicated that creating spaces for people sharing common experiences was a valuable one – not just on the app but in ‘real life’ dementia coffee mornings – but also valued the real changes that came about because of these spaces. Space needs to be made within community-level technologies for such change to be made in tandem with other stakeholders at multiple levels.

Adhering to these suggestions will represent an interesting design challenge which requires, as we describe above, designers’ *‘empathy becoming action’*: a concerted effort to improve the lives of people with dementia by working with their strengths rather than their weaknesses, and positioning them as being deserving, and able, to make decisions surrounding their own lives and circumstances.

#### **CONCLUSION**

This paper has contributed an account of Care and Connect, which aims to rate and review public places and services on their ‘dementia-friendliness’. We describe a series of themes relating from research engagements with people with dementia and their carers which used Care and Connect as a conversation guide, to describe themes of *trust, exclusion through inclusion, and empathy becoming action*. We go on to discuss this research’s implications for future HCI work on community and dementia in relation to engendering trust through relatability, representing time and place in technologies, sensitive ways of configuring inclusion in challenging research contexts, understanding users’ information needs, participatory design in online contexts and the future path of citizenship work within HCI for people with dementia.

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