

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

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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]. 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 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, and over a single session or short period whereas depression is a chronic illness which can recur throughout a person's life. There is therefore a strong need for systems that ensure 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].

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 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.

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/>).

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]. The 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. A true test of this question 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 wish to test:

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

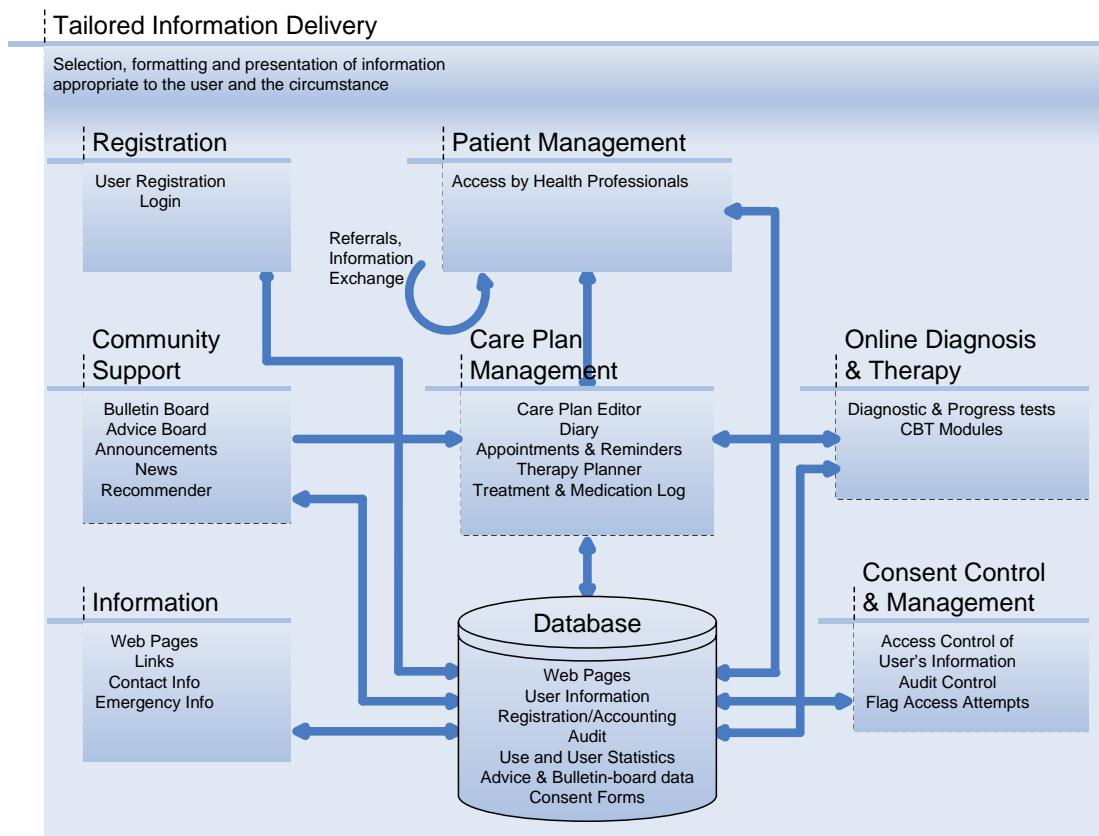


Figure 1: Architecture Diagram

To help understand the requirements for the first proposition, we are currently examining the logs of BlueBoard. Using anonymous, but consistent sign-ins, people use this board to either seek or provide support for each other. Anonymity is preserved by the moderators, and by a well-articulated policy for the use of this system. We employ language analysis and social network analysis-related tools to determine whether the individual postings express interpersonal trust, trust in the community, and distrust.

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 a set of planned experiments. We cannot yet report results, but we believe this is a good practical example to demonstrate the value of Privacy-Enhanced Personalization.

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