

**Digital Technology for Mental Health: Asking the right questions
#digitalMHQ**

**Steering Group meeting 5
Wednesday 19th April 2017, 11am - 3.30pm
Room A08 (ground floor), Institute of Mental Health, University of
Nottingham, Triumph Road, Nottingham, NG7 2TU**

Attending (alphabetical order): Debbie Butler, Chris Packham (AM only), Paul Radin, Mat Rawsthorne, Sandra Regan (Chair), Liz Rye, Lucy Simons, Alli Suddaby, André Tomlin.

Dialled in: Victoria Betton, Sophie Dix, Iris Elliott, Thomas Kabir.

Apologies: Kate Cavanagh, Kathy Chapman, Rachel Churchill, Katherine Easton, Chris Hollis, Louise Knowles.

Action points

| No. | Action point | Who | Due by | Status |
|-----|---|-------------|----------------|-----------------------------|
| 2. | Chris Packham to suggest Clinical Commissioner contacts to approach as partners in the PSP | CP/LS | Nov/Dec 2016 | ongoing |
| 4. | Review uncertainties from other mental health PSPs for relevance | LS/KE | By Jan 2017 | revisit this later (summer) |
| 11. | Ideas for further funding to be discussed with LS | ALL | Ongoing | ongoing |
| 33. | Section 5 of the protocol to be revised and amended. | LS/KE/AT/RC | March 2017 | Ongoing |
| 38. | All steering group members to identify and inform Lucy of key events and meetings for opportunities to publicise the project/survey | ALL | March 2017 | Ongoing |
| 39. | A printed copy of the survey to be produced for completing at face to face meetings | LS | April 2017 | Ongoing |
| 42. | Lucy and Thomas to liaise over workshops with children and young people. | LS/TK | April/May 2017 | Ongoing |
| 43. | Confirm a 5 year cut off for checking the evidence base is agreed by a quorate of clinical steering group members | LS | March 2017 | Complete |

| | | | | |
|-----|---|----------------|-------------------|----------|
| 44. | André and Rachel to provide a plan of the evidence checking strategy to supplement the project protocol | AT/RC | March 2017 | Ongoing |
| 45. | Steering group members to contact Lucy if interested in co-authoring the paper for Evidence Based Mental Health by the 31st March 2017. | ALL | April/May 2017 | Complete |
| 46. | Lucy to circulate the first version of the film for quick feedback this week so Inkwell can deliver the final version next week | LS/ALL | March 2017 | Complete |
| 47. | Lucy to revise the survey in response to the pilot feedback and discussions at the meeting. Steering Group members to provide rapid response | LS/ALL | March 2017 | Complete |
| 48. | Steering Group members to identify contacts and networks that can help us reach diverse communities. | LS | March/ April 2017 | Ongoing |
| 49. | Lucy to contact individually members of the Steering Group to populate the Partners' contact list | LS | March/ April 2017 | Ongoing |
| 50. | Lucy to discuss other methods for gathering uncertainties with relevant members of the Steering Group | LS/AT TK/LR | April 2017 | Ongoing |
| 51. | Victoria to share any materials about the taxonomy of digital for mental health being developed in another project | VB | April/May 2017 | |
| 52. | First draft of the taxonomy for the questions to be discussed at the next steering group meeting | AT/LS/ KE | April/May 2017 | |
| 53. | Andre to provide an updated plan of the evidence checking strategy with a report of the search strategy and databases accessed as an appendix | AT | April/May 2017 | |
| 54. | Andre to contact Gunther Eysenbach and John Torous about taxonomies of digital technology for mental health | AT | April/May 2017 | |
| 55. | Lucy to provide an update of extent of reach of consultation in mid-May to prompt further engagement by SG members | LS/ALL | May 2017 | |
| 56. | Lucy to produce a workshop pack for Steering Group members and other partners to use | LS | April/May 2017 | |
| 57. | Andre and Lucy to map Twitter communities and approach about dedicated Twitter chats | AT/LS | April/May 2017 | |
| 58. | Lucy to check timeline for data management, analysis and evidence checking with Kat and Rachel | LS | April 2017 | |
| 59. | Steering Group members to think about timing of the final workshop - weekday or weekend? | ALL | April/May 2017 | |
| 60. | Andre to provide a short paper with options for how the final workshop could use online methods for Sandra to take to the JLA team. | AT/SR | April/May 2017 | |

Notes of the discussion

1. Welcome, apologies and introductions

Sandra welcomed everyone to the meeting and noted the apologies. She noted that we were not

clinically quorate for all of the meeting and this could hinder progress if it occurs again.

2. Notes of last meeting and actions not covered by the agenda

Actions not carried forward on the agenda for this meeting:

2. Chris Packham noted that he is sending these to Lucy

45. Paper for Evidence Based Mental Health on the state of the evidence. Andre thinks this is still feasible and will start by having a look at the type of evidence the literature search has returned. Steering Group members who have expressed an interest in co-authoring this paper are Rachel, Andre, Mat, Debbie and Lucy.

Minutes of meeting on 22nd March were accepted as correct.

3. Data management - Looking at some questions!

The steering group split into two groups to spend some time reviewing a list of example questions that had already been submitted. We considered whether any questions were out of scope and the overarching themes that were emerging from the questions.

Overall, few of the questions were considered out of scope. This was reassuring that respondents were addressing relevant questions. A number of common themes were evident in the 35 questions reviewed. Ideas discussed included: human redundancy/replacement; balance of digital and nondigital interventions; relapse prevention; effectiveness; confidentiality/data security/safety; harms and adverse effects; access to tech; access to support to use tech.

Sandra listed four questions that needed consideration for the data management process.

(i) Framework for organising and managing the questions - will we apply an existing one or develop it iteratively from the submitted questions?

None of the steering group members were aware of an existing framework or taxonomy of digital technology for mental health that could be adopted. Therefore the view was that we would develop it iteratively in response to the questions. Victoria noted later in the meeting that the absence of a taxonomy is a problem in other areas of work. She is aware work is underway to develop one (by a London AHSN) which may have some relevance for this PSP (**action point 51**).

(ii) Will we start analysis of the questions while the survey is open or wait until it has closed?

The general view of the steering group was that work should start on the analysis and developing an iterative framework before the survey closes. It is expected the framework will be further developed in response to feedback from the Steering Group and new questions being submitted in the later stages, but this can be factored into the work plan. A first draft of the taxonomy will be reviewed at the June Steering Group meeting (**action point 52**).

(iii) How will we deal with questions that ask for information and we know the answer to them (e.g. Can an app be developed that can help people with homework between therapy sessions?)

Members thought that we needed to see the range and extent of these questions before deciding what to do. One option will be to provide answers to these and post on our website and circulate to partners. If individuals contact us directly with specific questions, we will provide the answer to them.

(iv) Would it be helpful to have a sub-group of the Steering Group to support the data management?

This was thought to be a good idea and volunteers were sought - Chris H, Chris P, Debbie, Mat and Liz all expressed interest.

Chris P raised a question about how we move from a the long list of questions to the shorter list for interim prioritisation - would there be criteria that we would apply, for example, the health burden, frequency of the question in the dataset etc.? Sandra confirmed that there would be a stage where the Steering Group would apply criteria to reduce the number of the questions - the JLA Guidebook offers suggestions on the type of criteria that can be considered, but that the Steering Group would decide which are relevant and appropriate in our case.

4. Evidence Checking

The telephone line was opened up for this agenda item for those dialing in.

Andre updated the Steering Group on the development of the Current Overview of Published Evidence (COPE) database as set out in the proposal discussed at the February Steering Group meeting. This database of published systematic reviews, looking at digital technology for mental health, will be our first port of call when checking for uncertainties. The database contains 1,772 references; the results of a literature search conducted by an expert health information scientist (Sarah Dawson from the University of Bristol) conducted in April 2017. The search aimed to find any systematic reviews, meta-analyses or scoping reviews about digital technology and mental health, published since 1 January 2012. The search strategy and details of the databases and results will be provided as an appendix to the evidence checking strategy document (**action point 53**).

These results have been entered into a Mendeley database - an online tool which will enable all the records to be reviewed, indexed (via a tagging system) and irrelevant records removed. We can work collaboratively on this database as it is online and any member of the team will be able to log in should they wish.

Again, we discussed whether an existing taxonomy could be applied for this process or whether we would develop this ourselves. No-one present knew of an existing one. Ideas for further research were to contact Gunther Eysenbach - editor of the Journal of Medical Internet Research and John Torous at Harvard Medical School (**action point 54**).

Victoria and Chris P agreed that a five year cut off for the COPE database was appropriate. The database will include records going back to 2012.

Sandra raised the question of how the evidence-checking strategy will be adapted to check questions which go beyond treatment uncertainties. Andre reported that Rachel Churchill had suggested that once we know what these questions are, evidence other than systematic reviews can

be searched and checked, e.g. primary research. It was also noted that the evidence checking approach may need to be adapted to capture relevant evidence that may not get picked up in mental health focused searches, for example, digital exclusion. We may also need to draw on wider literature such as Ofcom reports and sociological literature.

Given the size of the database after the initial search (1772 records), Sandra noted that we may have to take pragmatic decisions on refining management tasks to fit with the available resource. In which case it would be important to track and record decisions and assumptions.

Andre to amend evidence checking strategy document to reflect the discussions today which will be appended to the PSP protocol (**see action point 53**).

5. Gathering uncertainties

The telephone line was opened up for this agenda item for those dialing in.

5.1 First survey

An up-to-date summary of the demographic characteristics was presented by Lucy (downloaded this morning). She explained that while it looked as though a high proportion of people were skipping these questions, these figures included those people who answered the question on the first page of the survey (to move on to the next page) but did not progress further into the survey and did not submit a completed questionnaire. Lucy had reviewed the first 100 responses where questions had been submitted and found that only two of these left the survey before completing the demographic questions and pressing the 'submit' button. Therefore, the issue of incomplete surveys being included in the data set was not a large problem.

To date the responses were:

- **451** people have accessed the survey
- **178** progressed to submit a question and complete the demographics
- **421** questions have been submitted
- **93** respondents have lived experience of mental health problems, **38** are carers and **128** are health and social care professionals.

Each demographic category was reviewed in turn and ideas shared about how to reach those less well represented in the sample so far - a summary is provided below.

For the devolved nations

- Mental Health Foundation, especially the workshop in Belfast next week
- Scottish Recovery Network bulletin (Mat)
- Contacts in Wales & Scotland (Andre)

For young people

- Young Minds
- Anna Freud centre
- mHabitat's networks in CAMHS
- McPin mailing list of young people applying to their PSP
- MQ facebook page

- Xenzone/Kooth - Aaron Sefi and Kat Cormack

For older people

- Charities (Neil Chadborn at the CLARHC)
- East Midlands Aging Research Network (though it will be important to be clear we are not including dementia)
- Good things foundation (Mat has a contact?)
- Supporting memories project

For men

- Heads Together campaign
- Change mind campaign
- Notts County Mental health and football project (Debbie)
- Stephen Fry

For ethnicity

- East Midlands Centre for Black and Minority Ethnic Health
- Raghu Raghavan De Montfort University, Leicester

Generally

- Via liaison psychs
- Via researchgate

Andre suggested that we offer regular Mental Health Bloggers a 'guest blog' about the project that they can use on their blogs.

Lucy to provide an email update on the demographics in mid-May to review progress in reaching wider sections of the population (**action point 55**).

5.2 Other methods to gather uncertainties

Face to face workshops

Sandra shared her experience of holding face to face workshops in other PSPs and the implications of the different methods adopted. As we do not have the resource for Lucy or Sandra to be present at all these opportunities, it was agreed that a set of resources would be provided for Steering Group members or partners to hold their own workshops and send back the questions to Lucy for entering into the survey. It would be essential to capture whether questions were submitted by people with lived experience or professionals, but other demographic information was less important.

Workshop pack to include:

1. Film - off line version can be provided
2. Short PowerPoint giving overview of the project - to use as presentation or handout
3. paper version of the survey and survey information.

Lucy to produce the workshop pack and distribute to Steering Group members (**action point 56**). This will also be posted on the webpages as part of the 'media pack' for partner organisations.

Twitter chats

Andre suggested that these would work best when carried out in partnership with others who already hold Twitter Chats and have a participating audience. As it was noted that we need to engage more people with lived experience of mental health problems, we should approach these social media communities specifically. We would offer to help with a dedicated Twitter chat or ask the leader to mention the PSP at the end of their regular chat.

Andre and Lucy to map relevant Twitter communities and work on asking for their support with the project (**action point 57**)

Promotion

As a wide range of avenues for further promotion of the survey had taken place when discussing the demographics, there was no need for further discussion under this agenda item.

Timeline

Given the ideas for further promotion and for contacting people and organisations about workshops and Twitter chats, it was agreed to keep the survey open until the end of June 2017.

While work on the COPE database and question analysis can start in the meantime, this means the main period for this part of the project will be July - Sep 2017. Lucy to check with Kat and Rachel whether this works for them (**action point 58**).

Lucy proposed that we should aim to hold the final prioritisation workshop before the MindTech Symposium on 7 December 2017. Sandra noted that to achieve this we would need to complete interim prioritisation by end of Oct and be able to do the analysis of this early Nov. All agreed this was a good time to aim for so we can announce the top 10 at the Symposium. Steering Group members to begin to think about who should attend the workshop and whether it needs to be at the weekend to enable key people to attend (**action point 59**).

Andre proposed that digital methods are used at the final workshop to enable people not present in the workshop to contribute. He suggested some ideas and tools for broadcasting the event and also opening up discussions to larger group through Webinar-type material and voting software. Liz was concerned about participants being anxious and inhibited if the workshop is being watched by others online. While there was support from the group for introducing digital methods, the extent of this needed more consideration and discussion with the JLA team. Andre to provide a short paper with options for how the final workshop could use online methods for Sandra to take to the JLA team (**action point 60**).

5. Any other business/Steering Group meeting schedule

There was no other business

Steering Group schedule 2017

The next meeting will be a teleconference on Wednesday 7th June, 2 - 3.30pm.

Members present were happy to hold the next two face to face steering group meetings at the Mental Health Foundation in London.

| Meeting type | Date | Location |
|--------------------------------------|-------------------------------------|-----------------|
| Teleconference | Wednesday 7 th June | 14:00 – 15:30 |
| Face to face | Monday 10 th July | MHF, London |
| Teleconference | Wednesday 6 th September | 14:00 – 15:30 |
| Face to face | Tuesday 17 th October | MHF, London |
| Teleconference | Monday 13th November | 11:15 – 12:45 |
| Final prioritisation workshop | December (date TBC) | TBC |