

# Using design fictions as a tool for engaging citizens in debating future pervasive health systems and services

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## Abstract

The benefits provided by health-related technologies are often counterbalanced by the societal, legal and ethical challenges connected with the pervasive monitoring of people, as necessitated by such technological interventions. Through the ProtoPolicy research project we explored the co-creation and use of design fictions as a tool for open debate of pervasive health systems. Design fictions were co-created and tested in a series of design workshops with community groups in the UK. A thematic analysis of a debate among older people on a smart home and assisted living design fiction highlighted societal and ethical issues relevant to personal and pervasive health system design. We conclude that ethics, like 'usability', may be usefully based on engagement with directly or indirectly implicated publics and should not be designed into innovation by experts alone.

**Keywords:** Design Fiction; Speculative Design; Pervasive Healthcare; Personal Health Systems; Independent living; Ethics; Social Challenges.

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## 1. Introduction

Following the dramatic increase in the world's ageing population, numerous technological innovations are being proposed to support healthcare in our later lives. In the effort to develop the ageing well agenda, on one hand, the research and business communities are exploring and developing pervasive and personal health systems, with the aim of supporting independent and assisted living; and governments, on the other hand, are introducing policies that reinforce 'ageing in place' [1]. However, the health-related benefits offered by technology (e.g. independency, better quality care) are counterweighted by the societal, legal and

ethical challenges concomitant with the pervasive monitoring of people necessitated by the relevant technologies [2, 3, 4]. There is a need, therefore, for facilitating public engagement and discussion on the social, legal and ethical issues arising from current and, more crucially, emergent technologies in personal and pervasive health systems, and for facilitating an interaction and debate between policy makers and citizens. According to the European Commission, 'renewing the legitimacy of public policy-making, especially through greater citizen involvement' [5] is a significant challenge ahead of 2020.

In light of the above we present in this paper the ProtoPolicy research project and posit the use of design fictions as a tool for debating the societal, legal and ethical dimensions of personal health systems. ProtoPolicy was an

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exploratory pilot research project that ran from June to September 2015. The ProtoPolicy team adopted an inclusive, collaborative and creative approach to engage a range of stakeholders across community groups and Westminster to explore how design fictions could be used to imagine the future implications of political decision-making.

## 2. Related Work

Following an increasing use of personal and pervasive technologies, citizens are becoming data producers and more knowledgeable about their own health. However, citizen awareness of the level of information sharing and storage garnered in their use of personal health technologies is often low [6]. Several of the new personal health systems that are available offer self-health management, independent and assisted living and community healthcare benefits [7, 8, 9]. They often rely on personal health data and pervasive monitoring of patients raising many ethical, legal and societal issues, which manifest as both opportunities and challenges [10, 11, 12, 13]. The eHealth Action Plan 2012-2020 [14] highlights that patient and public engagement, and trust in the ethical, legal and socially considerate use of data is key to leveraging the potential of new technologies.

Moreover, policy-makers in public health and other sectors are realising the interconnections between decisions in their domains. Increased participation is an ethical and societal opportunity and one increasingly valued in regulatory and legal frameworks [15]. However, involvement of experts is still the most common method used for forecasting emerging health technologies and services excluding citizens from this process [16]. Therefore, there is a need for processes and tools that enable and facilitate the participation of citizens and policy makers in open debate on the social, legal and ethical complexities arising from technological intervention in personal and pervasive health systems, such as smart homes and assisted living environments.

In this paper we propose design fictions as a potential tool for facilitating citizen participation in the social, ethical and legal debates relevant to emergent technologies in healthcare. Design fictions – like short films, prototypes and graphic novels – are often provocative and engage people, encouraging them to envision, explain and raise questions about the direction of future technology and possible worlds. For instance, the genetically hierarchical society depicted in *Gattaca* (1997) on the one hand foretells the experimentation with biometrics that today's governments are pursuing; and on the other hand depicts what society could look like if the use of medical technology is taken to extremes.

Speculative design is an approach enabling us to think about the future prospectively and critically [17]. One of its principal assumptions is the negation of the status quo and initiation of a discussion on possible worlds through confrontation with tangible object or process, the so-called design fiction [18]. Speculative design uses design thinking tools and methodologies such as scenarios, brainstorming and rapid prototyping along with techniques borrowed from

art, literature, film, psychology, philosophy, anthropology and ecology to create design fictions – provocations or 'narrative elements to envision and ex-plain possible futures for design' [10].

Design fiction is about creative provocation, raising questions, innovation, and exploration.' [20] Design fictions go beyond that 'to account for the ways in which cinematic depictions of future technologies demonstrate to large public audiences a technology's need, viability and benevolence' [21]. Therefore one of the key values of design fiction is that it uses a fictional paradigm to catalyse debate about potential futures [22]. As a speculative design practice design fictions do not claim to predict the future; they place potential futures within our imaginative reach for consideration as to their preferability.

Fundamentally, design fictions are explorations of particular design spaces made possible, if not necessarily consequential, by combining current technological advances with our slow-changing social, legal and ethical practices. They prompt debate, enable research engagements and have potential to support real-world policy development.

Design fictions are concerned with progress, ideas for the better, but they take into account that better means different things to different people [23] and do not focus on implementation, but on discussing 'what-if' scenarios.

## 3. Research Methodology

A participatory design methodology [24] was used that included three stages, namely problem definition, co-creating design fictions, prototyping and testing.

In stage one, the policy and academic contexts for design negotiating political questions were explored through secondary research and an examination of the government policy documents around the theme of ageing was conducted at the time of the research project (early June 2015). This helped identify a number of related government policy initiatives (such as 'ageing in place', integrated health and social care, ageing well and several others) that could be explored in the second stage with the stakeholders. Extracts of these policies were explored in two co-design [25] workshops in Lancashire (n=14) and Cornwall (n=7) with community groups and older citizens. The workshops were conducted in June 2015, with participant ages ranging from 65-95. The first workshop included participants recruited from an AgeUK group and lasted half a day, whereas the second workshop included participants at a sheltered accommodation and was run over two days.

A range of techniques was used to explore the use of design fictions in negotiating political questions. All speculations, concepts and ideas that emerged from the workshops were captured via audio recording, photography and short video presentations. Stage three focused on translating the workshop insights and co-designed speculations into design fictions. Analysing and coding the captured data the research team worked with the project

collaborator, Design Friction, to develop a series of concepts for the design fictions.



**Figure 1.** Workshop participants interacting with the SOT design fiction material and leaving feedback

Following this two design fictions were realised and prototyped, namely the SOULAJE, a self-administered euthanasia wearable, and the Smart Object Therapist (SOT), which combines occupational health with experience in pervasive and assisted home technology to ensure that future smart home appliances correspond to user needs. The former design fiction was designed as a response to the workshop co-designers expressed needs for self-control and living with dignity and was aimed at opening further the debate around the ethical and legal aspects of technology-enabled assisted dying.

The second design fiction was developed as a response to the government policies of integrated care, ageing in place and assisted living in smart homes and was aimed at extending the debate around the ethical and social aspects of personal health and pervasive technology at home and social inclusion. Given the paper emphasis we will focus on the SOT design fiction in here.

### 3.1. The Smart Object Therapy design fiction

The SOT design fiction<sup>2</sup> comprised of three documents, namely a SOT job specification, the SOT intervention report and prescription and a short video breakfast TV style article featuring the SOT and a smart object home user.

Set in the year 2020 the SOT design fiction sets the speculative scene by presenting the skills a SOT is expected to have in the envisaged integrated health and social care service model, where older people age at home supported by an array of smart appliances. The job of a SOT is not limited to fixing technical faults but is centred on recalibrating human behaviour to facilitate interaction between smart

objects and their owners. The SOT intervention report and prescription design fictions present a possible world where the SOT has been called in to intervene between the homeowner and smart home to resolve an issue. The SOT design fiction creates an appropriate and open environment for debate by exploring ‘misbehaving’ smart home technology. In the scenario the smart self-refilling fridge of its diabetic owner, Mr Bell, caused havoc when it amended its owner’s dietary requirements and automatic food stocking after confusing Mr Bell’s grandson’s genetic traits for Mr Bell. The short video is a post-briefing interview between the SOT and smart homeowner following the SOT’s visit. The design fiction featured two professional actors who devised the scenario based on the three SOT documents under the direction of the research team.



**Figure 2.** Video screenshot of the dialogue between Mr Bell and the smart object therapist explaining the ‘prescription’

The design fiction artefacts were designed in order to engage people in conversation and debate, therefore leaving several elements and details unspecified inviting various interpretations, reactions and discussion from research participants. For instance, statements such as the ones below respond to the key job roles of the SOT job description and the SOT intervention report and raise questions about the nature and type of services being offered.

*‘Recalibrating human behaviour to facilitate interaction between smart objects and their owners, by evaluating the psychological compatibility of the older person with the smart home.’*

*‘A recalibration of Mr Bell’s behaviour is necessary to help the smart home reconnect with his profile and habits’*

## 4. Findings and Discussion

Following their development the design fictions and the concepts they encompassed were explored by seeking feedback from policy makers at a policy engagement event

<sup>2</sup> See:

[http://imagination.lancs.ac.uk/outcomes/Smart\\_Object\\_Therapist\\_Design\\_Fiction](http://imagination.lancs.ac.uk/outcomes/Smart_Object_Therapist_Design_Fiction)

in Westminster Palace in London in July 2015 and from citizens at a co-design workshop in Lancaster in September 2015. The event at Westminster and the semi-structured interviews with civil servants and a politician were focused on the barriers and opportunities to using design methods to negotiate political issues with citizens. The co-design workshop, which was run with the same group that initiated the design fictions, was focused on in-depth discussion of the design fictions, the underpinning speculations and the ethical, societal and legal issues they presented. In this paper, we focus on an analysis of the citizens' discussions in the workshop. The thematic analysis [26] of the discussion that followed the presentation of the SOT design fiction, as well, as the visual material collected during the workshop activities, revealed a number of ethical, legal and societal concerns that participants discussed.

#### 4.1. Societal challenges of pervasive health systems

In terms of the societal aspects of smart home technology for health systems, workshop participants expressed the need and desire for supporting older people to live independently, especially ones with long-term health conditions.

*'I have to say although I feel quite hostile to this I have also seen a more primitive version of this work well for somebody living independently with dementia. Their house was set-up with a lot of alarms, so that if she opened the door like at night time and didn't come back straight away then the police would be informed, you know a lot of things like that which meant that she was able live independently for much longer that she would have done otherwise and I suppose this is an extension of the same idea'*

Some participants used this discussion to also talk about robotics in care but recognised that there is value in health systems that do not diminish independence. In fact reducing independence was a concern that several people raised as a result of living in a home environment over-reliant on technologies.

Related to this was a lengthy discussion on social isolation being a potential result of peoples' over-reliance on smart home healthcare living environments. Instead of encouraging people to stay more physically active by going out and reinforcing social interactions between people, there was an expression of concern towards encouraging more sedentary and self-isolation behaviours by replacing human contact with 'smart' technology.

*'An unwanted side effect of that sort of technology is that it would actually keep people in their homes rather than encouraging them out*

*of their home on their day-to-day basis. This would have impact on their health and mental health, it's about interactions, about being stimulated all sort of other things not met by technology'*

The perceived benefits of the design fictions play a key role in the acceptance of the proposed pervasive healthcare technologies embedded in the SOT. Although there may be resistance to the use of technology by the individual critiquing/interacting with the design fiction this does not impede the identification of perceived benefits for other members in the society, as the following quote illustrates.

*'Somebody who needs this, like someone incapable who cannot go out, such as Dorothy, it's not good talking to me who enjoys going out shopping'*

The perceived benefits also extend beyond the initial intended service use framework of the design fiction to include food safety. This illustrates how the socialisation of the design fiction can open the discussion inviting people to explore additional possibilities and use of pervasive healthcare technologies and services.

*'I can see it having a role for food safety, for example you could have someone who is perhaps confused or becoming confused. The fridge could alert them that you need to eat these sausages today'*

#### 4.2. Ethical challenges of pervasive health systems

The SOT design fiction facilitated a discussion around the ethical and legal aspects of similar personal health systems.

Trust in the technology to perform as expected and technologies replacing humans in terms of healthcare services was a key topic of debate. For instance, the SOT job advert design fiction provoked another participant to raise a thoughtful question regarding the eligibility of non-human agents to apply for the SOT jobs. According to the participant the question was raised in response to the way the design fiction was written and what it therefore might imply.

*'Can robots apply for this job, cause it says candidates must demonstrate a strong autonomy and empathy for humans'*

Personal choice and control featured strongly across the SOT design fiction discussion. In the following quote a workshop participant responds robustly to the SOT design fiction service scenario, whereby food intake is controlled automatically by the smart fridge based on user's dietary needs:

*'I tell myself what I want to eat I'm not going to*

*ask any [smart] fridges'*

Ethical implications related to agency, personal choice between personal health home systems and their users were debated at length. For instance, workshop participants contrasted the Meals on Wheels project, offered in the UK to older people living independently, with the SOT highlighting the importance of the role of control in service acceptance and adoption.

*'This is a clinical solution... you are a diabetic so it's looking at sugar levels in foods, whereas the wheelchair food service does put that on you it's up to you to make the choice, your informed decision'*

### 4.3. Enhancing understanding of complex health technologies and services

Furthermore, participant previous lived experiences with emerging technology helped in forming better understanding of the design fiction concepts as well as acceptance of the role of healthcare technology in our lives, especially when positive outcomes are evident.

*'Jane reversed her type I diabetes and she has one of these wrist things which tells her exactly how much she's walked every day and it also monitors her sleeping patterns, so she can see that now by doing more exercise she is sleeping a lot better. So we are already starting on some of these.'*

Another interesting finding emerging from the theme analysis is that following understanding of the concepts embedded in the design fictions, some participants started warming up to these concepts. Although initially they were sceptical as the debate continued and they started to reflect more on these ideas they embraced the likelihood of such imagined future services or aspects of them being potentially realised in a near future scenario.

*'If you had some sort of a design at home that would allow you a safe discharge to go home, I think this is what they getting at with this [the SOT]'*

*'With technology you pick the things you see as useful. Don't you? You don't want everything all at once, but there might be things over time that they come up with that are useful'*

Other participants after more deep thinking and questioning current understanding and position on the subject accepted the need for some of the concepts embedded in the design fiction. These related mainly to the current need to navigate the often complex smart home appliances and the financial

constraints place on healthcare systems by an ageing population.

*"So it's already (the SOT] needed, we almost already need a technology therapist, now, to help us with a lot of these things [smart tech]"*

*'This is forwarding thinking of how we are going to carry on with the age of people going to 90s and 100s, how can we stop hospital admissions, how can we save money, so even all this seems fantastical'*

### 4.4. Capturing technical and legal requirements of pervasive health systems

In addition to the above, the design fictions acted as a prompt for technical requirements capture of the imagined futures. Examples of this included human computer interaction methods.

*"It could communicate with you; a message could come to your TV screen, cause older people like TV, that would say you may have your sausages or your rice pudding it balances with your salad"*

The design fiction also prompted the posing of questions regarding technical challenges and limitations. Examples included personalising the SOT for a family household.

*"Does it [the SOT] suit people living in a family? How does it individualize diets for more than one person? Does it cater for day to day choices with food?"*

Furthermore when the discussion moved into service delivery and adoption very insightful ideas were offered and discussed. Such as the following example where workshop participants provided an incisive suggestion as to who will more likely be the first adopter of such service.

*"Actually you will probably find the first people who will use this [SOT] would be London bankers who haven't got the time, they are stressed out or they are spending all their lives in the gym and they want to make sure they have the perfect health combination. They will be the ones that have the smart fridges that monitor and reorder and have it delivered because they do not have the time or the inclination to go to the supermarket."*

With regards to the specific SOT design fiction scenario people questioned the training and education background that such a techno-occupational therapist professional would need to have. Questions were raised as to whether such a role would have a person-centred approach and whether the

focus will be placed on the human or the smart and personal health technology.

*'What comes first? Is it an all in one house you move into or does the therapist come first to access your needs?'*

This led into discussions regarding the financial and legal aspects of personal health systems. A theme, which was extensively discussed, was that of the financial and legal framework of service provision. Questions were raised as to who would pay for the technology installation, home adaptation, technology support, as well as perceived cost and long-term economical value.

*'By the time you paid for all this technology, would it not be cheaper to have somebody pop round for few hours every day'*

Additional thought was given to accessibility of such future services to the public if a privately funded model is to be selected. A few participants even discussed possible financial models involving big supermarkets (linking it to food restocking), which created discussion around sharing of personal data, habits and personal health records.

*'You can see how supermarkets the likes of Tesco's would love to something like this. They could restock your [smart] fridge and in the process find out all about your food likes and habits and even your health condition'*

These examples illustrate enhanced understanding of more complex healthcare technologies and services and the ability of the design fictions to act as a tool for reflection as well as interrogation of future possibilities.

## 5. Conclusions

This paper has argued that research that drives innovation through analysis of ethical, legal and social challenges and opportunities is needed more than ever. Our thematic analysis of the findings, following the presentation of design fictions to citizens, who took part in the co-design process, suggest that there is an opportunity and a value in exploring design fiction and speculative design beyond their current use in design research. Building upon qualitative participatory and speculative design research, it has become clear that, ethics like 'usability' may be usefully based on engagement with directly or indirectly implicated publics and should not be designed into innovation by experts alone.

The design fictions provided a basis upon which workshop participants contributed technical and legal requirements for future pervasive healthcare services. Furthermore, they generated a rich discussion on the societal, legal and ethical implications of the presented concept related to personal health systems for independent living. By reflecting and discussing the technoscientific

elements of a design fiction citizens can engage in debate and critique of existing and potential healthcare service models.

In terms of the beneficiaries of the project, the researchers used the design fictions as tools to initiate discussion and workshop participants used them as prompts to form a debate. Several participants employed personal stories and lived experiences to relate to several of the societal and legal aspects of the introduction of smart home technology for healthcare. It was interesting to observe through the recorded data that there was a diversity of views expressed; and that participants who were initially skeptical warmed to the principles underpinning the personal health system concept as a result of working through the socio-ethical issues in debate.

Our future work involves testing and developing further the methodologies presented here in different domains, by looking at the ethical and societal aspects around the use of pervasive technology for dementia. Lastly, we recognise that this article has provided grounding for the investigation of design fictions as potential healthcare design practice and that the area merits further research explorations.

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