



Explanation before Adoption: Supporting Informed Consent for Complex Machine Learning and IoT Health Platforms

RACHEL EARDLEY, University of Bristol, UK

EMMA L. TONKIN, University of Bristol, UK

EWAN SOUBUTTS, University College London, UK

AMID AYOBI, University College London, UK

GREGORY J. L. TOURTE, University of Bristol, UK

RACHAEL GOOBERMAN-HILL, University of Bristol, UK

IAN CRADDOCK, University of Bristol, UK

AISLING ANN O'KANE, University of Bristol, UK

Explaining health technology platforms to non-technical members of the public is an important part of the process of informed consent. Complex technology platforms that deal with safety-critical areas are particularly challenging, often operating within private domains (e.g. health services within the home) and used by individuals with various understandings of hardware, software, and algorithmic design. Through two studies, the first an interview and the second an observational study, we questioned how experts (e.g. those who designed, built, and installed a technology platform) supported provision of informed consent by participants. We identify a wide range of tools, techniques, and adaptations used by experts to explain the complex SPHERE sensor-based home health platform, provide implications for the design of tools to aid explanations, suggest opportunities for interactive explanations, present the range of information needed, and indicate future research possibilities in communicating technology platforms.

CCS Concepts: • **Human-centered computing** → **Human computer interaction (HCI)**.

Additional Key Words and Phrases: explainable, health, user study, smart homes, consent, privacy, qualitative

ACM Reference Format:

Rachel Eardley, Emma L. Tonkin, Ewan Soubutts, Amid Ayobi, Gregory J. L. Tourte, Rachael Gooberman-Hill, Ian Craddock, and Aisling Ann O'Kane. 2023. Explanation before Adoption: Supporting Informed Consent for Complex Machine Learning and IoT Health Platforms. *Proc. ACM Hum.-Comput. Interact.* 7, CSCW1, Article 49 (April 2023), 25 pages. <https://doi.org/10.1145/3579482>

1 INTRODUCTION

More and more complex technological platforms are being developed to be installed and used within our private domestic spaces or kept on our persons, provided by corporations such as Google (e.g.

Authors' addresses: [Rachel Eardley](mailto:rachel@racheleardley.net), rachel@racheleardley.net, University of Bristol, Bristol, UK; [Emma L. Tonkin](mailto:e.l.tonkin@bristol.ac.uk), e.l.tonkin@bristol.ac.uk, University of Bristol, Bristol, UK; [Ewan Soubutts](mailto:e.soubutts@ucl.ac.uk), e.soubutts@ucl.ac.uk, University College London, London, UK; [Amid Ayobi](mailto:amid.ayobi@ucl.ac.uk), amid.ayobi@ucl.ac.uk, University College London, London, UK; [Gregory J. L. Tourte](mailto:g.j.l.tourte@bristol.ac.uk), g.j.l.tourte@bristol.ac.uk, University of Bristol, Bristol, UK; [Rachael Gooberman-Hill](mailto:r.gooberman-hill@bristol.ac.uk), r.gooberman-hill@bristol.ac.uk, University of Bristol, Bristol, UK; [Ian Craddock](mailto:ian.craddock@bristol.ac.uk), ian.craddock@bristol.ac.uk, University of Bristol, Bristol, UK; [Aisling Ann O'Kane](mailto:a.okane@bristol.ac.uk), a.okane@bristol.ac.uk, University of Bristol, Bristol, UK.



This work is licensed under a Creative Commons Attribution International 4.0 License.

© 2023 Copyright held by the owner/author(s).

2573-0142/2023/4-ART49

<https://doi.org/10.1145/3579482>

Nest¹ and Fitbit²), Apple (e.g. Air tag³ and Apple Watch⁴) and Amazon (e.g. Alexa⁵, as well as the Ring⁶ and Blink⁷ monitoring platforms). Several of these complex platforms use hardware, software, and algorithms that are often extremely hard to understand and explain to gather and analyse data. However, many such platforms aggregate the data gathered in such a way as to gain insights into the individual's activities, typically with the aim of meeting that individual's needs in a certain application area. It is challenging to present these complex technologies in a way that members of the public can critically engage with, contest, and accept [46, 59], but successful knowledge sharing is a crucial factor for making informed decisions about adoption as these technologies can affect an individual's privacy and health [29, 50, 72, 73].

When deciding to include technology within our domestic spaces or on our persons, potential users should be made aware of the benefits, risks, and limitations [1, 47, 51]. For example, these technologies can affect the spaces into which they are installed [71]; individuals, if given access, may potentially use or abuse the technology or data gathered (e.g. domestic abuse [44] or criminal intent [48]); and the technology may have limitations (e.g. issues that affect the capacity for installation within homes [65, 66, 19, 20]). The growing research field of ethics and explainability in interactive technology is dedicated to increasing platform transparency, helping people to understand the full extent and potential of technology platforms, and thereby enabling informed decision-making [4, 23]. Recent research explored the consent process for smart home technology and identifies information provision, recall, and understanding of key requirements as essential prerequisites for informed consent [37].

The methods used to explain the complex platforms must provide the individuals whose informed consent is sought with a neutral and understandable explanation that presents the platform as a whole [23, 46]. For users who are non-technical, the materials shared and language used are important, as excessively technical, or jargonised terminology could complicate the understanding of the platform [33, 40]. In this paper, we explore explanatory methods and strategies used by experts to provide information during the onboarding of a home health-based platform. Onboarding is the first stage of the informed consent process, providing initial information before the platform's installation [47], with experts describing the platform's hardware and data-gathering functionality. This process helps to assist members of the public who are not technical experts in understanding the platform, to aid in making an 'informed decision' about adoption [4] – a reasoned choice, relying on information about the platform's advantages and disadvantages.

We conducted two studies, using as a case study SPHERE, a sensor-based home healthcare platform, as an example of a complex technology platform (see section 1.1) [72]. The first study, an interview study, asked platform experts to describe the communication methods they use (e.g. types of conversations, linguistic devices, and conversational props) and reflect on their effectiveness in providing explanations. The second study, an observational study, asked platform experts to use their communication methods to onboard members of the public to their platform. The aim was to capture these communication methods in-situ. In doing this we identified additional techniques used by platform experts, such as building rapport, trust and navigating the messiness that is explaining in the wild. We use these findings to derive insights and discuss their relevance beyond the home, for instance in the workplace [58, 11] with companies increasingly asking to install

¹https://store.google.com/gb/category/connected_home?hl=en-GB

²<https://www.fitbit.com/>

³<https://www.apple.com/uk/airtag>

⁴<https://www.apple.com/uk/watch>

⁵<https://www.amazon.co.uk/b?ie=UTF8&node=14100223031>

⁶<https://en-uk.ring.com/>

⁷<https://blinkforhome.com/>

applications on employees' personal devices. We frame this study within contemporary research on ethics [36] and 'informed decision-making'.

1.1 Our Case Study

In selecting a platform for our case study, we identified several requirements. The platform must meet the definition given of a complex platform, that is, consist of a combination of multiple elements (e.g. hardware, software, and data analysis), and must be sufficiently novel that potential users will be unfamiliar with the technology (e.g. a novel brand of wearable is likely to be well-understood). The study requires access and engagement with platform experts involved in design and deployment. We also hoped to identify a platform that is linked to individual health or wellbeing, rather than more environment-focused concerns (e.g. security or fire safety).

The SPHERE platform is a sensor-based home health research platform and has been deployed in over 60 homes. The platform includes six sensor types, including two to three depth cameras, one environmental sensor per room, several 'gateway' sensors (networking and sensing platforms), several appliance power usage sensors, a water sensor and one wearable device per participant. These are combined to passively monitor activity within the home, and include humidity, water consumption, electricity, appliance usage, posture via a depth camera and activity via a wrist-worn wearable. Machine learning (ML) is used to fuse sensor data together and to predict location and daily activities. The project itself aims to share gathered data with clinicians to support understanding of patients' daily lives and the technology is under evaluation for use in the treatment of conditions such as hip and knee surgical recovery, dementia [55] and Parkinson's [56]. SPHERE has undergone an iterative development process informed by stakeholder feedback on sensor, data quality and consent acceptability [37].

We selected SPHERE as our complex platform for several reasons. SPHERE meets the above definition of a complex platform due to its combination of hardware (the sensors), software (a mobile tablet-based application for participants), data capture (e.g. the collection of data via timed and reactive methods), data analysis (using ML), an installation process (e.g. digital plumbing) and its physical positioning within a private domain such as the home. The platform is likely to be novel to most as few similarly multi-modal, potentially privacy-intrusive, and installation-heavy platforms have seen deployment in the digital health context, so we believed few participants would be familiar with the platform or many of its components. Additionally, we were given access to and had the ability to engage with the platform experts (e.g. those who designed, built, and installed the platform), and due to the ongoing development of the platform, it was possible for us to speak with deployment, outreach and technical staff involved during the design and prototyping phases – a more mature platform, no longer in active development, is likely to have a correspondingly smaller technical staff.

2 RELATED WORK

ML is increasingly used within healthcare technology, both in clinical and home settings. To support informed decision-making – for example, in the decision to make use of an ML system to facilitate clinical monitoring of a patient's symptoms – it is necessary for a joint understanding to be shared by (and hence explained to) both the clinician and the patient. The clinician's understanding of the platform enables them to make use of the collected data to make or support a medical diagnosis [59, 38, 22], allowing the clinician to provide the patient with information about their condition, diagnosis, and options [59, 1, 51, 7, 24]. Informed consent is an ethical and legal requirement [24, 45, 62]. However, consent is not straightforward: for example, a family member may persuade the patient to consent [52], a patient may be incapacitated and unable to consent, or patients may change their minds later [34], as with healthcare technologies [57]. As with the clinician,

the patient needs sufficient background knowledge provided through conversation or supporting documentation as well as time to think critically about the subject matter [39, 42].

2.1 Explainability and Informed Decisions

When explaining complex platforms, Gilpin et al. [23] contrast ‘interpretability’ and ‘completeness’, defining ‘interpretability’ as comprehension of a system’s decision-making, whilst ‘completeness’ is an accurate understanding of the operation of a platform. A more complete explanation allows the explainee to anticipate the behaviour of the system in a broader range of situations. Ploug et al. [59] argue for ‘contestability’ in AI, which is to say, systems that allow diagnoses to be ‘contested’ (e.g. opposed on the grounds of relevant information). Contestability is achieved through the availability of information and understanding of different elements of the platform (e.g. ML data usage, platform biases, technical performance, and the level of input in the diagnosis from the platform compared to that of the clinician [59]). Jakobi et al. [31] also note that the platform may be subject to ‘appropriation’, e.g. unfamiliar, or unexpected patterns of use may emerge. This raises the possibility that a participant’s understanding of a platform might evolve over time, so that the ‘explainer’ may later be required to become the ‘explainee’ to maintain a mutual understanding of the platform in use.

As Gilpin et al. [23] state, a good explanation should balance transparency and ethical disclosure with interpretability. Ploug et al. [59] argue for providing adequate and varied information that enables the explainee to gain enough of an understanding to be able to question and have the confidence to contest a decision, on grounds such as the type of data collected, privacy concerns or a medical diagnosis [59]. Lombrozo [46] explored the effect of balance, concluding that for interpretability, more straightforward explanations may be more successful than complex explanations [46]. Gilpin et al. [23] propose that the explanation’s interpretability and completeness should be neutral, so that they do not influence the individual either way. Finding this balance lies in communication; hence, language use is key [23].

2.2 Strategies for explainability

Explainers’ strategies for presenting a complex platform may vary based on many factors. For instance, Johnson [33] and Lakoff et al. [40] note that an individual’s background may affect language use and understanding of terminology. Those with technical knowledge, such as computer scientists, often use a ‘specialised vocabulary’ that can be interpreted as ‘metaphorical’ or ‘jargon’ by a member of the public [33, 40]. Burrows et al. [9] investigated methods of verbal communication around complex technical concepts. By exploring alternative wordings with non-technical members of the public and technical team members, such as replacing ‘data’ with ‘information’, they built a shared vocabulary describing the components of a complex platform [9].

Anthropomorphism and familiarity have also been shown as effective communication strategies. Nass et al. [53, 54] identified that technology may play anthropomorphic roles, with a perceived personality or social presence, enabling users to understand and interact with the technology as with a human. Fischer et al. [20] observed explainers using scenarios to define the benefits, data to describe purpose, and physical objects to explain hardware and networks. By contrast, Tolmie et al. [66] observed an expert talking to a more technical householder through more specialist technical language such as ‘phidget drivers’ (e.g. specialist software libraries for smart devices) and software frameworks. Fischer et al. [19] note that explanations of complexity become more accessible when the explainer can share information about the outcomes; for example, one might describe the types of data one hopes to gain from a complex platform in terms of their relevance to the explainee.

2.3 Explaining complex platforms

Recent innovation in domestic technology has provided opportunities for self-management of health and wellbeing needs [29, 73]. For example, Cheng et al. [12] use Google Home's voice interaction to run a conversational monitoring survey to provide people with Type 2 diabetes (T2D) with personalised advice [12]. Other types of domestic technology use sensor-based platforms to support the management of healthcare needs within the home. Woznowski et al. [70] and Helal et al. [27] combined sensors monitoring environmental data (e.g. motion, humidity, and light), wearable sensors and silhouette video sensors, monitoring posture, gait, and quality of motion. These platforms have been studied in the wild, with Helal et al. [26] using two project-based homes to monitor inhabitants and analyse data collected, aiding self-monitoring health conditions such as T2D. The SPHERE system [70] was designed for long-term deployment in up to 100 homes and used various passive sensors to collect health-related data [16, 18, 72].

Installing these platforms is a complex process of deployment, be this within industry [11], or within homes. In Tolmie's terms, 'digital plumbing' [66] is required. Tolmie et al. [65, 66] and Fischer et al. [19, 20] define this process as a negotiation: the platform with its technological limitations must fit within everyday household routine. These complex innovations and the mundane aspects of how they fit into everyday life are at odds with each other. However, there is a risk that aspects of the complexity might be glossed over if too much emphasis is put on 'digital plumbing' before adoption, or conversely that real-world consequences of the installation of these platforms might fade into the background when a member of the public who is not a technical expert is dealing with hard-to-understand aspects of the platform. Both are important aspects of explanation to support informed decision making for these potentially safety-critical systems.

Research surrounding explanation is often focused on the initial installation, such as work by Fischer et al. [20] and Tolmie et al. [66] on observing experts giving explanations of sensor functionality and of the platform's aims to household members during the installation process. However, the informed decision-making process starts before installation and continues throughout the platform's deployment. Pre-installation discussion can be 'overwhelming', as reported by Jakobi et al. [31], to household members struggling with the wide span of sensor technologies available. Jakobi suggests that lack of market transparency, lack of helpful information about use cases and best practices and overly technical presentation of smart homes are all factors cited by participants as reasons to abandon the selection of a platform. Other stakeholders, such as healthcare professionals or policy makers evaluating the efficacy of these platforms, may also benefit from participant-friendly explanations. As complex healthcare platforms develop towards affordable real-world tools, opportunities become available to explore communication about platforms with other stakeholders, for instance healthcare professionals, social workers and family members looking to support a relative [10].

In this paper we build on this related work on explanation and informed consent to explore, as a case study, the pre-installation onboarding process in which complex platforms are explained to those who are considering whether to adopt these platforms within their own homes. We approach this by (1) investigating how experts with different technical backgrounds explain a complex multi-sensor domestic platform to members of the public who are non-technical experts, and by (2) providing insights on how to explain these types of platforms to members of the public, what benefits it might bring, and what risks are associated with it.

3 METHOD

We conducted two sequential studies to understand how experts explain a complex technology platform to members of the general public who are non-technical experts. Both studies required written consent as approved by the University of Bristol ethics board.

The first study, an interview study, questioned a broad spectrum of eight experts (Ex1 to Ex8) whose roles ranged from community engagement to that of machine learning. The experts were asked to retrospectively self-report their communication strategies and reflect on their perceived or believed effectiveness. In the second study, an observational study, we gained an understanding of how these reported methods were used in practice by two experts (Ex8 and Ex9), both deployment technicians, in conversation with 10 participants (e.g. non technical members of the public) (P1 to P10) during onboarding sessions.

The two studies were independently analysed, with the interviews in the first study being audio-recorded and later transcribed verbatim by the first author. In addition, the eight experts involved in the first study had the opportunity to review their transcripts, with three edits requested due to small technical inaccuracies. The second study video recorded the onboarding sessions, which were transcribed verbatim by a professional transcription service. Following individual analysis, the individual findings of both studies were combined within the paper to synthesise insights that combine expert views with an in-situ view of observed behaviour.

3.1 Participants

We had two types of participants, the SPHERE experts who were part of both studies, and members of the public who took part in the onboarding session for Study 2.

3.1.1 The SPHERE experts. Overall, we engaged with a total of nine of the 11 SPHERE design and implementation team members (two female, seven male) who had worked on the platform for three to six years. These nine experts had a total of five job roles: Machine Learning (Ex1, Ex2, Ex3), Research (Ex4), Hardware (Ex5), Community Engagement (Ex6) and Deployment Technician (Ex7, Ex8, Ex9). Table 1 describes the nine team members' experiences of engaging with a diverse range of users (from families with young children to retired couples) and a wide range of members of the public through events (e.g. invited talks, science fairs, school visits and public/patient advisory boards). The experts had previously experienced designing and facilitating public demonstrations of platforms including the SPHERE platform in a science museum. Through these experiences, they informally developed, tested, and iterated their own communication strategies to explain the platform. Ex7, Ex8 and Ex9 routinely explained the platform before and during installation, and were

Table 1. The nine experts involved in the two studies – Study 1 (Ex1 to Ex8) and Study 2 (Ex8 and Ex9)

	Ex1	Ex2	Ex3	Ex4	Ex5	Ex6	Ex7	Ex8	Ex9
Public engagement, teaching & academic experience									
Training (University facility, Museums/Library)			X				X	X	X
Community-based workshops (Designing and running)		X				X		X	
Facilitating meetings (virtual/physical)	X	X	X	X	X	X	X	X	X
Presentation (funding & board members and academics)		X		X	X	X		X	
Presentation (member of public, community engagement)	X	X		X	X	X	X	X	X
Explaining SPHERE to participants within their home						X	X	X	X
Teaching (Supervision, tutoring, lectures)	X	X	X	X	X				
Demonstrations (Exhibitions, Science Fairs)	X	X	X	X	X	X	X	X	X
Media (Radio and television)				X					
Study 1: Expert interviews	X	X	X	X	X	X	X	X	
Study 2: Observation onboarding study								X	X

charged with getting informed written consent from end users, with Ex8 and Ex9 participating in the observation study. Unfortunately, due to holidays and work commitments Ex9 was unavailable for the Study 1 interviews and Ex7 was unavailable for the Study 2 observational sessions.

3.1.2 The members of the public. The 10 participants (four females, six males) were aged between 45 to over 75 years. All had been diagnosed with Type 2 Diabetes (T2D) and managed their condition through a mixture of tablet-based medication, diet, and weekly exercise. Out of the 10 participants, six lived in multi-resident households, four lived on their own, and one participant lived in rented accommodation. All owned a smartphone, nine owned tablets and five owned IoT devices including voice assistants, e.g. Amazon Alexa, Google Home, or smart lighting/heating controls. P1 and P6 were new to using videoconferencing software and during the initial pre-interview, P10 stated they had a learning disability and limited reading comprehension. Five participants were retired, three worked full-time and two were unemployed. Recruitment was done via social media (e.g. Twitter, Facebook), word-of-mouth, and information dissemination through relevant charities (i.e. Brigstowe Diabetes Peer Support⁸, and Diabetes UK⁹).

3.2 Data Collection

For the first study interviews, we asked eight experts (Ex1 to Ex8) to reflect on their engagement experiences. The retrospective interviews covered the following topics: (1) the procedures or processes that were involved in their job role; (2) the platform's design and functionality; and (3) the challenges around communicating the home healthcare platform. The eight semi-structured interviews lasted 45 minutes, included two researchers and one expert, and were conducted in person before COVID-19.

The second study, an observational study, was designed to simulate the standard onboarding sessions which ordinarily occur face-to-face within the potential participant's home. As COVID-19 made this impossible, we asked two deployment technicians (Ex8, Ex9) to run onboarding sessions for 10 participants over videoconferencing software. Each deployment technician completed five one-to-one sessions with participants (Ex8 presented to P3, P4, P5, P9 & P10, Ex9 presented to P1, P2, P6, P7 & P8). Each session lasted 90 minutes, 30 to 45 minutes for the observation onboarding session between the deployment technician and potential participant, 15 to 20 minutes for pre-interviews and 15 to 20 minutes for post-interviews. As the studies were sequential, the pre and post interview questions were revised to reflect the Study 1 findings.

3.2.1 Study 2 materials. To support the onboarding session, we used an A4-printed document [15] previously produced by the SPHERE team to aid in the explanation of the SPHERE platform as a whole. The designers of this A4 document [15] (fig. 1) used a user-centred design process to present the elements of SPHERE in a highly visual way (i.e. sensor devices; data extraction; platform installation and removal; training of the data; data processing and the ML algorithms which combine and interpret activities). As this document [15] was a tool that the SPHERE team had developed to support in the onboarding explanation of the platform, we included the use of this document within our study. The participants were given the option of either using a digital or a printed version of the document with all opting for the printed version, which was sent by post.

3.3 Data Analysis

For the interview data, using the transcript, three authors used Braun et al. [6]'s thematic analysis approach to understand the ways that domain experts communicate and explain the platform by

⁸<https://www.brigstowe.org/diabetes/>

⁹<https://www.diabetes.org.uk/>

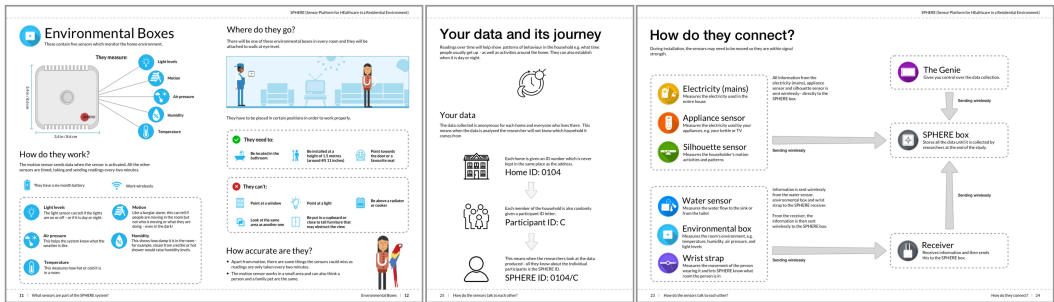


Fig. 1. Examples from the platform companion [15] (a) Environmental sensor, (b) SPHERE house ID and (c) SPHERE Network

individually open coding a transcript and discussing initial codes, which informed the coding of the rest of the transcripts by the first author. The development of themes (e.g. language style) and subthemes (e.g. acronyms and metaphors) was an iterative process between all authors using NVivo software [6, 49, 60]. The first author then coded the remaining transcripts, iterating upon the codes initially created. Using a mind map tool, we summarised the findings and representative quotes, and three authors further discussed and developed the themes [63].

For the observation study, the first author observed the onboarding sessions and reviewed the transcripts and onboarding session videos. The transcriptions and videos were then analysed separately. Transcripts were independently coded using Braun et al. [6] thematic approach, creating the first code book using NVivo [67]. The video data captured was analysed using interaction analysis [35] and any physical interaction within the camera’s view was noted. Initial codes were then iterated upon using a mind map tool [52], themes and subthemes were then discussed between authors and the findings and representative quotes were summarised, as in Study 1.

All authors engaged in discussions around the development and iteration of the final themes presented in the findings (see section 4), including the explanation strategies used and the perception of potential participants around informed consent.

4 FINDINGS

We first present the methods of communication experts use when presenting the platform to members of the public and their reflections on their effectiveness. We secondly present findings on explainer and explainee perceptions of the informed decision process with emphasis on the relationship between the platform expert and the non-technical member of the public.

4.1 Strategies (and workarounds) for explaining the complex system

4.1.1 Explanations with Personalisation. The experts reported that the language and technical level of information used varied depending on the perceived level of understanding of the explainee. “Different people have different levels of knowledge and different levels of interest. In my experience, [...], most participants would generally be quite interested in what different parts did” [Ex8]. Ex4 explained, “imagine that you were deploying a system” for “someone with high-level of IT skills [...] they might be very curious [...] and they might really want to look under the hood” while “there will be people at the other end of the spectrum who are deeply uninterested”. This desire for inclusivity was verified by Ex6, who reported reducing the complexity of the terminology they used, as some recipients “have never heard digital technology or digital health technology”. In contrast, some more complex aspects of the platform resist straightforward explanation: for example, “one of the tools is, for example,

doing principal component analysis, that what it does is reduce these number of dimensions into a number that you decide" [Ex2]. Others such as Ex6 report this language as confusing: "When they are using all that language, you have to be [...] 'I am sorry what?'" The experts reported these technical descriptions as unhelpful to members of the public and avoided using them in explanations of the platform, despite using them in the interviews.

During the onboarding observations, Ex8 and Ex9 adapted language, information, and presentation methods to support individual participants. Initially, Ex9 scoped each participant's understanding, saying: "Could I just ask a little bit first about yourself? So, do you consider yourself to be technical? Do you use a lot of technology in your daily life?". In contrast, Ex8 adopted a strategy of adapting on the go, stating that they would "zoom into areas if there's any interest in that particularly" or asking the participant to "stop me if you have any questions". This conversational technique was explicitly seen between Ex8 and P10 due to the participant's reported learning disability. Ex8 initially asked "Are you alright reading the page numbers or is that a tricky thing?" but as the session progressed, they raised the document to the camera so that P10 could see the current page and match with their own document (fig. 3a & fig. 3b). During the onboarding sessions the experts sometimes used technical vocabulary, e.g. "low energy Bluetooth transmitter" [Ex9]. If this internal team vocabulary was noticed, the experts quickly corrected themselves, "exception of the wearable – the wrist-strap device" [Ex9]. Acronyms were also used on occasion, with the experts quickly explaining the meaning, e.g. "it has a little 'PIR', so it's a passive infrared detector, it's like a burglar alarm" [Ex8].

4.1.2 Explanations Through Comparisons to the Familiar. The experts reported that they extensively compared the platform to familiar and existing objects, systems, and scenarios [5] to describe similarities and differences, sensors, data collected and user privacy.

For the healthcare applications, the experts referenced related assistive and health technologies, as well as medical practices. Ex4 stated that "for the patient it's the explainability of the whole process", identifying high-level context, rather than the decision-making process, as key – for example, the patient might ask "why have I now been prescribed this drug by this doctor?". Ex6 explained that the aspirational clinical purpose of the platform is to "monitor our health conditions" so that individuals could "be independent in our own homes with these certain conditions", and that storytelling helped the experts "set the scene, talking about [...] the growing population, incurable diseases like dementia, that our health service right now cannot deal with".

The experts found it useful to compare aspects of the platform with commercially available products, e.g. the wearable was compared with the commercial fitness tracker Fitbit, and privacy issues with recent controversy surrounding Amazon Alexa [41]. Ex6 recalled explaining the wearable, "relating it to a Fitbit because everybody's mum had a Fitbit". Ex7 also used the Fitbit to explain the wearable sensor (accelerometer) and to highlight additional functionality (homeowner's location within their home). For privacy, Amazon Alexa was referenced due to its continuously listening microphones and its mainstream media notoriety [41]. Ex6 explained why they used this example "as soon as you talk about Alexa, with anyone [...] kind of, a bit scary, a bit daunting, a bit invasion of your privacy".

The experts again reported using comparisons with the familiar to describe ML functionality, communicating level of certainty through three analogies: (1) A commercial product platform (e.g. Fitbit), where Ex3 speculated that product algorithms were not 100% accurate "so they want something that approximates your actual step count, but they are not that bothered if it's 5% to 10% wrong"; (2) The "stretch goal" concept popularised by a commercial service (e.g. Kickstarter) was referenced by Ex3 to describe the effort needed to gain the extra few percent of ML data accuracy; (3) the natural world's seasons (e.g. winter and summer) were referenced by Ex2 using the temperature difference of summer and winter: "we show some temperature and we say, this is

winter, and we show some other temperature and we say this is summer”. Ex2 encouraged explainees to think like the algorithm to empathise with its learning: “can you identify why are they different? [...] the model will look at it and will say, ok, [...] this is similar to the temperature in the summer”.

The experts reported using personas to explain location and activity awareness [14]. Ex3 described how the platform predicts that Bob was using the TV in the study, “we [analysts] can tell that was Bob because Bob is localised to within somewhere near that study”. Ex6 stated, “I always refer to a person called Barbara, and I imagine Barbara in a house, and I always use the idea, of her falling over” highlighting that “people [...] make themselves Barbara, they can make their mum or nan Barbara”.

During the onboarding observations, scenarios were used to communicate the healthcare benefits of the platform via analogy to common medical procedures, with Ex8 comparing data “snapshots” with “having an x-ray done that day and then [...] another x-ray to see whether something’s changed”. Although Ex8 and Ex9 didn’t use comparisons to the familiar for level of certainty, they did use comparisons with commercially available products. Both experts referred to the Fitbit in describing the platform’s wearable, such as Ex8: “It’s a bit like a Fitbit. Where it’s not like a Fitbit is it only works inside the building”. Both Ex8 and Ex9 made comparisons with “guitar pick-ups” when discussing the water sensors’ vibration and a “burglar alarm” for the motion sensor in the environmental boxes. Personas were used to create a ‘them and us’ construction of roles, describing their colleagues and their roles within SPHERE, “This is now into the land of the researchers” [Ex8]. When discussing the hardware, expert Ex8 states “one of our very clever researchers [...] came up with a new technology”. Referring to machine learning functionality, Ex9 states “we hand it over to our visual data scientists”. This ‘them and us’ comparison was also used to inform the participants of their role in using the SPHERE system, with both experts using “you” when asking a participant to do a task “So we’d ask you to...” [Ex8].

4.1.3 Explanations Through Metaphor and Anthropomorphism. The experts reported using metaphor and anthropomorphism to communicate the platform. Using the sensors’ physical characteristics and appearance, the experts reported describing and explaining different aspects of the platform. Ex3 referenced the passive infrared sensor on the ‘environmental sensor’ (fig. 2b) as a “little blob poking out”. The SPHERE Gateway was either “rabbit ears” or “bunny ears” [Ex8] (fig. 2a) with Ex7 explaining that this is because it has “two aerials sticking out”. Appearance was also used to describe the data visualisations, Ex1 stating that anonymised silhouette data “provides a cartoon version of the person”.



Fig. 2. The a) ‘rabbit ears’ gateway (left), b) ‘little blob poking out’ environmental sensor (middle) and c) Interactive demos of the platform’s capabilities – (i) The wearable, (ii) The environmental sensor and (iii) the Kinect silhouette camera.

Beyond the physical, the experts used metaphor to explain the functionality of the sensors, particularly when describing the limitations of the platform. An example of this would be the wireless signal strength, where Ex8 highlighted issues with building construction and how some homes acted “like a Faraday cage and stops wireless penetration in the building”. When deploying

the platform in homes, Ex3 stated: “you can think of them like little kind of space probes, because you cannot reasonably or cheaply go up and fix them”.

The experts used anthropomorphism [17] to describe human-like characteristics of the platform’s network and hardware, e.g. ‘talking’ and ‘listening’. Ex8 described wireless mesh network clients as a group or team, who “ideally need to talk to all their comrades”. Ex3 described sensor communication as a conversation: “‘hello I am a wearable’, and other things are kind of going, ‘Oh hey! I just heard from this wearable’”, and wearable battery power usage reporting as a statement: “‘hello, I have got a battery and it’s got this much voltage in it’”. Hearing was used by the experts to explain how sensors ‘listen’ to inanimate objects around the house. Ex5 described the water sensor as “listening to the water pipes”, homes with different water pressure having, “a quiet pipe, or a very loud pipe”. Explanations sometimes imply conscious thought on the part of the system. Referring to system limitations, Ex7 talked about the platform’s sensors with adjectives implying consciousness, for example, on sensor placement, “they should not be looking out of the window because it will be picking up movement outside of the house which would be confusing”, whilst two sensors should not point at the same location within the home as the platform “will think that there are two people when there’s actually just one”. Ex3 used this same form of description for wearable sensor location triangulation when out-of-range, “kind of ‘I don’t know. Can’t see them, can’t hear them, don’t know about them’”.

During the onboarding session, the two experts were observed using metaphors and anthropomorphism to communicate the sensors’ physical characteristics and appearance, not only verbally as reported during interviews, but visually via the experts’ hand gestures. Ex8 stated “As I say, we call these rabbit ears. I find this more friendly”, illustrating with two fingers and Ex9 placing two fingers above their head to highlight the receiver’s antenna (fig. 3(f & g)). For the environmental sensor, both experts described the passive infrared sensor on the front (fig. 2b), Ex9 describing it as a “little dimple” and pointing to his nose (fig. 3(h & i)). Again, the experts referenced human-like characteristics of the platform’s network and hardware with Ex8 describing the network as “how they talk to each other” and the environmental sensor being “quite fussy about its location”. As for metaphors, Ex8 again stated “some buildings will actually act like a Faraday cage and stop wireless signals” and described the ML data analysis as “a bit like a whodunnit, really”.

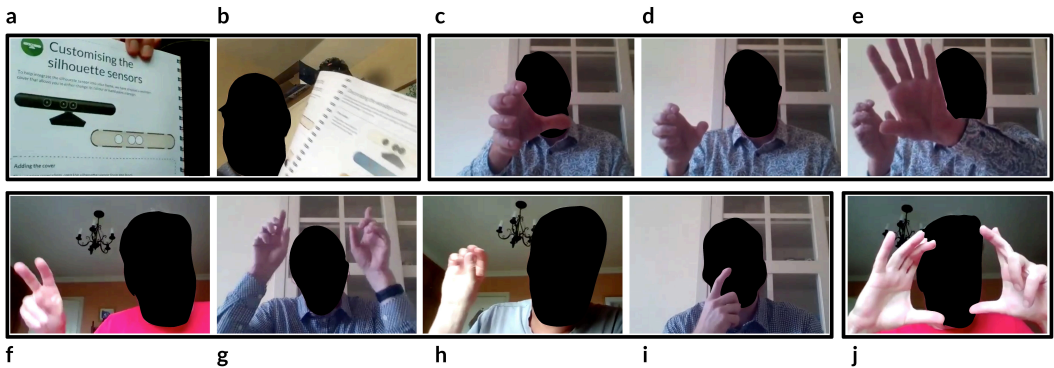


Fig. 3. Images from the onboarding sessions. (a & b) Ex8 and P10 sharing the document to help navigation. (c, d, e) Ex9 demonstrating a sensor installation (f & g) the ‘rabbit ears’. (h & i) the PIR sensor. (j) Ex8 showing the size of a sensor

4.1.4 Explanations through Physical Props. Experts also used physical props such as sketches and interactive demonstrations. Impromptu ways to visualise oral statements were used in discussions

between experts, such as sketching diagrams. These helped the experts themselves to articulate intangible aspects of the system, such as network protocols, to team members with different expertise. Ex6, a community liaison, described how “sometimes they would physically draw it out for me and explain, well this network does that with that sensor, and this network does that with that sensor”. Other visual approaches used by the experts included the sketching of storyboards. During meetings “we storyboarded out what we wanted them to say” [Ex6]. This enabled experts to collaboratively create a structured narrative to present to the public and potential platform adopters.

The experts used printed materials to communicate and explain, referencing them to describe the platform and respond to participant concerns. As Ex4, a researcher, stated, the participant information sheet (fig. 4a) “provided a particular level of detail, especially around the items that we knew from our conversations with members of the public, that they would be sensitive to”. Printed material, however, had its limitations. Ex6 highlighted how little explanation a project booklet provided, arguing that the little booklet (fig. 4b) “had like a photo, really briefly describing what each does, but even from that it wasn’t, I didn’t get a good idea”, before seeing a physical representation of the platform. The deployment technicians reported using props (samples of the sensors) during initial discussions within participant homes, allowing the participants to examine the physical size and appearance of the hardware. To help members of the public to understand the capabilities of the hardware, the experts (ML, Hardware, Research and Community engagement) reported building interactive demos that explained three types of hardware. The first used a wearable accelerometer (fig. 2ci) to illustrate supervised ML using three tasks (clapping, waving, and raising their hand). The second used several sensors to detect kettle use (fig. 2cii) and data fusion. The third, a Kinect camera (fig. 2ciii), involved a game of charades played using a silhouette representation of a person. Ex6 explained these interactive demos “are really good for people to understand, instead of just to hear about it. There is only so much understanding that you can get from listening and seeing a photo”. Demos help to explain platform functionality and reassure non-technical experts of the privacy protections in place. Ex6 would use this interactive demo to provoke people to think about the use of video versus the use of a silhouette camera in a private domestic setting: “could you tell who your friend was from the silhouette? No! Would that change whether you would want this in your home?”.

In the observation study, the experts and participants each had an A4 printed document containing information about SPHERE (see section 3.2). This document was used throughout the 10 onboarding sessions, with the two experts referring to the document to support the conversation. As Ex9 explained to a participant, they “refer to some pages as we go, [...] so that you can actually see what the sensors look like”. This was observed during the session with Ex8 walking the participant through a network flow diagram “If you look on the right-hand side we have the SPHERE box, and what we have

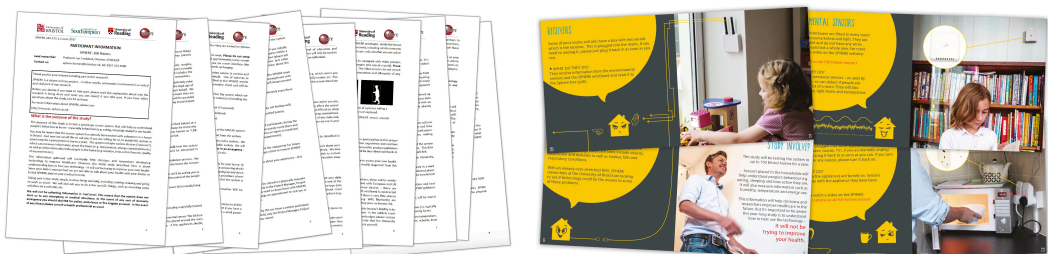


Fig. 4. a) The participant information sheet used to inform the potential participants about the platform, including benefits and risks. b) Example pages presenting (i) an overview; (ii) the environmental sensor; (iii) receiver and (iv) water sensor.

is all the data [...] It comes from three different sources. We have on the left-hand side the electricity and appliance sensor". When navigating the document, the experts gave the page number alongside context about the page content. For example, Ex8 described the project's use of pseudonymisation with "In fact, if we look onto page 28, you'll see that we give the home an arbitrary ID".

During the onboarding observations, the participants were unable to access samples of the sensors, explore technology demos or make use of impromptu sketches due to limitations imposed by COVID-19. To compensate for this, experts used their hands to explain the size of the devices (fig. 3j) and the document to explain the appearance of the hardware. Additionally, Ex9 pointed to their own Fitbit when describing the platform's wearable (fig. 5c), as a basis for comparison. The experts used their hands to illustrate the appliance sensor installation process "you pull the plug for your kettle out the wall, you plug this device in and you plug your kettle into it" [Ex9] (fig. 3(c, d, e)).

4.1.5 Bonding, building rapport and establishing common ground for explanations. During onboarding sessions, the experts introduced the platform's technology, its history, potential installation issues and outcomes from previous trials. Ex8 noted that "we've done a trial [...] [install] in 50 different homes, each for about a year". Both referenced prior research as a way to explain the platform's aspirations in monitoring different health conditions, such as clinical studies for "dementia sufferers [...] Parkinson's sufferers" [Ex8], with Ex9 explaining how the platform had helped to understand post-surgical recovery "we've monitored people before [...] an operation on their hip or knee, and then we've monitored them after they've come out of hospital to see [...] if there's a difference in the way that they move around". To show the ongoing development of the platform Ex8 discussed progress made to the water sensor, "we've got these water sensors and they've got a little turbine inside for measuring water flow, so when we go to people's houses you're going to have to basically saw into their pipework and put these in", going on to say that this has been updated and with the current water sensors "researchers came up with a new technology which is to clip on [...] microphones".

The experts also shared their personal limitations around the details of the content to build trust and rapport. Ex8 states "This is now into the land of the researchers, so if my interpretation gets fluffy, it's because my understanding sometimes does". Experts shared their personal opinions and personal taste also to build rapport, for example Ex8 who explained how participants perceived the ability of sensor casing customisation. "It's funny, we get such polarised views on this sort of bit, but, yeah, yeah, I don't care, but other people care a lot". Sharing personal lived experience related to the system also helped establish common ground, with Ex9 commenting on having the platform within their home "I know this from experience because I've actually had this platform installed in my own house for a short period". Beyond discussion of the platform, common ground was gained with other shared experiences, such as with P3 and Ex8 having a similar university experience, P3 stating "and then I went to university and studied [subject] and was thrown out" and Ex8 replying "I did that! [Laughs]". This back and forth allowed for conversation to flow, which helped the experts explain the system because they had built rapport, however this could also influence the conversation to get off topic, with P4 responding to the mention of a research project called CUBOID with, "It's funny, you've got a bone in your body called the cuboid as well" going on to say, "I'm a nurse, you see, so I know about these things".

During P2 and Ex9's session a potential installation problem was raised, with P2 discussing issues with their home WiFi. "The bricks that this house was built from were slag". This resulted in a joint problem-solving exercise that gave more context to how the system worked, with Ex9 explaining that they would need to use a "powerline network extender" that plugs into a "electrical socket next to the router" and "one in an electrical socket downstairs in the living room [...] it sends your network signal through the electrical system". Similar to the 'them and us' back and forth reported by the experts, the 'them vs us' narrative also helped build rapport, with P4 and Ex8 jointly making fun of

the document’s content, highlighting issues that they had with the examples of labels, P4 noting “*I think the knitting is funny*” and Ex8 replying “*I think the smoking was funny [Laughs]*”.

4.1.6 Explanations despite questions, distractions, disturbances, and repair. All onboarding sessions had interruptions, expected (e.g. participant queries) and unexpected – technical issues, environmental distractions, or conversations with members of their household or external parties.

Both experts perceived questions as an important aspect of adapting their explanation strategies to be bespoke for the user: “[*It’s*] useful if the participant is asking questions, because it means you can tailor it a little bit more” [Ex9]. Both paused regularly, checking with participants to see if they had questions before progressing with the document, for example Ex8 asking P9 “*Do you have any questions on that particular section?*” When participants asked questions, the experts were observed to be encouraging, with Ex8 stating “*that’s a good question*” and Ex9 using visual hand gestures to encourage the participant to continue (fig. 5a). Visually encouraging questions was also observed, with both experts’ postures changing to lean closer for projecting actively listening (fig. 5b). The experts expected these types of interruptions, although this wasn’t always clear: during the onboarding session between Ex9 and P8 there had been some issues with the internet connectivity, with P8 commenting “*one stage I went like that [Waving], because I couldn’t hear him, [...] It froze, and I couldn’t hear him*”. P8 reported wishing that Ex9 had made it clearer if they “*could interrupt*”.

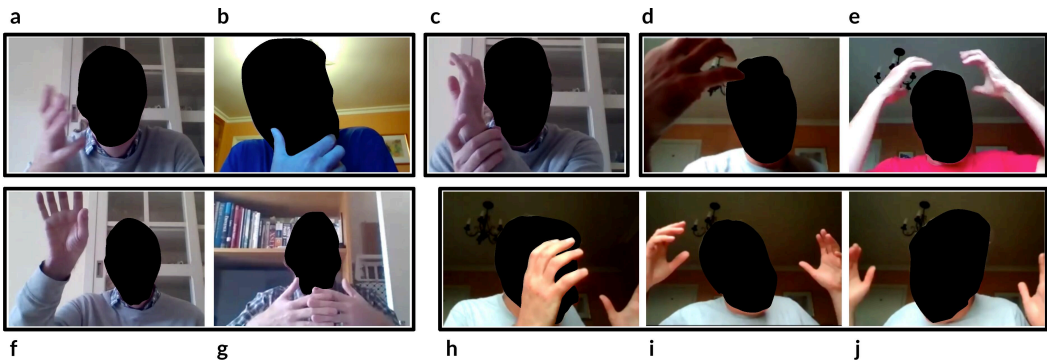


Fig. 5. (a) Ex9 gesturing for the participant to continue. (b) leaning in to listen to the participant. (c) demoing the Fitbit. (d) using their hand to illustrate the silhouette sensor (e) illustrating head camera placement (f) positioning of sensors (g) sensor fusion and (h, i & j) Ex8 using gestures to describe how data is kept secure.

Unfamiliarity and issues with the technologies used for the onboarding were barriers to explanation: P1 had not previously used the software and required a tutorial; P4’s device ran out of charge; P8 had internet connectivity issues; and P5 and P9 had audio or video camera issues. Due to environmental distractions, bright sunlight, and noise, Ex8 needed to close the curtains or shut the window, disrupting the explanation. Two participants (P1 and P8) were distracted by activity they could see outdoors and P1’s attention wandered as Ex9 was finding an item within the document. Four onboarding sessions were disturbed by a person leaving the room, Ex8 and P8 answering their front door, P9 checking if their cooker was off and P3 wanting an opinion from their partner. P1 and P3 also interrupted the onboarding session as they spoke to their partners, P3 due to a ringing phone and P1 requesting a bottle of water. Despite plans for the explanations, situated distractions interrupted the flow of the explanation, potentially impacting its effectiveness.

The experts (Ex8 and Ex9) used linguistic strategies to repair the interaction following interruption. For example, an experts would segue, e.g. “*Anyway*” [Ex8], “*Now, one of the things*” [Ex9], or navigate to the next page of the document “*page nine, appliance sensor*” [Ex8]. For larger disturbances, e.g.

closing a window [Ex8], or needing to leave the room, they would often employ humour to get back attention, e.g. Ex8 states “*slightly odd [...] because I could just smell the burning smells of food in my house*” then “*OK, right. Page 11, silhouette sensors*”. Participants were also observed trying to get back on track after an interruption using the document, such as P8, a retired deputy head teacher, stating as soon as they re-entered the room “*Sorry – all done yeah – Page 32 we’re on, aren’t we?*”.

4.1.7 Spatial communication and gestures to enhance explanations. The experts leaned on visual means of explanation as well as verbal means, including extensive use of hand gestures alongside language throughout the onboarding session. This included enhancing the explanation by illustrating sensors as objects, demonstrating sensor placement, and modifying their speech and using the space around them to highlight the stages of a technical process. To illustrate the silhouette sensors, Ex8 made a shape with their hand using the fingers to show a camera’s field of view (fig. 5d). Ex8 and Ex9 used their hands to express sensor placement, placing their hands on their head to describe the use of a head-mounted video camera (fig. 5e) or above eye level to indicate height of sensor placement (fig. 5f). Hand gestures were also used to help illustrate concepts, with Ex9 discussing “*Fusion of sensors*” and interlocking their fingers to illustrate the concept (fig. 5g). The experts used the area around them to describe multi-staged processes. Ex8 described the level of security of the collected participant data, illustrating a “*Fireproof box*” (fig. 5h) then into a “*Locked cabinet*” (fig. 5i) within a “*Secure room*” (fig. 5j). This points to the importance of video or in person explanation of complex systems.

4.2 Participants’ level of understanding and informed consent

As the aim of the onboarding sessions was to inform the participants about the platform, we sought to establish whether participants ultimately understood the platform well enough to make an informed decision.

4.2.1 Participants’ perceptions of the onboarding sessions. The participants were nervous about the onboarding sessions with P1 stating that they were “*dreading [the onboarding session] because [...] I’m not technical and I’m thinking, ‘Oh my Lord!’ But, no, as I said, [Ex9] was very good and [Ex9] explained it all wonderfully*”. All 10 participants stated that they were positive about the sessions, P3 describing how the expert “*went through the document [...] topic by topic and I didn’t have much in the way of questions but, you know, [Ex8] was able to cover any questions I had*”.

The participants reflected on the methods used by the experts to help inform them about the platform. For example, P4 described the language and technical detail used, viewing this as “*really important, because [...] some of your potential clients would not be technological, so they may struggle with understanding some of the [...] nuances*”. P3 additionally showed awareness of people’s different level of knowledge saying that those who are “*a little bit more technical, you don’t have to go through that explanation*”. P4 and P9 were able to comprehend the silhouette sensor by the experts comparing it to the original Xbox controller, with P4 stating “*I actually thought it looked like a games controller that one of my grandchildren’s got, [...] when [Ex8] explained to me that that’s actually where it originates, [...] that sort of all fell into place*”. The experts’ use of scenarios and personas (section 4.1.2) is echoed by P2’s reference to personal experience as they considered the benefits of the SPHERE platform, “*With somebody who was going into dementia, you could see the deterioration. I mean, my wife had dementia and, you know, again, I can understand how that would work*”. Participants also re-used scenarios as P3 explained data fusion, copying the scenario used by the expert, “*You know, you can sort of cross reference things like [...] electricity usage and humidity, you can tell that somebody is boiling a kettle*”. It was remarked by P9 that the physical prop (see section 4.1.4) improved the onboarding session stating “*if [Ex8] gone through that without the document, that would have been quite hard to understand*”. Combining the use of the physical document with an expert discussion did, P4 believed, provide “*the ability to be pitched at all levels of*

understanding". The participants did not mention any disturbances during the session (e.g. phone ringing). However, P4 suggested that the explanations sometimes precluded the questions they would otherwise have asked, "some of the things that I had thought in my mind, I didn't even ask because, like the data protection and information governance, I didn't – I could see that that was very well – it's being very well-managed".

Two issues were identified with the relationship between the expert and the participant, which impacted the explanation. P8 wished that Ex9 had made it clearer when they "could interrupt. It felt rude after a while. [...] I didn't want to interrupt because he was in the flow". P7 explained, "there was one point, the sensors, I thought, 'I'm not really' – there was too much technical detail, but only for a very short period. So, I'm not being critical".

4.2.2 Interpreting the participants' understanding and informed decision on adoption of the platform. The experts estimated the participants' level of platform comprehension through questions asked and ongoing body language. Ex8 noted, "when there are no questions people want to ask, you wonder whether they've got it or they just don't want to know". Going beyond language, there were other verbal cues for level of understanding with Ex9 explaining you can tell if someone is understanding as "they just seemed to make all the right noises". When asked about the onboarding session for the participants, the experts felt that most participants understood the platform. Ex8 explained that P9 "seemed to reasonably get the technical side of it, better than some people". When it came to P10, however, Ex8 was unsure of their level of understanding as they "seemed fine about it, but I don't know, I vaguely got the impression [they] kind of just wanted to get through it". Ex8 believed that P10 "gave the impression of understanding everything" but "when I asked, 'are you OK, did you understand?', he said so. I had to believe him to some degree".

Out of the 10 participants four (P1, P2, P5, P7) were happy to make a positive informed decision, while two (P3 and P4) commented that the decision was not theirs alone. As P3 stated "it goes back to the thing about agreement in the household and I can't speak for my wife on that, I don't think she's particularly worried about anything like that". P4 believed that once discussed with the household, consent would be given "I can't imagine that [they] would find it a problem or an intrusion, or an issue around data collection or information governance, that sort of thing". Two participants (P8 and P10) declined as they believed other household members would object, P8 saying, "I would be almost 100% certain my wife would not want to be involved in this project, so it would be difficult for me to be". Similarly, P6 declined as "I'm a renter so I wouldn't be able to install", being unable to get permission from the landlord. P9 gave consent, but with the understanding that this would depend on the "survey" results as that "tells you what is going to be put in your home and the likely places it's going to be put in". P1, P6 and P5 also underlined the importance of granular consent, P5 saying "It would make it a more reasoned decision, [to] cheery pick what you're going to install throughout my house".

5 DISCUSSION

Through interviews and an observational study, we explored methods used by experts, including physical gesture and verbal interaction, to explain a complex home health platform. The explanatory strategies that took place during direct interaction between the explainee and explainer had developed during numerous public engagement events, large scale recruitment of potential participants and platform deployments in over 60 homes. Using several reported techniques and observed workarounds, the experts attempted to provide non-technical potential users with accurate information in an understandable way. This research is framed by Gilpin et al. [23] and Lombrozo [46]'s understanding of an informed decision, particularly the need to present the platform understandably and accurately, giving the explainee a neutral overview. For Gilpin et al. [23], accurate understanding that aids critical thinking is key in the context of establishing consent, and for Ploug

et al. [59], provision of relevant information is argued to be a precondition of decision-making. This is particularly significant in reasoning about complex platforms with several sensor or analytical methods that might be beneficial to health if adopted and accepted, but which also impose limitations and potential risks. In our findings, the complex nature of the platform was addressed during both studies using multiple information types (spoken word strategies, sections 4.1.1 to 4.1.3; physical props, [15] and section 4.1.4; physical gestures, section 4.1.7), the availability of demos tailored to approach complex topics such as data fusion and participant privacy (section 4.1.4) and interactive approaches to explanation that importantly encourage open discussion around relevant topics.

The mutually shared understanding between explainer and explainee is also key to deployment, which is seen throughout our findings, from adapting the methods of communication for the explainee to building common ground by comparing the technology to the familiar. In our findings, there are indications that participants seek to involve other members of the household during the informed consent process regarding various aspects of the platform, even at an early stage, which is in line with Fischer et al. [19, 20], Tolmie et al. [65, 66, 67] and Grinter et al. [25]’s work, which characterises sensor placement within a home as a complex process, requiring platform acceptance within the household and joint work with the householders to optimise sensor placement and fit with participants’ social and physical routines.

Both Tolmie et al. [65, 66], and Fischer et al. [19, 20] observed conversations between experts and explainees during the deployment of a complex platform. However, our findings focus on users’ understanding before they decide to adopt a platform. By observing the onboarding before the decision has been made to adopt the complex ML and IoT enhanced health platform and examining the existing practices of those explaining the system to potential users, we provide insight into methods that can better support informed consent of health systems. Through this investigation, we captured the explanation of the holistic workings of the complex platform, beyond the focus on visible, tangible hardware that is placed within the home, and use these insights to identify several strategies used to explain complex platforms to aid informed consent, summarised in sections 5.1 to 5.2.

These insight on an informed consent framing of the onboarding process complement prior work by Gilpin et al. [23], Lombrozo [46], Burrows et al. [9] and Lakoff et al. [40]. Findings cast light on practical communication methods used by platform experts, such as tailoring language use or the level of detail offered to the individual explainee, comparing parts of the platform to commercial products or the natural world, using metaphors to describe the physical hardware, and using physical props [15] as well as gesture to aid in those conversations. The experts also scoped the explainee’s level of knowledge and experience, and made use of shared questioning, common ground and effective linguistic repair.

5.1 Metaphor, scenario and storytelling

To keep the explainee engaged, the experts used storytelling, referencing scenarios, personas and comparison with the familiar [5, 13]. The use of scenarios was previously highlighted by Fischer et al. [20] during a sensor-based platform deployment, with their expert using scenarios as a way to present to the household member the benefits of sensor deployment within their home. Van Notten et al. [68] define scenarios as ways in which you can present the platform’s ‘Why? What? And how?’, a method used by Ex6 in this study to explain the overall purpose of the platform. Fischer et al. [19, 20], Tolmie et al. [65, 66, 67] and Grinter et al. [25] noted that storytelling was also used by the household members when explaining how they used their home and establishing platform fit with their perceptions and real-world experiences of their homes. We found the experts reported using personas [13] (Ex3, Ex6) to explain how specific individuals’ activities could either be identified or supported by the platform. One storytelling method that the experts used that has not been covered in related work is the use of analogy to compare the functionality of the platform’s sensors with other commercially available

products with which the explainee is more familiar (see overview, section 4.1.2). With the proliferation of consumer technology in domestic settings and on-person, there is the opportunity to leverage storytelling using analogies with the familiar technology that provide scaffolding for the explanation of more complex machine learning IoT platforms.

Metaphor was widely employed by the explainers during both studies using verbal and physical gestures. The use of metaphor reflects Johnson [33]’s, Lakoff et al. [40]’s and Jentner et al. [32]’s findings that those with technical knowledge or those who present complex technologies (such as machine learning) use vocabulary that is ‘metaphorical’ during discussions to provide explanation at a level of abstraction that is accessible to non-technical individuals. The experts identified the hardware through physical appearance and familiar terms, for example, referring to the ‘SPHERE gateway’ as ‘rabbit ears’ during the observation study, with the experts making the shape of the ‘ears’ with their hands (fig. 4f-g). The limitations of the platform were verbally presented by reference to concrete concepts by the expert, for example, a home deployment was described as a space probe that you cannot easily gain access to. Anthropomorphism was additionally used by the explainers to verbally describe sensor activity and network capability [16, 17], going beyond what was directly observable and transforming difficult-to-explain aspects into familiar concepts, as well as attributing human-like characteristics to sensors [16] such as seeing, hearing, and thinking.

Scenario-based protocol descriptions involving stock characters (‘Alice’ and ‘Bob’ notation [Ex3]) are an established convention within several subfields of computer science, notably privacy and security [2]. The extent to which shared scenario-based descriptions of this type may support shared conceptualisation across groups with varied backgrounds remains an open research question. However, our study has shown that experts are using metaphor, scenarios and storytelling to explain concepts that were complex and multifaceted. We captured experts with highly technical knowledge using very creative methods in order to get across very technical aspects of the platform, showing the need for creative approaches to explanation in even a serious context such as supporting informed consent for a health platform installation.

5.2 Aiding the Explanation with Conversational Props

A conversational prop is an artefact such as a photo or a sketch on a napkin that aids conversations [8]. Three types of conversational props were used by the explainers: printed documents, physical sensors, and interactive demos presenting data. Our findings show that some conversational props are more useful than others, for example the initial printed document that Ex6 highlighted during the interviews (fig. 4b) were too high-level and did not provide a good overview of the platform. However, the printed document used during the observational studies, as P4 noted (Eardley et al. [15], fig. 1) provided a good balance to the verbal presentation. We found that explanations benefitted from rapport developed through reference to shared knowledge (e.g. P2, P4) and using humour, which acted as conversational props. This draws comparisons to the personalised data-focused explanations described by Fischer et al. [19], for whom a personalised ‘home visit sheet’ became a conversational prop, ‘providing situationally specific advice’ to homeowners [19]. Although there is value in paper resources, successful explanations, as we have highlighted in this paper, are likely to benefit from situated interaction and explanations grounded in participants’ own experiences. In the post-pandemic context and in practice, it is likely that an onboarding/informed consent session would not be in person, however mailouts and paper substitutes might be of use to help structure explanation before informed consent.

To demonstrate the use of the physical sensors, to present functionality, and to highlight the sensors’ size, shape and deployment position, experts initially used physical props (Ex8). However, during the observational study and due to the constraints of COVID-19, experts substituted these physical props with physical hand gestures describing the stages of installation (fig. 5c,d,e), sensor

size (fig. 5j) and deployment positions (fig. 5d,e,f). Fischer et al. [20] also observed that an expert use sample sensors to explain the hardware's functionality and connectivity. The observation that physical props play a vital role in explanations is corroborated by Watermeyer et al. [69], who find that medical communication with pharmacists benefits from the use of props such as pills and pill containers. Furthermore, experts had previously created three different demos (fig. 2c; see section 4.1.4) to illustrate aspects of the system. Such demos are widely used to explain sensors (e.g. [28, 43, 61]). Lechelt et al. [42] note that interactive demos encourage exploration, allowing curiosity-driven exploration of technology. Unfortunately, whilst these demos were considered effective by experts (e.g. Ex6), COVID-19 limitations rendered their use unfeasible in the onboarding study. As with paper, the likelihood of an in-person onboarding session is low therefore impacting the possibility of tangible props. Before a user has made the decision to adopt the technology, it might not be feasible to provide in person visits to the home as seen in previous studies of explanation. However, there are possibilities for physical props to still be used for virtual video onboarding sessions to ease the explanation of explanation, particularly for health sensors (see for example fig. 5c).

5.3 Informed consent and ethics

Through our two studies we have focused on the interactions between the explainee and explainer, and the tools used during the initial discussions. These key discussions provided potential participants with a much-needed overview of the complex platform before installation [47]. As stated by Gilpin et al. [23] and Lombrozo [46] information about the platform must be factually correct and presented in a neutral way, be it through the printed document [15] or through verbal descriptions of the sensors.

For this neutrality to occur, the tools selected, regardless of physical or verbal modality, cannot be persuasive. As Jacobs [30] notes there is a 'fine line' between persuasion defined as influence by reason and argument, and manipulation defined as persuasion by covert influence. Anthropomorphism [21], for example, encourages the expert or non-expert to place psychological qualities onto the technology by describing the platform as chatty, informative and helpful. While anthropomorphism may be a helpful communication tool, there is a risk that its usage could unduly influence a potential participant. Jacobs [30] recommends that any persuasive technology be deployed with attention to three criteria, (1) respect users' options and autonomy; (2) ensure awareness of the tools of persuasion in use; and (3) ensure that any persuasive technology align with the users' own personal goals [30].

In fact, we see that the diverse range of participant responses in our studies when asked about providing informed consent for platform installation as a sign of a balanced (factual and neutral) explanation [23, 46]. A large proportion provided their answer at the end of onboarding session (four positive and three negative) and the final three preferred a staged informed consent process [4], be this via discussion with other household members and/or the provision of further information to permit and improved understanding and potential negotiation of how the platform will be installed within the participants homes [20, 66]. This shows the importance of timing of the onboarding process beyond the explanation session, giving space for reflection beyond the explanation and allowing for households to discuss adoption of these platforms in their domestic settings, which are often shared. The process towards the adoption of domestic health technology has been shown to be a temporal and emotional journey [64]. We have encountered this even at the very beginning of the informed consent process of complex health platforms.

5.4 Insights into the Design of Explanation for Home Health Platforms

From this research, we gained insight on how experts who work on the development, maintenance and deployment of a complex platform such as SPHERE, explain the platform to potential adopters. Using these findings, we have developed ten insights that will help others to explain complex

domestic health platforms that support both understanding and critical thinking about risks and benefits to inform decision making, which span multiple communication modalities:

- (1) Understand the explainees' information needs: it is important to understand how technically knowledgeable the explainee is and to adjust the explanation accordingly. This can affect the language used or information presented; (derived from Ex4, Ex6, Burrows et al. [9] and Lombrozo [46]).
- (2) Simplify terminology: rather than abbreviations or jargon, use simple language that people use every day; (derived from Ex7, Ex6, Johnson [33] and Lakoff et al. [40]).
- (3) Use storytelling to engage the explainee: using scenarios or personas can help present the platform's 'why, how and what'; (derived from Ex3, Ex6, Fischer et al. [20] and Cooper et al. [14, 13]).
- (4) Use comparisons to existing products: use products or processes like those that you are trying to explain and highlight their similarities and differences. Comparisons can also be made anthropomorphically, using human characteristics; (derived from Ex7, Ex3 and Ex4)
- (5) Use metaphors for the invisible: metaphors help to simplify explanations and can be tailored to the explainee (derived from Ex8, Ex7, Ex3, Ex2 and Ex6, Jentner et al. [32], Arroliga et al. [3] and Lakoff et al. [40]).
- (6) Show physical hardware: this gives the explainee the context of the technology and if possible, use these artifacts to describe how the sensors connect to each other; (derived from Ex8, Ex7, Ex6, Tolmie et al. [65, 66], and Fischer et al. [19, 20]).
- (7) Use interactive demos: tangible and interactive representations permit exploration of a platform's limitations and benefits; (derived from Ex8, Ex7, Ex6, Tolmie et al. [65, 66], Fischer et al. [19, 20]).
- (8) Present the purpose and user journey: this provides the explainee with an overview of the platform, contextualising the technology, its use and the intended outcomes (derived from Ex4).
- (9) Consider the explainee's social context: sense-making within the household is not individual, but a joint, ongoing process between members of the household (derived from P1, P3, P4, P6, P8 and P9). This is reflected in section 4.2.2, in which several participants draw on family members' involvement in the consent process.
- (10) Be sensitive that consent can be a lengthy process, one that can involve an ongoing discussion with the explainee and other stakeholders (e.g. multiple-household members), and which may result in a reasoned decision against or for adoption of the platform (derived from section 4.2.2, Ploug et al. [59]).

6 LIMITATIONS AND NEXT STEPS

Although the experts had significant experience (i.e. with over 60 home platform installations), their experiences related to only one platform. Other platforms might benefit from different presentation methods. Due to COVID-19, we were unable to conduct the onboarding within participants' homes, which may have mitigated the problem of distractions within the home. Additionally, gestures sometimes occurred outside the visual field of the videoconferencing software. To improve presentation of complex information to members of the public who are non-technical, further research could develop and evaluate specific tools to support aspects of explanation, including documentation, videos, and interactive demonstrations. It is worth noting that all participants were resident in the UK, and several strategies employed may not generalise to other cultural contexts. The research focused on experienced explainers, so to understand how intuitive these approaches are, we would recommend that future work observe how those new to the task of explaining complex platforms initially approach the problem, and how their methods develop over time. Finally, future work may

focus on how these approaches can be streamlined for large-scale practical deployments and a greater diversity of explainers (e.g. medical professionals), and to what extent they are already employed, as well as exploring how informed consent and marketing are engaged with and interact with one another in the healthcare device sector.

7 CONCLUSION

Through retrospective interviews with eight team members who have built, maintained, and deployed a complex platform into over 60 homes and 10 observed onboarding sessions, we gained insight into the communication methods used to explain a home health platform to non-technical experts in preparation for informed consent. The interviews and observational study gave us insights into how the experts personalise explanations of the platform, tailoring the level of language and detail to that of the explainee. Communication strategies include comparing the platform to familiar products or environments (e.g. Fitbit), metaphors and anthropomorphism that help the explainer present abstract concepts and characterise sensors and interactive demos that allow the explainees to explore the benefits and limitations of the platform. These findings advance the knowledge base about complex domestic technology to provide insights on how to engage explainees through props and hand gestures.

ACKNOWLEDGMENTS

This work was performed under the SPHERE IRC funded by the UK Engineering and Physical Sciences Research Council (EPSRC), Grant EPK031910/1. The authors thank the SPHERE technicians and participants for their contribution to this study.

REFERENCES

- [1] Amina Adadi and Mohammed Berrada. 2018. Peeking inside the black-box: a survey on explainable artificial intelligence (XAI). *IEEE Access*, 6, 52138–52160. DOI: [10.1109/ACCESS.2018.2870052](https://doi.org/10.1109/ACCESS.2018.2870052).
- [2] Omar Almousa, Sebastian Mödersheim and Luca Viganò. 2015. Alice and bob: reconciling formal models and implementation. In *Programming Languages with Applications to Biology and Security: Essays Dedicated to Pierpaolo Degano on the Occasion of His 65th Birthday*. Chiara Bodei, Gianluigi Ferrari and Corrado Priami, editors. Springer International Publishing, Cham, 66–85. ISBN: 978-3-319-25527-9. DOI: [10.1007/978-3-319-25527-9_7](https://doi.org/10.1007/978-3-319-25527-9_7).
- [3] Alejandro C. Arroliga, Sara Newman, David L. Longworth and James K. Stoller. 2002. Metaphorical medicine: using metaphors to enhance communication with patients who have pulmonary disease. *Annals of Internal Medicine*, 137, 5_Part_1, 376–379. DOI: [10.7326/0003-4819-137-5_Part_1-200209030-00037](https://doi.org/10.7326/0003-4819-137-5_Part_1-200209030-00037).
- [4] H. Bekker et al. 1999. Informed decision making: an annotated bibliography and systematic review. *Health Technol Assess*, 3, 1, 1–156.
- [5] Lena Börjeson, Mattias Höjer, Karl-Henrik Dreborg, Tomas Ekvall and Göran Finnveden. 2006. Scenario types and techniques: towards a user’s guide. *Futures*, 38, 7, 723–739. DOI: [10.1016/j.futures.2005.12.002](https://doi.org/10.1016/j.futures.2005.12.002).
- [6] 2012. *Thematic analysis*. APA Handbooks in Psychology. American Psychological Association, Washington, DC, US, 57–71. ISBN: 978-1-43381-005-3. DOI: [10.1037/13620-004](https://doi.org/10.1037/13620-004).
- [7] Mayer Brezis, Sarah Israel, Avital Weinstein-Birenshtock, Pnina Pogoda, Ayelet Sharon and Renana Tauber. 2008. Quality of informed consent for invasive procedures. *International Journal for Quality in Health Care*, 20, 5, (July 2008), 352–357. DOI: [10.1093/intqhc/mzn025](https://doi.org/10.1093/intqhc/mzn025).
- [8] Tom Brinck and Louis M. Gomez. 1992. A collaborative medium for the support of conversational props. In *Proceedings of the 1992 ACM Conference on Computer-Supported Cooperative Work (CSCW ’92)*. Association for Computing Machinery, Toronto, Ontario, Canada, 171–178. ISBN: 0897915429. DOI: [10.1145/143457.143476](https://doi.org/10.1145/143457.143476).
- [9] Alison Burrows, Rachael Gooberman-Hill and David Coyle. 2016. Shared language and the design of home healthcare technology. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing*

- Systems* (CHI '16). Association for Computing Machinery, San Jose, California, USA, 3584–3594. ISBN: 9781450333627. DOI: [10.1145/2858036.2858496](https://doi.org/10.1145/2858036.2858496).
- [10] Carrie J. Cai, Samantha Winter, David Steiner, Lauren Wilcox and Michael Terry. 2019. "hello ai": uncovering the onboarding needs of medical practitioners for human-ai collaborative decision-making. *Proc. ACM Hum.-Comput. Interact.*, 3, CSCW, Article 104, (Nov. 2019), 24 pages. DOI: [10.1145/3359206](https://doi.org/10.1145/3359206).
- [11] Nico Castelli, Aparecido Fabiano Pinatti de Carvalho, Nico Vitt, Sebastian Taugerbeck, Dave Randall, Peter Tolmie, Gunnar Stevens and Volker Wulf. 2022. On technology-assisted energy saving: challenges of digital plumbing in industrial settings. *Human-Computer Interaction*, 37, 4, 341–369. DOI: [10.1080/07370024.2020.1855589](https://doi.org/10.1080/07370024.2020.1855589).
- [12] Amy Cheng, Vaishnavi Raghavaraju, Jayanth Kanugo, Yohanes P. Handrianto and Yi Shang. 2018. Development and evaluation of a healthy coping voice interface application using the google home for elderly patients with type 2 diabetes. In *2018 15th IEEE Annual Consumer Communications Networking Conference (CCNC)*, 1–5. DOI: [10.1109/CCNC.2018.8319283](https://doi.org/10.1109/CCNC.2018.8319283).
- [13] Alan Cooper, Robert Reimann, David Cronin and Christopher Noessel. 2014. *About Face: The Essentials of Interaction Design*. (4th ed.). Wiley, (Sept. 2014), 720 pages. ISBN: 978-1-118-76657-6.
- [14] Alan Cooper and Paul Saffo. 1999. *The Inmates Are Running the Asylum*. Macmillan Publishing Co., Inc., USA. ISBN: 0672316498. DOI: [10.5555/553473](https://doi.org/10.5555/553473).
- [15] Rachel Eardley et al. 2022. A case study investigating a user-centred and expert informed 'companion guide' for a complex sensor-based platform. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.*, 6, 2, Article 93, (July 2022), 23 pages. DOI: [10.1145/3534625](https://doi.org/10.1145/3534625).
- [16] Atis Elsts, George Oikonomou, Xenofon Fafoutis and Robert Piechocki. 2017. Internet of things for smart homes: lessons learned from the sphere case study. In *2017 Global Internet of Things Summit (GIoTS)*, 1–6. DOI: [10.1109/GIOTS.2017.8016226](https://doi.org/10.1109/GIOTS.2017.8016226).
- [17] N. Epley, A. Waytz and J. T. Cacioppo. 2007. On seeing human: a three-factor theory of anthropomorphism. *Psychological Review*, 114, 4, 864–886. DOI: [10.1037/0033-295X.114.4.864](https://doi.org/10.1037/0033-295X.114.4.864).
- [18] Xenofon Fafoutis, Atis Elsts, Robert Piechocki and Ian Craddock. 2018. Experiences and lessons learned from making iot sensing platforms for large-scale deployments. *IEEE Access*, 6, 3140–3148. DOI: [10.1109/ACCESS.2017.2787418](https://doi.org/10.1109/ACCESS.2017.2787418).
- [19] Joel E. Fischer, Andy Crabtree, James A. Colley, Tom Rodden and Enrico Costanza. 2017. Data work: how energy advisors and clients make iot data accountable. *Computer Supported Cooperative Work (CSCW)*, 26, 4, (Dec. 2017), 597–626. DOI: [10.1007/s10606-017-9293-x](https://doi.org/10.1007/s10606-017-9293-x).
- [20] Joel E. Fischer, Andy Crabtree, Tom Rodden, James A. Colley, Enrico Costanza, Michael O. Jewell and Sarvapali D. Ramchurn. 2016. "just whack it on until it gets hot": working with iot data in the home. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16). Association for Computing Machinery, San Jose, California, USA, 5933–5944. ISBN: 9781450333627. DOI: [10.1145/2858036.2858518](https://doi.org/10.1145/2858036.2858518).
- [21] B. J. Fogg. 2002. Persuasive technology: using computers to change what we think and do. *Ubiquity*, 2002, December, Article 5, (Dec. 2002), 32 pages. DOI: [10.1145/764008.763957](https://doi.org/10.1145/764008.763957).
- [22] Marzyeh Ghassemi, Luke Oakden-Rayner and Andrew L. Beam. 2021. The false hope of current approaches to explainable artificial intelligence in health care. *The Lancet Digital Health*, 3, 11, (Nov. 2021), e745–e750. DOI: [10.1016/S2589-7500\(21\)00208-9](https://doi.org/10.1016/S2589-7500(21)00208-9).
- [23] Leilani H. Gilpin, David Bau, Ben Z. Yuan, Ayesha Bajwa, Michael Specter and Lalana Kagal. 2018. Explaining explanations: an overview of interpretability of machine learning. In *2018 IEEE 5th International Conference on Data Science and Advanced Analytics (DSAA)*, 80–89. DOI: [10.1109/DSAA.2018.00018](https://doi.org/10.1109/DSAA.2018.00018).
- [24] Johanna Glaser, Sarah Nouri, Alicia Fernandez, Rebecca L. Sudore, Dean Schillinger, Michele Klein-Fedyshin and Yael Schenker. 2020. Interventions to improve patient comprehension in informed consent for medical and surgical procedures: an updated systematic review. *Medical Decision Making*, 40, 2, 119–143. DOI: [10.1177/0272989X19896348](https://doi.org/10.1177/0272989X19896348).
- [25] Rebecca E. Grinter, W. Keith Edwards, Mark W. Newman and Nicolas Ducheneaut. 2005. The work to make a home network work. In *Proceedings of the Ninth Conference on European Conference on Computer Supported Cooperative Work (ECSCW'05)*. Springer-Verlag, Paris, France, 469–488. ISBN: 9781402040221. DOI: [10.5555/1242029.1242053](https://doi.org/10.5555/1242029.1242053).

- [26] Abdelsalam Helal, Diane J. Cook and Mark Schmalz. 2009. Smart home-based health platform for behavioral monitoring and alteration of diabetes patients. *Journal of Diabetes Science and Technology*, 3, 1, 141–148. doi: [10.1177/193229680900300115](https://doi.org/10.1177/193229680900300115).
- [27] S. Helal, W. Mann, H. El-Zabadani, J. King, Y. Kaddoura and E. Jansen. 2005. The gator tech smart house: a programmable pervasive space. *Computer*, 38, 3, 50–60. doi: [10.1109/MC.2005.107](https://doi.org/10.1109/MC.2005.107).
- [28] Steven Houben, Connie Golsteijn, Sarah Gallacher, Rose Johnson, Saskia Bakker, Nicolai Marquardt, Licia Capra and Yvonne Rogers. 2016. Physikit: data engagement through physical ambient visualizations in the home. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. Association for Computing Machinery, San Jose, California, USA, 1608–1619. ISBN: 9781450333627. doi: [10.1145/2858036.2858059](https://doi.org/10.1145/2858036.2858059).
- [29] Amy S. Hwang, Khai N. Truong and Alex Mihailidis. 2012. Using participatory design to determine the needs of informal caregivers for smart home user interfaces. In *2012 6th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops*, 41–48. doi: [10.4108/icst.pervasivehealth.2012.248671](https://doi.org/10.4108/icst.pervasivehealth.2012.248671).
- [30] Naomi Jacobs. 2020. Two ethical concerns about the use of persuasive technology for vulnerable people. *Bioethics*, 34, 5, 519–526. doi: [10.1111/bioe.12683](https://doi.org/10.1111/bioe.12683).
- [31] Timo Jakobi, Corinna Ogonowski, Nico Castelli, Gunnar Stevens and Volker Wulf. 2017. The catch(es) with smart home: experiences of a living lab field study. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*. Association for Computing Machinery, Denver, Colorado, USA, 1620–1633. ISBN: 9781450346559. doi: [10.1145/3025453.3025799](https://doi.org/10.1145/3025453.3025799).
- [32] Wolfgang Jentner, Rita Sevastjanova, Florian Stoffel, Daniel Keim, Jürgen Bernard and Mennatallah El-Assady. 2018. Minions, sheep, and fruits: metaphorical narratives to explain artificial intelligence and build trust. In *Workshop on Visualization for AI Explainability (VISxAI)*. IEEE, Piscataway, NJ, (Oct. 2018), 7 pages.
- [33] Gerald J. Johnson. 1992. Talking about computers: from metaphor to jargon. *AI & SOCIETY*, 6, 3, (July 1992), 263–270. doi: [10.1007/BF02472798](https://doi.org/10.1007/BF02472798).
- [34] Carolyn Johnston, Michael Baty and Comfort Adewole. 2015. King’s college london student clinical ethics committee case discussion: a patient changes her mind about surgery – should her later refusal be respected? *Clinical Ethics*, 10, 1-2, 34–36. doi: [10.1177/1477750914567841](https://doi.org/10.1177/1477750914567841).
- [35] Brigitte Jordan and Austin Henderson. 1995. Interaction analysis: foundations and practice. *Journal of the Learning Sciences*, 4, 1, 39–103. doi: [10.1207/s15327809jls0401_2](https://doi.org/10.1207/s15327809jls0401_2).
- [36] R. A. Kadam. 2017. Informed consent process: A step further towards making it meaningful! *Perspect Clin Res*, 8, 3, 107–112. doi: [10.4103/picr.PICR_147_16](https://doi.org/10.4103/picr.PICR_147_16).
- [37] Mari-Rose Kennedy, Richard Huxtable, Giles Birchley, Jonathan Ives and Ian Craddock. 2021. “a question of trust” and “a leap of faith”—study participants’ perspectives on consent, privacy, and trust in smart home research: qualitative study. *JMIR Mhealth Uhealth*, 9, 11, (Nov. 2021), e25227. doi: [10.2196/25227](https://doi.org/10.2196/25227).
- [38] Elham Khodabandehloo, Daniele Riboni and Abbas Alimohammadi. 2021. Healthxai: collaborative and explainable ai for supporting early diagnosis of cognitive decline. *Future Generation Computer Systems*, 116, 168–189. doi: [10.1016/j.future.2020.10.030](https://doi.org/10.1016/j.future.2020.10.030).
- [39] Emily R. Lai. 2011. Critical Thinking: A Literature Review Research Report. Research Report. Pearson, (June 2011). <http://images.pearsonassessments.com/images/tmrs/criticalthinkingreviewfinal.pdf>.
- [40] George Lakoff and Mark Johnson. 2008. *Metaphors We Live By*. University of Chicago Press, Chicago, IL, 256 pages. ISBN: 9780226468013.
- [41] Josephine Lau, Benjamin Zimmerman and Florian Schaub. 2018. Alexa, are you listening? privacy perceptions, concerns and privacy-seeking behaviors with smart speakers. *Proc. ACM Hum.-Comput. Interact.*, 2, CSCW, Article 102, (Nov. 2018), 31 pages. doi: [10.1145/3274371](https://doi.org/10.1145/3274371).
- [42] Susan Lechelt, Yvonne Rogers and Nicolai Marquardt. 2020. Coming to your senses: promoting critical thinking about sensors through playful interaction in classrooms. In *Proceedings of the Interaction Design and Children Conference (IDC '20)*. Association for Computing Machinery, London, United Kingdom, 11–22. ISBN: 9781450379816. doi: [10.1145/3392063.3394401](https://doi.org/10.1145/3392063.3394401).
- [43] Kevin Lefeuve, Soeren Totzauer, Michael Storz, Albrecht Kurze, Andreas Bischof and Arne Berger. 2018. Bricks, blocks, boxes, cubes, and dice: on the role of cubic shapes for the design of tangible interactive

- devices. In *Proceedings of the 2018 Designing Interactive Systems Conference (DIS '18)*. Association for Computing Machinery, Hong Kong, China, 485–496. ISBN: 9781450351980. DOI: [10.1145/3196709.3196768](https://doi.org/10.1145/3196709.3196768).
- [44] Roxanne Leitão. 2019. Anticipating smart home security and privacy threats with survivors of intimate partner abuse. In *Proceedings of the 2019 on Designing Interactive Systems Conference (DIS '19)*. Association for Computing Machinery, San Diego, CA, USA, 527–539. ISBN: 9781450358507. DOI: [10.1145/3322276.3322366](https://doi.org/10.1145/3322276.3322366).
- [45] R. Lemaire. 2006. Informed consent – a contemporary myth? *The Journal of Bone and Joint Surgery. British volume*, 88-B, 1, 2–7. DOI: [10.1302/0301-620X.88B1.16435](https://doi.org/10.1302/0301-620X.88B1.16435).
- [46] Tania Lombrozo. 2007. Simplicity and probability in causal explanation. *Cognitive Psychology*, 55, 3, 232–257. DOI: [10.1016/j.cogpsych.2006.09.006](https://doi.org/10.1016/j.cogpsych.2006.09.006).
- [47] Ewa Luger and Tom Rodden. 2013. An informed view on consent for ubicomp. In *Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp '13)*. Association for Computing Machinery, Zurich, Switzerland, 529–538. ISBN: 9781450317702. DOI: [10.1145/2493432.2493446](https://doi.org/10.1145/2493432.2493446).
- [48] Travis Mayberry, Ellis Fenske, Dane Brown, Jeremy Martin, Christine Fossaceca, Erik C. Rye, Sam Teplov and Lucas Foppe. 2021. Who tracks the trackers? circumventing apple’s anti-tracking alerts in the find my network. In *Proceedings of the 20th Workshop on Workshop on Privacy in the Electronic Society (WPES '21)*. Association for Computing Machinery, Virtual Event, Republic of Korea, 181–186. ISBN: 9781450385275. DOI: [10.1145/3463676.3485616](https://doi.org/10.1145/3463676.3485616).
- [49] Nora McDonald, Sarita Schoenebeck and Andrea Forte. 2019. Reliability and inter-rater reliability in qualitative research: norms and guidelines for csw and hci practice. *Proc. ACM Hum.-Comput. Interact.*, 3, CSCW, Article 72, (Nov. 2019), 23 pages. DOI: [10.1145/3359174](https://doi.org/10.1145/3359174).
- [50] Alex Mihailidis, Jennifer N. Boger, Tammy Craig and Jesse Hoey. 2008. The coach prompting system to assist older adults with dementia through handwashing: an efficacy study. *BMC Geriatrics*, 8, 1, (Nov. 2008), 28. DOI: [10.1186/1471-2318-8-28](https://doi.org/10.1186/1471-2318-8-28).
- [51] Tim Miller, Piers Howe and Liz Sonenberg. 2017. Explainable AI: beware of inmates running the asylum or: how I learnt to stop worrying and love the social and behavioural sciences. *CoRR*, abs/1712.00547, 7 pages. arXiv: [1712.00547](https://arxiv.org/abs/1712.00547).
- [52] Harry R. Moody. 1988. From Informed Consent to Negotiated Consent1. *The Gerontologist*, 28, Suppl, (June 1988), 64–70. DOI: [10.1093/geront/28.Suppl.64](https://doi.org/10.1093/geront/28.Suppl.64).
- [53] Clifford Nass, B.J. Fogg and Youngme Moon. 1996. Can computers be teammates? *International Journal of Human-Computer Studies*, 45, 6, 669–678. DOI: [10.1006/ijhc.1996.0073](https://doi.org/10.1006/ijhc.1996.0073).
- [54] Clifford Nass, Youngme Moon, B. J. Fogg, Byron Reeves and Chris Dryer. 1995. Can computer personalities be human personalities? In *Conference Companion on Human Factors in Computing Systems (CHI '95)*. Association for Computing Machinery, Denver, Colorado, USA, 228–229. ISBN: 0897917553. DOI: [10.1145/223355.223538](https://doi.org/10.1145/223355.223538).
- [55] NHS. 2020. About dementia. <https://www.nhs.uk/conditions/dementia/about/>.
- [56] NHS. 2019. Parkinson’s disease. <https://www.nhs.uk/conditions/parkinsons-disease/>.
- [57] Aisling A. O’Kane, Helena M. Mentis and Eno Thereska. 2013. Non-static nature of patient consent: shifting privacy perspectives in health information sharing. In *Proceedings of the 2013 Conference on Computer Supported Cooperative Work (CSCW '13)*. Association for Computing Machinery, San Antonio, Texas, USA, 553–562. ISBN: 9781450313315. DOI: [10.1145/2441776.2441838](https://doi.org/10.1145/2441776.2441838).
- [58] Filipa Pajević and Richard G. Shearmur. 2017. Catch me if you can: workplace mobility and big data. *Journal of Urban Technology*, 24, 3, 99–115. DOI: [10.1080/10630732.2017.1334855](https://doi.org/10.1080/10630732.2017.1334855).
- [59] Thomas Ploug and Søren Holm. 2020. The four dimensions of contestable ai diagnostics - a patient-centric approach to explainable ai. *Artificial Intelligence in Medicine*, 107, 101901. DOI: [10.1016/j.artmed.2020.101901](https://doi.org/10.1016/j.artmed.2020.101901).
- [60] [SW] QSR International Pty Ltd., NVivo 2020. URL: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>.
- [61] Yvonne Rogers and Henk Muller. 2006. A framework for designing sensor-based interactions to promote exploration and reflection in play. *International Journal of Human-Computer Studies*, 64, 1, 1–14. DOI: [10.1016/j.ijhcs.2005.05.004](https://doi.org/10.1016/j.ijhcs.2005.05.004).
- [62] Yael Schenker, Alicia Fernandez, Rebecca Sudore and Dean Schillinger. 2011. Interventions to improve patient comprehension in informed consent for medical and surgical procedures: a systematic review. *Medical Decision Making*, 31, 1, 151–173. DOI: [10.1177/0272989X10364247](https://doi.org/10.1177/0272989X10364247).

- [63] [SW] SimpleApps, SimpleMind 2020. URL: <https://simplemind.eu/>.
- [64] Ewan Soubutts, Amid Ayobi, Rachel Eardley, Kirsten Cater and Aisling Ann O’Kane. 2021. Aging in place together: the journey towards adoption and acceptance of stairlifts in multi-resident homes. *Proc. ACM Hum.-Comput. Interact.*, 5, CSCW2, Article 320, (Oct. 2021), 26 pages. DOI: [10.1145/3476061](https://doi.org/10.1145/3476061).
- [65] Peter Tolmie and Andy Crabtree. 2008. Deploying research technology in the home. In *Proceedings of the 2008 ACM Conference on Computer Supported Cooperative Work (CSCW ’08)*. Association for Computing Machinery, San Diego, CA, USA, 639–648. ISBN: 9781605580074. DOI: [10.1145/1460563.1460662](https://doi.org/10.1145/1460563.1460662).
- [66] Peter Tolmie, Andy Crabtree, Stefan Egglestone, Jan Humble, Chris Greenhalgh and Tom Rodden. 2010. Digital plumbing: the mundane work of deploying ubicomp in the home. *Personal and Ubiquitous Computing*, 14, 3, (Apr. 2010), 181–196. DOI: [10.1007/s00779-009-0260-5](https://doi.org/10.1007/s00779-009-0260-5).
- [67] Peter Tolmie, Andy Crabtree, Tom Rodden, James Colley and Ewa Luger. 2016. “this has to be the cats”: personal data legibility in networked sensing systems. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW ’16)*. Association for Computing Machinery, San Francisco, California, USA, 491–502. ISBN: 9781450335928. DOI: [10.1145/2818048.2819992](https://doi.org/10.1145/2818048.2819992).
- [68] Philip W. F. van Notten, Jan Rotmans, Marjolein B. A. van Asselt and Dale S. Rothman. 2003. An updated scenario typology. *Futures*, 35, 5, 423–443. DOI: [10.1016/S0016-3287\(02\)00090-3](https://doi.org/10.1016/S0016-3287(02)00090-3).
- [69] Jennifer Watermeyer and Claire Penn. 2009. “come let me show you”: the use of props to facilitate understanding of antiretroviral dosage instructions in multilingual pharmacy interactions. In *Health Communication in Southern Africa: Engaging With Social and Cultural Diversity*. L. Lagerwerf, H. Boer and H. Wasserman, editors. Rozenberg, Amsterdam, NL, (Jan. 2009), 191–216.
- [70] Przemysław Woznowski et al. 2017. Sphere: a sensor platform for healthcare in a residential environment. In *Designing, Developing, and Facilitating Smart Cities: Urban Design to IoT Solutions*. Vangelis Angelakis, Elias Tragos, Henrich C. Pöhls, Adam Kapovits and Alessandro Bassi, editors. Springer International Publishing, Cham, 315–333. ISBN: 978-3-319-44924-1. DOI: [10.1007/978-3-319-44924-1_14](https://doi.org/10.1007/978-3-319-44924-1_14).
- [71] Eric Zeng and Franziska Roesner. 2019. Understanding and improving security and privacy in multi-user smart homes: a design exploration and in-home user study. In *Proceedings of the 28th USENIX Conference on Security Symposium (SEC’19)*. USENIX Association, Santa Clara, CA, USA, 159–176. ISBN: 9781939133069.
- [72] Ni Zhu et al. 2015. Bridging e-health and the internet of things: the sphere project. *IEEE Intelligent Systems*, 30, 4, 39–46. DOI: [10.1109/MIS.2015.57](https://doi.org/10.1109/MIS.2015.57).
- [73] Gottfried Zimmermann, Tobias Ableitner and Christophe Strobbe. 2017. User needs and wishes in smart homes: what can artificial intelligence contribute? In *2017 14th International Symposium on Pervasive Systems, Algorithms and Networks 2017 11th International Conference on Frontier of Computer Science and Technology 2017 Third International Symposium of Creative Computing (ISPAN-FCST-ISCC)*, 449–453. DOI: [10.1109/ISPAN-FCST-ISCC.2017.66](https://doi.org/10.1109/ISPAN-FCST-ISCC.2017.66).

Received January 2022; revised July 2022; accepted November 2022