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tel: +44 1970 62 2400
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Mobile early detection and connected intervention to coproduce better care in severe mental illness

Pauline Whelan^{abc}, Matthew Machin^{abc}, Shôn Lewis^{abc}, Iain Buchan^{abc}, Caroline Sanders^{ab}, Eve Applegate^d, Charlotte Stockton^a, Sally Preston^a, Robert Andrew Bowen^a, Zhimin Ze^e, Chris Roberts^a, Linda Davies^a, Til Wykes^e, Nicholas TARRIER^e, Shitij Kapur^e, John Ainsworth^{abc}

^a The University of Manchester, UK

^b Manchester Academic Health Science Centre, UK

^c Farr Institute @ Health eResearch Centre (HeRC), UK

^d Division of Clinical Psychology, University of Liverpool, UK

^e Institute of Psychiatry, Psychology and Neuroscience, King's College London, UK

Abstract

Current approaches to the management of severe mental illness have four major limitations: 1) symptom reporting is intermittent and subject to problems with reliability; 2) service users report feelings of disengagement from their care planning; 3) late detection of symptoms delay interventions and increase the risk of relapse; and 4) care systems are held back by the costs of unscheduled hospital admissions that could have been avoided with earlier detection and intervention. The ClinTouch system was developed to close the loop between service users and health professionals. ClinTouch is an end-to-end secure platform, providing a validated mobile assessment technology, a web interface to view symptom data and a clinical algorithm to detect risk of relapse. ClinTouch integrates high-resolution, continuous longitudinal symptom data into mental health care services and presents it in a form that is easy to use for targeting care where it is needed. The architecture and methodology can be easily extended to other clinical domains, where the paradigm of targeted clinical interventions, triggered by the early detection of decline, can improve health outcomes.

Keywords:

Smartphone application; Mobile Health; Mental health; Self-management; Connected health.

Introduction

Severe mental illness, including what is diagnosed as schizophrenia and psychosis, usually appears early in adult life and has a high risk of relapse. Relapses often result in unscheduled hospital admissions, with substantial suffering of the individuals affected and their families, and high costs for mental health services. Current approaches to the management of mental illness are limited by sporadic monitoring that takes place during consultations with mental health staff who ask service users to recall symptoms from as much as a month earlier. This has led to problems with averaging, reliability and recall, and has made accurate clinical assessment difficult [1]. Maintaining remissions and supporting recovery represents a major challenge for mental health services, which have lacked an approach that is personalised, responsive and service user-focused. Moreover, a recent report by the Care Quality Commission, the independent regulator of health and social care services in England, noted how service users often

do not feel involved in their care planning [2], while National Guidelines stress the importance of service user self-management of symptoms [3]. Over recent years there has been an explosion of mobile, ubiquitous and connected health technologies, which can be used to detect diagnostic signals from individuals with much greater precision and resolution than ever before. These technologies promise to transform healthcare [4] and could support the coproduction of care between service users and care professionals [5].

In severe mental illness, the early detection of a change in symptoms can be used to trigger early intervention and so prevent relapse [6,7]. We have extended the standalone ClinTouch app [1] to close the loop between service users and care teams to enable the early detection of relapse and the targeting of interventions. We anticipate that this will improve patient outcomes by preventing relapse and hospitalisation. A reduction in hospitalisation will result in costs savings for healthcare providers.

Methods

To our knowledge, ClinTouch is the only system in the UK that offers a validated mobile assessment technology for severe mental illness with real time symptom reporting, online monitoring, relapse detection and the proven ability to integrate with existing mental health services. The use of smartphone apps within mainstream mental health care services in the UK is nascent and innovative and current clinical approaches to the management of mental illness typically rely on infrequent face-to-face consultations. The clinical aims of the ClinTouch system are to provide improved modes of personalised clinical monitoring and to enhance service user self-management. From a technical standpoint, the challenges include: a) developing a secure system that can collect and monitor service user symptoms in real-time; b) providing a reliable system to store service user clinical data; c) allowing flexible integration with diverse electronic clinical record systems across providers in the UK National Health Service (NHS); d) providing a way for clinical staff to easily view and monitor service user data; e) presenting summaries and visualisations of data that are relevant, understandable at a glance, and actionable; f) detecting deterioration in symptoms and risk of relapse; and g) supporting clinical research by making collected data available to researchers.

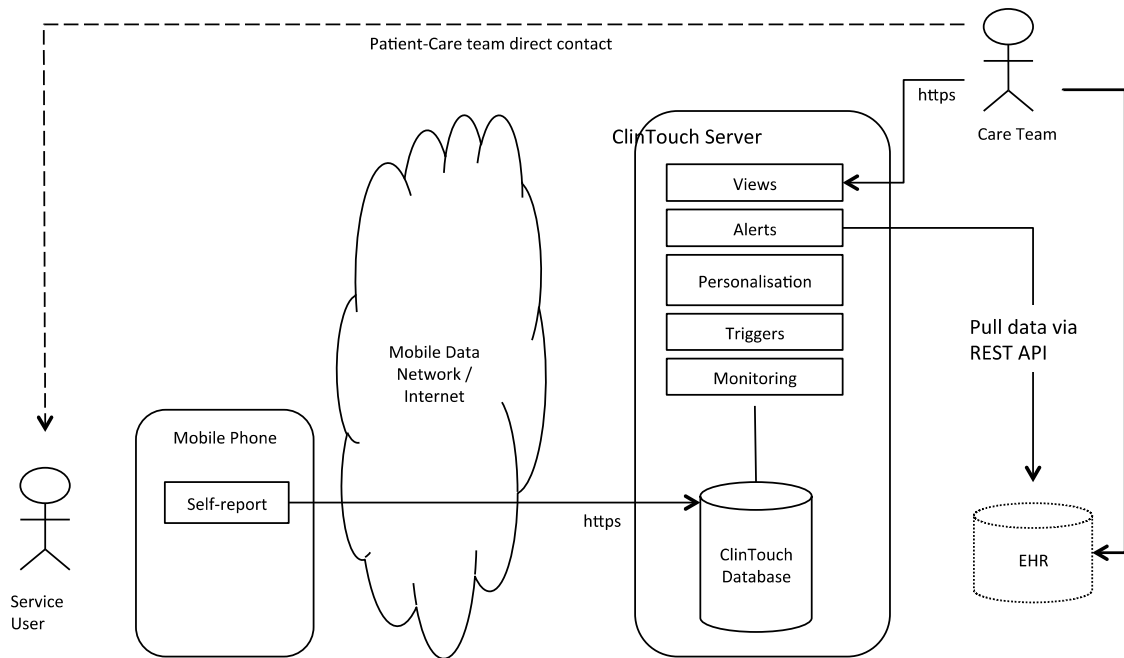


Figure 1 – Overview of ClinTouch system architecture. Service users use the app on their smartphone to capture continuous, longitudinal symptom data, which is transmitted in real-time through the mobile phone network to the central ClinTouch database for persistent storage, hosted on a backend server. This server also hosts a process running the clinical monitoring algorithm and provides a web-based interface for health professionals to configure service user accounts and to view data and alerts. Another process on the server manages data exchange between the ClinTouch system and the electronic health record system.

The architecture of the ClinTouch system is shown in Figure 1. The core elements of the system include: a smartphone application which allows service users to record their symptoms several times a day and wirelessly uploads the data to a central secure ClinTouch server; a web-based interface, which allows mental health staff within the provider organisation to view the uploaded symptom data, and a custom clinical alert algorithm, which is run over the collected data. All communication to and from the ClinTouch server (from the app, from the web-based client and via the REST API) is secured over https. All symptom data are stored against a unique participant identifier on the phone, uploaded as soon as possible and then stored securely in the ClinTouch database.

An agile, user-centred design methodology was adopted throughout the project. An iterative approach to development

was supported by a series of focus groups conducted with care staff and service users, who provided input on requirements and qualitative feedback on software prototypes and designs.

Smartphone Application

A smartphone application prompts service users to record their symptoms several times a day at pseudo-random intervals. Data are then wirelessly and automatically uploaded to the ClinTouch server. The mobile assessment technology uses gold-standard rating scales and has been shown to be reliable and valid for assessing psychotic phenomena [1]. Drawing on Sama et al's [8] categorisation of user engagement, derived from the transtheoretical model of change and behaviour modification models, the app supports self-monitoring and progress tracking, which are achieved through collection and summary displays of symptom data.

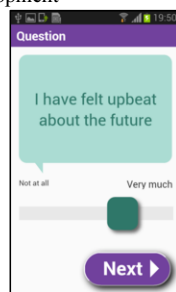


Figure 2 – A screenshot of the question response page on the smartphone application.

Figure 3 – A screenshot of the ClinTouch web interface: web page shows the screen for handling an alert raised by the clinical algorithm when it detects a high risk of relapse.

Web Interface

A web-based interface allows mental health staff to securely view the symptoms recorded by the service users in their care. The web interface supports multiple user roles, restricting access to service user data based on the logged-in user and allowing researchers to export symptom data for further analysis. The web interface provides configuration screens for adding and editing service user and staff accounts to the ClinTouch system. When adding service user accounts, questionnaires to be displayed on the smartphones for symptom monitoring can be personalised.

Clinical Algorithm

A custom-developed clinical algorithm is run across the symptom data to detect risk of relapse. If a high risk of relapse is detected, an alert is raised in the system. ClinTouch can be configured to either send an alert email automatically or third parties can integrate with the system through a REST API [9] provided by the ClinTouch server. In addition to email notification, the alert status of a service user (ALERT or OK) is viewable via the web interface. A raised alert must be manually cleared by the care provider via the web interface, where an alert resolution must be entered for auditing purposes (see Figure 3). The alert algorithm is highly personalised for individual service users at the time of configuration of the service user within the ClinTouch system. The weighting for symptoms for relapse used in the algorithm can be further edited after the participant has started using the smartphone application. This allows for ongoing personalisation following clinical assessment.

Results

The ClinTouch system has been developed based on findings from two pilot studies which used the smartphone app. The first pilot study confirmed that symptom reporting within the smartphone app is a valid way for assessing psychotic phenomena [1]. This pilot study involved 44 participants and used six pseudo-random alarms per day, for one week. Compliance (defined as completion of at least 33% of datapoints over seven days) was found to be 82% among participants. The second pilot study extended the time period

for which participants used the smartphone app to six weeks and involved 7 participants. Of the 6 participants who completed the study, compliance was 80%. The majority of participants reported finding the app helpful.

The current ClinTouch system embeds the smartphone app within the loop of care to enable real-time clinical monitoring and detection of relapse. The system has been successfully deployed in two English NHS provider organisations. At the time of writing, 34 service users and 12 staff members are actively using the system as part of a randomised controlled trial to assess the system's feasibility for use in clinical practice. The total number of participants involved is set to rise to 40 during the course of the trial.

Input from staff and service user groups throughout the development of the software has ensured the software is meeting the needs of end users. Feedback from our user groups highlighted the importance of an engaging user interface for the smartphone application. Development resources were consequently invested in this area, leading to a professionalised smartphone application and ensuring quality of the user experience. Service user focus groups led to increased personalisation of the smartphone application, including a) the ability to enter contextual data to accompany symptom data and b) the ability to customise the look and feel of the application. The design of the web interface was guided by staff input, who defined the formats used in the display of symptom, alert and export data.

As NHS provider organisations in England do not have a standardised technical platform for maintaining electronic clinical records, the software was developed with the flexibility to integrate both with diverse electronic clinical record systems and to operate as a standalone solution. To support integration, a secure REST API [9] allows secure pulling of the alert data from the ClinTouch system by a third party. The system can also operate in standalone mode with the web-based interface operating as a fully functional platform with a comprehensive view of service user data. In practice, both solutions proved useful: one NHS provider organisation integrated ClinTouch with their electronic clinical record system prior to the start of the trial; at the second site, delays in the development of the local electronic

clinical record system meant that the ClinTouch system has been used in standalone mode.

While qualitative feedback from staff who have engaged with the system has thus far been largely positive, strains on mental health services generally in the UK have meant that it has been difficult for some staff to find the time to use the system. It is hoped that as more staff engage with the system, the value of ClinTouch for enhancing care will be more widely recognised and will drive further engagement. Service user feedback highlighted the need for further personalisation of the app and future development will focus on this area.

Discussion

The ClinTouch system was designed to address the gaps in current care provision. The problem of intermittent symptom reporting is overcome in ClinTouch by incorporating a validated assessment tool within the smartphone app where symptoms can be recorded in real-time. Service users can use the app to self-manage and monitor their symptoms and work collaboratively with their care providers which could help address previously-reported feelings of disengagement. As symptoms are monitored in real-time by a clinical algorithm which alerts care staff when risk of relapse is high, ClinTouch could facilitate earlier intervention and reduce hospital admissions.

For clinical staff, ClinTouch provides enhanced, personalised clinical monitoring. For service users, ClinTouch provides tools to assist with self-management. For mental health services, the system can reduce costs by facilitating early intervention, and reducing unscheduled hospital admissions. ClinTouch has been successfully deployed across two English NHS provider organisations and aims to improve the care of individuals who experience psychosis.

ClinTouch has proven ability to both integrate with existing electronic health records systems and to operate as a standalone platform. The platform provides a rich feature set, including: display and capture of questionnaire data via a personalised smartphone application; wireless uploading of questionnaire response data; a web-based interface for viewing symptom data in tabular and dynamic graphical format; a data export facility for researchers; and a mechanism for generating alerts based on a personalised clinical algorithm for detecting risk of relapse. Ongoing challenges include engaging a broader care provider population and providing further personalised modules within the app.

Conclusion

The ClinTouch system was developed to close the loop between service users and health professionals, and to address key limitations of current approaches to the management of severe mental illness. ClinTouch provides an end-to-end secure platform, incorporating a validated mobile assessment technology, which allows service users to record symptoms in real-time; a web interface to display service user data to service users and care staff; a clinical algorithm that runs on submitted symptom data to detect risk of relapse; and an alerting system to flag the need for clinical intervention. ClinTouch integrates high resolution, continuous longitudinal symptom data into mental health care services and presents it in an intuitive format that enables clinical staff to target care where it is needed. The system is currently being trialled in two NHS provider organisations in England. The architecture

and methodology can be easily extended to other clinical domains, to enable early detection of decline and improve health outcomes.

The ability to identify the need for early intervention through real-time personalised monitoring has widespread applicability across a range of health conditions, where early intervention is key to preventing adverse outcomes. The ClinTouch platform offers a psychometrically well-founded customisable framework for real-time symptom capture, data visualization and analysis, which has been successfully deployed in mental health and is ready to translate to other contexts of co-produced self and professional care.

References

- [1] Palmier-Claus JE, Ainsworth J, Machin M, Barrowclough C, Dunn G, Barkus E, Rogers A, Wykes T, Kapur S, Buchan I, Salter E, Lewis SW. The feasibility and validity of ambulatory self-report of psychotic symptoms using a software smartphone application, *BMC Psychiatry*, 2012; 12:172. doi:10.1186/1471-244X-12-172.
- [2] Care Quality Commission, Monitoring the Mental Health Act in 2012/2013, 2014. http://www.cqc.org.uk/sites/default/files/documents/cqc_mentalhealth_2012_13_07_update.pdf (accessed 18 December, 2014).
- [3] National Institute for Health and Care Excellence, Psychosis and Schizophrenia in adults: treatment and management, 2014, <http://www.nice.org.uk/guidance/cg178/resources/guidance-psychois-and-schizophrenia-in-adults-treatment-and-management-pdf> (accessed 18 December, 2014).
- [4] Fiordelli M, Diviani N, Schulz PJ. Mapping mHealth research: a decade of evolution. *J Med Internet Res*, 2013, 15(5):e95. doi:10.2196/jmir.2430
- [5] Boye N. Co-production of Health enabled by next generation personal health systems. *Stud Health Technol Inform*, 2012, 177:52–8.
- [6] Birchwood M, Spencer E, McGovern D. Schizophrenia: Early warning signs. *Advances in Psychiatric Treatment*. 2000, 6(2):93-101. doi: 10.1192/apt.6.2.93.
- [7] Gleeson JF, Rawlings D, Jackson HJ, McGorry PD. Early warning signs of relapse following a first episode of psychosis. *Schizophr Res*, 2005, 80(1):107-11.
- [8] Sama PR, Eapen ZJ, Weinfurt KP, Shah BR, Schulman KA. An Evaluation of Mobile Health Application Tools. Eysenbach G, ed. *JMIR mHealth and uHealth*. 2014;2(2):e19. doi:10.2196/mhealth.3088.
- [9] Fielding RF. Architectural Styles and the Design of Network-based Software Architectures. Doctoral dissertation, University of California, Irvine, 2000. http://www.ics.uci.edu/~fielding/pubs/dissertation/rest_arch_style.htm (accessed 18 December, 2014).

Address for correspondence

Dr Pauline Whelan
Centre for Health Informatics
Institute of Population Health
Vaughan House
University of Manchester
M13 9PL
England
pauline.whelan@manchester.ac.uk