Journal of Responsible Technology 12 (2022) 100049

Contents lists available at ScienceDirect

Journal of Responsible Technology

journal homepage: www.sciencedirect.com/journal/journal-of-responsible-technology

Reflections on RRI in “TAS for Health at Home”

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ARTICLE INFO

Keywords:
Trustworhty Autonomous Systems
Healthcare
Home
Responsible Research and Innovation
Reflection

ABSTRACT

We reflect on our experiences using Responsible Research and Innovation (RRI) in the project “TAS for Health at Home”. Driven by a multi-disciplinary research team that consisted of experts in mental health, stroke rehabilitation, management of multiple sclerosis, human factors, human-computer interaction, privacy, cybersecurity, architecture, and Patient and Public Involvement (PPI) groups, the project aimed at eliciting user perceptions of autonomous systems supporting healthcare regimes at home. We discuss the home as a unique place to consider RRI approaches and reflect on the actual process of carrying out RRI within the project, including the multi-disciplinarity of the project, our engagement with PPI groups, and how we involved the wider community concerned with Trustworthy Autonomous Systems (TAS). We conclude by summarising our reflections and providing a first step towards RRI-based guidelines for developing healthcare technology for the home.

Introduction to the “TAS for Health at Home” project and the RRI process

As part of the multi-year, multi-institution research hub “Trustworthy Autonomous Systems” (TAS), the project “TAS for Health at Home” described here set out to explore how assistive technology could and should be designed to support healthcare at home using principles of Responsible Research and Innovation (RRI) embedded in the UK’s research landscape through the so-called AREA framework (UKRI, 2022), partially based on work by Stilgoe et al. (2013).

The AREA framework (UKRI, 2022) consists of four dimensions, summarised in Fig. 1, which maps these dimensions onto our project timeline: anticipation (A, red), reflection (R, yellow), engagement (E, green), and action (A, blue). The points and activities in the project at which the research team actively applied the AREA framework are highlighted with the corresponding coloured circles. Literature review, the Moral-IT cards, early and lively discussions within our team of multidisciplinary subject experts, and early engagement with public and patient involvement (PPI) groups (stroke rehabilitation and people with multiple sclerosis (pwMS)) allowed us to anticipate (A) condition-specific and common issues and reflect on these for the design and use of a smart mirror system for healthcare experiences. The continuous engagement (E) with our PPI groups and internal discussions informed the design of the focus group activities (A) and allowed for deep reflection (R) and acting (A) on these reflections. The multi-disciplinary experts (from mental health, psychiatry, human factors, human-computer interactions, mental health nursing, psychology, and architecture) engaged with all four dimensions of the AREA framework throughout the project, acting by adjusting research activities such as the focus groups, in response to the previous anticipation, reflection, and engagement. We also engaged with the wider TAS community through various events, including Kick-off presentations, an RRI and EDI (Equality, Diversity, and Inclusion) workshop, and two conferences. From month 8, the project Team welcomed an artist in residence (engage, reflect, act) to explore interactive mirrors in relation to the human body and creating meaningful and trustworthy experiences in people’s lives. The final stage of the project was data collection, which occurred through focus groups of people with MS and people who

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https://doi.org/10.1016/j.jrt.2022.100049
Received 20 January 2022; Received in revised form 27 July 2022; Accepted 26 September 2022
Available online 2 October 2022

had a stroke.

To make engagement with this topic more tangible, we employed an existing ‘smart mirror’ as a concept and technology probe. This mirror was envisioned as a piece of technology installed in a variety of home spaces, including the bathroom, bedroom, and entrance, where it would be able to visually assess a person with a medical condition and support them in their management of symptoms, monitor their physical and psychological state, suggest modifications to their treatment plan, interface with carers (medical professionals, family, close friends), and help with daily activities, such providing reminders for meetings, activities, and medication.

Below, we discuss the challenges and successes of the process of carrying out RRI from the researchers’ perspective. We begin by considering the importance of RRI for autonomous healthcare at home, including trust considerations, then discuss the main areas of RRI application for the project: working in a multidisciplinary team, working with PPI groups, and engaging with the wider TAS community.

RRI for trustworthy autonomous systems for healthcare at home

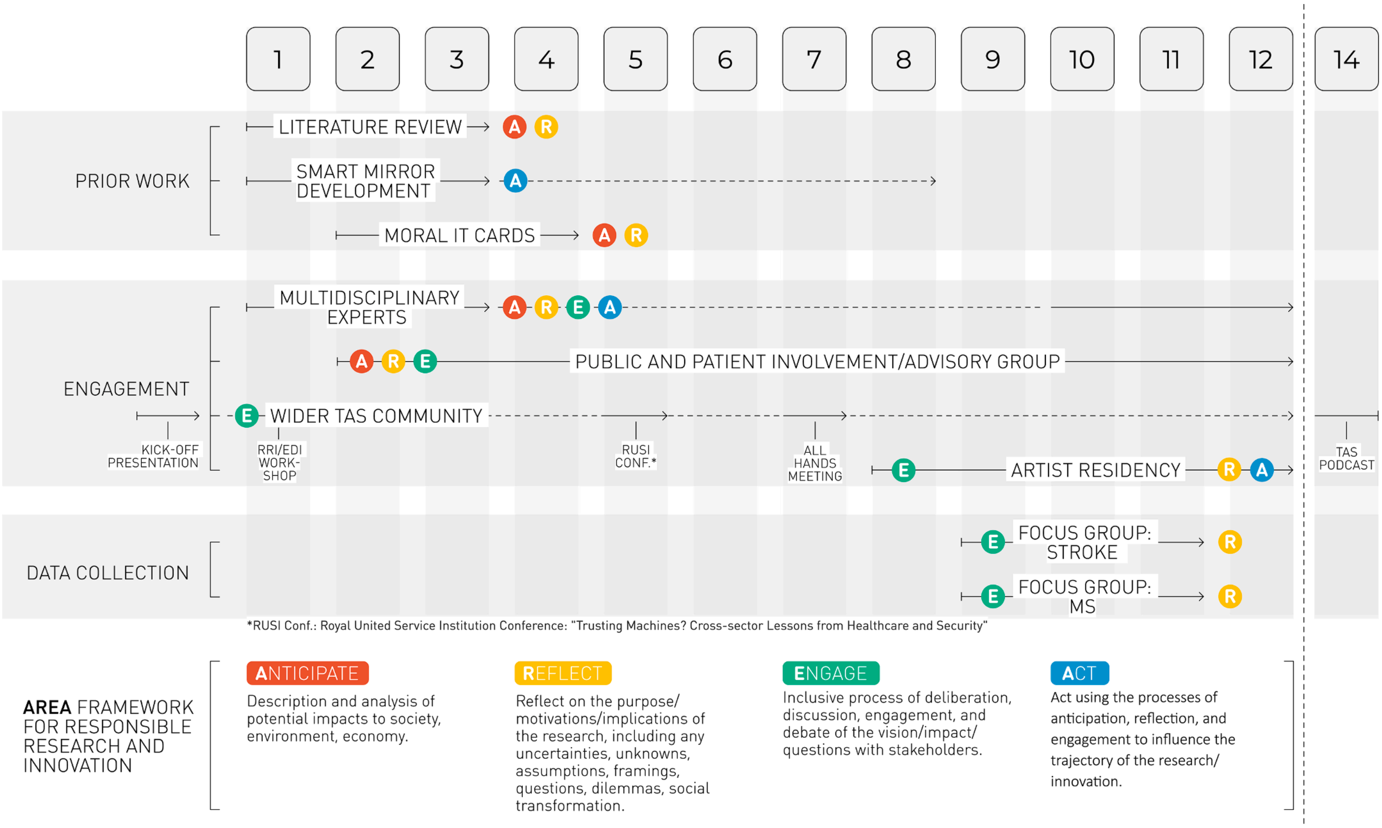
Over the past several years, there has been growing interest in home healthcare technologies. Exacerbated by the Covid-19 pandemic, homes have become places for many previously elsewhere-located activities, including work, education, and healthcare. For example, many GPs (general practitioners) began to offer routine, non-urgent appointments via video conference; it is likely that an increasing number of healthcare appointments will occur with patients not needing to leave their home. Evolving approaches to healthcare delivery offer new opportunities for the research and design of healthcare experiences at home, requiring especially sensitive approaches to RRI. There are increasing opportunities for these experiences to use digital systems capable of facilitating and making autonomous decisions regarding healthcare delivery to healthy populations and people with a variety of health conditions.

Trust and trustworthiness in healthcare settings

Adjekum et al. (2018) reviewed trust in digital health systems, defining trust as a relationship between a trustor and a trustee to which “the trustee’s reliability (possessing a good reputation), competence (having the technical skills to perform the task at hand), and integrity (generally acting in an honest way)” are central. A key finding of their review is that “personal, technological, and institutional factors” enable or hinder trust in digital health and suggest that reliably “measuring trustworthiness” of digital technologies will be important to implement these novel approaches to healthcare. Aitken et al. (2016) also identify transparency as an intrinsic part of trust, separating it into informational transparency (“disclosure of information on which decisions are based“), participatory transparency (“enabling […] participation in decision-making processes”), and accountability transparency (“decision-makers are held accountable”). Translated to the smart mirror context, this means that to be trustworthy the mirror would need to communicate its information in an open and unaltered way, allow users to contribute to its decision-making, and communicate accountability for wrong decisions. By doing so, such a mirror would have to have (or build over time) a good reputation by being a reliable tool for each user, demonstrating that it has the technical “know-how” to perform the required tasks, and doing so in an honest way. These trust attributes are often embedded in the notion of a home.

The home – a unique place for the delivery of healthcare

The home is a special place, often associated with “security, safety, familiarity, comfort, and happiness […] a place of retreat and a place of control, where [one] can discard the social persona and be [oneself].”



*RUSI Conf.: Royal United Service Institution Conference: "Trusting Machines? Cross-sector Lessons from Healthcare and Security"

Fig. 1. Project timeline + application of AREA framework. Research elements (prior work, engagement, data collection) mapped to duration by month and dimensions of AREA framework (anticipate, reflect, engage, act).

(Soilemezi et al., 2017). In the terms of trust and trustworthiness described above, the home is an environment that reliably provides protection, comfort, and happiness through a set of tools, such as lockable doors/windows (protection), a heating system (comfort), as well as materials and lighting (happiness).

At home, people trust that they are in a physically and psychologically safe space: they will not be exposed to undesired circumstances and people, allowing them to engage in activities they would not do in public (e.g., intimate physical activities), express emotions (e.g., arguments) and consume substances and media. Each space affords different activities and vulnerabilities; people may be most vulnerable or unguarded in the bedroom or bathroom, as places linked to our most intimate feelings and behaviours, and therefore require the highest degree of trust in protection and comfort, for example manifested in lockable doors or translucent windows. The home can also hide violence and abuse; for example, a perpetrator might trust the soundproofing of a space to not reveal noises of violence. The kitchen, dining/living room, and corridors are spaces that are less likely to elicit highly intimate behaviour, as they tend to be shared between more people and are potentially more exposed to the outside world via larger windows or glass walls. Occupants here might trust that such spaces provide the necessary room, setting, and equipment for social activities, entertainment, and the provision of food. Each of these defined zones in the house then require different approaches to trust and RRI in the development of technology depending on the range of vulnerabilities and exposures experienced and expressed within them. The socio-economic status of occupants must also be considered as linked to spatial affordances such as lower income families likely having smaller homes (Fornara et al., 2022) with fewer opportunities to, for example, avoid each other.

Devices in the home

The spatial distribution of user vulnerabilities is even more complex when we consider that some digital devices involved in healthcare delivery are mobile. Mobile phones, tablet computers, and laptops frequently move between rooms and outside the home, while other devices such as kitchen appliances, televisions, audio equipment or smart mirrors only infrequently (or never) move between rooms and can be considered static. Each of these device locations and use scenarios need to be carefully considered in the context of RRI. For example, users may (purposely or not) reveal more intimate information about themselves depending on their own location and the location of the device. Another level of complexity is added when we consider that numerous devices, whether static or mobile, connect to cloud services and thus potentially have access to the same information, which can be intimate or not. People may also change their identity or persona depending on the device being used and their location.

Being aware of monitoring in the home and accessing health data

The various combinations of devices and spaces in the home also provide opportunities for dense monitoring of people (triangulating data from multiple, distributed sensors) living with a health condition, which can provide comprehensive insights into fluctuations in symptoms and wellbeing based on their location within the house and the time of day. In addition to monitoring behaviours "in-situ", monitoring at home can also have the benefit of longitudinal routinised monitoring, potentially able to reveal subtle changes over time that are difficult to identify or realise by an individual. Such ubiquitous monitoring for healthcare purposes at home needs, however, to be carefully considered and calibrated to the individual, while ensuring that technology cannot and should not entirely replace humans in the care process.

Anticipating user behaviours and abilities, as well as reflecting upon the spatial configurations of the home, any person being monitored will need to be aware when and where they are being monitored, as well as having access to their own data in a format accessible to them, such as in high-contrast or as audio description etc. At the same time, they should be able to make their data available to others involved in their care, such as healthcare providers and family members, if this is beneficial to their care and they wish to share such data. The complexity increases when the person being cared for is deemed 'incompetent', which may be related to a range of factors such as cognitive impairment, age, or mental ill-health. This issue of competency is related to the concept of 'capacity to consent' (e.g., Appelbaum & Grisso, 1988) and will have direct impact on data collection, ownership, and individuals' ability to assess the consequences of sharing medical data with others.

Dealing with visitors and accidental data capture

Visitors to the home may also be monitored by the system, either by design or by accident. A smart mirror may detect a carer or family friend while they are washing their hands and begin recording their behaviour or physiological data; it must be ensured that consent is sought, and that data will be deleted if requested. The mirror may also monitor how carers perform their tasks for the benefit of the cared-for person, and log care sessions while intelligently adjusting the care programme based on the recorded data. Anticipating ethical dilemmas and additional vulnerabilities, we should consider that an autonomous healthcare system at home might detect, for example, a skin condition in a visitor, indicating underlying health issues. Should the system make the visitor aware of their potential condition? How does the system (and visitor) deal with a false positive? What is the ethical decision-making process of a home healthcare system to report or not report a potentially serious healthcare condition to a visitor or a national health service?

Reflecting upon on the location of the monitoring device (smart mirror or otherwise), other ethically unclear situations might occur. For example, entirely unintended data collection is possible if a smart mirror, for example, was located next to the entrance door of a home where it could potentially sense delivery people when the door opens to receive a package. Authentication methods such as voice, facial recognition etc. may be used to avoid accidental data capture. Conversely, healthcare systems at home must also ensure that data about the person being cared for is not "left open" on devices for visitors to see, as this might reveal personal medical conditions. The same may apply to other family members, such as children or grandparents (and others) who may not be able to interpret data accurately and may worry unnecessarily.

RRI approaches are extremely important in the development of healthcare systems for use in the home, and we have raised several important questions that we addressed through our RRI approach. We now discuss how this approach was applied, highlighting the process and practicalities of carrying it out rather than providing clear cut results which answer these questions.

Working in a multidisciplinary team

As the complexity of healthcare provision at home shows, it is critical to involve experts from multiple disciplines to ensure RRI in the development of the entire system and experience of healthcare at home. We have, therefore, assembled a multi-disciplinary team of experts to explore the multitude of challenges in this area of research. Our experts include specialists in mental health, stroke rehabilitation, management of multiple sclerosis, human factors and psychology, human-computer interaction, privacy, cybersecurity, architecture, and PPI groups. Throughout the project we had monthly open discussions around the topic of healthcare at home in general terms as well as specific to stroke rehabilitation, multiple sclerosis, and mental health. At the start of the project these discussions were particularly useful in helping us to understand the differing approaches and methodologies across the various disciplines.

Multi-disciplinary discussions: challenges

As the discussions developed, we encountered challenges in designing a project around such a broad range of viewpoints. These included finding common definitions of terms, methodological approaches, and validity of data. Such discussions took time, much longer than anticipated, to come to a shared understanding of the project aims and achievable methodologies.

Multi-disciplinary discussions: our solutions

As a partial solution, the project leads approached each discipline expert separately, to identify their specific aims for the project, discuss methodological approaches, and consolidate the responses to produce an outline of priority themes for the project. We also used a feedback sheet to collect specific issues and the prioritised themes for each researcher, from which we could produce a ranked list of questions to raise with PPI groups and participants. We also used individual meetings with our discipline experts to identify themes from our data that underpinned the analysis. In future, it would be advisable to ensure that there is sufficient time built into any multi-disciplinary research project to "level the playing field" among the disciplines to allow them to come to a collective understanding of the project-specific language, as well as its aims and methodological approaches. An additional solution was to anchor discussions around an ideation card activity, the Moral-IT cards.

Moral-IT cards

Following Papanek's (2019) well-established design philosophy of moral and environmental responsibility of designers, and applying it to designing and developing healthcare technology, we used the Moral-IT ideation cards early in the project to establish common ground and anticipate the potential impact of healthcare technologies on its users. These cards are designed to highlight potential ethical questions surrounding the development of technology, encouraging reflection and engagement in ethics-by-design (Urquhart & Craigon, 2021). Because of their emphasis on reflection, Moral-IT cards integrate well into the AREA framework of RRI (see Fig. 1). The cards are structured around a traditional deck of cards, with 13 cards each for the 'suits' of Privacy, Ethics, Law, and Security.

Moral-IT cards: challenges

The teams were initially introduced to these cards in a structured workshop session with a facilitator, during which we found that every card in the deck had some relevance and provided potentially interesting topics to pursue for the project. Some of the cards provided direct questions that we went on to ask our PPI groups — the "engage" and "act" dimensions of the AREA framework – while others provided prompts for future internal reflections. The challenge was deciding which of the cards were most relevant, as each could have led to hours of discussion and potentially had merit for our research focus.

Moral-IT cards: our solutions

As a solution, we created our own task around the cards; for each card question, every team member was asked to provide a response considering the specific smart mirror technology, and to highlight where they felt this prompted potential questions to the PPI groups or study participants. The cards turned out to be extremely useful in framing our thinking and helped us to bring together some of the disparate discussions we had been having into a more structured format that then helped us to design the studies. On reflection, being able to carry out some more sessions with the cards throughout the project may have been beneficial, however we feel that this would require some form of expert facilitation with someone who is highly familiar with the card deck and who could provide structured activities that make the best use of the deck.

Public and patient involvement

A principal component of RRI is the involvement of users in dialogue (UKRI, 2022). We initially intended to put together our own advisory groups for the project, consisting of members of our target user groups: pwMS and people who have had a stroke, and other potential stakeholders such as carers and family members. However, in part due to the necessity that all our meetings were run online we struggled to recruit enough people who could commit to meet regularly. Instead, we approached existing groups who already met regularly and attended some of their meetings to discuss the project. This included a PPI group for pwMS already working with one of the universities, and a support group for younger adults who have had a stroke. Discussions with both groups have been enormously productive and illuminating (Furniss et al., 2021), as they were quick to point out their personal challenges of engaging with digital technologies both in general and in managing their care. For example, difficulties to use a keyboard or being able to point accurately due to limited motor function were common, and people in both groups may have dysarthria (difficult or unclear articulation of speech) so that voice input may not be consistently understandable by a device.

PPI challenges

Working with PPI groups comes with various challenges: several members of the groups work full-time, limiting their availability for meetings. Others are involved in numerous research projects; in this case, there is also a chance of encountering research fatigue in PPI groups, resulting potentially in lower turn-out or lessened engagement in meetings, as well as a potential for 'bias' arising from experience of similar projects. The groups we engaged with also tended to prefer in-person meetings rather than video calls, as such technology can amplify cognitive challenges and fatigue. Because of this, our online meetings tended to have fewer attendees than usual. It is not always easy to respond to cues such as body language online or notice when someone might be struggling to contribute, and this is exacerbated when the group includes people with communication difficulties. Another consideration in engaging PPI groups is that attendees may have expectations, such as symptom relief, which not all research projects can meet. For example, our project was a highly exploratory project that investigated attitudes towards technology but did not deliver prototype technologies.

Although not brought up by our PPI groups, we anticipate that, depending on different combinations of medical condition and technology and the subsequent varying experiences of users, issues may also arise around gender, race, and age. Whilst we do not wish to speculate too far, or put words into our participants' mouths (against the ethos of RRI), we may also anticipate that research taking place in an individual's home, rather than in a group situation, may elicit different responses to our technology probe; similarly deploying new technology rather than discussing it hypothetically may have associated challenges. Letting a researcher (or a team of researchers) into one's home also requires a degree of trust and that the researchers are deemed trustworthy, which might take time to establish. These are issues that need careful consideration for future "in the wild" research.

Our PPI "solutions"

In accordance with the AREA framework, we reflected on the needs of our PPI groups and acted by scheduling meetings outside of working hours to facilitate attendance by full-time workers. We also tried to engage with the PPI groups by presenting our research in an entertaining and exciting way to overcome research fatigue. As researchers we found the need to change our usual approach, for example by shortening meetings, and adjusting modes of presentation, including our own speech patterns, such as speaking more slowly and clearly to attenuate some of the issues of online meetings (sound clarity, ability to read lips and facial expressions). We also ensured that there was someone available who could provide support for communication difficulties. To avoid mismatched expectations, it is important that the attendees also get personal value from the PPI sessions. It is important to recognise and anticipate that those who participate in PPI groups will have their own motivations for taking part, and those who do not engage are a potentially important (but lost) voice in these activities.

Anticipating the additional challenges of potentially meeting users in their homes, solutions should aim at ensuring equal, diverse, and inclusive practices. To establish trust between researchers and participant, it will be important to have transparent communication of the research and technology deployment, allow for participatory decision making (e.g., where and how to install the technology, perhaps even making modifications to the technology to better fit the home and user), and have accountability procedures in place. Also, allowing sufficient time for this trust to be established may be necessary, for example by sequencing explanatory meetings ahead of the formal study, including a pre-study visit to the home. Any engagement with participants in their own home should make accommodations for the study participant, as well as other household members and include them in the research and technology deployment. Whilst this is not a situation we encountered on this project, due to not being able to deploy the mirror in real life, these are important considerations for future research with the technology.

Engaging the wider TAS community

Beyond the PPI groups and our team of multi-disciplinary experts, we engaged with the wider TAS community repeatedly throughout the lifecycle of the project, as shown in Fig. 1, including (conference) presentations, workshop attendance, workshop delivery, and a podcast contribution. These interactions, especially from the workshop we ran, informed the subsequent data collection in the focus groups, as this allowed us to develop and refine questions and scenarios, while testing the technology to be used prior to engaging participants. This engagement with other researchers required concise and comprehensive descriptions of the project to experts less familiar with the topic. This broader scientific engagement expanded our experience horizons (e.g., thinking about different medical conditions, age, gender) and increased the diversity of viewpoints of the research project.

Conclusions: technology development and RRI

Our experience of the RRI process has been mostly positive, utilising a variety of viewpoints, providing a wider access to user groups (incl. PPI groups) and helping us to consolidate knowledge from multiple disciplines on one topic: trustworthy autonomous healthcare at home. None of the team would have been able to individually explore autonomous healthcare at home in the same way. The various disciplinary perspectives informed our decisions, while the discipline experts also helped us gain access to specific user/PPI groups. However, it has not been without its challenges.

Our reflection has shown that Responsible Research and Innovation is a key element in developing healthcare technologies both in the home and more generally. While the process can be challenging to implement, it ensures that researchers and innovators engage with relevant stakeholders as early as possible and as soon as it is sensible. A diverse research team also ensures that a range of methods can be utilised to best engage the various stakeholders in a participatory process of technology development. Fig. 2 (columns from left to right) shows our process of RRI, represented through **RRI tools, RRI Challenges, RRI Solutions**, which informed **RRI for technology development** for healthcare (smart mirror), revolving around the purpose of the technology, the development of the technology, and its interface upon which we expand below.

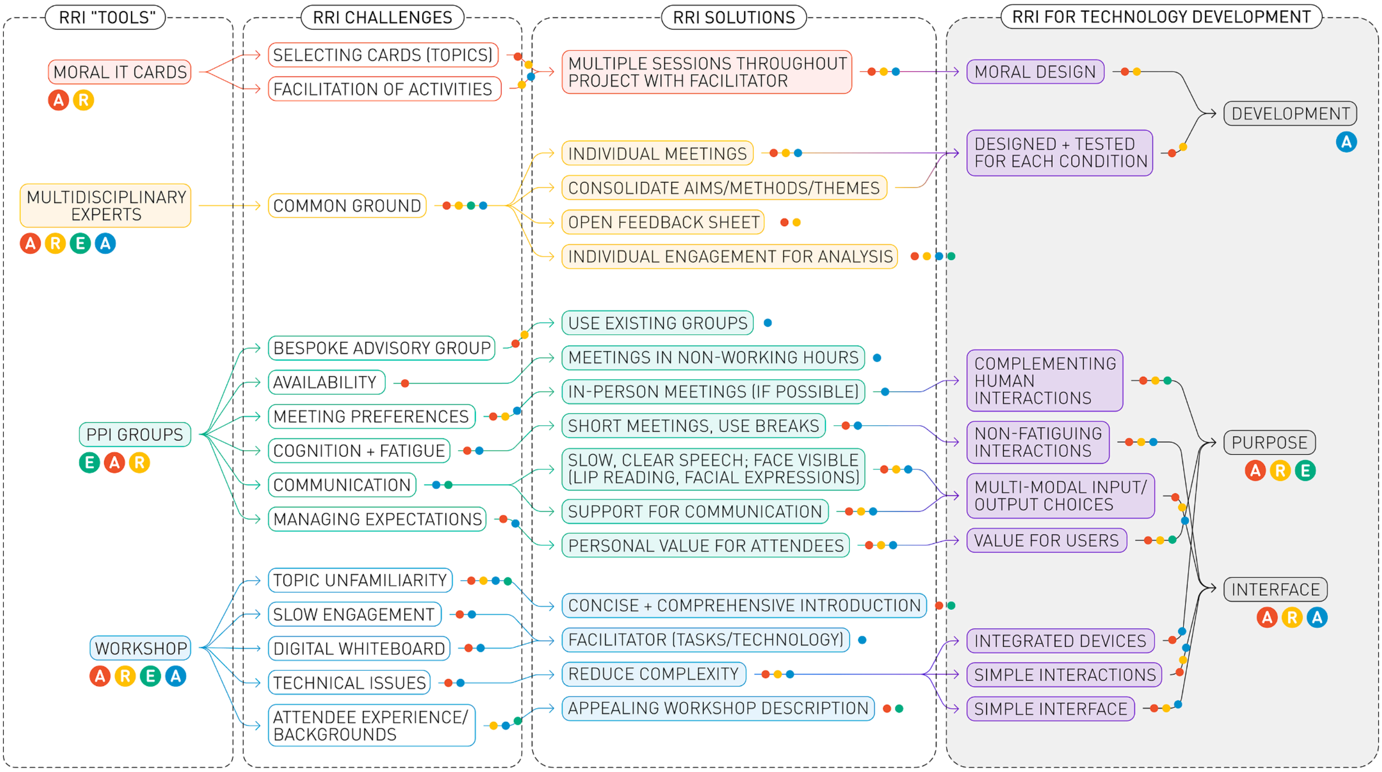


Fig. 2. From RRI challenges to technology development: (from left) RRI tools this project employed, RRI challenges the research team encountered, RRI solutions the team developed, RRI for technology development. See Fig. 1 for definition of AREA framework.

Purpose

The purpose of healthcare technology should be derived from engagement with specific stakeholders, such as PPI groups. Healthcare technology, as described by our PPI groups, should complement rather than replace human interactions, create value for the user, and make life easier by integrating (with) already existing devices. Healthcare technology should centre on the wellbeing of its user, as described by Kafaee et al. (2021). Healthcare technology like a smart mirror can supplement, for example, a rehabilitation plan, providing a presence in the home that can monitor and engage the user between appointments with a medical professional. Doing so, it does not replace contact with another human being but provides a service to the user that, without such technology, might be difficult (or impossible) to receive. Ideally, healthcare technology also integrates with an existing ecology of devices, such as smart phones or even a smart home hub, which would provide additional monitoring and intervention opportunities to support and protect the user.

Development

Purely based on our work (though there are many more factors to consider), the development of healthcare technology should be based on moral design as well as sufficient specificity to each medical condition. Our engagement with PPI groups has emphasised that even within the same general medical condition, the needs and abilities of users differ significantly, which needs to be considered and for which provisions need to be made. As described above in the context of the AREA framework, the Moral-IT cards (Urquhart & Craigon, 2021) are one tool that helps to develop technology with a basis in moral design through reflection of a variety of issues such as privacy (e.g., limited data collection, transparency) and security (e.g., confidentiality, physical safety), helping to anticipate ethical issues of technological systems. Identifying these issues early helps to discuss them with stakeholders and design the technology with a "built-in" ethical approach.

Interface

Our PPI groups and multidisciplinary experts described a variety of issues around the design of technology interfaces that can be specific to a medical condition. For example, someone who has suffered a stroke may have motor impairments, which can make it difficult or impossible to use a keyboard or mouse. In such a situation, voice input would offer another input modality, while visual, audio, and haptic output can facilitate communication with the user. Making such input simple and direct (minimising the number of steps) will also reduce overall strain and, thus, limit fatigue and frustration. Any interface of healthcare technology should be non-fatiguing, provide multi-modal input and output choices, keep interactions as well as the interface itself simple, so that everyone can use it.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgments

This research was funded by the UKRI Trustworthy Autonomous Systems Hub grant (EP/V00784X/1).

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