Technology for Mental Health
Opportunities, Challenges and Working Together
NewMind Network workshop

Held 7th July 2015 at NCVO, London

Executive summary

The aim of the NewMind Network workshop on technology in mental health was to gain input from charities into ideas developed from the Network's previous work, to understand the charities' perspectives and to ensure that future research will be grounded in real life experiences. Service user and carer groups advising on research, UK charities and researchers attended the workshop and the day consisted of presentations and group activities exploring how technologies could help people with mental health problems, learning disabilities or dementia.

Examples of charity and industry experiences with technology development were presented (by Mind, Alzheimer's Society and KMS solutions).

Ethical issues highlighted as important in technology development and its use in mental health included user involvement in creation, research and development; ownership of data; empowerment of the individual; and purpose and use of data.

The main focus of the day was on interactive sessions exploring how technologies could help people with mental health problems, learning disabilities or dementia. Four scenarios representing the outcome framework were considered and opportunities, desired outcomes and potential issues were identified for each scenario.

Charities and service user participants found the workshop stimulating and enjoyed the opportunity to engage with researchers. They would like to see a more central role for user and carer involvement in developing technologies, and would like to increase understanding of the mental health field and its specific issues. Worries about technologies replacing 'real services' were expressed.

Workshop

The workshop involved representatives of UK charities (12), service user and carer groups advising on research (6) and researchers (17) from the Universities of Dundee, Lancaster, Manchester and Nottingham.

The day consisted of presentations and group activities exploring what technologies could do for people with mental health problems, learning disabilities or dementia.

Presentations

Two examples of charities' experiences with technologies were presented:
Elefriends, a social media peer support community (by Mind) was very well received. The resource-intensive service seemed to cover a huge unmet need, even though it was not designed as crisis support.

It would still benefit from more peer leadership and being moderated past midnight, when some people may need the support most.

The online catalogue of available products provided by the Alzheimer's Society (AS) demonstrated the need for effectiveness evaluation and quality assurance of technologies, as it is not clear which products "work" and therefore AS does not make any recommendations. A general lack of co-design of technology by people with dementia was also highlighted. Technology has an important role but does it really improve services?

One industry example developed by Manchester based KMS solutions – a GPS enabled wristband for tracking of people with dementia, cognitive impairment or other vulnerable adults – outlined the potential for technology to be developed in a simple and responsive way . Participants agreed that this could be useful for certain service users with learning difficulties, subject to there being proper involvement of users in the future development of any products to minimise concerns over such ethical issues as deprivation of liberty and data ownership.

There was a discussion of ethical issues with technology development and its use in mental health. The top-ranked ethical principles by both charities/users and researchers were: user involvement in creation, research and development; ownership of data; empowerment of the individual; and purpose and use of data. There were some subtle differences between the ranking of the two participant groups: level of control over tech was ranked higher by researchers, while charities/users chose purpose and use of data and also gave more importance to the effectiveness of the products, importance of language, nannying vs. positive risk taking, and the nature of marketplace (commercial vs. NHS) than researchers did (see Annex 1).

Interactive Sessions

The main focus of the day was on interactive sessions exploring how technologies could help people with mental health problems, identifying opportunities and issues, assessing if the outcomes were desirable or viable, and the practicalities of achieving them. Four scenarios representing the outcome framework were considered, and key desired outcomes and potential issues were highlighted for each scenario (the detailed outputs are shown in Annexes 2 and 3).

(1) Enhancing social interaction - help individuals build strong social networks.
Outcomes
- identify patterns of behaviour, create personalised outcomes
- co-design with user input
- integrate with social media, involve others, help them to support better
- build confidence, keep connected but support independence
- make communication easier
- improving medication adherence

Issues
- big brother effect
- rick of increasing stigma

(2) Supporting personal aspirations - support individuals in overcoming barriers to setting and achieving personal goals;
Outcomes
- personalised outcomes, self-management
- choice, not a prescribed solution

- positive risk taking
- break big challenges into small tasks
- feeling safe and supported, yet empowered
- goal setting (in dementia and learning disabilities too)

Issues

- technology errors
- cost and access
- risk of isolation, loss of carers and human company
- risk of being paternalistic

(3) Optimising care - build a picture of individuals' mental health, empowering self-management and informing more effective intervention;

Outcomes

- greater support, build peer support and community
- co-designed
- support of self-management
- optimising for the individual (not for the NHS)
- medication management
- e-therapy - can increase access but should allow for personal preferences
- scope for more non-pharmacological interventions
- recognising triggers and coping strategies

Issues

- data ownership, security, sensitivities
- 24 hour monitoring - similar to being sectioned?
- risk of increased social isolation, less human interaction
- increasing inequalities, language barriers

(4) Early warning and prevention - identify problems early, supporting the deployment of coping strategies and allowing timely intervention;

Outcomes

- improved communication
- control over information sharing
- personalised outcomes, lifestyle prompts
- individuals in control of their condition
- build peer support and self-management
- avoid emergency admissions and deterioration
- activate support from family and friends, or medical intervention

Issues

- medication adherence issues
- some assumptions not valid in mental health (diagnoses accurate, reliable etc..)
- difficulties in assessing early signs
- risk of isolation, loss of human touch
- personalised (e.g. triggers), correct parameters for each individual
- control of speed of intervention escalation

General Impressions of the Day

In general, the charity participants enjoyed the event and found the day stimulating and the workshop format working well for sharing opinions and learning from each other. They were pleased to have the opportunity to engage with researchers and have some input into future research plans.

Researchers found the input from service user and carer groups and UK charities to be very valuable in broadening the perspective of the Network from the traditional medical model and clinician perspectives and proposing a focus on developing services to reflect technological and societal changes. It was recognised that some of the case scenarios and presentations suggested that the degree of user and carer involvement had not previously been very detailed.

It was recognised that a balanced approach is needed, and the perspectives and opinions of experts by experience should have a central role in technology development if people are to be the final users of the products by choice rather than by prescription. Co-production of technologies with users should be an integral part of every step of the process, starting from the inception of ideas and concepts.

Data security and data sharing and other ethical issues need to be carefully managed. Many anxieties persist, for example, regarding data security and data use, and many people are still not well trained in using technology.

There was a genuine enthusiasm for technology use in mental health, though concerns were voiced about technologies replacing human contact and 'real services'. This is a worry for many people using mental health services, especially in the current context of funding cuts, and could potentially give rise to a negative perception of the role of technology use in mental health management. Workshop participants generally agreed that technology's role should enhance and improve the care pathway rather than change it completely.