

Discussing a ‘Design-led’ Approach to Pervasive Healthcare

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ABSTRACT

This paper attempt to trigger a debate about the possible existence of a design approach or a design process that can deliver a pervasive healthcare system that is focused on acceptance by its users, that is about improving their daily lives and the healthcare they receive. while at the same time such approach or process should support the healthcare industry in cost-cutting and efficiency gains

CCS CONCEPTS

- Design • Analysis and design of emerging devices and systems
- Ubiquitous and mobile computing design and evaluation methods

KEYWORDS

Interaction Design, Design Methods, Pervasive Healthcare

ACM Reference format:

Ben SALEM, Aysar GHASSAN. 2019. Discussing a ‘Design-led’ Approach to Pervasive Healthcare in the Context of UK State-funded Healthcare Provision. In *Proceedings of Pervasive Health '19: 13th EAI International Conference on Pervasive Computing Technologies for Healthcare, 20-23 May 2019, Trento, Italy*. EAI, Bratislava, Slovakia, 4 pages. <https://doi.org/10.1145/1234567890>

1 Introduction

Pervasive Healthcare is a distributed, preventive and assistive approach to the delivery of healthcare services [3] which is based on a combination of connected mobile and innovative platforms [1]. It is a system for self-care and medication compliance, which is particularly suitable for chronic diseases with low to medium risks, but which have a high impact on the patient’s Quality of Life (QoL). A Pervasive Healthcare solution allows a patient to care for themselves throughout their daily life and within the comfort of

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Pervasive Health '19, May 20-23, 2019, Trento, Italy
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ACM ISBN 978-1-4503-6126-2/19/05\$15.00
<https://doi.org/10.1145/3329189.3329230>

their own home. It also prevents medication non-compliance, which is caused by a combination of: lack of knowledge, short consultations, complexity of treatment, duration of disease, inadequate understanding, poor health education, forgetfulness and lack of information [29]. Pervasive Healthcare constituent technologies, to be effective, need to be present in their users’ daily lives, accompanying them. They and are heavily dependent on being thoroughly accepted and regularly engaged with to be successful. They should provide support and assistance in helping to understand one’s condition and how to best manage it. However, most Pervasive Healthcare reported in literature focus on system integration, data collection and processing, context modelling (i.e. what is the user doing) and detection of anomalies (e.g. unusual event) [1, 23, 24]. They do this at the expense of addressing the acceptance and the benefits of the presence of technologies in people daily lives. This is in contrast with what has been advocated in some literature [4], and in particular the importance of usage, learnability and aesthetics as elements of design of Pervasive Healthcare [2]. Indeed, design guidelines have been established [15], alongside Health Promotion Guidelines and Models [18, 21].

It helps to contrast Pervasive Healthcare to Health 4.0. The latter is an alternative direction for health care that advocates the personalisation of health care for patients, health professionals and carers relying on Internet of Things, cloud computing and fast mobile network to deliver a near real-time health care [28]. The emergence of pervasive healthcare, as a credible direction for the future of healthcare, raises many challenges and issues. The pervasiveness of the system suggests that it is continuously present in the patients’ daily life. This requires acceptance, reliability and robustness. The closeness of some of the system’s components to the user, highlighting ergonomics, intrusiveness, obtrusiveness and visibility as issues to be addressed. So are personalisation, privacy and data sharing. There are also challenges in terms of the contribution Pervasive Healthcare should make in terms of improvements to the user’s QoL and the patient’s quality of care.

The increased burden on the resources of lifelong care for patients, increasingly outpatients (O/P), who are elderly or suffering of chronic ailments is an increasing challenge, which is made worse with the dwindling social and community care infrastructure. Pervasive Healthcare Systems attempt to alleviate the burden on health services and at the same time improve some aspects of healthcare. They can potentially have significant benefits to the

healthcare industry, to the outpatients themselves and to society as a whole.

1.1 Pervasive Healthcare Potential

Pervasive Healthcare as an approach to delivering some aspects of healthcare to outpatients is a promising avenue with high potential. To realise the Pervasive Healthcare potential it is important to concurrently look at such systems from a variety of perspective: (1) from healthcare, ensuring that the Pervasive Healthcare System (PHS) complement, assist and facilitate the continuous and personalised care for outpatients, (2) from the outpatient, delivering an intuitive, enjoyable and beneficial system and constituents, (3) from the viewpoint of close relative, empowering them to be more aware of the condition and state of mind of the outpatient. An example of a Pervasive Healthcare system is illustrated in fig. 1.

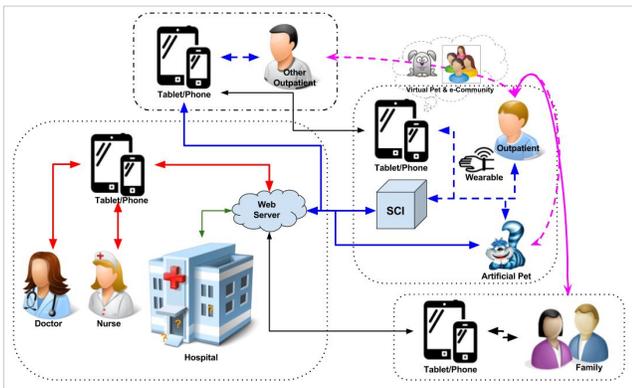


Figure 1: Example of a PHS: Outpatients as the end users, rely on a combination of an artificial pet, a wearable, a shape-changing interface and an application to interact with the system and with moderated social networks. Healthcare professionals rely on an application to stay informed of the outpatient condition. Close relatives rely on a different application to stay informed of the outpatient condition, and to stay connected with them (as proposed in [25])

For Healthcare professionals, a Pervasive Healthcare makes sense if it helps them have a more up-to-date and finer understanding of the outpatients in terms of their condition and of their behaviour, routine and attitude towards it. The PHS is not intended to replace, but to complement and assist doctors, nurses and pharmacists.

From the outpatients' perspective, Pervasive Healthcare helps improve their self-care, adopt a more effective set of routines, habits, behaviours and practices pertaining to their condition, and in general a better healthier lifestyle. It also helps them better understand their condition and how to manage it.

The Pervasive Healthcare innovation also support the emergence of an outpatient community moderated by healthcare professionals and helping them break a sense of isolation and loneliness often associated with their condition. It also helps close relatives to understand the condition of the outpatient and provide support that is timelier and better informed.

1.2 UK State-funded Healthcare Provision

In the United Kingdom (UK), healthcare is provided as a public provision by the *National Health Service* (NHS). The NHS was set-up in 1948 with the vision that “good healthcare should be available to all, regardless of wealth” (see [19]). The NHS remains free at the point of access, making the UK one of very few nations where healthcare is a free public service. One of the resulting outcomes, is that NHS patients are not concerned about costs but only about *promptness* and *quality* of care. Aspects such as A&E treatment, care for chronic conditions (in particular cancer) and waiting time operations tend to concern patients (see for example [6]). This situation contrasts to most economies where some form of health insurance is required. To take the United States as a very different example, the big challenge for patients is the high cost of healthcare at the point of access. In the US, *Value* of health care is a key factor in patients' choice with regards their options for medical treatment. In the UK, patient survey of their General Practitioner (GP) – the NHS Primary Care Practitioner (PCP), has indicated that out of circa 750K patients surveyed between 2007 and 2018, 84% had a good overall experience of the GP surgery (clinic), 96% have confidence and trust in the healthcare professionals they saw at the surgery, 93% were involved as much as they wanted to be in decisions about their care. Interestingly there are no questions in the survey about costs or value of the care (NHS Patient Survey 2018, [20]).

There are 18 millions UK residents sufferers from chronic conditions, with the majority managed by their GP, at the same time the patient population as a whole is suffering from more conditions, and obesity is projected to affect 60% of men, 50% of women adults and 25% of children by 2050 [7]. The current evolutionary trends of healthcare at the GP level are for increased number of visits (currently an average 6 per annum per patient), a drop in the number of GP (since 2008 there has been a decline of 11%), and an increase in the costs of running GP practices (now at more than 60% of the NHS budget) [7].

2 A DESIGN PERSPECTIVE TO PERVASIVE HEALTHCARE

A host of design research argues that a design perspective to solving problems places the interests of users as the centre of the problem-solving process (e.g. [10, 26, 9]). Indeed, commonly, research argues enabling users to participate in solving problems which affect them is key to producing optimal design interventions [12]. Recently, NHS has trialled participatory practices in the quest to provide better healthcare for patients. GP surgeries have been the location for one such trial. For many years, the NHS has provided a network of what it terms GP surgeries across the UK. GP clinics are often located near pockets of housing stock and provide patients with a first port of call for non-emergency treatment from doctors (and associated healthcare professionals, including nurses). The GPs provide health checks, can perform minor surgery and are able to diagnose illness and prescribe treatments. If necessary, the GPs can refer patients for consultation with specialists in hospitals. Severe resource constraints mean that patients currently have a very

limited time to consult one-to-one with their GP. The latest study indicates that, on average, patients in the UK see their GP for 9 minutes, 22 seconds. This consultation time is lower than for patients in other developed nations, including the USA, Sweden, Canada Spain and Japan [14]. Indeed, patients in Sweden see their GP for an average of 22.5 minutes per appointment. The British Medical Association has argued that this duration is not long enough for GPs to be able to effectively diagnose illness, claiming that GPs need to see their patients for 15 minutes per consultation [14].

To exacerbate the issue, some patients find it difficult to communicate one-to-one with their doctor in this short time-frame [5]. Problems in communication between doctors and patients have long been reported. To illustrate, Taussig [27] argues that use of specialized scientific language helps physicians to exercise authority over patients' bodies and associated illnesses. To illustrate the use of specialized language, figure 2 shows an anatomical drawing of the human wrist.

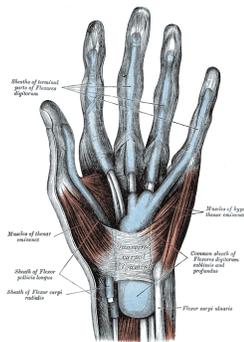


Figure 2. An anatomical drawing of a hand from [13]

The lack of familiarity with scientific terminology plays a part in reducing understanding and ownership that patients feel they have over their own illness. Indeed, on this point, Taussig [27] (p.5) argues, "the moral and metaphysical components of disease and healing are concealed by the use of the natural science model."

A lack of understanding can lead patients to engage in non-compliance, which can cause physicians to chastise patients [27]. Non-compliance can further worsen the communication between the two parties.

To tackle resource issues and problems with communication between doctors and patients, the Royal College of General Practitioners introduced a shared healthcare initiative in which up to 15 patients with related medical conditions consult with a single GP [5]. Such initiative implements some of the community-building proposed as part of Pervasive Healthcare. The trial has included patients with long-term conditions such as asthma, chronic back pain and rheumatoid arthritis (an auto-immune condition). Reportedly, the trial has been quite successful. Some doctors report that the initiative has been effective as it has "stopped them repeating advice" [5] and therefore enables them to make better use of their time.

Some patients found it valuable to communicate with people experiencing the same illness. On this point, one patient claims that "The good part about it is people ask questions that you might not have thought of asking yourself [...] It is nice to see other people, talk to them and get their experiences as well. And everybody who is there seems pleased to be there." [5]. This type of feedback from patients suggest that the initiative works to challenge the dominance of the authoritative medical model, thereby providing what might be termed a more *human-centred* approach to healthcare.

Seen through a design perspective, it is possible to argue that patients have benefited as they have participated more effectively in their own experience of healthcare. With regard the aims of the pervasive healthcare model, the initiative run by the Royal College of General Practitioners has had some success in tackling issues which are key in fostering medical non-compliance, namely those of short consultation time, and patients having a lack of information and less than ideal levels of understanding. The trial, in part at least, appears to be a cost-effective way of delivering improved healthcare. Seen in this way, the initiative highlights the value of the pervasive healthcare model. Indeed, Prof Helen Stokes-Lampard, Chair of the Royal College of General Practitioners has foreseen that the number of shared appointments will continue to grow in the next decade [5].

In a similar perspective, in a previous study Salem & Hampton [25] have identified areas in clinics at a hospital that were correlated to outpatients' UX. These findings highlighted the potential for Interaction Design to address some of the clinic's shortcomings and to provide support and assistance to the outpatient in their daily lives. In particular, Salem and Hampton argue the need to allow outpatients to configure and personalise the provision of healthcare they are the recipients of, and to closely adapt and match the care routines they need to adopt to their lifestyle and condition.

3 A CRITIQUE OF THE DESIGN-LED PERSPECTIVE

To critique the design perspective pervasive healthcare, it is necessary to examine the issue of *solutionism*. The term *solutionism* was coined by the architectural researcher Michael Dobbins [11]. Dobbins reflects on design philosophies which influenced the creation of Modernist city infrastructure which spread across the globe following the end of World War Two. Dobbins claims that Modernist city planning was driven by the desire to create solutions that could, in one fell swoop, tackle a range of complex social and technical problems. Dobbins criticizes this mindset for ignoring the wide range of issues which affected people in the post-war era and terms it "the 'magic bullet' model to solv[ing] problems" (ibid, p.182; original emphasis). Building on Dobbins' work, the sociotechnical researcher Evgeny Morosov [17] criticizes contemporary Human Computer Interaction literature which claims that design can be used to tackle complex social problems. Morosov uses the example of *BinCam* to illustrate his position. *BinCam* was developed by researchers at Newcastle University,

UK. It is a technologically-enabled, game-like project designed to reduce the amount of household waste going to landfill.

Morosov argues that the aims of the BinCam project background complex social issues which influence why may or may not choose to dispose of waste in a sustainable manner in favour of foregrounding overly-simplistic solutions:

“A weekly score is calculated for each bin, and as the amounts of food waste and recyclable materials in the bins decrease, households earn gold bars and leaves. Whoever wins the most bars and tree leaves wins. Mission accomplished; planet saved!”

Evgeny Morosov ([17], p. 2)

We argue that the discussion of solutionism can be applied to the critique of the shared consultation initiative introduced by the Royal College of GPs. The NHS faces many complex issues which affect its current and future ability to provide effective healthcare. Because of space constraints, this paper discusses just one issue, a severe medium-term shortfall in the number of GPs. Indeed, recent estimates state that the NHS currently has more than 2500 fewer GPs than it needs to provide effective healthcare. By the 2029, the shortfall is predicted to grow to around 11,500 [8]. The shortfall of GPs has been caused by a prolonged shortage in funding which the UK government has allocated to training these professionals. The government has proposed making more use of other healthcare professionals like physiotherapists and pharmacists to fill the gap in provision [8]. This move may have negative consequences as these healthcare professionals are not trained to the same level as GPs in diagnosing and managing illness.

The success of the design-led shared GP consultation initiative works to foreground issues such as the *experience* of patients and patient *participation* in healthcare whilst backgrounding the problem of a shortage of *funding* and the ever-increasing shortfall of GPs. The GP consultation initiative therefore allows the UK government to background its responsibility of adequately resourcing the NHS.

Similarly, and by extension, the promised success of Pervasive Healthcare works to foreground *personalisation*, *quality*, *accessibility* and so forth. There is a risk that at the same time Pervasive Healthcare will forego the need for personal human contact with health professionals, emotional support by carers and just simply human assistance in times of physical or mental distress.

3.1 Case 1 A solutionist HCI Design

The success of the introduction of “welfare toys”, robots that exploit the therapeutic effects of pet ownership is the inspiration for our project Mollycoddle. The “Palo” robotic seal¹ is a good example of the effectiveness of robotic animal therapy. At the launch of the project we were interested in the development of a robot which role would be to nurture social and interpersonal skills to its user. A robot that was also cute and inviting to hold and cuddle. We proposed our robot as a mollycoddle, for affective

support of outpatients with chronic condition. In that sense a mollycoddle is a boy that is overprotected and pampered, the idea would be for the robot pet owner to act towards the robot as if it were a mollycoddle.



Figure 3. Example of a Solutionist HCI Design approach: Miko a Mollycoddle robot to support long term patients

Miko is essentially a head with a long tail and a tail end (see fig. 3). Miko’s head has two ears and two large eyes. The eyes were inspired from Japanese Anime characters and are out of proportion to the rest of the head. The face is kept to a minimum of details (actually just a general form) to allow for a maximum of possible emotions. Miko has a heart that is made of a modified hard disk drive to be used as a sound transponder. Fed with mp3 audio files of heart beats, the hard-disk will produce vibrations which can only be felt when Miko is held. This is the impression of a living being with a beating heart. When other audio files are played, the high pitch sounds are heard while the bass tones can only be felt as vibrations, this create a haptic display.

The prototype was built with all the electronics enclosed into a rubber ball within the head of the toy. A layer of soft material was then added and then covered with the blue fur. The tail had an asymmetric weight attached to a DC motor which produced vibrations, this was enclosed in a table tennis ball, and in a soft material. The result was a humming tail that gave the impression of a little creature in the tail.

3.2 Case 2 A Non-Solutionist Design

We developed a Shape Changing Interface (SCI) device to visual some information pertaining to an outpatient condition (chronic psoriasis) and daily life. We narrowed the definition of a SCI to one of a physical device for the representation of digital content. It is a device featuring changes of physical attributes for both inputs and outputs, in an action/reaction arrangement. These physical changes are reversible [16] and can occur with or without human agency [22]. A SCI is also a mediator between a user and the represented content, for the manipulation by the user of the content.

¹ https://youtu.be/S-CXH3wrT_M (visited April 2019).



Figure 4. Example of a non-solutionist Design: A Shape changing Interface for Outpatients suffering from psoriasis.

We have followed a design approach that should deliver a device that:

- Possesses affordances that trigger actions that relate to the functions of the device and the user's intentions towards that function,
- Is based on a metaphor related fragility and temporality,
- Embodies high aesthetic value.

The device design was inspired from the idea of a dewdrop on a leaf (see Fig. 4). Both the leaf and the drop contribute to the interactivity of the device by featuring physical attributes that are changeable either as a result of user actions or interface actuation, as implemented in the first prototype. The leaves glowed in different colours to indicate an event happening on the day (winter colour for work, spring for family, summer for social, and autumn for medical), the orb would glow to indicate time for medication, and a series of dot would indicate time of the day and time of optimum UV sunlight. The orb features 3D patterns that could be used to play music. Finally, the base of the device was used to set privacy levels (in phone, tablets and any other connected device), swiping a finger at the edge from left to right (private/do not disturb) or from right to left (available).

CONCLUSION

We believe in a design-led approach to Pervasive healthcare as an effective mean to deliver qualitative improvements to the lives and the care outpatients suffering from a long-term condition would receive. Issues to be addressed are not solely functional or qualitative: Better care, on-time advice, and medication compliance. They are also qualitative and holistic, the main purpose of a Pervasive Healthcare System is providing healthcare but also, we believe, addressing personal lifelong issues that are detrimental to happiness, fulfilment and wellbeing.

In discussing a design-led approach to Pervasive Healthcare, we believe there are two trappings to be avoided. The first one being the labelling of Pervasive Healthcare a complex problem in need, to be realised, of an approach such as design that can tackle complex problems. The second being the hiding behind keywords such as User Experience, Participatory Design, Quality of Life, and so forth as a mean to justify cost cutting, de-humanisation and trivialisation of healthcare.

ACKNOWLEDGMENT

Thanks to first author previous students Sam MITCHELL, Emma MALLEN, Rhob EDWARDS, Ellie HEWITT and Andrew SUTHERLAND for their DewDrop project and pictures (fig. 5).

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