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

Steering Group meeting 3
Wednesday 22nd February 2017, 11am – 15.30pm
Room A08 (ground floor), Institute of Mental Health, University of Nottingham, Triumph Road, Nottingham, NG7 2TU

Attending *(alphabetical order)*: Debbie Butler, Kate Cavanagh (teleconference 11-1pm), Kathy Chapman, Rachel Churchill, Katherine Easton, Iris Elliott, Chris Hollis, Thomas Kabir, Paul Radin, Mat Rawsthorne (11-12:30pm), Sandra Regan (Chair), Liz Rye, Lucy Simons, André Tomlin.

Apologies: Victoria Betton, Sophie Dix, Louise Knowles, Chris Packham, Alli Suddaby

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
25.	All members to add their suggestions to the Partners' contact list.	All	Feb 2017	ongoing
30.	Lucy to amend the Communications plan with agreed approach to using social media and the hashtag	LS	March 2017	
31.	Lucy to amend the sections 1-4 of the Protocol with the points discussed and circulate for agreement within a defined timeframe	LS	March 2017	
32.	Sandra and Lucy to draft an invitation email for Steering Group members to use to recruit more partners to the project.	SR/LS	March 2017	
33.	Section 5 of the protocol to be revised and amended.	LS/KE/ AT/RC	March 2017	

34.	Lucy to revise the survey and circulate for feedback	LS	March 2017	
35.	Lucy, Debbie and Mat to recruit 10-12 volunteers to pilot the survey – half from a lived experience perspective and half from a clinical. Steering group members to support this if needed.	LS/DB /MR	March 2017	
36.	Sandra to provide the feedback form for the piloting	SR	March 2017	
37.	All steering group members to review the partners list and add further contacts.	ALL	March 2017	
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	
39.	A printed copy of the survey to be produced for completing at face to face meetings	LS	April 2017	
40.	All to review the Communications plan and send any comments to Lucy by 15th March 2017	ALL	March 2017	
41.	Sandra to seek advice about gathering uncertainties via social media (alongside the online survey)	SR	March 2017	
42.	Lucy and Thomas to liaise over workshops with children and young people.	LS/TK	April/May 2017	
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	
44.	André and Rachel to provide a plan of the evidence checking strategy to supplement the project protocol	AT/RC	March 2017	
45.	Steering group members to contact Lucy if interested in co-authoring the paper for Evidence Based Mental Health by the 31stMarch 2017.	ALL	April/May 2017	

Notes of the discussion

1. Welcome, apologies and introductions

Sandra set the scene for the meeting and reminded the group of some of the agreed ways of working. All members introduced themselves to the group.

André suggested that we think about how we want to use the project hashtag - #digitalMHQ - and whether there are types of information that we don't want to share publicly. It was agreed that we would use it for general updates on the progress of the project and signpost people to the project webpages. We would not share personal information or ask for people outside of the steering group to participate in project decisions. Any discussions on social media may influence decisions the steering group take. Lucy to add a line in the communications plan about this (**action point 30**).

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

Sandra highlighted the action points not covered by the agenda for the meeting:
2: Lucy still to work with Chris Packham on commissioner contacts
4: Guidance is required on what we are looking for when reviewing the top 10 for other mental health PSPs. Rachel reflected that other questions that didn't make it into the top 10s may be more relevant. This action point to be returned to once the first survey is underway.
9: Sandra reminded the group to check the project webpages.
11: Lucy confirmed that the Maudsley BRC are contributing £5K which should cover the costs of the final workshop. Other ideas for additional funds still welcome.

The notes from Steering Group 2 were accepted as correct.

3. Finalising and signing off

3.1 Title

The title of the PSP was agreed and signed off - Digital Technology for Mental Health: Asking the right questions. The website and project documentation have been updated to reflect this.

3.2: Protocol sections 1-4

Sandra guided the discussion through the first four sections of the protocol and a number of amendments were suggested as recorded below (**action point 31**).

Section 1
  - Rachel raised the point that many digital technologies are being used in combination with existing treatments and we should reflect this in the introduction section.
Section 2
  - Chris reflected that although it's not possible to produce an exhaustive list of possible technologies in the scope, we should include the potentially transformative emerging examples, such as virtual reality and avatars.
  - Thomas noted that we should be clear that any change to the scope needs to be agreed by the Steering Group only.
  - Sandra suggested that the Steering Group might want to consider what to do with questions that are already answered? (e.g. Bipolar UK added these to their FAQs)
  - Rachel reminded us that in earlier discussions, we had agreed to include commissioners in our group of health and social care professionals who we wanted to submit questions

The discussion around scope raised the issue of what we will do with questions that apply to technology that doesn't yet exist. The group discussed how the indicative research questions are more likely to focus on questions that apply to a range of technologies (e.g. reach, access, effectiveness, experience of, relationship with), rather than questions about specific technologies (e.g. apps, wearables etc)

Section 3
- A few individual members of the Steering Group asked for corrections to their details in the list of members.

Section 4
- In response to a query about the role of partner organisations, Sandra clarified that their key role is reaching out through their networks to the people who we want to respond to the survey. All Steering Group members to review the partners list and add in contacts that we can approach. Sandra and Lucy will draft an invitation letter to go out to new partners which Steering Group members can use to establish the connections (**action point 32**). When we launch the survey, we will provide templates of communications to partner organisations which can be adapted and modified to best suit their audience.
- Mat raised the issue of how we would deal with questions being submitted that relate specifically to branded or particular digital products, especially if a large number seemed to be coming from a similar source - would this be deemed as a conflict of interest? Sandra gave an overview of the data management process which would manage these issues - specifically duplicate questions are combined (so volume doesn't necessarily overly influence the indicative research questions) and questions about specific products are likely to be re-phrased to be about the type of technology (e.g. questions about Big White Wall would be rephrased to be about online peer support platforms). This needs to be specified in Section 5 of the protocol (**action point 33**)

The discussion about methods and data management gave rise to further discussion points:
- Chris asked how we retain the questions that do not make it into the top 10, but may well be very useful research questions. Sandra explained the final reporting documentation required by the JLA which retains all of the questions, linked with their provenance, so that all the questions would be available to the research community. The top 10 is used as a vehicle to engage research funders and others in discussion about the most pressing priorities.
- Chris was also interested in whether all the questions would be in the PICO format. Sandra clarified that while this is not a requirement of the JLA, it is helpful to do it if the questions are suited to that format. But we should not try to fit questions which are not specifically about treatments into this format if not suitable.
- Rachel and André suggested that relational databases would be a more useful tool than the spreadsheets that the JLA currently uses. Given their previous experience with other PSPs and as they will be working concurrently on the Children and Young People's PSP with McPin, they are in a good position to try out new methods and propose improvements to the JLA approach. Iris echoed this from her work on the Depression PSP. Thomas suggested that some overlap of timescales with the two PSPs may mean some cross-learning/development would be possible.
- Sandra commented that some PSPs have worked with Access/SQL databases rather than in Excel, to good effect, and that as long as the final output can be provided in the necessary format, PSPs are free to manage the data as they please.

- A linked discussion is around the challenges for interested researchers in searching PSP outputs on the JLA website. For example, for these two mental health PSPs it would be useful to search within the datasets from previous PSPs for questions that might have been out of scope, or low priorities, but the way they are presented does not make this easy.
- It might also be useful for all mental health PSPs to be analysed for similar priorities, but this would need raising with the JLA management team at NIHR Evaluation, Trials and Studies Coordinating Centre (NETS-CC) and funds needed to support.

3.2: Terms of Reference

These were agreed and signed off. The approved version is held in the Google drive for reference.

4. Gathering uncertainties

4a. First survey

An online survey is the main route PSPs use to gather uncertainties. However, we have to recognise that there are limitations to this approach and we may want to consider other methods to promote engagement and to reach a wider demographic (see 4b below). Lucy and Debbie have worked to develop an initial draft of the survey text along with discussions with Liz and Mat, which was circulated for discussion.

There was a lengthy discussion about the phrasing of the opening statement on the draft survey and how this related to the scope. Kathy identified that the phrase did not relate to the two key concepts in the scope: (i) intended benefit and (ii) impacts. Paul felt that the inclusion of the word 'benefit' continues to suggest we are only looking for the positive impacts of technology and may inhibit people from responding with questions about negative impacts. Some members favoured a concise and open question, while others felt this could be off putting. Time was spent considering a number of different options for the wording, while it was also noted that the phrase would be supported by introductory text and other communications such as project leaflet, the short animated film, podcast etc (as set out in the Communications Plan). We discussed how we needed to engage people with the way that they currently use technology even if they think they are reluctant users. This discussion was not resolved in the meeting, therefore two versions will be circulated for consideration.

The proposed process for developing the survey is as follows:

- next iteration (version 2) for review by the Steering group with specified deadline (**action point 34**)
- pilot version 3 with a small number of identified volunteers (**action point 35**)
- Sandra to provide a feedback form for the piloting (**action point 36**)
- revise survey following piloting and circulate to the Steering Group
- aim for sign off at the next Steering Group meeting on 22 March

Most PSPs run the survey for three months. When the survey is launched a closure date is not publicised, but responses are monitored. Disseminating the survey will be the responsibility of all Steering Group members through building up the partner's list and inviting key individuals in

relevant organisations to publicise the survey (**action point 32**). Sandra and Lucy to draft an invitation email that all steering Group members can use to invite new partners (**action point 37**).

Lucy is keen to build up a calendar of relevant events (conferences, workshops, seminars etc) where we can publicise the survey while it is open. All steering group members to review their diaries for relevant events and notify Lucy (**action point 38**). Printed copies of the survey will be made available to take along to face to face events (**action point 39**). These can be posted back to Lucy for entry into the database. It will not be feasible to organise for printed surveys to be left in venues and arrange collection.

Communications plan

With advice from James Harris at the Mental Health Foundation and the new Communications Manager at the IMH, Carole Appleby, Lucy has produced a communications plan. This will be continually added to and up dated. It includes a list of all the communication resources to be produced, including the short animated film and suggested wording for these resources, for example Tweets, Facebook posts and copy for newsletters. All to review this plan and send any comments to Lucy (**action point 40**).

4b. Other methods

Two main routes for engaging people who may not respond to the online survey were discussed:

social media and face to face meetings/workshops.

Social media

André suggested that we could gather uncertainties via social media channels. He reflected that the click through rate from posting links on social media was low and engagement via the medium itself can see higher response rates. The group discussed the pros and cons of this approach - the main one being that little would be known about the respondents so we may have difficulty tracking where the uncertainty comes from, which is an important part of the JLA method. It is also likely that responses will come from outside the UK However, given the focus on this PSP, using digital communication platforms to gather uncertainties does seem particularly apt. It may be possible to pilot this approach with this PSP and deal with the data separately from the online survey. However, as this would be a deviation from the JLA method, Sandra needs to take advice on the implications (**action point 41**).

Face to face workshops and meetings

The online survey may not reach all the groups and people we would like to engage. Another method to consider is to meet people face to face and facilitate a workshop to capture questions. The project does not have funds to resource setting up and running workshops, so the only approach we can consider is piggy-backing on the meetings and sessions of groups that already exist. The workshop can be designed as a learning session around digital technology as a way to give something back. Thomas explained that McPin are already planning workshops for the Children and Young People Mental Health PSP and offered for us to make these joint workshops. Lucy has

previously discussed holding workshops in conjunction with the service users at the Maudsley BRC (**action point 42**).

Other issues

Iris noted that some organisations in Wales may only disseminate materials if they are available in Welsh. There is no budget for translation in the project, so we would be reliant on identifying a partner organisation who could offer translation. We may also want to target other non-English speakers with other methods, however, we also need to mindful of the project timeline.

5. Review evidence checking strategy

Sandra explained that the JLA minimum requirement for checking for treatment uncertainties is Cochrane, NICE, SIGN and Royal Colleges from the last 3 years. In addition, other sources may be considered, such as protocols of trials, international guidelines. The key thing is that sources should be robust, relevant and appropriate to the scope of this PSP (which goes wider than treatment uncertainties).

André and Rachel circulated their proposal for the evidence checking strategy. The main points to note are:

- They propose creating a **COPE Database (Current Overview of Published Evidence)** for each PSP, which summarises current knowledge in the field, taken from systematic reviews published in the last 5 years.
    - The Steering Group discussed what date range to include and agreed 5 years was a sensible cut-off (subject to agreement by a quorate of clinical members: **action point 43**)
    - The Steering Group discussed including RCTs in the literature search - Rachel suggested doing this after the survey uncertainties have been gathered and in response to specific questions.
    - It was agreed to also check for relevant NICE guidelines.
- Sandra asked Rachel and André to provide a strategy statement for inclusion as an appendix with the protocol (**action point 44**).
- They propose exporting the uncertainties gathered from the survey into a **Database of Questions**, in which duplicates can be removed, uncertainties coded and organised into PICO style questions where appropriate.
- They will investigate appropriate technology to use for the above work, but we are currently favouring Mendeley for the COPE Database and Excel for the Database of Questions.
- The Steering Group discussed writing a summary of existing digital mental health research ('A State of the Evidence') and submitting it to the EBMH journal as an interim output from

the PSP. Rachel agreed to lead on this with input from André, Lucy, Iris and others (**action point 45**).

6. Any other business/next meeting dates

There was no other business

Steering Group schedule 2017

The next meeting will a teleconference on Wednesday 22nd March.

Meeting type	Date	Location
Teleconference	Wednesday 22nd March	09:30 – 11:00
Face to face	Wednesday 19th April	Nottingham
Teleconference	Wednesday 7th June	14:00 – 15:30
Face to face	Monday 10th July	London (TBC)
Teleconference	Wednesday 6th September	14:00 – 15:30
Face to face	Tuesday 17th October	London (TBC)
Teleconference	Monday 13th November	11:15 – 12:45
Final prioritisation workshop	December (date TBC)	TBC