Experience based design of a mobile phone system (ClinTouch/ Careloop) for supporting service users with serious mental illness in community settings

Caroline Sanders
Senior Lecturer, Centre for Primary Care, University of Manchester

Shôn Lewis
Professor of Adult Psychiatry, University of Manchester, & Honorary Consultant, Manchester Mental Health & Social Care Trust
Researchers: Julia Segar, Andy Bowen, Eve Applegate, Matthew Machin, Pauline Whelan, Zhimin He, John Ainsworth, Richard Hopkins, Linda Davies, Dionysios Ntais, Til Wykes, Charlotte Stockton-Powdrell

Service user and carer advisory group: Dawn Perry, Neal Sinclair, Kate Lurie, Helen Yeoman, Peer & Deborah Bhatti
Empowering and supporting self-care & recovery
Monitoring for prevention/ early intervention
Supporting behaviour change
Information at the point of care
Service redesign - collaboration /workflow
Improving quality and efficiency

- **Enabling** efficient tasks/ practices
- **Transforming** the nature of mental healthcare and consumer control

NHS Confed, 2013
Careloop

Community Mental Health Team

Personalised set 12-18 items (90 seconds)
Aim

• To understand the perspectives and experiences of key stakeholders (MHS users, carers and staff) in order to co-design and pilot an appropriate mHealth system for supporting self-management and service provision for people with Serious Mental Illness within community settings
Qualitative methods

- Qualitative in-depth interviews & focus groups
  - 31 service users, 9 carers, 30 staff
- 3 monthly meetings of Service User and Carer Advisory Group
- Iterative analysis feeding into design
Findings - Key Themes

1. Current experience and capacity for smartphone use and improving system usability
2. Empowerment and self-management for recovery
3. Enabling interaction and support from care providers
4. Staff workload and potential for smarter working versus additional burden
5. Barriers to use and potential risks
Current experience and capacity for smartphone use

• Many service users were already routinely using smartphones
• Some would like to have a smartphone but costs too high

The internet, I use it for watching media, newspapers...when I'm feeling down, there's a webpage on there called Sane, I use that as well. (SU6)

Most of the people in this client group that I know, all of them do have a mobile phone. (SU3)

I can get internet on my phone as well... I use WhatsApp... (SU4)
Improving system usability

Remember how good you feel when you go for a run
Empowerment and self-management

- Value of enabling insight into symptom changes
- Overcoming problems with recall

This process by helping them understand their rhythms of illness... We’re not going to get that recovery without that more detailed information that can come through that real time recording.

(staff 1, site 1)

Sometimes when they’ve left I can go down... when they’re back I forget everything

(SU11)

Because I don’t always know when I’m getting ill. ... there’s a lot of tell tale signs, but I can’t always tell

(SU8)
Summarising symptom changes

How am I feeling?
- Talk to someone on your care team if you would like to know more about psychosis
- You can learn more about voices and beliefs on the Rethink website by tapping here

Last week
25/11/15-01/12/15

Last 30 Days
02/11/15-01/12/15
Staff views on enabling empowerment & recovery

- Staff talked about the value of tailoring use of the system to enable recovery.
- Need to be realistic.

Moving towards...recovery, we [may] miss that alert, but we say...how did you manage?... Have a system that recognises the reality of the world. (staff, FG5, site 1)

I mean with recovery in mind... we're moving towards more of stepping up and stepping down, it's maybe reassuring for service users to have that device when they step down... (staff, FG5, site 1)
Self-management & Recovery: idea for a personal diary

• Service users wanted to add free text to put scores in context

I still do have a diary, because I can’t remember what I did yesterday, so I can go back...

I’d rather have that to be private, just like a little journal... If you said yourself I’ve had a really bad day today, just to make a note of why...if you could capture that moment...
Enabling interaction and support from care providers

- Offers reassurance and support
- System might enable more effective and timely contact with care co-ordinator

I think, because if it helps my care coordinator **gauge what's going on** she ... might say well, X is feeling a little bit down, I'll go **visit him**. (SU10)

I try and keep in my head the baseline...but **after not seeing them for four weeks we don’t know** what kind of stuff in between ... (SU FG1)

if you don’t answer it for a couple of days and you haven’t seen a care coordinator it would register... That’d be a lot better for us... (SU FG1)
Staff workload and potential for smarter working versus additional burden

- Too much ‘paperwork’ and heavy case load restricts time with clients
- Clients also aware of heavy workload for staff
- Mobile system could enable ‘smarter’ working but need to ensure it does not add to workload

it is a lovely job to have but it's sometimes [you] haven't got enough energy to do all of it, and the pressure of it as well. (staff 8, site 1)

once per day is more than enough because the nurse or whoever gets this data has to sift through it and if he or she has 20 patients on their caseload... that's a lot of data (SU10)
Interface for staff

Start Date: 01-November-2015
End Date: 01-December-2015

Options:
- I feel like giving up
- I have heard voices

Clear All
- I have felt upbeat about the future
- I have felt that there is little point in trying
- I feel like the future holds little for me
- I feel like giving up
- I have felt sad
- I have felt miserable
- I have had no interest in seeing other people
- My mood has affected my appetite or sleep
- I have felt worthless
- I have heard voices
- I have found it difficult to concentrate on other things
- This stopped me from doing things
- Hearing the voice(s) upset me
- I have seen things that other people can't see
- I have found it difficult to concentrate on other things
- This stopped me from doing things
- Seeing these things upset me
- I have felt worried, nervous or anxious
- My heart has been racing or I have been
Barriers to use and potential risks

• Potential problems of focusing in greater detail on symptoms
• Some concerns about privacy
• Staff concerns about expectations and risks

I can see that there must be a very small part of the client group that are distrustful of new technology, or think that it’s here to put thoughts in my head. (SU3)

If you look back and then and after a certain length of time you think oh I was down then, why? Then your emotions could go down again... I mean I’m willing to try it for a month and just see how it goes. (SU2)
Summary/ discussion

- Co-design based on experiences of users and providers of care to ensure fit for purpose (technical & implementation)
- Real time data viewed to add insight into patterns and triggers of symptoms
- Need flexibility and personalisation to fit with recovery model of care & individual needs
- Potential for more effective communication and timely intervention
THANK YOU!