

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

Steering Group meeting 2
12th December 2016, 11am – 12.30pm
via teleconference

Attending (*alphabetical order*): Victoria Betton, Debbie Butler, Kathy Chapman, Katherine Easton, Iris Elliott, Chris Hollis, Paul Radin, Sandra Regan (Chair), Kristin Schmidt, Lucy Simons, Andre Tomlin.

Apologies: Rachel Churchill, Thomas Kabir, Louise Knowles, John Loder, Chris Packham, Mat Rawsthorne.

Action points

| No. | Action point | Who | Due by | Status |
|-----|---|---------------------|-------------------------------------|-----------------------------------|
| 1. | To audio record subsequent steering group meetings to enable checking of equality of contributions if needed. | LS | Jan/Feb; May; Sep/Oct 2017 | ongoing |
| 2. | Chris Packham to suggest Clinical Commissioner contacts to approach as partners in the PSP | CP/LS | Nov/Dec 2016 | ongoing |
| 3. | Devise and agree evidence-checking strategy that meets the requirements of this PSP | AT/RC /SR/LS | Spring 2017 | complete |
| 4. | Review uncertainties from other mental health PSPs for relevance | LS/KE | By Jan 2017 | revisit this later (summer) |
| 5. | Agree preferred term for 'patients and carers' appropriate for this PSP | ALL | Nov/Dec 2016 | Complete |
| 6. | Statement of scope to be revised by CH, LS and SR for review and agreement by the Steering Group | CH/LS /SR ALL | Nov 2016 | Complete |
| 7. | Revised title ideas to be sent to LS | ALL | Nov/Dec 2016 | Complete |
| 8. | LS to develop a communication plan with support from Communications manager at IMH, AT, VB and SD. | LS | Nov/Dec 2016 | Ongoing |

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| 9. | LS to develop draft content for the project webpage (for Steering Group feedback) and materials for others to use for dissemination | LS | Nov/Dec 2016 | Complete |
| 10. | LS to develop a working document containing the partner list which can be added to and expanded by all Steering Group members | LS/ALL | Nov 2016 | complete |
| 11. | Ideas for further funding to be discussed with LS | ALL | Ongoing | ongoing |
| 12. | Terms of Reference for the Steering Group to be updated and circulated for comment with Protocol | LS | Nov 2016 | complete |
| 13. | Any outstanding personal biographies and declaration of interest forms to be returned to LS. | ALL | Nov/Dec 2016 | ongoing |
| 14. | Meeting dates until Dec 2017 to be circulated and set in advance | LS/ALL | Nov/Dec 2016 | complete |
| 15. | PR and LS to agree ways of working outside of teleconferencing | LS/PR | Nov/Dec 2016 | Complete |
| 16. | Lucy to set up Google folder for the project and share with steering group members | LS | Nov 2016 | complete |
| 17. | Sandra to send Lucy the top ten from the Bipolar PSP when available. | SR | Jan 2017 | Complete |
| 18. | Steering group members to feedback on ideas for the strapline to follow the project title. | All | Feb 2017 | Complete |
| 19. | Iris to send Lucy the selective and indicative descriptions used by the Mental Health Foundation | IE | Dec 2016/ Jan 2017 | |
| 20. | Lucy to develop the definition of 'People with lived experience of mental health problems' for review by the Steering Group | LS/ All | Feb 2017 | Complete |
| 21. | Chris H and Lucy to revise the statement of scope and circulate for review | CH/LS / All | Feb 2017 | Complete |
| 22. | Sandra to discuss the implications of altering the scope once the PSP is underway | SR | Feb 2017 | Complete |
| 23. | Chris H and Lucy to add a clause into the scope to explain how we will deal with responses that are out of scope. | CH/LS | Feb 2017 | Complete |
| 24. | Lucy to circulate the amended Terms of Reference | LS | Dec 2017 | Complete |
| 25. | All members to add their suggestions to the Partners' contact list. | All | Feb 2017 | ongoing |
| 26. | Lucy, Iris, MHF communications team and Andre to work on a communications plan. | LS/IE AT | Feb 2017 | Complete |
| 27. | Lucy to seek expressions of interest for members of two sub-groups: (i) Survey development (ii) Methods to reach the relevant populations | LS/ All | Dec 2016/ Jan 2017 | Complete |

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|-----|--|-------|----------|----------|
| 28. | Andre to liaise with Rachel Churchill about the evidence checking strategy | AT/RC | Feb 2017 | Complete |
| 29. | Lucy to circulate options for teleconferences in 2017 | LS | Feb 2017 | complete |

Notes of the discussion

1. Welcome, introductions and notes of last meeting

Sandra welcomed everyone to the meeting and explained the suggested ways of working for teleconferences. All participants introduced themselves.

An update on any action points not covered in the agenda was given. Sandra offered to send Lucy the top ten from the Bi-polar PSP when available (**action point 17**).

The notes of the meeting were accepted as correct.

2. Protocol and Terms of Reference

2.1: Title/name of PSP

At the last meeting, it had been suggested that a different title for the PSP might improve accessibility and make it easier to communicate information about the project. However, most participants thought the title 'Digital Technology for Mental Health' was clear enough, and there was a call to not turn this into an acronym. However, it was suggested that a strapline after this title would help explain the focus of the project especially as 'Priority Setting Partnership' may not make this clear. Suggestions for this strapline included:

- Asking the right questions
- What do we need to know?
- How can we make it work for us?

It was also noted that any name needed to work for the communications, such as domain name and Twitter account. Steering Group members to feed back on the straplines to guide a decision (**Action point 18**).

2.3: Preferred term instead of 'patient'

The JLA generally use the term 'patient' in other PSPs, but it was recognised that this term doesn't work in our context, where people may not be using NHS services or view themselves as patients. A term is needed that encompasses people who self-identify as having mental health support needs, those already seeking and accessing help and people supporting/caring for others. However, because the scope of the PSP excludes digital technology being used for primary prevention, the term has to differentiate from the public in general.

It was suggested that the term ‘people with lived experience of mental health problems’, with an additional definition which explains what is encompassed by this term and what is excluded may be acceptable. Iris offered to send Lucy the selective and indicative descriptions used by the Mental Health Foundation (**action point 19**). Lucy to develop the wording around this and seek feed back from the Steering Group (**action point 20**).

2.2: Scope

Steering Group members raised an issue with the statement of scope which had been circulated after the last steering group meeting. Primarily, the concern was that by focusing on the benefits of technology, we risk promoting an overly positive view of technology for mental health and therefore, could fail to allow participants to raise their perspectives and questions about when technology does not have the intended benefit (e.g. may be risky, may not work as intended or may even bring about actual harm). The outcome of a lengthy discussion (also returned to at the end of the meeting) was that the general negative impacts of using any digital technology (e.g. cyber bullying, dependence on devices, fraud, identity theft, grooming etc) were out of scope of the PSP, but questions about the unintended harms and negative consequences of technologies intended to benefit mental health are in scope. Lucy and Chris to revise the statement of scope and qualifying definitions; Steering Group members to review and feedback (**action point 21**).

However it was also recognised that until we begin gathering in people’s questions and uncertainties we won’t know what we will get. Sandra offered to discuss with other JLA advisors, the implications of altering the scope later in the project if we receive large volumes of responses that are out of scope, as this will demonstrate the importance of these issues to our populations (**action point 22**). A clause will be added into the scope to explain what we will do if this occurs (**action point 23**).

2.4: Terms of Reference for the Steering Group

The Terms of Reference document is the standard one used by JLA Steering Groups. It has been amended to reflect our decision on the quorum needed for meetings to be able to make decisions. It will also be amended to reflect our preferred term for ‘patients’. Lucy to circulate and seek agreement from all members (**action point 24**).

3. Review Partners list

Lucy and Kat have started to compile a database for all partners whose role will be to support the dissemination of the survey. This will be a working file (Google Sheet) in the Google drive. All Steering Group members can access and amend this file to add in contact suggestions (**action point 25**). The point was made that we would need people’s permission for holding their personal data (email address and telephone number) in this file.

4. Communications update

Lucy reported that Communications support from the Institute of Mental Health was depleted because the Manager had recently left. Iris offered support for communications from the Mental Health Foundation Communication team, and along with input from Andre, it was agreed to form a small group to work on a communications plan to be reviewed and amended by the Steering Group (**action point 26**). It is particularly important that the communications are accessible and grounded, therefore feedback and support from the Lived Experience members of the Steering Group will be important.

Lucy reported that simple webpages were now on the MindTech website. She will follow up with people who still need to supply a biography, photo and logo (where appropriate) (action point 13).

Lucy has set up a Google folder and set the permissions for everyone to be able to access (even without a Google account). Kat and Lucy's preferred way of working will be on documents in this folder – collaborations are much easier this way. In future meeting papers will be in this folder rather than sent as email attachments.

5. Next steps and timeline

5.1: Survey/gathering questions

Example surveys from other PSPs have been circulated for information. Sandra explained that the key points for consideration included:

- Whether to use only online surveys or also distribute paper surveys
- How much information to include upfront
- Whether the same survey would be used for people with lived experience and health and social care professionals
- What type of demographic questions to include
- What methods in addition to the survey we may need to use to hear from the range of people we want to
- How we would search the literature for questions and uncertainties.

The Mental Health Foundation have reach in the devolved nations of the UK, which will be important for making the project UK wide. Steering group members agreed that methods such as workshops, focus groups and linking with other existing groups/events would be important especially to reach those communities which are easy to ignore and are often seldom heard. Some work to map the relevant communities and populations, including the professional networks was required.

The protocol will need to be developed to set out the plans for gathering questions/uncertainties, including the questions to ask, populations to reach and methods for doing so. Smaller sub-groups drawn from the Steering Group will be a useful way to make progress on this for Feb 2017 (**action point 27**).

5.2 Evidence checking strategy

Andre to link with Rachel Churchill on this and update the group at the next meeting (**action point 28**).

6. Any other business/next meeting dates

Paul returned to the discussion on scope, further emphasising the importance of questions around the unintended negative consequences of technology which may be intended to benefit in the scope (the summary under point 2.2 includes the discussions from this part of the meeting).

Steering Group schedule 2017

The next meeting will be at the Institute of Mental Health, Nottingham on Wednesday 22nd February 2017. Lucy to circulate for dates for future teleconference meetings (**action point 29**).

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