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SOCIAL MEDIA AND AUSTERITY: ONLINE PEER SUPPORT IN MENTAL HEALTH COMMUNITIES

Pilot Project Interim Report

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Executive Summary

This project focuses on the role that digital media can play in shaping mental health communities in a culture of austerity. Mental health services (NHS and third sector) are facing significant funding cuts, and digital technologies are increasingly being recruited to try to 'fill the gaps' left by reductions to physical services. This project aims to identify some of the consequences of increased digitisation of mental health care and support, through investigating users' peer support practices on one of the first major UK mental health digital media initiatives, Mind's peer support website www.elefriends.org.uk. The project is a partnership between Universities of East London, Roehampton and the mental health charity Mind.

Aims:

- To identify the cultural practices of online peer-support in mental health communities during austerity.
- To produce detailed understanding of service user knowledge, experience and preference with regard to peer-support, and its impact on well-being and resilience.
- To further develop partnerships between the project team, Mind, service users, Network+ members and related digital technology-mental health initiatives to produce guidelines and strategy for future policies and practice.

Key Questions:

- How is austerity changing peer-support in mental health communities?
- What forms of mental health peer-support are made possible by Elefriends?

- What are the policy implications of increased use of social media for peer-support?
- What kinds of partnerships between researchers, service providers and users do we need to develop productive strategies for understanding and enabling positive community mental health?

Progress:

The project commenced at the beginning of March 2014. So far we have organized the collection of the online data (posts and conversations of 157 Elefriends users over a three month period). This resulted in a large set of data that has been cleaned and organized. Analysis of the online data is underway at the time of writing. The second part of data collection is interviews (via Skype) with up to 30 Elefriends users about their experiences of seeking and providing peer support through the site, and how the context of austerity in shifting the possibilities for community support, is underway, and expected to be completed shortly (early July).

Two workshops have been scoped and planned. Workshop 1 will be focused on disseminating findings and sharing learning with other digital media mental initiatives locally and nationally. To this end, Tucker has joined the Newham Partner Forum (a local forum involving Newham CCG, CaMHS, Mind and a number of local third sector organizations. Links have also been made with Leeds NHS and MindTech at Nottigham University. Leeds NHS is very active in digital media, and MindTech have been commissioned by Innovation Labs to evaluate seven digital media mental health interventions (websites and apps). Representatives from these groups have been invited to workshop 1.

A second workshop will be run for Elefriends users, as a way of talking with them about the project and its findings. This will enable

user feedback to be incorporated into the impact plan and legacy of the project. Both workshops will run in September 2014, following completion of the project as this will allow dissemination of the findings. This is important as there is currently very little evidence of the value of digital media mental health tools.

Preliminary Analysis

The online data collection produced a significant data set, larger than anticipated by the project team. There are two reasons for this. Firstly participant recruitment was so fast that more people signed up than we had planned (157 in three days). Recruitment was conducted through the Elefriends site itself, so it was 'open' to any user until we could ask Mind technical support to 'close' the option on the site. We did not want to exclude anyone who had signed up so we kept all in. Secondly, it was difficult to anticipate the size of each participant's data profile as we did not know how much people post. The online data set totaled 1167003 words.

Given the size of the online data set we decided to conduct content analysis, as it is not possible to conduct substantive qualitative analysis on such a large data set. The content analysis will provide valuable insight into the more commonly used words on the site, with the subsequent qualitative analysis of Skype interviews providing depth and context to the online content analysis. We are exploring the value of conducting co-word content analysis (an increasingly important tool in digital social research with roots in science and technology studies). Co-word provides analytic insight into the relationships between commonly co-occurring words in users' posts. This helps identify meaning between co-occurring words, rather than base analysis solely on frequency of single words.

Outcomes

- Invited presentation at the 'Living in the cuts: Policy, politics and everyday lives in the recession' ESRC Novella conference at British Library, May 2014
- We have been invited by MindTech (Nottingham University) to run a seminar presenting the project and its findings in December.
- We have met with Mind Chief Executive (Paul Falmer) to discuss the project and arrange presentation of findings to Mind in September.
- We have been invited to participate in a symposium of digital technologies and caring communities at the European Association of Science and Technology Conference in Poland in September.
- A Wordpress site to detail all aspects of the project, e.g. events, project team, impact plans, findings.

Dissemination

We have to date disseminated our work in a number of ways. We have made a number of connections with NHS, academic and third sector organisations that are working, or interested in developing work, in the area of digital media and mental health. A number of future dissemination opportunities have emerged through these connections (e.g. invited talks) once the project has finished. We have given conference presentations and have future ones in planning (in the UK and Europe). We are also developing a project website that will act as an online hub for information about all aspects of the project.

Next Steps

- Complete the online data analysis.

Organise completion of transcription of Skype interviews.
 Analyse Skype interviews
 Plan presentations at EaSST conference, Mind and MindTech
 Go live with Wordpress site