



UNIVERSITY OF LEEDS

This is a repository copy of *Social Media and Austerity: Online Peer Support in Mental Health Communities. Follow on Project Final Report.*

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/114816/>

Article:

Tucker, I. and Goodings, L. (2015) Social Media and Austerity: Online Peer Support in Mental Health Communities. Follow on Project Final Report. Working Papers of the Communities & Culture Network+, 6. ISSN 2052-7268

Reuse

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>



**Social Media and Austerity: Online Peer
Support in Mental Health Communities:
Follow on Project Final Report**

Dr Ian Tucker (University of East London)

Dr Lewis Goodings (University of Roehampton)



EXECUTIVE SUMMARY

The original ‘Social Media and Austerity’ pilot project focused on the role that social media can play in shaping mental health communities in a culture of austerity. This project aimed 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.elfriends.org.uk. The project was a partnership between Universities of East London and Roehampton and the mental health charity Mind.

This follow on project sought to develop an innovative approach to online user engagement. An animated storyboard of pilot project findings was produced and posted on Elefriends. Responses were collected to the storyboard from the Elefriends users. This aim was to validate the findings and give the users an opportunity to comment on the overall analysis of the data and the use of the storyboard as a way of disseminating the findings.

Further analysis of pilot project data was undertaken in order to examine how talk of treatment acts as a central topic for community engagement on Elefriends. The pilot project identified this as a core issue for which people sought (and provided) online peer support. Elefriends provides the opportunity to connect with others facing the same challenges re treatment (e.g. managing side effects). This analysis will facilitate knowledge transfer with other health related online peer support arenas that we have built relationships with during pilot project (e.g. with MindTech - NHS Technology Healthcare Co-operative).

AIMS

1. To develop an online ‘animated storyboard’ of pilot project findings to encourage user engagement with the Elefriends community.
2. To prepare for future knowledge partnerships by harnessing evidence of the way people speak about treatments in Elefriends.

PROJECT ACTIVITIES

1. The animated storyboard

The follow-on funding allowed Mind, in collaboration with project team, to commission PAN (an animations company Mind often commission for design related work) to create a storyboard of the findings from the pilot findings. A similar approach was used to recruit participants for the pilot project. The project team and Mind agreed this was the most appropriate way to disseminate findings in an accessible way to the Elefriends community, and to seek feedback. The findings from the project were condensed into blocks of information to produce the storyboard form of communication (see Appendix). As with all documents sent to the Elefriends community, the storyboard uses the image of the friendly Elephant who features on the site and is the central method through which Mind communicate with users of the site.

The storyboard was posted to the site via the Elephant meaning that it would have appeared in the newsfeed to all members. It was also posted to a separate location on Elefriends. We asked the community to report on the storyboard and to get in touch with their views on the findings. The feedback was very positive and the community, on the whole, agreed with the findings in the storyboard. As the comic strip was posted on the site any user on the site could provide feedback (i.e. not just those who took part in original research). Users could feedback through clicking the 'like' and/or 'I hear you' buttons, and/or provide additional comments if desired. It was also possible to 'like' and/or 'hear' each individual feedback comment. The following feedback was received from users of Elefriends:

33 'likes/hears' without comment

Comments

Thanks for sharing Ele :)

I like the comic a lot. It covers a lot of what happens here and explains it well. I like the pictures and want to colour them in
(5 others liked)

yes it feels horrid to be ignored but it's when people comment that it makes a world of difference when you have nobody
(5 others liked and 1 hear)

A rather nice cartoon Ele, have got a copy of it for future reference. Must say a few of those images are sad to see. Though we are a big community & we all care. :)

(2 others liked)

Number one word is hugs :) love it!!! Can't remember what I googled to find this place but I'm so glad I did

(5 others liked)

Offline support (a long post!!) - I was told by an nhs psychiatrist that there was no further support on nhs 2 yrs ago. That I had to just stay on the same ad's... This was despite me completely isolating myself at home except for work, appts and essential family visits. I had to go private for 6mths to an amazing consultant who actually understood, listened, talked with me and to me, discussed and was proactive and supportive. I then got referred back to a different nhs psychiatrist who is lovely. He talks to/with me also, is friendly, human and respectful. My meds in this 6mth period were totally changed, I paid for private counselling too, and I've just had first appt with a consultant psychologist... Being told there was "no further psychotherapy help" by original consultant psychiatrist was just plain wrong!!? She couldn't seem to recognise that I am struggling, yet I can work in a high functioning job. She gave the impression that actually, relative to others, I was lucky. Yet the loss of functioning privately to me, was just as, if not more than, severe relative within my life and situation. Every/any person can develop severe MH probs, irrelevant to their background/upbringing or intelligence/capabilities or opportunities they have had/have. I am now back on track, and extremely lucky to have an understanding GP (I had appts over many yrs, being dismissed, before I found him). I now have an interactive psychiatrist. A care coordinator. An occ health therapist. And now the start of appts with a consultant psychologist... Very Lucky... It's taken yrs, I'm not sure there'll be an answer to 'me', but they are looking and helping now. Should we have care based on "luck" and "dogged persistence over years" though?? xxx (If any Elefriends have been courteous and patient enough to read this far and long, then mark that as one of your "daily positives" !! ;P :-) !!) xxx

(18 likes and 12 hears)

What you've gathered is what I suspected would be found from the study. People in general are increasingly more online, elefriends has tapped in to this, as well filling the gap left by the nhs to some degree. Weve all contributed to a community, all involved should be proud.

(7 likes and 1 hear)

Florin, thank you for writing that. I share your frustrations. The health authorities need to understand that mental health problems can afflict anyone and that we all need help. It is not ok to just stay alive - we need support to live our lives to the full and to flourish. It makes me angry

when people have to fight and when often family have to advocate for what is needed. Help should be available to all and should be responsive, and even preventative, rather than requiring a great fight each time we need it.

(5 likes and 4 hears)

I'm glad that I took part and I am glad to help such a supporting site. X

(2 likes and 1 hear)

I am from the Philippines, and I admit sometimes I feel inferior because all the ele family are British or Irish. But for nearly a month, I feel like I am part of the ele family. Most eles are friendly and supportive. No matter how weird are my posts sometimes, yet the eles are still supportive. I admit it didn't improve much on my condition, but with eles, I feel I can have an escapism, I have a family to run to. I hope the elefriends can extend in some parts of the globe, especially here in the Philippines, because depression and suicide rate here is alarmingly high. Wish for the best and success of Elefriends.

(5 likes and 6 hears)

Thank you for sharing this with us Ele, very interesting i must say :) xxx

Your words here are so true , I'm so pleased to be a member of the herd ele . Big trunk hugs to all off you . Xx

That's the sweetest thing Aww :')

The results are very true and good

What an interesting read, thanks for sharing!

Everything mentioned is true, there are 'stages' of depression from feeling really low(isolation at home and within ele friends) to being at the other end of spectrum and showering other eles with lots of support! (So no one should feel they don't belong,,as stated).

It is true also, when you feel better mentally you use ele friends less, to dip your toes in shallow waters, so to speak (trying it alone, yet comfortly knowing ele friends is there ready to back you up).

I feel it is very well worded and will help others / new members joining us. ;)

Comments on Feedback

Overall the feedback was positive and demonstrated that the findings from the pilot project resonated with the experiences of Elefriends, and as such were validated by the feedback. Undertaking the online user engagement activity allowed us to (re)connect with the Elefriends community, and demonstrate what was achieved by the pilot project, as well as express our gratitude to those who took part. It also demonstrated what is possible when using social media for both research and user engagement activities (e.g. comment by user from Philippines who expresses feeling part of the community despite geographical location).

Mind are pleased with the community engagement that the storyboard represents. This is the first of this form of research that has taken place in Elefriends and Mind has used the findings in their future plans for Elefriends.

2. Harnessing information on treatments in Elefriends

The second part of the follow on project was to analyse one of the core topics that shapes communication on Elefriends, and as such acts as a key constituent of the online community. Beyond the various forms of general support that are present in Elefriends medication was identified of one of the key topics users sought and provided support for. Of particular interest was the ways the site, as a digital technology, is used to manage the psycho-physiological impacts of psychiatric medication. Furthermore, how this happens at a community (collective) level, and not just as an individual experience. The analysis has been written up as journal article that is currently under review. We include a summary of the article below:

Introduction

Psychiatric medication remains the mainstay of psychiatric treatment. Many of the discussions that take place in Elefriends are based on the experiences of a variety of different medications. As part of the supportive community, many people discuss what to expect from taking particular medications and potential side effects. This project sought to focus on the social elements of medication consumption, particularly the 'indirect action' that accompanies the 'direct' action of the biological effects of medication (Choudhury, McKinney & Kirmayer, 2015). The indirect action(s) of interest here are the ways that people can speak about taking medication and how people exchange information on what to expect from different medication experiences.

Living with medication requires people to make sense of the biochemical impacts of medication. Medication can enhance, limit, shape, and impede the body's capacity to act, and as such

medicated bodies are experienced as on going sites of care. This is particularly the case at times when the body's medicated state changes (e.g. increasing dosage, introduction of new drug). As such knowledge is not always easily gained, as medication can disrupt the body in unpredictable ways, and enact new kinds of feeling and sensation. Seeking support for medication through Elefriends involves trying to translate the sensory data of individual medicated bodies into the digitally mediated space of the site.

Method

Through an initial phrase analysis (He, 1999) of the online data set, 'medication' was identified as a key topic discussed on Elefriends. The specific references to 'medication' were then identified in the data set. For this, a dictionary of terms that related to the word 'medication' was devised, which included shorter versions of the word (e.g. 'med', 'meds'), words that have a similar meaning (e.g. 'drug', 'antidepressant', 'treatment') and specific names of popular medications (e.g. 'Citalopram', 'Sertraline'). The search resulted in approximately 1,100 posts that included a reference to medication. These posts were then analysed using discursive techniques.

Findings

The findings from the project will be discussed in relation to the following themes and discussed below in more detail:

- *Bodies switching between regimens*
- *Self-experimenting with the medicated body*
- *Immediacy and the medicated body*
- *Trigger warnings*

Bodies switching between regimens

CHARLOTTE: Just wondering if anyone has any experience on Sertraline? I've googled it (probably worst idea) with me being due to start it next week. I've been on citalopram before which I have read is similar, and I didn't have nasty side effects with that it just stopped working. Just wondering if it has helped anyone etc? I know everyone is different with meds though! Sending hugs to everyone. Xx

RACHEL: changed from citalopram to sertaline a couple of weeks ago. It's honestly been amazing for me![...]

AMANDA: I swapped from citalopram to sertraline.. Gradually coming off one and going onto the other. I don't recall any side effects.x

CHARLOTTE: Ooooooh thank you, that's good to know! My doc put me on mirtazapine cos I have trouble sleeping and that's a sedative but one of the main side effects is weight gain and I have gained so much in six weeks it was making me more miserable! So she's prescribed me sertaline and I'm hoping that because I've been on citalopram before I won't get some of the horrid side effects I have read haha. Did you get any side effects? X

CLARE: I'm on it and it helps me. No weird side effects xx

CHARLOTTE: Thanks Clare! I'm hoping I'm gonna be okay cos I've been on citalopram. Any side effects will be better than my insatiable appetite and gaining a shed load of weight on mirtazapine! Haha xx

Extract 1 illustrates how communication around the anticipated aspects of medicated bodies is developed at a community level. Amanda responds to Charlotte's post by stating that she has similar experience (swapping from Citalopram to Sertraline) but with a slight difference ('coming off one and going onto the other'). As it is not possible for Amanda's experience to match Charlotte's exactly (something Charlotte predicts, "I know everyone is different with meds though!"), Amanda presents her response in a somewhat hedged manner - 'I don't recall any side effects'. There is an implicit recognition that her affective knowledge cannot be mapped directly to Charlotte's medicated body. Amanda is confirming that she is not an expert on Charlotte's body (she does not affectively know Charlotte's body) and is therefore conscious that Charlotte's experience might not match hers. However, to Charlotte, this expertise is of value as it is based on experience and confirms that people make switches of this kind and that she should not anticipate any unexpected side effects.

Self-experimenting with the medicated body

In the previous extract Charlotte described an anticipatory act of trying to manage the potential affective pressure of upcoming changes to her body. In the following extract we see a different kind of change, which centres on a period of experimentation during which medication was not taken. Managing the body at this time involved living with a higher level of affective vigilance than is normally experienced.

BEATRICE: Am starting to feel calmer now - still somewhat sorrowful but thankfully I feel too tired to get upset yet again. Two hours now until I can go to pick up my oh-so-missed meds! I know I need them, I know I've missed them yet somehow it feels like being taken back to an institution where I'll be safe but where the outside world won't feel like it does now. I'm a mess of contradictions, perhaps I've watched Rainman too many times as I can relate to it so much & it's one of my favourite films (I realise there will probably a collective 'huh?!' to that!!) but feeling very much like the character Ray - spent a few

days going through so many emotions but was still out there, he experienced life in all its full colours & full volume but then inevitably has to go back to the institution where he's safe but it's not the same - back to black & white, & nothingness. This makes sense to me & I realise it might not make sense to any other Elefriend out there & perhaps I'm now Really Weird Beatrice after you've read this. Perhaps though, someone somewhere will get it & maybe, just maybe, I won't feel so alone & far away in my weird head.....

.....

TOM: I would be totally f_eD without medication, even more weird than I probably sound already.

.....

SOPHIE: I think a lot of us eles have a love hate relationship with our meds. Too much stigma, too many thoughts.

BEATRICE: Squizzles Forever!!! :-D xxx

BEATRICE: I hear ya Sophie - it's such a complex thing isn't it - I need them yet I feel like this - still if they help keep me plodding along.....hugs xxxx

Describing a period without medication is not something Beatrice can readily do with her mental health team, as it risks being seen as non-adherence. Elefriends provides an audience with whom disclosure is not bound up with same risks. This is a new forum for talking about her medicated body, it provides a simultaneity to Beatrice's experiences, felt through her body and Elefriends. There is a support in connecting to other medicated bodies at times in which engaging with mental health services is not possible (either due to time of day and/or content of description). The constant availability of the site can be useful at times when people feel in particular need of support, e.g. when experiencing psycho-physiological problems. In the following extract we see Lisa's body experiencing affective changes from taking medication, and her attempts to make sense of them through presenting her body in all its immediacy to the site.

Immediacy and the medicated body in Elefriends

LISA: my heart's racing.... taken my meds... :0(am i ever gonna be ok.. just don't think i am. Too damaged,too broken to be ever fixed...and no one has the patience to even try.

.....

LOUISE: Keep holding on Lisa, give your meds time to take effect, is there anything you can do to distract you from the physical symptoms, music or relaxation tape xxx

LISA: just laid in bed...tv on.. got like a fluttering feeling inside.. i don't know if it's my heart..i don't know what it is...xxx

LOUISE: I think we can get hyper vigilant and notice even the slightest change in our bodies, I know it's a horrible feeling but try to think of something else, breathing and

counting breaths, tightening and relaxing everything starting from you toes and working up your body, thinking of you xxx

LOUISE: Just thought there is a free ap called headspace, which is mindfulness guided meditation xxx

LISA: it's on my left and sidetop of my rib cage...fluttering... so sick of it all. i'm exhausted...and that's making me cry again..just struggling .xxxxx

Whilst Lisa is trying to gain greater affective knowledge of her body, Louise is encouraging her to try to forget the body, to externalise rather than internalise her attention. However, the sensations Lisa describes are directly related to her distress at this time, and as such her whole identity as someone suffering with mental distress is bound up in her body and its affective capacities. Indeed, despite Louise's suggestion that Lisa may be over sensitised to her body at this moment ("try some relaxation techniques"), Lisa is focused on trying to transmit her feelings and attempts to do this in greater levels of detail. The initial description of a "racing heart" and "fluttering inside" is followed by a more specific description of the fluttering ("on my left and side....top of my rib cage"). At each stage a more detailed form of noticing and reporting emerges. We suggest the reason for this attention to the body is twofold. Firstly, because of the prominence of the sensations felt in that moment through which the body makes itself known and presents itself as in need of attention. Secondly, because Lisa is used to describing her distress in relation to her body in terms of the physical a/effects of taking medication. For instance, if her body is feeling 'okay' then her distress is likely to also be 'okay'. If her body is not feeling good then her feeling of distress is likely to increase. Lisa is trying to manage this through seeking assurance that she will be okay. Overcoming the bodily sensations is her way of doing that. Indeed, it is her body that is being used to judge whether she will be okay. In the following section the role of Louise's body is heightened when the question of addressing her distress in greater levels of detail comes to the fore.

Trigger warnings

LOUISE: Oh Lisa I wish there was something I could do that would take it away for you, it must be exhausting for you I'm sending Louise the cat over to snuggle up xxx

LISA: :0(thanks Louise....i'm really tired... could really do with a friend right now..but they seem to be few and far between....ignore me,just upset.xxx

LOUISE: I can't ignore you Lisa, you mean too much xx

LISA: sat hugging my pillow...wishing my life was so different xx

LOUISE: I wish things were better for you as well Lisa, are there things you could makes steps towards changing when your feeling a bit stronger? Xxx

LISA: *i can't say on here...too triggering...but i want so much for things to change...but i've been hurt so badly,i'm struggling to get passed it all...i tried to move forward...i try....in my head i think i'm ready..in my heart,i'm not,i can't. too painful. too scared. xx*

LOUISE: *Sorry Lisa didn't mean to delve, it sounds as if you have been through a lot, I really hope that given time you will heal and find a way to move forward, keep taking baby steps Lisa, you will come out the other side of this stronger than you are now xxx*

LISA: *you don't need to apologise ...it's ok hun.... i really need to talk...but instead i s/h. i'm just hurting so much xxx*

LOUISE: *we all find our own way of dealing with stuff Lisa , be it s/h alcohol or otherwise, they are all coping mechanisms, maybe at this time your not ready to talk about things, you'll get there xxx*

LISA: *s/h tonight....not so good. i can't live like this.*

LOUISE: *Hope you are ok Lisa, in that you haven't hurt yourself too much, you must be so tired , has your meds started to take some effect for you? Xx*

LISA: *i'm knackered...but so upset...and so sore,stopped bleeding.... stupid,i feel stupid. :(*

LOUISE: *Your not stupid Lisa, I'm glad the bleeding has stopped, keep the area clean do you put any ointment or a dressing on? Maybe a warm milk now Louise the cat should have arrived by now to help you snooze xxx*

The extracts of Lisa and Louise highlight the challenges in managing one's medicated body in Elefriends. The site offers an instantaneity to support, allowing people to talk about their distress and care for others at any time of day or night. However, the visibility of one's activity on the site creates a shared concern regarding how support should work, e.g. including 'trigger warnings' for particularly distressing posts. This limits the extent of support, as people do not feel able to post about possible 'root causes' of distress (e.g. past traumatic experiences). As such, even at times when severely distressing activity is talked about (e.g. self harm) support can only feature in terms of managing its effects ("keep the area clean") and forms of general support that emerge on the site (sending "Louise the cat"). It is very much about managing the present, rather than dealing with the 'difficult pasts' (Brown & Reavey, 2015) of those who use the site.

Summary of analysis

The opportunities Elefriends presents for managing one's medicated body are limited by a shared set of concerns that shape communication on the site. A collective consent not to elicit distress in others is present, with 'trigger warnings' commonly labelling posts and/or comments that others may find distressing. Consequently support tends to focus on present concerns (e.g.

effects of medication) rather than a deeper process of attending to issues in people's pasts that may have led to the emergence of distress. The immediacy of the site leads to a form of support for the present, not the past. The affective benefits are apparent, with Elefriends facilitating collective forms of affective knowledge on the site about medication. The fact this is knowledge from experience rather than professional expertise (e.g. psychiatry) is particularly important. Professional expertise cannot be affective expertise, as it is always by proxy. Despite its mediating existence Elefriends does provide access to others' affective knowledge, which is not a feature of more traditional forms of care spaces (e.g. consultation rooms). Attending to the new possibilities within a gradual (and consistent) move towards the inclusion of social and digital media in mental health care (and the inherent reliance on peer support therein) requires an increased social scientific focus. Doing so will help to highlight the new relations developing between bodies in distress and the mass communicative power of social media sites such as Elefriends.

CHALLENGES

As with the initial pilot project undertaking social media research presented certain challenges in the follow on. The online user engagement was able to be integrated into Elefriends, and as such, made available to all registered users. However, we received approximately forty pieces of feedback, the majority of which were 'likes' and/or 'hears'. Unfortunately they offer limited details, so it's hard to draw meaningful conclusions. The comments were more informative. With regard to the analysis of medication support we were only able to include comments and posts from participants who had provided informed consent. This led to occasions where we had usable data from several members of a thread on the site, but not all. Consequently we could not present threaded posts and comments in all their detail. We were though fortunate that many participants were members of the same friendship groups on the site, which left us with a large amount of viable data.

REFLECTIONS

What we learnt from feedback

The animated storyboard approach proved an innovate and reasonably successful way of presenting findings to users of Elefriends. It was befitting of the style of communication on the site, and elicited some useful user feedback. This is an approach that could be used for online user engagement in other social media sites (with style and content tailored to site in question).

Presenting the feedback in the style of the site (e.g. using image of the ‘Ele’) provided an easily accessible way for the findings to be presented.

What we learnt from follow on analysis

The follow on analysis provided insight into the ways people used Elefriends in seeking (and providing) support for experiences of taking psychiatric medication. Elefriends facilitates a community of support for *medicated bodies* that is not present elsewhere (e.g. in traditional care settings). Elefriends, as a technology, helps people to understand the physiological impact of taking medication. It also helps people to gain *affective knowledge* of their bodies, through connecting with other medicated bodies. Mental health professionals cannot provide support from a position of direct experience, only other users can do this. Elefriends offers the possibility to communicate with a large number of other people and as such has considerable potential to help people manage the challenges associated with receiving psychiatric medication (e.g. side effects).

In terms of CCN+ the follow on has added to the contribution of the pilot project in the following ways:

- The follow on project has highlighted experiences of medication as one of the key areas that people seek and provide support through Elefriends. This adds to the findings of the pilot project regarding how people felt about the site and the obstacles to care and support online. These findings can feed into the wider digital health arena in terms of knowledge regarding how digital technologies are shaping peer support in mental health.
- Elefriends, as a leading UK mental health social media site, is providing opportunities for peer support without the constraints of geographical location. It is proving successful in doing this, particularly during a prolonged period of funding cuts to mental health services and associated voluntary sector organisations. The pilot project identified medication as a core area for peer support. It is not clear the extent to which this is related to austerity, as users tend to speak directly about their experiences and support required when in need, rather than reflect on the wider context of the available offline support. It is clear though that the opportunity to connect with a large number of people with similar experiences of taking medication is not something available to the same extent offline.
- The question of peer support is central to Elefriends, and many new digital media tools in mental health. The pilot project and follow on have demonstrated how people feel about using Elefriends to provide peer support, and the areas and topics around which peer

support revolve. This highlights how the online community is developed and maintained in Elefriends. However, the pilot project findings demonstrate a potential limit to peer support, particularly when it comes to the most severe experiences of distress (e.g. self harm). At such times being online can be an obstacle to care and support as users are conscious not to *trigger* distress in others (e.g. by talking about experiences that may relate to others' past lives (e.g. histories of abuse). At these times, in person peer support could potentially be a more valuable form of support.

The next stage will be to disseminate these findings with the aim of developing new and existing knowledge partnerships in related areas. The following activities have been undertaken or are in planning:

- Follow on analysis has been written up for journal publication, and is currently under review (August, 2015)
- Findings presented to Mind through their 'Lunch and Learn' programme (June, 2015)
- Invited presentation at 'Social Media and Affect' symposium at University of East London (March, 2015)
- Visit to Datakind, a new charity focused on 'using data for social good' to discuss findings from the project and challenges of conducting digital social research
- Findings will be disseminated through existing relations with other mental health related digital media projects (e.g. MindTech, Newham NHS Providers' Forum)

