Towards a Trusted Mobile Platform for Self-Management of Chronic Illness in Rural Areas

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ABSTRACT

Disease self-management interventions have the potential to greatly benefit both sufferers of chronic illnesses and healthcare providers in rural areas. In this paper, we discuss our progress towards building an information architecture for delivering self-management interventions in rural areas of the UK and India using second-generation mobile devices, and outline the key trust and privacy challenges in realising such an infrastructure. We illustrate our discussion with an example depression intervention scenario.

1. INTRODUCTION

Chronic illnesses, such as diabetes and depression, pose a difficult problem for healthcare providers, requiring a substantial allocation of clinical resources over a prolonged period. This problem is made worse in rural settings, with populations often spread out over large areas, and limited clinical resources situated beyond convenient reach of patients. Unconventional and ad-hoc healthcare arrangements, such as mobile clinics, can result in sporadic and inconsistent care. A patient’s medical record may be fragmented, with different clinicians and health workers holding different pieces of information relevant to their own areas of expertise.

A growing body of evidence suggests that changes in lifestyle or behaviour can help alleviate symptoms of some chronic conditions. This has led to the development of self-management behavioural interventions which can empower patients to conveniently manage their own symptoms, while allowing healthcare providers to allocate their resources more effectively. Rural areas in particular stand to gain from the deployment of interventions which, for example, reduce the necessity for patients and clinicians to make long and frequent journeys, and allow greater numbers of chronic patients to be easily monitored by fewer clinicians.

In rural India, Internet-enabled mobile phones are becoming more common, making mobile phones an attractive platform for the deployment of such interventions. The TRUMP project seeks to investigate some of the key issues surrounding the deployment of self-management interventions on mobile devices in rural areas of India and the UK. In particular, we are investigating the issues of trust and privacy which arise when medical data is generated and shared among individuals involved in an intervention. In the remainder of this paper, we discuss mobile phone-based interventions for sufferers of depression, with particular focus on trust and privacy issues. We then outline some of our ongoing work towards a trusted platform for these interventions, and potential future directions.

2. MOBILE INTERVENTIONS

Interventions typically comprise sequences of activities, to be carried out at specific times by various parties. For example, an intervention may require the patient to carry out some exercise activities, and then perform some self-reporting steps to allow progress to be monitored by a clinician. Interventions may employ complex information flows which require (possibly sensitive) information to be shared between participants, such as patients, clinicians, pharmacists, family members and support groups. The effectiveness of these interventions depends not only on the patient’s compliance, but also on the acceptance of the intervention’s information-sharing requirements by all involved parties.

Mobile phones provide an ideal platform for the delivery of such interventions. Easily carried by a patient, they can display context-relevant advice and prompts, and allow information to be conveniently transferred between patients and clinicians over a network connection, or via SMS messages. Modern mobile phones are often equipped with web browsers, have (limited) on-board storage and can take advantage of built-in or external sensors, such as heart-rate monitors, GPS receivers and pedometers, to augment self-reported feedback.

In rural areas however, neither smartphones, nor the infrastructure required to support them, may be particularly widespread. Connectivity and available bandwidth may vary between regions. Therefore, mobile interventions for rural areas must be capable of operating opportunistically in uncertain and changing network environments.

Example Intervention.

Studies have shown that exercise can have an anti-depressive effect, and can help address the symptoms of depression. It is also known that patients who are prescribed courses of anti-depressive medicine often fail to adhere to or complete the course. Reasons for this may include illness, patient characteristics, side effects and the nature of the doctor-patient relationship.

Short Message Service, allows messages of up to 140 characters to be sent between devices.
Predictability of the system to the user. For example, patient behaviour of the system.

It is necessary to permit all participants to effectively audit the intervention, as well as contextual data from sensors, such as time, location, heart rate, weather conditions, and so on. This is necessary to permit all participants to effectively audit the behaviour of the system.

Trust may also be engendered by increasing the perceived predictability of the system to the user. For example, patients may be reluctant to provide accurate information at monitoring points due to uncertainty about the consequences of doing so. However, with a sufficiently specified intervention, the platform can show users which automatic actions would be taken, or whether any actions would be incumbent on clinicians, in response to their input.

On the other hand, trust is also an important issue for clinicians charged with making critical decisions in an intervention, who must be able to place a degree of trust in the data generated by the patient on a mobile device. To support this, the platform should enable the formation of trust assertions about other participants, or the information they produce. For example, reliability of self-reported exercise statistics could be assessed by comparison with heart rate data. Past reporting behaviour, as well as information from other sources, can be used to make assertions about patients in the future. However, as before, these processes must be made transparent to all users.

Privacy.

Finally, the platform must enable all participants in an intervention to express their privacy preferences in machine-readable formats. Policies express the actions that can, must or must not be taken with regards to some information items, expressed in policy languages (e.g. OWL-POLAR). While patients may wish to employ strict privacy controls, this can render interventions infeasible. For example, policies may prohibit the gathering and sharing of information critical to an intervention’s success. We consider an intervention feasible if it does not require any information transfers which violate the participants’ policies. Given a set of policies and a specification of an intervention’s information flows, it is possible to automatically determine whether an intervention is feasible. If it is not, a set of conflict resolutions can be computed which specify how to modify the policies or information flows so that the intervention is feasible.

Participants can then negotiate to find the most acceptable resolution which allows the intervention to proceed.

4. ARCHITECTURE

An overview of our architecture is presented in Figure 1. Since our focus lies with the trust and workflow components, we are investigating off-the-shelf, open-source PCHR software which implements this functionality (Part 1, Figure 3, of which Indivo® is a prominent example).

A workflow enactment module (2) is necessary to coordinate execution of the intervention represented in a workflow language. Execution is policed by the policy module (2), which enforces user- and system-level policies, and provides conflict-resolution services. A trust module (3) produces trust assertions based on the past behaviours of participants according to the intervention workflow. This is supported by a provenance module (4) which annotates data as required to produce trust assertions. Finally, the security layer (5) provides lightweight authentication and encryption services for the layers below.

5. CONCLUSION

In this paper, we have briefly outlined a mobile-phone based platform for the self-management of chronic illnesses, giving specific attention to the key trust and privacy issues. While we used an example depression intervention to motivate our discussion, we are also investigating other chronic illnesses, such as type-2 diabetes. Rural environments present a challenging domain for these interventions, but also present an opportunity for positive transformational impact. However, such impact will not be possible unless the platform is demonstrably secure, transparent and privacy-preserving when storing and transferring sensitive information.

http://indivohealth.org/
**Initial Briefing**

**GP Weekly Briefing**

**Medication Prompt**

**Exercise Prompt**

**Record Heart Rate Data**

**PHQ9 Prompt**

**GP Weekly Debriefing**

**Final Debriefing**

**Repeat: Weekly**

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**Figure 1: Example depression intervention workflow**

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**Figure 2: TRUMP platform architecture overview.**

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**References**


