

Digital Technology for Mental Health Priority Setting Partnership

Steering Group meeting 1
24th October 2016, 11am – 3.30pm
Institute of Mental Health, University of Nottingham,
Jubilee Campus, Nottingham, NG7 2TU

Attending (*alphabetical order*): Rob Barnsley (in place of Louise Knowles), Victoria Betton, Debbie Butler, Kathy Chapman, Sophie Dix, Chris Hollis, Thomas Kabir, Chris Packham (in place of Julie Hankin), Paul Radin, Mat Rawsthorne, Sandra Regan (Chair), Lucy Simons, Allison Suddaby (in place of John Loder), André Tomlin.

Apologies: Rachel Churchill, Katherine Easton, David Waldram.

Action points

No.	Action point	Who	When	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	
2.	Chris Packham to suggest Clinical Commissioner contacts to approach as partners in the PSP	CP/LS	Nov/Dec 2016	
3.	Devise and agree evidence-checking strategy that meets the requirements of this PSP	AT/RC /SR/LS	Spring 2017	
4.	Review uncertainties from other mental health PSPs for relevance	LS/KE	By Jan 2017	
5.	Agree preferred term for 'patients and carers' appropriate for this PSP	ALL	Nov/Dec 2016	
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	
7.	Revised title ideas to be sent to LS	ALL	Nov/Dec 2016	
8.	LS to develop a communication plan with support from Communications manager at IMH, AT, VB and SD.	LS	Nov/Dec 2016	

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	
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	
11.	Ideas for further funding to be discussed with LS	ALL	Ongoing	
12.	Terms of Reference for the Steering Group to be updated and circulated for comment with Protocol	LS	Nov 2016	
13.	Any outstanding personal biographies and declaration of interest forms to be returned to LS.	ALL	Nov/Dec 2016	
14.	Meeting dates until Dec 2017 to be circulated and set in advance	LS/ALL	Nov/Dec 2016	
15.	PR and LS to agree ways of working outside of teleconferencing	LS/PR	Nov/Dec 2016	
16.	Lucy to set up Google folder for the project and share with steering group members	LS	Nov 2016	

Notes of the discussion

1. Welcome and introductions

Sandra welcomed everyone to the meeting and to the project. Paired conversations were used as an icebreaker and to facilitate introductions.

2. Background and context

Sandra gave a presentation about the James Lind Alliance (JLA) and the methods of a Priority Setting Partnership (PSP). This was followed by Chris Hollis giving a presentation on the rationale for this PSP at this time.

The discussion which followed these presentations raised a number of pertinent issues.

Transparency and equality

Transparency is a key principle for JLA PSPs and it is important to keep track of the balance of contributions from patients and clinicians throughout the process to ensure we can demonstrate equality of contributions to the PSP. It was recognised that reaching consensus was not always a neat and easy process. The group will need to be prepared for dealing with differences of opinion and conflicts. The JLA provide tools and methods for tracking equality when gathering and prioritising uncertainties. Members who have been involved in other PSPs commented on the quality of the facilitation in achieving consensus in the final workshop.

This led to a discussion about how we manage and record the discussions in the Steering Group to make sure the different voices are heard and equally contribute to decisions and agreed actions. One idea proposed was to audio record the sessions. It was agreed that this would be implemented in future meetings (**action point 1**). The notes of the meetings would be a summary of the discussions, rather than a precise record of who contributed specific points. Having access to recordings of future meetings would be a way to resolve any differences of opinion about post-meeting decisions or actions.

Partners and Stakeholders

Group members sought clarification about the role of partners and other stakeholders. **Partners** are the people and groups we need to connect with as routes to reach our potential **stakeholders** who will submit their questions/uncertainties to the PSP. In addition to patients and clinicians, the importance of perspectives from a range of other groups were discussed, including:

- i. those who fund the NHS and commission local services
- ii. people who do not currently use digital tools
- iii. people from Black and Ethnic minority backgrounds and other groups who are over represented in mental health service and whose voice is seldom heard.
- iv. digital developers and technical experts

The need to connect with NHS service commissioners as partners was agreed and Chris Packham can provide some introductions to mental health commissioners (**action point 2**). The PSP also needs to identify partners and methods to reach people who do not currently use digital for their mental health and other seldom heard voices. In relation to digital developers, it was recognised that they may have vested interests in particular questions/uncertainties, so it would not be appropriate for us to partner with them. However, we may need to draw on their expertise for technical questions, so could adopt a model similar to NICE where people are invited in to give evidence around a particular issue. Links with this community are available with the Steering Group if required.

Post meeting note: *Sandra checked in with JLA colleagues and their advice is that NIHR (specifically) will not be looking to fund named technology, and is interested in the utility of the principles that may emerge so the PSP shouldn't think to be fettered by what is considered to be possible in the foreseeable future (e.g. next 5 years) as things can change.*

Gathering uncertainties

The JLA has a specific definition of a treatment uncertainty: 'no up-to-date, reliable systematic reviews of research evidence addressing the uncertainty about the effects of treatment exist, or up-to-date systematic reviews of research evidence show that uncertainty exists'. This allows for literature searches that include Cochrane and NICE, but the JLA recognises that where a PSP extends its scope beyond treatment uncertainties, a different strategy for evidence checking may be needed. Because this PSP is dealing with uncertainties that may be broader than treatments, we will need to devise an additional strategy (**action point 3**).

There have been a number of other PSPs in specific mental health conditions which may have gathered uncertainties relevant to our work, therefore we should review these, both the top 10s and longer lists (**action point 4**).

Terminology/language

The JLA generally uses the terms ‘patients’ and ‘clinicians’ which group members thought did not work as well for this PSP. As the professionals involved span a number of disciplines and both health and social care services, the preferred term instead of clinician is ‘health and social care professional’. The preferred terms for patients and carers remains to be decided (**action point 5**).

3. Shaping the PSP

3.1 Scope

It is essential to be clear about the scope of the PSP at the outset and it needs to take account of the time, funds and other resources available to the PSP for the data management after gathering in uncertainties. The wider the scope the likelihood of more data and a larger task at this stage. Given the limited resources for this PSP, the group agreed on the need to narrow the scope and be specific about what types of digital technology we are interested with and for whom. Therefore the discussion focused on the ‘what’ and the ‘who’.

What do we mean by digital technology?

After discussion, a consensus emerged that focused on digital technologies that are directly accessible to patients, which they can use and interact with and are directed at their own recovery and management of their symptoms/conditions. Technologies outside of healthcare, such as social media, were also recognised as important, so the scope would not be confined to only technologies developed specifically for mental health. While other technologies for example, diagnostics or information managements systems for services, were recognised as important, these would not necessarily be directly accessible to patients to use personally.

The discussion also highlighted that we are interested in how technologies can be used to improve people’s lives and did not want to gather uncertainties about the risks and dangers of using digital technologies.

Who are we concerned with?

The group discussed how the term ‘mental health’ could encompass primary prevention/mental health promotion, wellbeing and wellness as well as mental illness and a defined set of conditions. After discussion, a consensus emerged that focused on people who are seeking help for their mental health problems. We wanted to avoid restricting the scope to defined conditions or people with specific diagnoses. ,

However, there was clear support for some exclusions from the scope. These were primarily, technologies for promoting public mental health or population mental health and dementia, primarily because the nature of the condition and related technology would widen the project significantly and beyond our resource. However, we were reluctant to apply an upper age cut off

which would exclude older people with other mental health problems such as depression or anxiety. Therefore, questions related to using technologies for co-morbidities such as depression with dementia would be in scope.

Geographical focus

The group thought it was important to limit the scope to the UK context and there was no rationale for widening out to Europe or further internationally. However, including all of the UK raised further questions about the different health system in the devolved nations and the ability of the Steering Group to effectively reach stakeholders in these areas.

Revised scope statement

A revised statement will be circulated to the Steering Group for comment and further revision, if necessary, prior to agreement on the final statement (**action point 6**). We will aim to complete this within two weeks.

3.2 Building our audience/Partner list/Communications plan

A shorter, more accessible title for the PSP would help with communication about the project. Any suggestions and ideas to be forwarded to Lucy (**action point 7**).

A project communications plan is required and Lucy has support from the Communications Manager at the Institute of Mental Health with this. Additional help and input from André Tomlin, Victoria Betton and Sophie Dix will also be valuable (**action point 8**).

MindTech will host a webpage about the project. From this Lucy will develop materials that can be used by all Steering Group members and other partners to disseminate information via websites and newsletters (**action point 9**).

Some group members were keen to capture some of the process of the PSP by documenting the journey (and not simply focus on outputs). It was suggested that a blog-style would work well for this. Debbie Butler offered to write about her own personal experiences of the project and share this with the Steering Group, in the first instance.

André offered to host an 'event' on the Mental Elf Service at the point when this would be most useful to the project, for example a themed blog, webinar or Tweet chat. He is also starting to develop some live public events, called Mental Health Question Time, and has one planned around digital for mental health, which could be scheduled at a time useful to the PSP.

If resources allow, developing other materials such as a project logo, short videos or animations would be valuable. We may also want to consider advertising on social media.

The group took part in a brain storm to identify people and organisations to build our partners for the project. Lucy will compile these into a Partner list which can be added to and built over time with specific contacts (**action point 10**).

4. Next Steps overview

4.1 Stakeholder list and communication plan

(see above)

4.2 Agree methods for identifying uncertainties

This will form the focus of the next stages of the PSP.

5. Nuts and Bolts

5.1 Budget

Lucy reported that sufficient budget had been secured from the Steering Group member organisations to commence the project. This will cover the costs of the JLA adviser, Information Specialist and Steering Group meetings. However, further funding is required to complete the project. Most notably, we need funding for the final workshop and any of the communications activity identified above. All Steering Group members to be mindful of where further funding could be secured and work with Lucy on this (**action point 11**).

5.2 Timeline

A project timeline has been drafted and will be closely monitored by Lucy, Chris and Sandra. The PSP is planned to complete at the end of December 2017 as this is when MindTech is funded until at present. Key timings are: survey launch around March 2017, interim stage prioritisation around October 2017, final workshop in December 2017.

5.3 Setting quorum for meetings

Sandra introduced the idea that the Group may wish to set a quorum for meetings so that we are meeting the principle of equality of perspectives. Members of the group agreed this was important and at least two patient/carer and two health and social care professionals are needed to participate in any meeting (face to face or remote) for decisions to be made. The Terms of Reference for the Steering Group will be amended to reflect this (**action point 12**).

5.4 Declarations and biographies

Lucy has circulated requests for biographies for inclusion on the project webpage. She had also circulated declaration of interest forms. Any outstanding ones to be forwarded to Lucy as soon as possible (**action point 13**).

5.5 Meetings ahead – face to face and by phone

Continued work by the Steering Group will be by 4-6 weekly teleconferences and 3-4 face to face meetings throughout the project. Members asked that all meetings dates are set in advance (**action point 14**).

Paul explained how he would not be participating in teleconferences. Lucy will work with him to agree different ways for him to effectively contribute to the project between the face to face meetings (**action point 15**).

Lucy to set up a Google folder for sharing project documents (**action point 16**).

6. Any other business

There was no other business.