Shared Language and the Design of Home Healthcare Technology

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ABSTRACT
Words and language are central to most human communication. This paper explores the importance of language for the participatory design of smart home technologies for healthcare. We argue that to effectively involve a broad range of users in the design of new technologies, it is important to *actively develop a shared language* that is accessible to and owned by all stakeholders, and that facilitates productive dialogues among them. Our discussion is grounded firstly in work with end users, in which problematic language emerged as a key barrier to participation and effective design. Three specific categories of language barriers are identified: jargon, ambiguity, and emotive words. Building on this we undertook a workshop and focus group, respectively involving researchers developing smart health technologies and users, where the focus was on generating a shared language. We discuss this process, including examples that emerged of alternative terminology and specific strategies for creating a shared language.

Author Keywords
Participatory design; language; smart home technology; healthcare technology; inclusive design; personas.

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

INTRODUCTION
There is a growing emphasis on enabling people to make more and better-informed decisions about their own health and care [21]. Achieving this requires empowering end users to be involved in the development of appropriate solutions. With technology playing an important role in addressing many current healthcare challenges, it is critical that the language concerning these technologies does not exclude potential users at any stage. Technical language can be daunting for some people and, consequently, inhibit an inclusive participatory design process. Similarly, language that is incomprehensible or that carries negative connotations can deter the adoption of unfamiliar but potentially vital technologies. The language used to talk about healthcare technologies must therefore be informative to a wide audience, and facilitate sense-making and learning.

The HCI community has long been interested in the home as a setting for healthcare provision, with smart home solutions emerging as one promising area of research [11, 22, 27]. Many of these research projects aim to combine networked sensors and data processing techniques, with a view to monitoring various health conditions. In recent years, there has been a departure from visions of smart technology for passive use, in favour of supporting users to manage and customise their networked home [9, 13, 31]. This will require systems to be sufficiently intelligible for a diverse range of people, who should understand how to control and expand their smart home technologies as required. But users, in particular those who do not have a technical background, may find it difficult to understand the complex reasoning of sensing technologies and lack the motivation to spend time learning how they work [41]. Current person-centred approaches to this challenge include: providing *incidental intelligibility* that focuses solely on supporting users with the task they are trying to accomplish [41]; limiting intelligibility to the *high-level rationale* of on-going automation processes, with the option of getting further information if necessary [29, 31]; and focusing on *deviations from users' routines*, since regular actions become embedded and often go unnoticed in everyday life [31, 41]. While we agree these are promising approaches to support collaboration in situ between humans and their smart homes, to our knowledge no research has investigated intelligibility at the front end of the design process.

In this paper we argue that to involve a broad range of users in the participatory design of smart home technologies for health and care, it is necessary to actively develop a shared language that is accessible to all stakeholders and that facilitates productive dialogues among them. In the following, we explore the issue of problematic terminology, which arose inductively through an ethnographic study and consulting with user advisory groups. We describe the process of co-creating appropriate alternatives with end

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users and researchers on an interdisciplinary project, as well as a first iteration of the suggested terminology.

This work makes several contributions:

- It highlights the importance of actively developing a shared language throughout the design process.
- It identifies three key categories of language barrier: jargon, ambiguity, and words that, while neutral to some, are highly emotive to others.
- It discusses the process of co-creating a shared language for smart home technologies for health and care.
- It presents examples of a shared language and identifies specific strategies to creating shared languages.

We begin with a review of research that considers the challenges of participatory design, with particular focus on the issue of communication and language.

RELATED WORK

Participatory design has been an established field for several decades, lending strength to the view that involving users as partners in design and decision-making processes contributes to more usable and more desirable outputs [26]. It is also increasingly acknowledged that health and care services benefit greatly from such participatory approaches to designing, delivering, and evaluating interventions that support patients to self-manage their conditions. Patient involvement can occur at various stages of the research process, from identifying research priorities [19, 35] and informing patient information and consent procedures [6] at the front end, to co-designing appropriate interventions [38].

Based on their experience of designing healthcare technology with older adults and pregnant women with diabetes, Ballegaard et al. argue for the importance of valuing the *citizen perspective* when designing self-monitoring technologies for everyday life [5]. This means that people possess unique expertise depending on their different roles, which may be related to their role as a patient but often transcends this narrow perspective to include everyday practices. In addition to target end-users, there are various other stakeholders whose perspectives matter to the design of healthcare technologies such as carers, clinicians and developers. This inclusive approach to participatory design introduces the challenge of facilitating communication between heterogeneous audiences and across disciplines [40]. This can be especially tricky when designing emerging technology that that may be unfamiliar to many of these stakeholders.

Words and language are central to most human communication. We rely on them to translate internal thoughts and share them with others. However, people's backgrounds often create the context for the meaning they want to convey. Johnson observes that the language of computer science can present difficulties even to computer specialists reading outside of their field of expertise [23]. He argues that because computer scientists deal in man-made realities, the language they use to describe them tends to be idiosyncratic and can easily be perceived by outsiders as jargon. Johnson attributes this to several causes: the structures behind computer discourse are so mental and abstract that it tends to be action-heavy and noun-heavy (an example of this are awkward hyphenated nouns, such as 'user-extendibility'); a desire for an uncomplicated style can lead to omitting details that would otherwise provide intelligibility to laypersons and novices; the prevalence of metaphors can be problematic when referring to intangible and unfamiliar realities. While metaphors play an important part in human cognition and in the language of computer science, there is a danger they can be interpreted literally. This can then lead to reverse situations where characteristics of the metaphor are imposed onto the referent, thus constraining it.

Using incomprehensible language can result in a breakdown in communication. In participatory design, this type of language barrier means that design partners' views may be misunderstood or go unheard. Wynn and Novick advise that facilitators and designers should be conscious of sociolinguistic factors to ensure the process produces reliable outputs [40]. In their analysis of a cross-functional team meeting, they noted that discourse of a professional or managerial nature was perceived as more relevant. In contrast, people with less authority tended towards using illustrative discourse rather than abstracted statements, which meant their contributions were prone to being overlooked or disregarded. Perceived relevance also affects the likelihood of people learning new terminology. Computers communicate an interpretation of the tasks performed on them but, if people performing these tasks perceive that interpretation as irrelevant, it impedes the understanding of the system [4]. For technology to be perceived as meaningful it must adequately communicate its functionality, therefore awareness of problematic language enables designers to improve interaction with their systems. Indeed, many problems reported with using a computer are attributed to complexity and jargon [20, 33], so using accessible language has implications for the adoption of new technologies.

Despite the challenges inherent to involving diverse stakeholders in the design of emerging and unfamiliar technologies, there is also an opportunity to co-create a language that is meaningful and accessible to all. Given that much of the terminology used in computer science is arbitrary and often lacks consensus across fields [23], as new technologies are constructed it makes sense that their language is informed through participatory design. Furthermore, understanding the use of language can help focus on what users actually need, rather than being weighed down by speculations about problems that may arise during interaction [4]. Our work was conducted within an interdisciplinary research project that aims to develop a smart home system for health and care purposes. This context of developing technologies that are not yet widely deployed in people's homes provided us with unique circumstances to explore issues pertaining to the language.

PROBLEMATIC LANGUAGE

Alongside the evidence in prior literature, the issue of barriers to participation due to problematic language emerged inductively as a key theme in our own recent research, which focused on the design of smart home technologies to support health and care. Our research was carried out within the SPHERE (Sensor Platform for HEalthcare in a Residential Environment) project, a large-scale interdisciplinary research project, which aims to address a range of healthcare needs through data fusion and pattern-recognition from a single platform of non-medical networked sensors in the home environment [42]. The platform under development integrates a wide range of environmental and energy sensors, depth cameras such as Microsoft Kinnect, and low-energy wearable sensors powered by energy transfer. Within this broad project, our own research focuses on user-centred and participatory design, with a view to informing and shaping other research activities. This has included detailed ethnographic studies in peoples' homes, user-centred design activities and engagement with public and specialist advisory groups. It was within this context, and specifically through our initial ethnographic work and advisory group meetings, that problematic language emerged as a key barrier to the participatory design process.

Ethnographic Study

At the outset of the SPHERE project, and in order to gain a more detailed understanding of peoples relationship with technology in the home, we conducted an ethnographic study with 19 people, across 15 households. The sample comprised a diverse group of people aged 19 to 77, with a median age of 51. Participants ranged from having no formal qualifications to having a Master's degree. Participants included people who reported being healthy, in addition to people who reported living with one or more diagnosed health conditions such as long-term pain, cardiovascular disease and cancer. We used purposive sampling to include households with experience of telecare as well as households with experience of home sensors that monitored energy usage but not health, among others.

Data were elicited through a combination of traditional ethnographic methods and participatory techniques, specifically: interviews in participants' homes, conducted in one or more home visits and including a Technology Tour [36]; cultural probes [18]; and a focus group in the prototype SPHERE house. The focus group included a demonstration of the system by a technology researcher. Interviews were audio recorded and transcribed in full. All data were inductively coded using a thematic approach to analysis [7]. Further details about this study are available in [10].

User Advisory Groups

SPHERE has two advisory groups. The public advisory group has 14 members, comprising people from the general public. The professional advisory group has 8 members, comprising professionals working in social care and with people in their homes. These groups meet every two months to discuss and provide feedback on research, concepts and early prototypes. We also collaborated with a Patient and Public Involvement (PPI) group, which has a similar role to the user advisory groups and provides the perspective of people who have musculoskeletal health conditions such as osteoarthritis and osteoporosis.

During the early stages of the SPHERE project, a pilot version of the sensor new platform was installed in a two-bedroom residential property. Both user advisory groups and the PPI group visited this house on separate occasions, to give their initial thoughts on the deployed technology. Similarly to the focus group in the ethnographic study, these visits featured demonstrations of the system by a technology researcher. We made detailed field notes that included direct quotes, during and immediately after these focus group sessions.

Findings

We found that problems with language fell into three categories. First, people reported difficulty understanding specialised language or jargon. Second, we found that ambiguous terms could be a source of confusion and participants often wanted more detail. Third, certain words carried negative connotations and were deemed too emotive by participants. We report these findings here, along with alternatives suggested by the participants.

Jargon

Technical jargon was a concern that many participants raised from the outset. They felt that overly technical language might alienate certain users who could benefit from using the system, in particular older adults. One 66-year-old male participant conveyed this during an ethnographic interview:

"I'm sorry, but a thing you are going to have to do very quickly, if you are going to use this for older people, is change your technology terms into everyday terms. And you need to be doing that now, not 3 years down the road, because you've got to ask people with knowledge of technology and you need to also ask people with no knowledge of technology, which is slightly more important here in a way. And you need to say to your people who are writing the program and say to the people who are selling the program, you can't use technology words because people don't understand it."(EP1)

It became clear that some people were reluctant to seek clarification when language got too technical, which often led them to become disengaged in conversations. During the focus group, one female participant confided that she was put off learning about technology when her friend and her son tried to encourage her to use a new device:

"If I sit down listening to somebody and they keep jabbering on about something, when I don't understand I go 'Yeah, yeah, yeah.' I do that to [my friend] and I do that to my son. If they're jabbering on about something that I don't understand I just go 'Yeah, yeah, okay.'" (EP5)

We observed the problem of unintelligible jargon first-hand when technical researchers gave demonstrations of the system in the prototype SPHERE house. Mentions of a *Raspberry Pi* (a credit card-sized single-board computer) elicited humorous responses about recipes and delicious desserts. Other examples of terms that people often did not understand included 'accelerometer', 'algorithm', 'home gateway' and 'hub'.

Words that are ambiguous

A question we were frequently asked by participants, both in the ethnographic study and in the user advisory groups, was *"What do you mean by 'technology'?"* Confusion around the term arose because researchers used it to describe a broad range of devices, from common household appliances to unfamiliar sensors that could be used within a smart home. Both these examples qualify as technology yet they were perceived very differently by the participants, which could be explained by their familiarity and by people having different expectations of the devices. Conversely, participants had their own perceptions of what can be described as 'technology'. During the Technology Tours, we asked participants to show us round their home and to talk about the technology in each room. We intentionally left this request vague, as we were interested in what was meaningful to each participant. Responses varied widely, with some participants even mentioning their reading glasses as examples of technology. Interestingly, this did not appear to be a correlated to people's technical background. For example, one participant who was an electrical engineer began his Technology Tour by talking about his AGA cooker (a cast iron heat storage stove and cooker):

"This is an important part of technology because it's warm. It's an oven. It's variable. If you open that you've got a device to switch it down and, if you need to, switch it off. It does not depend on electrical supply and, being an electrical engineer, that's quite important to me – that the electrical system might go completely wrong, but this will always be warm, as long as there's gas coming down the little pipe." (EP18)

The problem with using accurate but vague terms was that participants tended to feel there was insufficient information. Referring to a particular sensor as *technology* did not provide adequate detail about the functions of that sensor or allow people to create expectations about its use.

Words that are emotive

For many people, the word 'camera' conjured immediate fears about privacy. Even before understanding the purpose of the cameras within the smart home system, several participants were adamant they would not have them in their homes. 'Camera' was associated with spying and intrusion. But views changed once we explained that the cameras would only collect skeletal data, which would be further processed to the point of becoming unrecognisable. Participants felt that it was important to emphasise that cameras would not collect *"photographic data"*, with one member of the user advisory groups stating:

"Realising that a camera isn't a camera has really dispelled my fears." (AP1)

The cameras deployed in the prototype SPHERE house were Kinnects and were not immediately recognised as cameras, which participants saw as an advantage. Given that the Kinnects would not be used as conventional cameras and indeed did not resemble conventional cameras, participants felt very strongly that a different word should be used to describe them. In the words of one member of the PPI group:

"'Camera' is a very emotive term." (AP3)

While 'data' was perceived as an ambiguous term that did not provide much indication of what it actually was, it also elicited strong negative reactions. This was attributed to negative associations such as 'data breach' and 'data leak' that get frequent exposure in the media. Explaining that the SPHERE system aims to collect and process data about people's daily lives was met with distrust, with many participants saying that they would not want such technology in their homes.

Emerging alternatives

Alongside the identification of problematic language, the focus groups, perhaps unsurprisingly, became a natural forum in which people would begin to suggest alternative languages. For example, the term that people felt was most critical to replace was 'camera', because negative assumptions about what they might do overshadowed potential benefits they could have in a smart home system. Alternative suggestions included 'physical sensor', 'body sensor', and 'movement sensor'. Similarly, participants felt that 'information' was an appropriate alternative to 'data'. Other examples included referring to 'algorithm' as a 'calculation' or 'processing', and referring to the 'Raspberry Pi' as a 'mini-computer'.

One strategy that people used to refer to unfamiliar technology in the SPHERE house was to borrow terminology from systems that they knew and used. However this had the potential to create another form of miscommunication. For example, one participant in the PPI group who wanted to inquire about the 'home gateway' referred to it as 'base station', a term they were familiar with from its used in telecare systems:

AP1: Where's the base station?

AP2: Are they really called 'play station'? Doesn't sound very serious.

This then created miscommunication with another member of the group who was not familiar with telecare systems.

This example demonstrates how personal perspectives can affect meaning and perception.

EXPLORING ALTERNATIVES

Building on the natural emergence of alternative language in our advisory and focus groups, our next study took the deliberative step of exploring communication and alternative languages with the researchers responsible for the technical development of the SPHERE platform. It is important to note that while this broader research team are responsible for the technical development of the platform, most do not have a background in user-centred design or human computer interaction. Their backgrounds include research areas such as machine learning, wireless power transfer and energy harvesting, sensor networks and computer vision. One challenge for a user-centred design team, working within such an interdisciplinary project is fostering an empathic understanding of users amongst more technology-focused researchers, who may not typically or regularly engage with the people who will ultimately use the technology they develop.

One of the key aims of our workshop was to provoke reflective thinking from another person's viewpoint. To assist in achieving this we chose to use personas. The personas technique, introduced by Cooper [12], comprises the use of archetypal representations of users as a way to communicate rich information about how people behave, what they want to achieve and what they fear as users. In this section we describe an ideation workshop, which aimed to explore how best to communicate with diverse end users.

Materials

We used four evidence-based personas, which we developed based on findings from our ethnographic research. We analysed these findings using a thematic approach to identify relevant user attributes, which we then used as a framework to develop the personas using the ethnographic data. These personas have different socio-demographic characteristics and further differ in terms of their experiences of technology, their experiences of health and care, and their thoughts on smart home technology for health and care. A sample persona is provided as supplementary material. The personas along with details about their development are available in [10]. In addition, we compiled a list of problematic terms that emerged during the ethnographic study and through working with the user advisory groups. These terms, which pertain to the type of technology used within the SPHERE project, are listed in Table 1.

Accelerometer	Algorithm	(Depth) camera
Data	Enclosure	Harvesting
Home gateway	Hub	Interface
On-body	Platform	Prototype
Raspberry Pi	Sensor	Streaming
Technology	Transmission	Wearable

Table 1. List of banned words.

Participants

We circulated an invitation to the workshop via email to all members of the SPHERE project, across three universities and other partner institutions. A total of 20 members of the team took part, including the director, project manager, researchers, and recruitment partners. Workshop participants had diverse backgrounds, working in: environment sensing; video monitoring; body area sensing and communications; data fusion and mining; system integration; ethics; health research; and public engagement.

Procedure

We organised the participants into four groups, ensuring that each group had a mix of people from various backgrounds. Each group was given a different persona and a type of technology that was used within the project, but that differed from the type of technology that was most familiar to the group's members; these technologies were a depth-sensing camera such as the Microsoft Kinect, an energy-harvesting device, an environmental sensor node, and a user interface with dashboard (Figure 1, Figure 2, Figure 3, Figure 4). All groups were presented with the same list of banned words, which they had to avoid using for the workshop activities. Thinking about their assigned persona, each team was then asked to discuss how they would describe:

- SPHERE system as a whole;
- Their assigned type of technology;
- What happens to the data collected by the sensors.

After this brainstorming, each group introduced their persona to the rest of the workshop participants and shared their ideas about effective ways to communicate with their persona. The whole activity lasted around 1h 30m and participants were engaged throughout.

Findings

In this section, we describe the findings from the workshop. Since each persona has a unique user profile, we present these findings as case studies for each persona. Each case includes a summary of the persona's key characteristics, the technology the group was given to describe, and their proposed solutions.

Rick

Persona Summary: Rick is a 53-year-old warehouse operative, who has no formal qualifications. Rick lives with dyslexia and this has affected his use of technology. For Rick, being able to work is what makes him feel healthy and well. When he had health concerns in the past, it was always his wife who made him go to the doctor. However, now that he is divorced, he is very reluctant to seek medical advice and care. Rick lives with his teenage daughter but he spends most of his day at work, so he wonders if a smart home system might allow him to know what she gets up to while he is at work.

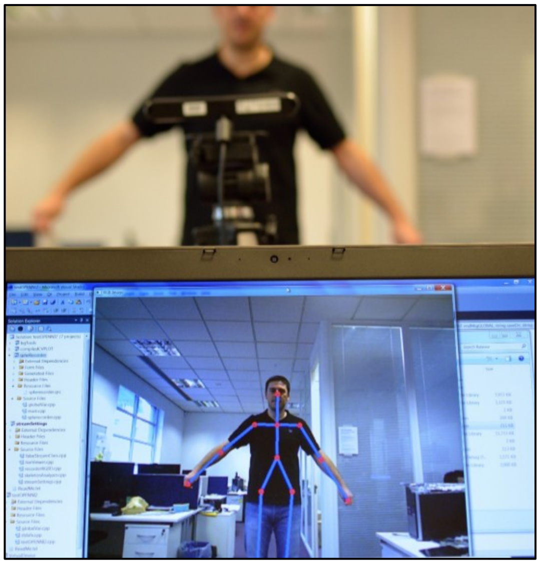

Figure 1. Kinnect and visualization of skeletal data.

Assigned Technology: The group working with Rick was given a depth camera to describe. An example of a depth camera is the Microsoft Kinect (Figure 1).

Proposed Solutions: To describe the system as a whole, this group felt it was important to emphasise that it could help with early detection of health conditions and, consequently, reduce the need for taking time off work. They also thought that given Rick's reluctance to visit the doctor, the system could be described as a way to access informal care when necessary. To describe the depth camera, they suggested explaining that it was used to assess movement, with phrases such as *"to keep track of basic activities to keep you safe from harm"*, *"to look at your normal patterns, so it can tell if something unusual is happening"*, and *"to test movement, for example to look at muscle pain, to detect falls or stroke"*. In terms of data, this group was concerned with potential privacy and ethical issues of consent that might arise if Rick used the technology to see what his daughter did during the day. During their discussion, team members used 'computer' instead of 'sensor', 'equipment' and 'device' instead of 'technology', and 'measurement' instead of 'algorithm'.

Wendy

Persona Summary: Wendy is 64 years old and retired. She has multiple health conditions, including heart disease and diabetes. Wendy lives on her own and, a few years ago, she moved into sheltered accommodation that had a telecare system already installed. Other than that, Wendy doesn't have a lot of technology around the home. She has concerns about her privacy, especially because she feels she doesn't understand much about technology.

Assigned Technology: The group working with Wendy was given an energy-harvesting device to describe (Figure 2). The energy harvesting device is used to transmit energy to a writ-worn activity monitor.

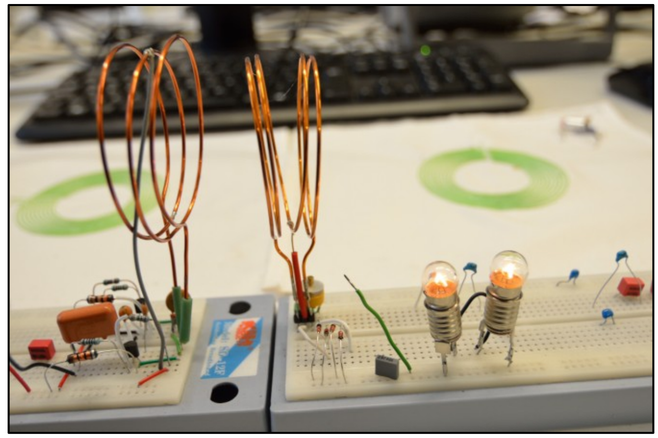

Figure 2. Prototype energy harvesting device.

Proposed Solutions: To describe the system as a whole, this group also focused on benefits that would be specifically relevant to Wendy. These included *"a way to enable you to keep living your life independently, in your own home"*, *"to help keep track of your basic activities, to keep you safe in case of emergencies"*, and *"it works out your normal patterns, so we can tell if something unusual is happening"*. The group suggested using analogies to describe the energy harvesting device, for instance *"it sends out power to charge [the wrist-worn activity monitor], just like with an electric toothbrush"*. This group thought it was important to make it clear to Wendy that the device was not sending out any 'data', which they referred to as 'information'. They also discussed how to enable Wendy to decide who has access to information collected by the sensors.

Maxine

Persona Summary: Maxine is 74 years old. She feels comfortable using ICT, as it was central to her work as an archivist and she continues to use it daily in her retirement. However, technology is mostly kept out of the way, because Maxine likes her home to reflect her family history and other interests. She is reluctant to believe that technology can ever replace the human element of healthcare services, but wants to keep an open mind about how her circumstances might change in the future.

Assigned Technology: The group working with Maxine was given an environmental sensor node to describe (Figure 3). This node is a small plastic box that contains air quality sensors, temperature sensors, humidity sensors, noise level sensors, luminosity sensors, and passive infrared (PIR) motion sensors.

Proposed Solutions: To describe the system as a whole, this group used practical examples of what it could do. They used person-friendly terms even to replace words that were not banned, such as suggesting the technology would be *"useful to spot certain symptoms and conditions"* rather than to 'monitor'.

Figure 3. Prototype sensor node.

They thought the sensor node was best described in terms of how it would fit in with Maxine's home, for example *"it can be positioned in different places and possibly hidden from view"*, *"it's like a smoke alarm"*, and *"it will be silent"*. This group also referred to 'technology' as 'equipment', in particular when describing sensors as equipment that had particular features.

Stanley

Persona Summary: Stanley is 38 years old and has been living with long-term pain for all his adult life, but it got so bad in recent years that he is unable to have a steady job. He has seen several specialists, yet none has been able to diagnose the cause of his pain. Stan is very keen to understand his condition and has tried several strategies, including different forms of exercise and keeping a food diary. Stanley doesn't consider himself an expert in technology, but he likes using it to manage his daily life. Stan is motivated by what technology can do for him, so he will often abandon technology that he thinks isn't relevant or beneficial.

Assigned Technology: The group working with Stanley was given a dashboard to describe (Figure 4). This dashboard is displayed on a tablet and shows information collected by the sensors, such as occupancy, environmental readings, and energy consumption per room.

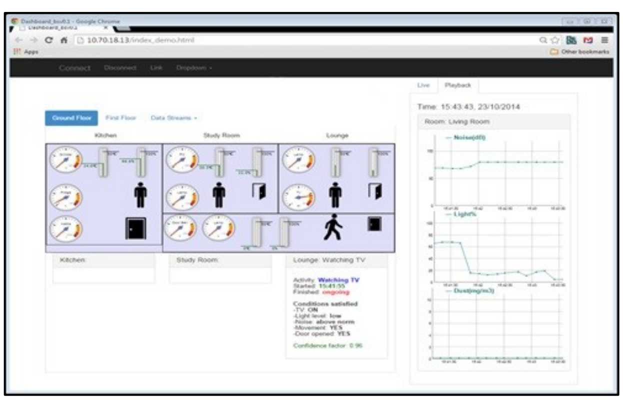

Figure 4. Prototype dashboard.

Proposed Solutions: Again, this group felt that the system was best described to Stanley by focusing on how it could address his individual needs. The group felt that this approach would be more relevant than focusing on the value of a unified platform. The group would describe the 'dashboard' to Stanley as a 'screen' that could show a variety of 'information' (instead of 'data'), such as how much energy was being used in different rooms. They also felt that Stanley would value knowing that he could learn about his condition through interacting with this 'screen'.

Reflecting on the workshop

We circulated a feedback questionnaire to the workshop participants via email. In this questionnaire, we asked how the workshop had changed the way they talked about the SPHERE technology to other people in the team, the way they talked about the SPHERE technology to the general public, and their approach to designing the technology. This feedback was generally positive. The following are examples taken from completed questionnaires:

"After the workshop, it is clear that there are some communication problems, also between different work package members. I have been trying to always clarify critical points and use proper words during meetings." (SP1)

"It changed the way I describe SPHERE technologies from a technical point of view to a way that people can understand and find useful." (SP6)

The feedback also revealed that the workshop had raised empathy with the end users, beyond the issue of problematic language:

"Never forget the users' expectations when we design our work." (SP3)

"Can't take anything for granted about how things will be used." (SP5)

We put up a large poster in the project's shared office, which has the list of banned words and invites the researchers to continue suggesting alternatives. This list of suggested alternatives thus continued to grow after the workshop. However, since not everyone who works in the office was able to attend the workshop, not all the suggestions meet the aim of providing accessible alternatives to problematic terminology. Interestingly, though, the poster has been annotated with comments regarding the appropriateness of suggested alternatives. In Figure 5, it is possible to see *(←no!!!)* written beside the suggestion 'depth sensor'.

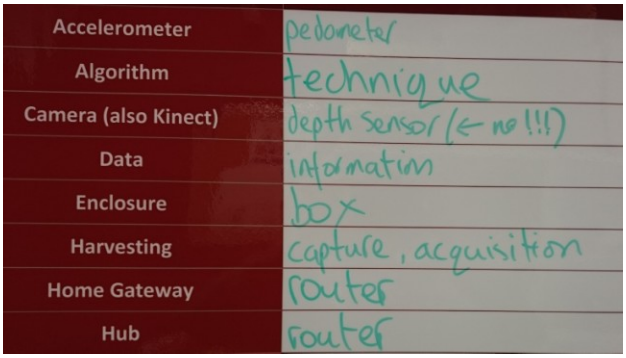

Figure 5. Terminology poster with suggestions and comments.

USER EVALUATION OF SUGGESTED TERMINOLOGY

To evaluate the suggested terminology, we conducted a focus group in the SPHERE house with 5 members (4 female and 1 male) of the user advisory groups. We talked through the list of problematic terminology that we compiled, as well as the alternatives suggested by the researchers. This process reiterated the importance of finding appropriate alternatives for particular terms, such as 'camera' (*"So wrong!"*) and 'energy harvesting device' (*"Too sci-fi and freaky"*).

There was consensus on some good alternatives, including 'calculation' and 'measurement' instead of 'algorithm', 'capture' instead of 'harvesting', 'small computer' instead of 'Raspberry Pi', 'detector' instead of 'sensor', among others. There was much discussion about a suitable alternative for 'camera', as might be expected. Upon reflection, participants felt that 'physical sensor' and 'body sensor' seemed too personal and intrusive (*"Like you might be wearing them"*). 'Movement sensor' was considered ambiguous and easily confused with other sensors that measure movement, such as PIR sensors and accelerometers. The group finally agreed that 'quality of movement sensor' was an appropriate alternative to 'camera', as it accurately reflected the function of this type of sensor within the SPHERE system.

There were also instances of bad alternatives, though only a few. Specifically, the group did not agree with using 'somatic' and 'corporeal' instead of 'on-body', and 'pedometer' instead of 'accelerometer'. Interestingly these bad suggestions were made through the wall poster and may have been written by people who had not taken part in the workshop. These people would therefore not have benefitted from the persona exercise, which was specifically designed to promote reflective thinking based on examples of potential end users.

The focus group were generally happy with using analogies and examples to describe the technology. Sometimes there was a feeling that we wanted to explain too much and that, in reality, people do not always need a lot of detail. The following quotes were taken from a discussion about coming up with an alternative for 'energy harvesting device':

"You're explaining too much! Just say you don't need to charge it." (AP7)

"Focus on what it's doing rather than how. Most people don't know how a microwave works, they just know it does something to their food and that's enough." (AP5)

DISCUSSION

We have argued that language plays an important role in participatory design, in order to support the inclusive and equitable participation of all stakeholders. This is especially important when designing healthcare technologies that aim to reach wide audiences, whether these technologies have generic or condition-specific purposes. We agree with the perspective that citizens possess unique expertise that extends beyond their role as a patient [5]. This means that it is crucial to consider not only the diverse stakeholders that are involved in the design and deployment of healthcare technologies, but also to acknowledge that the individual characteristics within each stakeholder group may vary widely. Failure to have a sensitive understanding of the variability in terms of language and discourse can hinder a successful participatory design process, as people may be inhibited from participating or their contributions may be disregarded. We found this to be true in our own user studies, with participants describing situations where unfamiliar technical language triggered disengagement from conversation and a reluctance to learn about new technologies. We now discuss our findings, in particular concerning key language strategies, the need to achieve a balance of shared language that is both appropriate and informative, the dynamic nature of shared languages, and our reflection on this methodology as a means to stimulate empathy, in multi-disciplinary teams and amongst stakeholders.

Focus on what it's doing

It was apparent there was some concurrence between the alternative terminology proposed by the researchers and by participants in the ethnography study and user advisory groups (e.g. replacing 'data' with 'information'). This suggests there is scope to develop terminology that is meaningful to various stakeholders and across disciplines. However, we encountered examples where users felt they were receiving excessive and perhaps irrelevant information. In these instances, people were more interested in what the technology does and, specifically, what it can do for them. Indeed, all groups thought giving examples to explain the personal benefits of the technology would be an effective communication strategy. Likewise, all groups proposed using analogies (e.g. to compare the technology under development to more familiar technology) as another useful strategy. By referring to something familiar to explain something less readily understood, designers could avoid the pitfalls associated with the more commonly used metaphor strategy [23].

We were interested to learn that language could be perceived as a greater barrier than the technology itself.

One example of this was 'camera', which participants felt was charged with negative connotations. In reality, most negative expectations about it did not correspond to the functions intended for the device within the SPHERE project. We feel that this is another example where it would be beneficial to focus on what the technology does.

Balanced language

Findings from our ethnographic study and consultations with user advisory groups indicated that problems with language could be attributed to three factors: the use of technical *jargon*, the use of words that are *ambiguous*, and the use of words that are *emotive*. The participants struggled with overly technical language but, conversely, they also objected to terms that were vague and not sufficiently informative. This is partly due to the fact that blanket terms such as 'technology' describe vastly different devices, with correspondingly different expectations from users. Using ambiguous words prompted requests for clarification, as participants wanted to infer more details from the terminology. However, the user advisory group felt there were instances when designers' desire to convey details might be greater than people's desire to receive them. It is therefore important that terminology does not alienate potential users, but it should also be informative enough to be perceived as relevant. Our work shows that achieving this balance of language requires a participatory approach that brings together many stakeholders, but equally calls for sensitivity from the designers who facilitate this process. We firmly believe, as our participants did, that it is critical to rethink terminology that prevents people from using potentially beneficial technology.

The evolution of languages

Generating appropriate terminology for technology is in itself an ongoing process, as new technologies are constantly being developed. We argue that this should be an integral part of participatory design embedded at the front end of the process, for two reasons: first, a shared language ensures all stakeholders are empowered to contribute to the design process; second, accessible language removes one barrier to the adoption of new and unfamiliar technologies. We also envisage that these languages may evolve over time, particularly when people become familiar with the technology and adopt it in their daily lives. This challenge might be at least partly resolved by revealing different language layers as participants become confident users of a technological system or want to access more technical information about the system. While issues pertaining to language during sustained use of technology were beyond the scope of our study, it is a fruitful area for further research relating to design of technology for home settings [8, 17, 32].

Empathy in design

A key lesson to emerge from our study was that the active creation of shared languages can be a powerful tool to generate empathy in multi-disciplinary teams and amongst stakeholders. Through participating in the workshop and using the personas to explore the issue of problematic language, the researchers proposed a number of alternative terms and strategies for communicating with different end users. This process made visible to the researchers the diversity of end users and provoked their interest in taking a personalised approach, for instance by providing users with examples of how the technology could benefit them personally and how it would fit in with their everyday lives. When talking about the personas, the researchers referred to them by name, they discussed their wants and needs, and consequently some suggested additional terms for the list of banned words. Even though the poster we put up in our open plan office inviting people to continue suggesting alternative terminology produced mixed results, it stimulated discussions and even enticed other researchers to annotate the poster with thoughts about these suggestions. The fact that some suggestions made on the poster might not accord with the needs of users may be explained by the poster being available to a broader audience who did not attend the workshop. We argue that the process of creating a shared language using personas may help foster reflective thinking and empathy amongst the more technically focused members of a research or development team. Our evidence for this is preliminary at this stage, but we believe there is strong potential for this point and it is worthy of more detailed exploration. This can help inform existing literature on empathy in design and HCI [24, 30, 343739].

CONCLUSION

Despite the importance of language in participatory design and in the adoption of new technologies, it has been an underexplored area in HCI. This paper emphasises the importance of considering language at the front end of the design process. Data gathered through an ethnographic study and through meetings with user advisory groups evidenced the need for a shared language that avoids the use of jargon, ambiguous words, and emotive words. We have given specific examples of problematic terms, as well as detailing how we used them in a workshop to sensitise researchers on an interdisciplinary research project to the need for an accessible language. The shared language we developed and our findings about appropriate ways to communicate with diverse stakeholders will continue to develop and inform our approach moving forward. For example, we have used this new terminology in our recruitment materials for future studies and tailored these materials to suit different audiences. It is crucial that the development of accessible language runs alongside the development of new technologies.

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