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# Authenticity, Relatability and Collaborative Approaches to Sharing Knowledge about Assistive Living Technology

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## ABSTRACT

Health and care providers are increasingly looking to online and peer-to-peer services to supplement existing channels of assistive living technology (ALTs) provision and assessment. We describe the findings from 12 co-design workshops with 28 people from the UK representing a range of older people with and without health conditions, users of ALT and carers for people using such devices. The workshops were conducted to explore issues related to finding reliable information about ALT with the goal of gathering requirements for the design of a peer-to-peer knowledge sharing platform. Our analysis highlights how a current reliance on peers and informal networks relates to a desire to establish the authenticity and relatability of another person's experience to one's own circumstances. This connects to a perceived mistrust in information where provenance and authenticity is not clear. We use these to critique the wisdom of taking an e-marketplace and recommendation service approach to ALT provision and assessment, and offer alternatives based on our findings.

## Author Keywords

Assistive technology; peer-to-peer healthcare; online health communities; older people; ageing; co-design.

## ACM Classification Keywords

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

## INTRODUCTION

The study of collaborative and peer-to-peer communities around issues to do with personal health is an important area of CSCW research [15,16,20,22]. Forums, message boards and online information resources, that are often collectively contributed to by members of the public, have been demonstrated to be a useful means for bringing

people together who have similar conditions and health needs [30], providing a shared understanding of what it means to live with specific conditions [22], and support a widened awareness of how to live healthily [16]. Such collaborative approaches to healthcare have been particularly influential in the UK, where patients are encouraged to review and rate the public health services they have used [1], to contribute their knowledge and experience to online resources [17] or share advice with peers via online communities [14].

We extend current CSCW research on collaborative approaches to personal health by exploring the applicability of existing approaches to peer knowledge sharing in the context of searching for expertise and information around assistive living technology (ALT). ALT is a broadly defined category of products or devices that enable older people or those with disabilities to live more independently than would otherwise be possible [49]. Our research was undertaken in the UK, where historically most ALT assessment and provision has been state-provided by local government authorities as part of social care services. As with much social care provision in the UK, ALT is an increasingly mixed-economy (private and state funded) and market-oriented domain. This comes with a shift in policy towards supporting patient and consumer choice—suggesting those who require ALT have a greater autonomy in deciding what they use and buy. However, there are well-known issues such as a lack of public awareness of what is available, inappropriate selling, and a large proportion of ALT abandonment by owners shortly after first use [37]. This is problematized further in the UK as the ALT market is mostly formed of small and relatively unknown companies.

In line with the UK Government's 'digital by default' strategy [11], local authorities are looking to online services as a way to resolve some of these challenges. This has led to a range of online information portals and marketplaces for ALT being piloted by different authorities (e.g. [24, 39]), while there are moves to incorporate peer-to-peer elements through user-generated feedback on ALT products and retailers [33]. In our research, we set out to understand the information, advice and expertise seeking needs of people who are purchasing or in receipt of ALT. Our aim was to explore the ways in which online services and digital platforms—including

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those being piloted by local authorities—may meet these needs. We conducted a series of 12 design workshops with groups of existing users of ALT, family caregivers and older people who considered themselves potential future users of ALT. Our workshops set out to explore the problems that people faced in finding information about ALT that is relevant to their needs. Through discussion and design activities we explored the formal and informal sources of advice and guidance participants already accessed and the barriers faced in relating advice to individual circumstances. We offer two main contributions to CSCW discourse on collaborative approaches to healthcare. First, we highlight the ways in which the trustworthiness of advice and expertise in this context is tightly related to the perceived relatedness of content and access to local resources to assess this advice. Second, we highlight how the practical but highly personalized nature of the information requirements for users of ALT raise implications for the ways in which online communities that support the collaborative exchange of information are designed. In response, we contribute a series of design considerations for collaborative information sharing, focusing on how online communities may be enhanced to support the informational needs of ALT users and how future infrastructuring [29] work is needed to enhance cooperative work between public and private stakeholders and the public.

#### **THE CONTEXT: ALT PROVISION IN THE UK**

ALT covers a wide range of potential devices ranging from small aids (e.g. jam-jar openers or grabbers to help pick up objects) to home adaptations (e.g. stair lifts and bath steps) and electronic aids (e.g. fall alarms and pill dispensers). Up to 13m people in the United States currently use some form of ALT to help them everyday [47], while in the UK it is claimed up to 3m people would benefit from digital ALT services [10]. While there has been substantial growth in the range of ALTs available in recent years, there is a widely acknowledged lack of public awareness about its benefits and the relative quality between devices [13].

Our research was conducted with the eventual goal of developing tools and platforms that help existing and future users of ALT to access and share relevant information resources with each other. The research was conducted in the UK, and there are further particularities to ALT provision here that impact on potential use and access. Historically, aids and adaptations have been provided by local government authorities. This typically involves Occupational Therapists (OTs) visiting people in their homes to assess their physical and cognitive requirements in relation to their daily living activities—although more recently assessments may be made over the phone by an OT's assistant who follows a decision tree. From these assessments OTs provide recommendations for what equipment and adaptations should be provided, which are then delivered and installed by the local

authority or its appointed contractors. However, this is only done when the ALT required meets a need that the Local Authority has a duty to provide for, e.g. bathing. Changes to social care in the UK however mean that people are now being provided with 'personal budgets' by their local authority, with a view to tailoring assessments and allowing individuals to spend their budgets as they see fit [8]. As a way of supporting people in making decisions about how, where and what to spend these budgets on, local authorities have started to commission online services and portals. Some are developing information gateways that provide links to products, service providers and charities specifically focused on the needs of older people (e.g. [24]). Many more have purchased generic online marketplaces that have lightweight self-assessment tools that then list a catalogue of products and services recommended by that local authority that may meet that person's needs (e.g. [39]). There is wide acceptance within authorities, however, that these online resources are somewhat limited in their value as they still require significant management and updating (which invariably means they are out-dated quickly). Furthermore, they offer few opportunities for members of the public to contribute their own knowledge and expertise, or provide ways for them to articulate whether a recommended vendor or information source was of any value to them. As such, there are calls from some authorities, charities and ALT service providers for recommendation services that integrate catalogues with the everyday expertise and contributions of citizens [33].

#### **Collaborative and peer-to-peer healthcare**

In many respects, the above debate surrounding ALT information and provision in the UK is representative of wider changes to the delivery and experience of health care resulting from greater access to the Internet and collaborative information sharing. Over the last decade there has been a huge growth in interest in the role that collaborative approaches to healthcare can play in providing new models of patient-centred and peer-produced health information and advice. A significant body of research has investigated how online health communities (message boards, email lists, blogging platforms and forums) provide valuable resources for people living with specific conditions [4, 30, 36]. It has been argued that involvement in such communities can empower patients by offering them new channels to understanding their condition and understanding why decisions about treatment have been made [4]. Maloney-Krichmar and Preece's [30] seminal work highlights some of the core qualities that online communities may offer people experiencing specific health conditions. This includes providing a channel to communicate anxieties and concerns to supportive others [30]. Online communities also enable community members to participate in a myriad of ways, such as being able to provide data and facts to others, to proactively and subtly

request information and support, or just provide praise to others [30]. The literature on online health communities highlights a number of qualities that typically support active participation, including their increased anonymity which supports greater disclosure [23], confronting people with experiences that are similar or opposed to their own [31], and as a way of finding experience-rich information that is hard to find through formal channels [15].

HCI research on online health communities in HCI has thus far focused primarily on their emotional support qualities (e.g. [23, 30]) or on ways to increase participation [31]. This has included studies of such communities for older adults [27, 36] and family caregivers [46]. However, there has been relatively little work on exploring the ways in which people identify expertise relevant to their needs. Exceptions to this include [6, 7] which highlighted the strategies that women with breast cancer take when trying to identify ‘everyday’ experts. We expand this work but deal with a context where there is no established common ground between individuals whose needs (and their understanding of these needs) are in flux and where access to local ALT resources is of greater concern than social support.

#### **Recommender systems and online marketplaces**

A further area relevant here is the growing literature on recommendation services and online marketplaces, both of which have grown enormously in popularity over the last decade. Websites such as TripAdvisor, Urbanspoon and Yelp provide the public with a wealth of reviews of local hotels, restaurants and bars. A significant amount of research on recommendation services has focused on improving the algorithms underlying recommendations (e.g. [19]) or developing tools and visual cues to support making sense of reviews on these sites (e.g. [51]). Brown’s [5] ethnographic work of review site users, however, highlights some of the motivational factors for use of these sites in the first place instead. It was noted that such sites allowed people to pre-visit locations and establishments, arming them with information in preparation for a visit.

Review and recommendation services have also become an integral component of online commerce and marketplaces. Online commerce research has highlighted how negative reviews of products have a greater impact on subsequent sales than positive reviews [9], and reviews are particularly influential when products are new and less well known [21]. Furthermore, reviews on sites like Amazon become more influential in the context of ‘experience products’ [38]—i.e., those products that require use or consumption in order to judge their quality or worth [28]. In a similar vein, it has been noted that on Amazon those reviews considered ‘helpful’ are typically those including experiential insights based on the context of using a product and advice on how to best use it [42].

The reliability of online reviews has often been debated. It is not uncommon to see news stories of how business owners place false reviews [43] on TripAdvisor. In 2012, Amazon deleted several thousand ‘fake’ reviews after public complaints [44]. Similar concerns have been raised about the reliability of user-generated reviews as they have started to become influential in the domain of healthcare. In 2009 the UK’s NHS opened a rating and review function on their Choices website allowing patients and their families to rate NHS services and write short reviews backing up their score. Proponents have argued that this enables doctors and staff to better understand patient experiences and improve services in the future [1]. Those challenging the idea have questioned the impact overtly negative and positive reviews may have on trusted relationships between patients and health professionals [32]. Clearly, the perceived reliability of such information becomes even more critical when moving from leisure to health.

As noted already, the popularity of review sites across a number of domains has led to calls that user-based recommendation services could increase the wider public awareness of ALT and the purchasing of more appropriate devices by users [41]. Indeed, ALT recommendation sites already exist (such as GadgetGateway [53]), and it is possible to purchase and review ALT and mobility aids from Amazon.com and affiliated merchants. But these sites are notable for their absence of reviews and poorly updated content. Furthermore, there is not yet a sense of how appropriate such resources may be to existing or future ALT users. In our work we examined the reasons existing resources may fail to attract reviews, and what critical factors related to the experience of ALT use need to be accounted for in the design of such online services.

#### **DESIGNING THE RESEARCH**

In designing our study, we worked closely with a social enterprise set-up whose aim is to improve choice and independence for older people in the UK. In developing our approach, we explicitly drew on insights from the literature on peer-to-peer health and online health communities as well as the experiences of our collaborators. We focused the study around exploring three interrelated issues.

First, while there is a widely acknowledged lack of knowledge and awareness around ALT, there is an equal lack of research into precisely how people go about looking for information and advice on it in the first place. Therefore, a primary focal point of our study was to *explore the information seeking strategies and the local resources and strategies* that participants draw upon when trying to find advice and guidance on ALT.

Second, we wished to understand the perceived differences between accessing and using advice and recommendations online as compared to advice received in person. That ALT has historically been supplied and funded by the state

involving in-person assessments may mean participants may place different levels of expectation on interactions occurring online or offline in this domain. Furthermore, given the noted recent publicity in the UK press around the fallibility of online review sites, we felt it important to understand if participants *trusted certain sources of information related to ALT more than others* and what implication these may have for online service provision.

Third, we were not just interested in understanding how people might find information, advice and resources related to ALT but *designing new resources that help them in finding out about the right ALT*—i.e, ones that met their particular needs and came from reputable sources. The self-assessment of need in the context of ALT is particularly challenging as individuals will likely be going through significant personal or familial changes. Furthermore, in many instances it may be a family member or friend acting as a carer who is informally assessing needs, adding further layers of complexity.

The overall goal of exploring these three interrelated issues was to identify the requirements for new collaborative and peer-to-peer online services that support the public in locating expertise in ALT relevant to their needs.

### Participants

We undertook a series of design workshops with people representing a diverse range of beneficiaries and users of ALT. In recruiting participants we explicitly aimed to work with older people who either had experienced living with a range of ALT devices or helped others in acquiring them. In total we met with 28 participants, with a mean age of 70 years. Our oldest participant was 84 years old, with our youngest being 43. 19 (68%) of our participants were female. Of those participants older than 65, 66% considered themselves frequent users of the Internet from their home through personal computers, tablets and smartphones. This is above the UK average for this age range (47%) [35]. At the same time, our participants reported generally low-use or knowledge of online communities, social networking and recommendation services (two participants used Facebook, and 4 had used TripAdvisor). None were aware of the online services provided by their LAs or any local ALT charities.

The range of experiences among our participants and their motivations for taking part in the research were diverse. 8 identified themselves primarily as frequent users of ALTs. Of these, only 1 participant had not directly purchased their own aids or adaptations, having received theirs primarily through their local authority. The remaining 7 ALT users had used a mixture of products purchased by themselves, provided by the state or given to them by friends and family members. 10 further participants self-identified as carers for their partners or parents who had chronic conditions and disabilities. They configured their participation in the research in reference to their

experiences of purchasing, installing and maintaining ALTs on behalf of those they cared for. Their motivations for taking part ranged from wanting to find out about new gadgets to a desire to share their frustrations of struggling to find information about ALT. The remaining 10 participants did not self-identify as either users of ALT nor carers but as individuals that were concerned about their own future welfare. They drew upon the narratives of friends and family members to motivate their participation in this research—highlighting the problems that significant others in their lives had faced in finding reliable information around ALT, and the problems they had with both state provided and privately purchased aids.

It is important to note that while the above distinctions are useful to illustrate the diversity of the participants, individuals would often sit between group boundaries. For example, one participant came to the workshops with the intention of discussing his experiences of searching for equipment and devices for his Mother who was living with dementia. But he was also a wheelchair user, and frequently drew upon his personal experiences of assessing his own needs. Similarly, individuals who identified themselves as ‘users’ of ALT also acted as carers for spouses, brothers and sisters, who themselves had gone through similar experiences.

### Co-Design workshops

We met the participants in 6 separate groups. In arranging the groups, we did not aim to separate participants into distinct categories. Rather, we wished to place their experiences and views ‘in dialogue’ [50] with one-another. We met each of the 6 groups twice in a series of 2 design workshops (12 workshops in total). The aim of these workshops was to elicit rich discussions and undertake co-design activities related to the three core issues we wished to explore. We carefully constructed our methods to reflect the challenge of supporting participants in imagining the role technology may play in a context where it is yet to intervene greatly, and also to engage them in dialogue with each other around their potentially diverse experiences and needs. In the following sections we describe the methods used in these workshops.

#### *Workshop 1: Introductions and Invisible Design*

The first workshop opened with participants introducing themselves to one-another and being invited to explain their interest in the topic of the workshops. This was structured through asking each participant to start with ‘I’m here because...’ and then detailing their motivations for participating in the research. Following this, participants were invited to recall their experiences of ALT—including how they had come into contact with it, where they had accessed or purchased it from, and how they ended up with the equipment and devices that they or their family members owned. This provided opportunities to explore a wide range of commonalities and differences between participants in relation to our first issue of concern: *the information seeking strategies and the local*

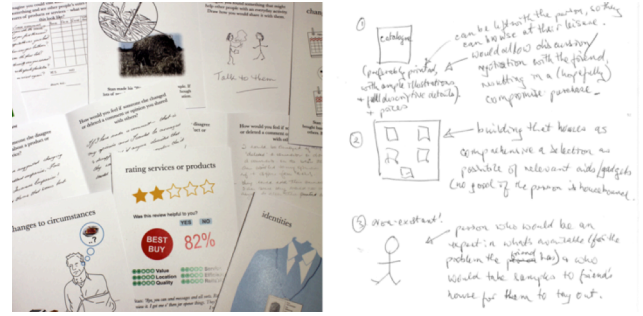


**Figure 1. A still from the 'Cucumber' invisible design film with Stan explaining to Billy the service he has signed up to.**

resources drawn upon when making decisions around ALT. During this discussion-based activity—which lasted between 60 and 90 minutes—the researcher visually documented the different resources (organisations, retailers, publications, people) participants referred to as a map for all to see.

This activity was followed by a presentation of an Invisible Design film [3] called *Cucumber*. In Invisible Design films the focus is on the dialogues between characters who discuss a technology that is in the scene but never seen. This technique has been highlighted as particularly useful in undertaking co-design with older people in the early stages of a design process [3]. We developed our Invisible Design Film with a view to engaging participants in speculations around the relationship between the characters and issues to do with online information exchange and sharing advice and tips with peers. The aim here was to explore the second focal point of whether participants *trusted certain sources of information related to ALT more than others* about ALT and the differences between receiving advice from strangers and friends.

The *Cucumber* film opens with an older gentleman—Billy—sat in his armchair watching TV. A “knock knock” is heard followed by a male voice: “it’s only me!”. Another older gentleman—Stan—enters the room holding a bag of shopping. Upon closing the door a picture falls off the wall behind Billy. As a result, what ensues is a back and forth between the two with Stan talking about a new service he uses to get advice and tips from people to fix problems like this. But Billy refuses to accept Stan’s advice. He questions whether those giving tips would be “cowboys”. When Stan explains “he bought a knife sharpener, based on a recommendation”, Billy replies with “Aye, from a guy who makes knife sharpeners”. After some more discussion, Billy starts to come round to the idea, but Stan says: “You’ve got to sign up. I can ask for you, but if you want one you’ve got to sign up. You should. You’d be good man.” Billy sits back in his chair: “Ah well. Maybe” he sighs. As with prior Invisible Design films humour plays an important role, emphasized by the film’s ending of Stan giving Billy a cucumber, the reason for him visiting in the first place.



**Figure 2. A collection of Topic Cards with written responses (left) and an example of participant drawing in response to design activity on rear of card (right).**

After watching the film, participants were asked to comment on the film and then to address the ‘invisible design’ (the imagined online peer-to-peer ALT community) associated with it. This discussion would last anywhere between 30 to 60 minutes. In their entirety, the workshops lasted up to 3 hours in length.

### Workshops 2: Participant-led topic cards

At the end of the first workshops each participant was provided with a pack of 8 prompt cards (Figure 2). Inspired by the Questionable Concept technique [48], the prompt cards were designed to gather further reflection on issues touched upon in the *Cucumber* film. Each card had an illustration on the front with a title and a quote from the film. Inside, there were two open-ended questions and a small design activity for participants to respond to. The cards were intended to provoke deeper discussion and reflections on the design of the peer-to-peer platform. For example, the ‘membership’ card posed questions related to the provenance of information and whether participants would feel differently if people providing recommendations were recognisable members of a community. The design activity here asked participants to ‘write or draw what you would like to know about other members of the community’. It was explained to participants that they did not have to respond to all of the cards and that the second workshop will be based on discussing the cards that they had completed.

The second workshops were structured around each participant selecting a prompt card to discuss and allowing them to lead discussion around this issue. Participants took it in turns to talk about the card they had chosen, why they had chosen it, and what their responses were. The researcher would invite the other participants to talk about their own responses to the same card (if they had done so) with a view to drawing out further overlaps and contrasting views around the design of the platform.

### Data analysis

Each workshop was audio recorded, resulting in approximately 28 hours of data. These recordings, along with written responses on the cards, were transcribed. Combined with the visual material, this was treated as a data corpus on which an inductive thematic analysis [2]

was performed. The analysis proceeded through the development of single-word codes that summarised textual excerpts at the sentence level for text and an artefact level for visual material. Codes were grouped together to generate 4 themes from the data: (1) *expertise and advice*, (2) *authenticity and transparency*, (3) *family, friend and peers as a resource*, (4) and *reliability and testability*.

### EXPERTISE AND ADVICE

The opening ‘I’m here because’ discussions provided a structure for participants to discuss their existing strategies and challenges for finding information about ALT. As noted, none of the participants were aware of existing online resources provided either by their local authority or by charities and non-profits. Indeed, a lack of awareness of any sort of information or support was common:

*“If I wanted to go and buy some fruit, in 15-20 minutes I could’ve visited 6 shops and bought some. If I want to see somebody about the arthritis in my wrist, I haven’t the faintest idea who I would go and see.” – M2*

In making sense of this situation, M2 was aware that at some level that as his challenge was related to his arthritis then it may be seen as a medical issue. But at the same time he was aware that it was not a concern with the medical condition itself but the impact that it has upon his life. He was not seeking advice on how to remedy his discomfort but rather how to alter the environment around him to make conducting activities as comfortable as possible. It was difficult for participants to make sense of this complex relationship however. There was still an expectation among a large majority (n=15) of participants that their doctor would be able to advise them. M4, for example, spoke at length about how he visited his doctor on a number of occasions and asked about *“things to help him around the home”* following being diagnosed with polymyalgia rheumatica. All that his doctor provided after several visits was suggestions on what Internet search engines and search terms to use to find information. This raised further challenges for M4, as he did not consider himself *“very good at operating the home computer”*. He had a view, shared by others, that his doctor had the credibility and qualifications to provide informed advice. In reality, however, there is little interaction between doctors and local authorities in assessing the needs of an individual.

M4’s experience also illustrates how participants felt comfortable visiting their doctor to ask for advice, but did not feel at ease with the idea of having an Occupational Therapist visit their home and *“assess”* them. In M4’s case this was partly a result of not wanting to be *“bothersome”*, to *“escalate the situation”* and be seen to be *“making more out of it than I need to”*. While a trip to the doctor’s surgery for advice was acceptable, there was clear discomfort at the idea of someone visiting his home to assess him. This also illustrated a desire across participants that while advice and guidance was desired, so was a feeling of dealing with and managing it individually or within the

family: *“My husband had a bypass on the damaged nerves in his hands and arms, and I’d never thought about getting help. We just got on with it.” (F14).*

To a small number of participants (n=4), however, it was surprising that the issue of information and advice seeking around ALT was worthy of investigation. F3 for example had used a number of aids at home since she had surgery 10 years ago: *“I have a lot of gadgets, help and all sorts of things. It surprises me that some people don’t know where to go.”* F3, along with two of the family carers (F12 and F17), had received all of their aids from their local authority—however, none of these participants were aware of the upcoming changes to state provision that meant how they accessed and used this service would change. M1 was also surprised at others’ lack of knowledge of how to seek advice. Having lost his sight 10 years ago, he has since received monthly newsletters from the Royal National Institute for the Blind: *“I get a product newsletter [...] They send their stuff out to blind persons to be tested, and ask them at the end for a review on it”* (M1). He trusted this because it came as a recommendation from a charity he trusted and as he had been a *“reviewer”* himself a number of times.

### AUTHENTICITY AND TRANSPARENCY

It was clear that ALT was a particularly problematic topic when it came to trusting sources of information. While there was a lack of awareness at three levels—that ALT exists, what its potential benefits are and where to go for advice—there was a great awareness of sources of advice that should not be trusted or were lacking in authenticity. All but 3 participants recalled stories of door-to-door salesmen who appeared to target their or their older family members’ homes to sell expensive adaptable furniture and equipment. Two participants explained how they had purchased a large number of electronic aids for themselves (M4) and for their mother (F14) based on adverts in newspapers and catalogues received in the mail. Adverts for products would come with grandiose claims and quotes from customers about how the gadget had changed their lives, yet it was common for gadgets to break within weeks of purchase. The sharing of these negative experiences was combined with a general sense across all the groups that older people and carers in emotionally distressing situations had heightened vulnerabilities, and a prime target of rogue traders and salesmen *“hard selling”* (F11) inappropriate products: *“I think we are aware that there are many people trying to talk us into agreements that are not true and people who try to gain from other people’s lack of knowledge.”* (F7). This reinforced a reliance on state services, as they were seen to be more trusted and independent in their advice.

The deep sense of distrust surrounding ALT was particularly evident during the invisible design activity when participants speculated about the relationship between the characters in the *Cucumber* film. First, some participants raised concerns about the unstated motivations of people providing *“seemingly unbiased advice”*. The



**Figure 3. Topic card responses from F10 (left) and F18 (right) highlighting preferences for in-person and hands-on experiences of sharing advice with others.**

scriptwriter had intended Stan to come across as trying to help his friend Billy by giving him advice on how to adapt based on what he had seen online through the device “in his bag”. Approximately half of the participants (n=12) deemed that Stan had hidden motivations however. They specifically latched onto a part of the script where Stan reiterated to Billy the need to ‘sign up’ to this service in order to receive information. A number of participants reacted angrily and felt “uneasy” (F3) at this point. This was in part because there was an expectation that the ‘free’ aspects of the service would be temporary: “the first month would be free and then you have to pay for it afterwards” (F2). Furthermore, there was a view that even if Stan was acting in the best interests of Billy, then there was too much ambiguity on: “who it is exactly that is providing the recommendations in the first place” (F6).

The lack of transparency of whom was providing a particular recommendation or piece of advice was seen as a particular problem with existing review sites. During the Invisible Design activity, participants picked up on the qualities that Stan’s service shared with services such as TripAdvisor. Those participants who had used such sites felt that people providing reviews would be doing so for underhand reasons: “How true are they? Are these reviews put together by Amazon?” (M1); “I tend not to look at those sorts of things, because you get just rants.” (M2); “[I’m] never sure if the “put downs” have been posted by competitors.” (M5). Others spoke about the “unsettling” experiences of receiving emails from sites such as Amazon making suggestions about what other products might meet their needs: “It’s like, “We noticed you bought this.” So, it’s as if they’re keeping tabs on everything that you do.” (F1). Such emails were seen as invasive rather than helpful and participants felt companies were only interested in selling products rather than genuinely finding something that was of interest or relevance to them. Based on these comparisons it was clear that having viewed the film the majority of participants did not consider Stan a friend or an ally, but a deceptive individual trying to influence Billy.

#### **FAMILY, FRIENDS AND PEERS AS A RESOURCE**

Given that most of our participants did not rely on their local authority for assessments around their needs—and

visiting their doctor or trusting commercial advertising was not a viable option—there was often a reliance on family members, friends and people in similar circumstances as sources of advice and guidance. For example, 4 of the older participants relied on their adult children to perform lengthy searches on the Internet to find information on their behalf: “I’ll just ask him [her son] to have a look for me now” (F15). It was notable however that those who stated having the most success identifying and purchasing new equipment were those who had had chance conversations and meetings with friends and peers. Returning to M4’s experience, the resolution to his information challenge was through a chance meeting with an old friend he was visiting for an unrelated reason: “She found out I had got PMR. She produced four pages of information on it, with ways to change your home and bits of equipment to do small things in the kitchen and bathroom.” (M4). In a similar vein, in the topic card discussions in the second workshop 12 participants chose the ‘sharing solutions’ card to discuss with the group. In these discussions they recalled chance exchanges of information and knowledge related to ALT between friends. F2 explained how she met an old friend at the bus stop recently after a long period of not seeing her:

*“She needed her walking stick but she kept dropping it, [...] she had to stop going into town. Somebody had told her about this thing [it] goes round your wrist, and the other on the stick [...] such a little thing has made all the difference to her life, she’s independent again.”*

F2 was so impressed with this adaptation that she made a note of its design for future reference, and shared it with everyone in the workshop. She explained how she knew of other people with similar problems, and would share this tip with them (Figure 3). Relatedly, 5 female participants explained how they would regularly go to coffee and tea mornings with friends. At these get-togethers they would allow “only 10 minutes for ailments!” (F8) and use this as an opportunity to talk about their problems and exchange ideas about changes they had made to their homes to make their lives easier. Such exchanges of information and advice also frequently occurred during our workshops. At the first workshops more experienced participants would offer suggestions to others on gadgets to help with specific activities and routines in their homes. At the second workshops, participants brought catalogues or print-outs of products they had spoken about previously. M1 proudly demonstrated his ‘pen friend’, which allowed him to record and recall messages from barcodes stuck onto objects. As he had very limited eyesight, this “gadget” was perfect in helping him find items around the home and not have to rely on his wife all the time. The other participants in this group were engrossed in his demonstration, exclaiming: “That would be handy on my prescriptions” (F6); “I need one of them now!” (F4). Indeed, several participants suggested that one way of resolving the issue of a lack of knowledge about ALT would be to provide spaces for



informal get-togethers at community facilities, mimicking our workshops (Figure 3).

### RELATABILITY AND TESTABILITY

Friends and peers were also influential due to the commonalities (or not) that they had with one-another. As such, their accounts, advice and experience were more easily 'relatable' to a participant's own situation than people whose background and provenance was unclear. For example, F4 explained how she valued the opinions of her female friends in particular *"because what a man might find easy to use, I with little, rotten grip might find very difficult to use. I think only my older lady friends understand this"*. Participants who already used various forms of ALT found that the *"best recommendations"* they had received tended to be from people with very similar disabilities, conditions and life experiences to their own. F8 and F9, who both suffered from rheumatoid arthritis, found meeting people of a similar age with symptoms of a similar severity on a social level provided them with a great amount of advice in relation to useful aids to buy for their home. Friends were also important *"recommenders"* due to the social and cultural commonalities people felt they had with one-another. A small number of participants relied heavily on age-related or condition specific charities for any advice in relation to ALT. While in some cases this was motivated because they were seen to be trusted and independent organisations, in others the motivation was they felt the people making recommendations could more easily relate to their own circumstances. Participants found comfort in knowing advice would be coming from someone whose life experiences may not be far removed from theirs: *"It is re-assuring that they have had 'hands on' experience of needs similar to your own"* (F4). Suggestions from friends in particular came with a contextual understanding of that person's values, tastes and life experiences.

Relatability was also important in supporting reflection upon one's own circumstances and needs. Participants who were active users or seekers of ALT all spoke of the trial and error approach they had to take to the purchase and use of aids and adaptations. This was not just a limitation on available information on products, but also a limitation on their understanding of their or their family member's needs. Returning to M4's experience, he spoke candidly about his experiences of being diagnosed with polymyalgia rheumatica:

*"I'd never even heard of it until it hit me. I was travelling up from London, got to Durham, started to get my thing ready, and found I couldn't get out of the chair and I couldn't reach my case above my head or anything. A young lady in her thirties got my bag down for me and stood me up, and opened the door at Newcastle so I could fall out, because it only stops for three minutes. For the next five weeks when I went to bed, my wife had to turn me in bed, this sort of thing."* – M4

M4's situation was not unusual among the older participants. The onset of his condition was dramatic and fast. He had no time to prepare for or adjust to the

situation and was immediately confronted with the fact that he could no longer do even the simplest of activities he could before. But through relating his experiences to that of his friend in a similar circumstance, M4 began to come to a realisation of how he needed to *"approach"* everyday activities. Others explained how situations such as this were alike to a personal *"crisis"* where their lives or the lives of the person they cared for changed dramatically in a short space of time. During these periods of great transition, individuals felt as though they were continually playing catch-up with their changing needs and understanding of how daily activities needed to be adjusted or adapted. As such, it makes it impossible to know what to look for in order to help, as the reference point (the body) continually changes. These concerns were not just limited to those experiencing the onset of a condition or returning home following surgery—carers also commented on the great challenge of making quick decisions on someone else's behalf: *"you have to make decisions about adaptations very quickly, because the hospital is going to chuck her out."* (M8). In both M4's and M8's circumstances, the search for items to adapt the home was a process of continually asking questions about their or their Mother's needs—and indeed, the failure for M4 in finding suitable equipment to make his life easier continually allowed him to understand what his needs were not if nothing else.

Finally, even if shared knowledge was relatable at some level, then some form of physical access to locations where these items could be tested was of utmost importance. There were two reasons for the apparent need to visit locations nearby to see potential purchases. First, participants valued the people and organizations surrounding products as much as the product itself. They would carefully choose not just what they wished to purchase but also whom they would buy them from. Second, and perhaps more challenging in practice, was the view that ALTs are a type of *'experience product'* [34] that require holding and experiencing prior to purchase in order to assess that they meet one's needs. One of the great challenges here is that not only is there great diversity in the range of devices available but also in the needs of potential purchasers, users and their homes. F12 had cared for her Mother for 15 years and had a great amount of experience buying small aids or investing in larger adaptations to support her mobility. As a result of not knowing where to source certain devices locally, she often relied on purchasing adaptations online or over the phone based on advice she had seen on online message boards. Frequently what was delivered was not appropriate for her Mother's specific physical needs or for the space requirements in her home: *"You think, What an absolute waste. If only we'd had the chance to go somewhere and try out a prototype, it would have saved all of that money"* (F12).

## DISCUSSION

Our findings highlighted that our participants appreciated the opportunity to make informed decisions around the types of ALT that they purchase and use. At the same time, they frequently struggled in identifying sources of information that were reliable, authentic and relevant to their own needs. While online information resources and catalogues are being introduced, none of our participants were aware of these. There was a reliance on perceived ALT experts—such as doctors. But an equal lack of awareness of what is available by these experts, along with a lack of co-ordination between health providers, local authorities, and charitable organisations, introduces barriers to accessing informed advice. The lack of such resources and experts to draw upon further complicated periods in life where time is of a virtue and individuals have to quickly adapt or make quick decisions on the behalf of others. Therefore, rash decisions can be made, inappropriate equipment purchased or installed, and ALT thus become disused and abandoned in people's homes.

As was expected at the outset, there were also issues to do with the trustworthiness of ALT information sources. There was a lack of trust in online reviews and advice. While this was generally expected given wide scepticism around the authenticity of content on review services such as TripAdvisor, there were concerns very specific to the domain of practical ALT advice that problematized online content further. The lack of context and transparency on who may be providing advice and recommendations impacted not just on its credibility but also its relatability. There was a deep sense that such content would be inappropriate for decisions that may significantly impact on a person's life. Yet at the same time it was clear that making decisions was a highly collaborative activity, and participants had great trust in advice and recommendations from friends and peers they personally knew. Furthermore, we saw how the interactions between participants—most of whom never met each other prior to this research—promoted dialogues and the sharing of tips, advice and knowledge around ALT. Friends, peers and fellow participants were trusted for the same reasons that online content was not: they knew these people well in social circles; or they regularly saw them in their community; or they knew enough about their friends' lives to assess how relatable a recommendation may be to their own needs; or their peers were aware of accessible locations to buy, request or even test out these devices; or through in-person dialogue and rich descriptions they were able to assess whether one person's suggestion was immediately relevant to their own needs.

The existing agenda of the UK Government and its local authorities around information portals, online marketplaces and recommendation services currently fails to account for complex and subtle needs of individuals searching for advice and recommendations for ALT. However, while there was a great amount of mistrust and

reservation about the role of digital technology in the sharing of relevant knowledge and advice, this was not necessarily a blanket suspicion or disregard of online content. Indeed there were clear opportunities for developing online communities and resources that are collectively and collaboratively contributed to. Our findings can inform the design of the growing number of technologies addressing issues of trust in peer-to-peer healthcare and bridge online communities with locally relevant and community developed information resources. The following sections discuss these areas to develop and offer general reflections on our findings and approach.

### Supporting collaborative contributions and legibility

Our findings highlighted how the trustworthiness of advice was related to the capability for individuals to relate these to one's own circumstances. Prior work has explored the issue of trustworthiness among peer-produced health content, noting for example overtly emotional accounts [18], an inability to see similarities between a stated situation and one's own context [52], and commercial overtones of websites [41] all being barriers to trust. A popular response has been to develop interface cues that communicate the trustworthiness of content to a user—for example, through ranking content based on network analyses [12], by highlighting the expertise of a contributor [29] or by using 'bandwagon' cues to visualise the popularity of content to other community members [26]. While these types of cues may provide an immediate sense of the value of contributions, they assume a critical mass of users and also a community that is coherent in being able to assess the value of content. As we have highlighted, our specific context deals with a situation where there is no existing online user base and, even if there were, users would be diverse in ways that makes such cues redundant.

A potentially more fruitful approach here might be to support deepened and more contingently sensitive engagement from and between contributors and readers. Insight can be gleaned here from discourse analyses of online health communities that have highlighted the ways in which users negotiate the trustworthiness of content. For example, Sillence [40] noted how members of an online community for men with prostate cancer would negotiate the applicability of requests for advice to their own experiences through the careful curation and reading of profile content. Requests for advice were met with requests for greater detail, with members providing examples of their own experiences at the same time to illustrate the types of insight needed to meaningfully respond. As such, the trustworthiness of content was facilitated through threading advice with examples of personal experiences and linking to external resources that acted as evidence. These observations come from an online community in practice—however, they raise three opportunities for design in regards to the ways in which

such interactions between members could be supported by interface cues.

First, carefully worded *contribution cues* could act as prompts and suggestions for the type of language used and detail to add when posting content (e.g., an experience of ALT). For example, it was clear from our workshops that the great potential of ALT is that it can enable people to continue independently performing routine activities they value. Contributors may be prompted to focus on their personal story as a journey—what had changed in their life, what impact this had on their everyday routines, and how a device improved this situation (or not). A similar story-based approach could be taken for those requesting support or advice. Through conveying their experience in this way, community members would increase opportunities for others to identify how relatable their experience is to their own circumstances.

Second, working alongside contribution cues we might imagine those reading the content are provided with *legibility cues*. We saw in our workshops that a core quality of understanding the relatedness of accounts was dialogue between participants. Here, polite questioning of experiences was used as a way to explore the relatedness of another participant's experiences to their own. However, what was an atmosphere of polite scrutiny in a workshop can all too easily become more toxic online (e.g. [45]). As such, we suggest here that legibility cues are 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. These questions may be generated by other readers and contributors, highlighting the ways that contributions and requests for information could be read or interpreted to support legibility. The aim here would be to engender a level of personal scrutiny valued in workshops without necessarily promoting an atmosphere of conflict around the validity of a contribution.

Third, online ALT services would benefit from *enriched profiles and contributions* that embrace multiple forms of content creation. One benefit of our topic card approach was that some participants were able to express anxieties and frustrations better through visual imagery and drawings than they could in text or in person. It also supported the expression of practical information in a more coherent manner—such as F2's sketch of an adaptation. We also saw opportunities for video and photo sharing to act as a conduit to making experiences and advice more relatable as well. Visually documenting equipment in use in 'real' home environments would be crucial to helping others envision its relatedness to one's own circumstances. But furthermore, user-contributed content in this form would support a greater amount of authenticity and the evidencing of ALT experiences. This would be particularly important given the wide mistrust of promotional material around ALT.

### Infrastructuring localised resources

The success of taking a peer-to-peer approach to sharing experiences related to ALT is not just dependent on contributions being relatable, but also having awareness of the local availability of ALT in the first place and being able to test them. Information and advice can only help so much in a context where people's circumstances can be so different—from their physical capabilities through to what they value aesthetically and the environment they live in. Therefore, any peer-to-peer service must integrate online content with signposts to locations where gadgets and technology can be touched, seen and tested.

While technically the development of signposts within an online community to trusted locations is very feasible (for example, using locative media and mapping systems), there are a number of reasons to doubt the efficacy of a primarily technical response. ALT retailers and service providers and disability centres do exist in the UK, but they are still highly distributed, reflecting their publically funded heritage. That means facilities and resources available to people in certain locations may not be reflected in others—even across the same city, depending on authority boundaries. Instead, we suggest a more appropriate response would be to explore opportunities for infrastructuring—the alignment of social (i.e. people and practices) and material (i.e. artefacts and technology) resources [25,28]. In CSCW, the notion of infrastructuring has been used as a focal point of studying the ways that people and organisations cooperate in order to facilitate the operation and integration of collectively shared resources, knowledge and technical systems (e.g. [25]). However, it is rarely considered how infrastructuring may be proactively supported and the ways in which socio-technical platforms may be supported in developing over time (notable exception being [28]). We can envisage infrastructuring in the domain of ALT occurring at two levels.

A primary infrastructuring activity would be to develop greater coordination and information sharing between existing public, privately and voluntarily provided ALT services. In regards to seeking expertise and advice, we saw how there is a need to engage health providers to act as trusted intermediaries for any online resource and support those seeking advice in facilitating its access and use. But there is also a need to ensure that those resources already in development (information portals and online commerce) provided by local authorities signpost one-another and are updated with accurate and relatable listings of products and services available in the local area. This requires further work around who exactly is contributing and updating information on such sites, their ongoing governance, and whether communities or user advocates themselves might contribute content when new local facilities and resources become identified.

Secondly, infrastructuring activities could orient around resource mapping and identifying gaps in resource and

service provision. Building on Grimes et al's [15] notion of 'deeply local' online communities, the ambition here should be to use local knowledge to map what ALT relevant facilities and resources are accessible within a specific locality. At one level, it could be imagined that this would lead to the mapping of resources and expertise beyond retailers and disability centres, to include local advocates and 'lead users' that are willing to act as demonstrators and 'show and tell' their own equipment to those who are requesting help. Furthermore, through mapping, imbalances in ALT availability and provision across localities might be highlighted. Thus providing opportunities for further engagements with public and private bodies to improve local ALT provision and the availability of facilities and, thus, awareness of ALT in specific geographical communities.

### Reflections on our study and findings

As a final point, it is worth us reflecting a little on the findings of our study and our methodological approach, given the exploratory nature of our work and our atypical methods. First, it's important to note that we did not set out to build an online platform and study its use. Rather our work set out to study a context where there is great societal change and no existing reference point for online peer-to-peer exchange. Our methodology responded to this by providing structure and activities to support participants in expressing their experiences and imagining how these may be altered in the future. Although developing an online platform and deploying it in a field trial could be the subject of future work, our findings suggest that further infrastructural work is required before this would be fruitful and meaningful.

A further point to reflect on is our decision to explore this context through workshops where relevant parties were brought together to engage in activities and discussion relevant to this understudied domain. The workshops were successful in as much as they revealed a myriad of issues and design opportunities for online services and technologies in this domain. However, future ethnographically informed research in this domain is required that targets in more detail some of the core issues identified in this study.

It is also worth reflecting on the methods that we used to engage our participants in discussion, especially as they may seem non-trivial. As noted by Briggs et al. [3], Invisible Design films in particular are challenging to produce and require great care in balancing the narrative context of characters, emphasising a technological intervention (the design) but being explicitly non-committal about what its form or function is. Briggs et al. [3] highlighted how these films can be frustrating to participants—and indeed we had reactions from some participants who just “*wanted to know what was in the bag*” (F3) or felt “*if it had told us what was in his bag then it would have been much better*” (F12). One of the main purposes of these types of films however—and especially so in

*Cucumber*—is to avoid discussion that focuses on form and promote debate around the experiences of the characters in screen. As such, the film succeeded at this, albeit in a way not imagined by the research team. Rather than focusing on Stan and Billy's relationships with the unseen individuals that were offering advice and recommendations to Stan, participants focused on the relationship between these two on-screen characters. Interestingly, what was scripted as two 'mates' having a catch-up was frequently taken to be one more active individual enforcing his way of doing things on his 'friend'. These insights were still useful however, as they highlighted immediate challenges to trusting advice from others in this context—challenges that are further emphasised when taken to online environments.

### CONCLUSION

In this paper, we have focused on exploring the challenges and opportunities that are facing the use of peer-to-peer approaches to knowledge sharing in the context of ALT provision in the UK. We noted that peer-to-peer exchanges may have the potential to widen awareness of ALT to those who may need it. Yet to make any online community or service in this space meaningful and relatable, content and contributions must communicate rich insights about the context that the advice comes from. Yet perhaps of most importance is the need for supporting the testability of others' experiences and signposting physical locations to try ALT in one's own community. As it stands, such facilities are few and far between. Therefore, future design activity may focus on the development of tools and platforms that support the sharing of these locations, and encourage peers to meet and share their experiences with each other in person. This raises great implications for the ways in which governments in nations such as the UK are replacing public services that have relied on interactions between people with digital alternatives. Rather than taking a 'build and they will come approach'—as is the case with the existing tactic of developing information portals and online marketplaces—we have argued that this is a context that requires infrastructuring and the development of tools to support this process.

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