
Socio-material design for computer mediated social sensemaking

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Abstract

Telemonitoring healthcare solutions often struggle to provide the hoped for efficiency improvements in managing chronic illness because of the difficulty interpreting sensor data remotely. Computer-Mediated Social Sensemaking (CMSS) is an approach to solving this problem that leverages the patient's social network to supply the missing contextual detail so that remote doctors can make more accurate decisions.

However, implementing CMSS solutions is difficult because users need to know who can see which information, and whether private and confidential information is adequately protected. In this paper, we wish to explore how socio-material design solutions might offer ways of making properties of a CMSS solution tangible to participants so that they can control and understand the implications of their participation.

Author Keywords

Social media; social sensemaking; telemonitoring; chronic illness; eHealth; values; privacy; confidentiality;

ACM Classification Keywords

H.5.3. Group and Organization Interfaces: Collaborative Computing.

Introduction

Raw data from telemonitoring solutions is often hard to interpret by remote clinicians who lack firsthand experience of its creation. Recent studies highlight how difficult it can be to establish baseline or 'normal' readings for individual patients [1] and how worrying 'scores' need to be verified by contacting the patient or carers to weed out false positives [2] and prevent false negatives [3]. For example, in people with Chronic Obstructive Pulmonary Disease, oximetry readings can be outside the normal range due to recent exertion or external stresses and hence do not require medical intervention [2]. On the other hand, patients may report feeling worse even though telemonitoring values do not suggest immediate problems [3]. Mediating a connection between the patient's physiological condition and the physician's diagnostic skill using only remote sensors and analytic software is hard because processes of learning and contextualisation are needed before data can be meaningfully interpreted [3]. This leads to expensive workarounds compromising telemonitoring's ability both to deliver cost savings and to provide a scalable solution to escalating healthcare demand.

While these basic issues remain unresolved, sensor technologies are making significant advances. Wearable, self-powered sensors able to form ad-hoc networks significantly enhance the potential for gathering continuous streams of diagnostic data (e.g. [4]). Although offering the possibility of pre-emptively diagnosing rare events (e.g. cardiac events), and richer sources of data for stratifying patients into treatment groups, significant problems are posed by the interpretation and management of the high volumes of data generated. Medico-legal problems arise if the data

contains indications of a serious incident or a significant deterioration that is not detected by the analysis algorithms, but would have been clearly visible to a trained team of analysts. One approach to solving these interpretation problems is through adding more sensors. For example, actigraph might be able to detect the exertion level of COPD patients and this could then be factored in to the interpretation of quantitative oximetry values. However, key contextual information such as subjective condition, [3] or external stressors [2] is impossible to detect with sensor technology. Much of this information can be gathered from social sources – which opens up the possibility of computer-mediated social sensemaking.

Computer-mediated social sensemaking

In this approach, patients and their family, friends and carers can choose to provide a parallel stream of contextual detail that assists accurate interpretation of the telemonitoring data. We envisage that this social data stream should be built into telemonitoring solutions from the start and integrated in a scalable, transparent way. However, this poses several challenges.

Challenge 1: Designing to support emergent individual and collaborative interpretative practices.

When new telemedicine solutions are introduced, existing responsibilities are redistributed between stakeholders and new forms of work emerge. Patients often become engaged in diagnostic practices and auxiliary healthcare workers to play an 'unscripted' role in mediating interpretations of 'signal' data [3,7]. CMSS builds on these processes and acknowledges that interpretative practices are not restricted to individual agents, such as doctors, but are distributed through the

system. CMSS aims to encourage and exploit distributed interpretation by providing appropriate support and resources for each individual's contribution. Given access to their own data patients in particular can take a stronger role in managing their own condition. Patients pooling data can create community-led interpretation or motivational mechanisms and embark upon community driven research.

Challenge 2: Facilitating collaborative production and capture of contextual detail.

Social Data Analysis research explores methods both for motivating participation and eliciting relevant and useful crowd contributions. Strategies to maximise participation include delivering benefits such as engrossing gameplay, enhanced status and financial reward [4]. We need to explore how well these strategies transfer into a CMSS context where motivation and quality become entangled with the divergent priorities and bodies of expertise of professional and lay contributors. A key ethical issue here is that maximising participation must not lead patients, family, and carers to unknowingly disclose more than they would normally be comfortable with – this is an issue with all of the big social media networks such as Facebook.

Challenge 3: Blending sensor data and contextual detail into appropriate sharable visualizations.

This concerns the appropriate forms of the shared analytic objects created by a CMSS approach. These should be capable of being interpreted and elaborated by diverse stakeholders, support negotiation and iterative refinement of contributions. It is here that the multidisciplinary nature of CMSS research comes to the

fore with the requirements to understand and apply shared sense-making, human-factors, data analytics and visualisations in a distributed collaborative setting. These visualisations need to be detailed enough to allow detection of disease relevant patterns, but obscure enough to protect individual detail.

Challenge 4: Obscurity versus translucence

When engaging in this collaborative sensemaking activity, there also needs to be a component dedicated to establishing boundaries. The key trade-off here is between preserving obscurity [4] and allowing social translucence [5]. Obscurity as defined by Hartzog and Stutzman means that information which a person does not want to be disclosed cannot be inferred from the freely available information. On the other hand, social translucence as defined by Erickson and Kellogg allows others access to apparently irrelevant tidbits which might be important indicators of e.g. personal stresses. Striking a balance between obscurity and translucence is hard. Even if users are made aware of all ways in which the information they provide could be used, they often don't understand the implications may unwittingly consent to sharing information that they intended to be protected (c.f. [6]). We suggest that appropriate visualizations of network ties and levels of trust might be able to mitigate the risk of accidental disclosure. For example, if medical professionals actively engage in CMSS they risk giving insight in the clinical decision-making process and in the process unwittingly document misinterpretations and false analyses. This could leave them open to being sued for malpractice. Without careful attention, health care professionals may therefore prefer system configurations that trade clinical effectiveness for medico-legal safety.

Conclusion.

Clearly there are an important series of design challenges in striking the delicate balances needed to make participation acceptable to allow the desired intermingling of expertise and experience from the different stakeholder groups. Patients need to be able to share personal details in ways unconfined by the materialities of proximity and human interactions. Doctors need to feel confident that they will not be blindsided by accountabilities that they cannot control, and all stakeholders – patients, their health care professionals, and their family, friends, and carers - have to adapt to a landscape where roles and responsibilities are reconfigured. The important design task then is creating a new form of virtuality that makes consequences of participation clear, allows trust, and does not embed uneven power relations. One way to tackle this problem is to think beyond conventional devices and screen-based interfaces to forms of object-based representations that give a material form to the virtual properties underpinning the system. For example, could the patient's social network be represented as tokens on a gameboard, where tokens closer to the centre are more trustworthy than tokens near the edge. (Re)positioning of a token could invoke or restrict privileges, and its removal strips them? Not only would this make the patient's social network explicit, it would also make it palpably negotiable.

In the workshop, we will illustrate possible designs that address the four challenges identified above based on reanalysis of data which was collected in the framework of a large qualitative study of telemonitoring in Chronic Obstructive Pulmonary Disease

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