

Combining Personalization and Privacy to Deliver Remote Care to People with Depressive Illnesses

Stefanie Kethers, Peter Lamb, Shijian Lu, Cécile Paris, Ross Wilkinson
CSIRO ICT Centre, Australia

GPO Box 664, Canberra ACT 2601, Australia

Stefanie.Kethers@gmail.com, {Peter.Lamb,Shijian.Lu,Cecile.Paris,Ross.Wilkinson}@csiro.au

Kathleen Griffiths

Centre for Mental Health Research, Australia National University, Australia

Building 63, The Australian National University, Canberra ACT 0200

Kathy.Griffiths@anu.edu.au

ABSTRACT

In this short position paper, we describe our approach to developing a system for delivering remote services to people suffering from depression and similar mental illnesses. Our initial system architecture has two key components: a tool for helping the consumer and their carers develop and manage her care plan, and a consumer-controlled consent control and management tool. We believe that the former will give the consumer much-needed control over their long-term care, and that the latter will support the development of the user's trust in the system.

Author Keywords

Online mental health delivery, Health data privacy.

ACM Classification Keywords

H.5.2 User Interfaces — User-centred design, J.3 Life & Medical Sciences — Health, J.4 Social and behavioral Sciences — Psychology.

INTRODUCTION

Mental health is designated an Australian health priority and is recognized as the third largest source of Australia's disease burden, after cardiovascular disease and cancer. In particular, depression is the leading cause of disability in Australia [6]. It is also the leading risk factor for suicide. However, many people with depression do not receive help [1], and mental health service delivery in Australia is inadequate [7]. Given the size of the problem, the economic constraints and limitations on the availability of a trained workforce the existing models of mental health delivery are unlikely to address all the unmet need. Arguably, the use of a remote mode of delivery to provide mental health services to people with depression could increase the coverage and quality of care and reduce its cost. Web-based services can provide self-help in the form of: information that increases health literacy/knowledge (which can promote help seeking and engagement in the care process); automated therapy programs that reduce the severity of symptoms; and mechanisms that facilitate online mutual support. The

Internet also permits ongoing engagement of users through automated tracking. Web support services based on cognitive behaviour therapy have proven to be effective [2], and telephone counseling is a promising mode of distal mental health service delivery [5]. However, these services are often delivered anonymously, independently and over a single session or short period. However, depression is a chronic illness which can recur throughout a person's life. People with depression require systems that enable them to manage their own illness, to access the level of help that is needed when and where it is needed and to do so within a system that ensures continuity of care across time and providers.

A research team formed by CSIRO and the ANU Centre for Mental Health Research (CMHR) is currently investigating the creation of an e-clinic – a remote clinic to deliver support and continuity of care for consumers with depressive illnesses. Continuity of care requires a 'living' care plan. Importantly, the consumer must be involved in developing and managing this plan, including in the decisions regarding its access, and the various people involved must receive appropriate information. Privacy and personalization are thus key to such a system. We are investigating both a privacy approach to enable a consumer to be in control of their own privacy regime [3], and a personalization approach to put the consumer in charge of their own user model [4].

ONLINE MANAGED CARE IN MENTAL HEALTH

We have developed an initial system architecture, shown in Figure 1, that centers around a Care Plan Management tool. The care plan results from an automatically generated care plan based on evidence-based clinical practice guidelines and the negotiation between the consumer and selected members of the care team – the latter might include general practitioners, psychiatrists, psychologists, allied health providers, support groups, family, friends, etc. Consequently there are risks that privacy might be compromised. It will also be necessary to manage issues

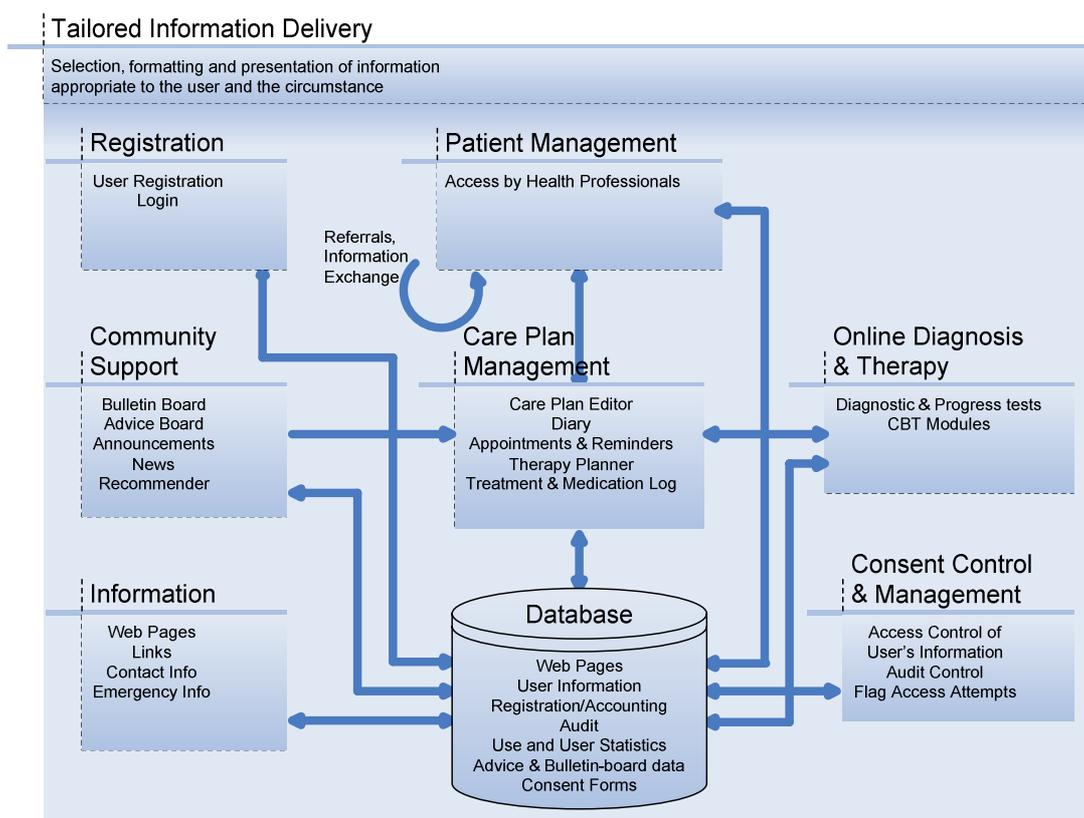


Figure 1 Architecture diagram

regarding the personalization of information for different users of the system. What a person might discuss with or allow a GP, a psychiatrist, a carer, or their support group to view is likely to vary markedly and to differ for different consumers.

An important aspect of the Care Plan Management tool is that it should allow a consumer and the care team to collaborate on the construction of a care plan without requiring that all the collaborators engage at the same time. There must be means for the parties to communicate suggestions and rationale about how the plan is constructed so that a mutual understanding and agreement is reached. The Care Plan Management tool should also support, but not require, simultaneous engagement on a plan, using either the e-clinic's systems or other means such as telephone, or face-to-face communication.

Other crucial modules include a Consent Controller and Manager, which ensures that all communications satisfy the scrutable privacy policy, and a Tailored Information Delivery module that ensures that appropriate and personalized information is delivered to each participant. The proposed system also includes a set of information services that incorporate existing services developed by CMHR (e.g., BlueBoard, an online virtual support group for people suffering from depression (<http://blueboard.anu.edu.au/>); MoodGYM, an online

automated therapy program (<http://moodgym.anu.edu.au/>); and BluePages, an evidence-based information program (<http://bluepages.anu.edu.au/>).

The user interface to the Consent Controller and Manager must provide a simple and understandable view of the consumer's decisions on who, in what circumstances and which parts of their personal information they are willing to share with others; their professional care team, non-professional carers, or other participants in e-clinic. We believe that the ability to understand their controls, and access by the consumer to audit logs showing who has been permitted, or denied, access to their personal records is an important contributor to the users' trust in the system's ability to manage and share their data according to their wishes.

FUTURE WORK

Of course, e-clinic will be useful only if it is being used. For this to occur, the consumer must trust the system, the support, and the people involved in the provision of care. We already know that consumers are willing to use such systems on a sessional basis, and that they obtain benefit [2]. One key question is whether people with depressive illnesses will trust a system that requires sharing of their records with others to enable continuity of care. The building of trust can be supported by giving users the means to control the privacy of their records and who can access,

view, and add to them. However, trust cannot be guaranteed by such a privacy control module. Much of the trust in the *system* will depend on the trust the consumer has in the *people* that the consumer interacts with through the system – carers, GPs, psychologists, psychotherapists, etc. – and thus depends not only on the technical, but also on the social environment of the system.

A second key question is whether (and how) a diverse group of people – the consumer, their carers, GP, and other health providers – can work together to create, maintain, and manage the consumer’s care plan over an extended period. Again, this includes the consumer defining and maintaining privacy rules that determine (and possibly change) who has access to the care plan in the long term.

Thirdly, we need to understand how information can be delivered in a personalized way to the diverse range of people accessing the system. Again, privacy control plays an important role since if information is needed from the consumer’s medical record for presentation to another person, then the consumer’s consent control must be respected.

A true test of these questions requires extensive field trials of a comprehensive, robust system. For practical reasons, we are building preliminary trials that demonstrate the effectiveness of key components first.

We currently have a set of propositions that we feel are important to the development of an e-clinic as proposed in this paper:

1. whether trust in the e-clinic system can be developed to a level that assists a consumer to maintain continuity of their treatment;
2. whether care plans that are useful and understandable to all participants can be developed collaboratively;
3. whether privacy policies that are useful and understandable to all participants can be developed; and
4. whether information delivery can be appropriate, consistent and understandable, even though participants might have very different knowledge and roles.

We plan to test these propositions by a combination of qualitative and quantitative methods, including:

- To test proposition 1, we are in the process of analysing the social networks forming and changing, and the language used in an online mental health community’s log files to understand how trust (both in individuals and the whole community) and distrust form in such socio-technical systems. We will also conduct surveys of members of online mental health communities to further explore the formation of trust relationships within such a system.

- To test propositions 2 and 3, we will develop mock-ups and conduct focus group sessions to gain a deeper understanding of the requirements and constraints on the care plan management tool and the consent control manager.
- To test proposition 4, we will analyse and evaluate existing online information services for people with mental health problems, and conduct surveys and focus group sessions to better understand consumers requirements.

CONCLUSION

In this short paper, we have described a situation where both privacy and personalization are important to the provision of a valuable service. We have outlined our approach to the problem, a preliminary architecture, and directions for future work. We cannot yet report results, but we believe that e-clinic system provides a good practical example to demonstrate the value of Privacy-Enhanced Personalization. While our initial engagement is in mental health, particularly in the management of depression, we believe that this architecture is applicable to other chronic conditions that require support and continuity of care and where much of the care can be self-managed, but its quality improved by care plan management and online support.

REFERENCES

1. Andrews, G. and Henderson, S. (eds.). *Unmet Need in Psychiatry: Problems, Resources, Responses*. Cambridge University Press (2000).
2. Christensen, H., Griffiths, K.M. and Jorm, A.F. Delivering depression interventions using the Internet: positive results from a large randomised controlled trial. *British Medical Journal* (2004), 328:265.
3. Cranor, L.F. and Garfinkel, S. *Security and Usability - Designing Secure Systems that People Can Use*. O'Reilly (2005).
4. Czarkowski, M. and Kay, J. A. scrutable adaptive hypertext. In De Bra P., Brusilovsky P. and Conejo R (eds): *Proc. AH'2002*, Springer (2002), 384 - 387.
5. Leach, L.S. and Christensen, H. A systematic review of telephone-based interventions for mental disorders. *Journal of Telemedicine and Telecare*, in press (2006).
6. Mathers C, Vos T, Stevenson C *The Burden of Disease and Injury in Australia*. AIHW Cat. No PhE 17. (1999) Canberra: Australian Institute of Health and Welfare.
7. Mental Health Council of Australia & Brain & Mind Research Institute (MHCOA & BMRI): *Not for Service*. Canberra: MHCOA & BMRI (2005).