Mental Health Intelligence Network

Consultation for Public Health England with mental health service users, families and others interested in mental health and wellbeing.

Introduction

Public Health England, through the Expert Reference Group for the National Mental Health, Dementia and Neurology Networks, commissioned a lay consultation to support the development of the Mental Health Intelligence Network (MHIN). The consultation was commissioned January 2014 to run for three months. It sought the views of people directly affected by mental health problems and a wider group of individuals interested in the mental health and wellbeing agenda. The purpose was to provide a lay reaction to the concept of the MHIN, comment on draft materials providing constructive feedback as well as creating recommendations. The recommendations focused on aspects to change before website launch and ideas for an on-going lay consultation function beyond the set up phase. The project was not a usability test of the website, but fed into the drafting of MHIN content material.

Method

Twenty-one workshops across England were run by 9 facilitation teams engaging 172 people, many of whom were mental health service users or carers. All consultation attendees were given a £20 thank you voucher and travel expenses were covered. Several interviews with mental health activist carers and voluntary sector organisation leads were also carried out. In both workshops and interviews, draft MHIN web copy was reviewed and community mental health profiles were discussed illustrating the type of data that would feature on the MHIN.

Our findings

The consultation raised many concerns among the lay public over the relevance of the MHIN for a lay audience. It also surfaced concerns over the title of the site; 'intelligence' was not favoured as an appropriate term for describing the translation of mental health or wellbeing statistical data, information and best practice guidance. New wording for the strapline was proposed and a strong steer that the language used on the site needed adjustment to reflect a recovery focused mental health approach and public well-being. We recommended the strapline was along the lines of: *Making data and information accessible to improve the mental health of your community*.

The MHIN has multiple audiences, the primary audience being mental health commissioners, and a key feature of the resource will be access to health and wellbeing data profiles. How these different audiences access and make use of the MHIN was discussed by the consultation participants. From a lay perspective, there was interest in the data but a disconnect between many people's primary concern, managing their own mental health or supporting another person's mental health, and the content of the MHIN providing community level profiling data on a vast array of indicators.

A key ask was to ensure the MHIN spoke to the lay public directly, explaining how the available data could be used for supporting the development of community responses to mental ill health, illustrating how commissioners use information in commissioning services, and being clear what the site was not about (i.e. it does not provide general mental health and wellbeing information or signposting and support which can be found elsewhere).

Consultation participants also emphasised the home page content was vital and lay input required to get the tone and focus pitched appropriately for commissioners, policy makers, practitioners and lay audiences; many recommended the site created interactive features including case study pod-casts.

We asked workshop participants if they would use the site and 126 provided a response: 39% would, 24% were unsure and 37% would not. We suggest that to aid lay audience engagement with the site some "how to" guides should be produced helping to steer the navigation of the data and interpretation process of profiled data outputs. The site would benefit from lay involvement in usability testing, on-going development work and impact assessment.

The consultation set the MHIN goals to achieve within the first 6 months including: undertake usability testing to create a portal suitable for multiple audiences; the site would have more interactive features; guidance on how to use the site would be available in easy access "how to" guide downloads; data features would be enhanced to allow for analysis by demography as well as geography; examples of how the site had led to practice change would feature as case studies; a steering group involving lay input would be created to guide future development.

Our recommendations

The consultation identified various ways the MHIN could improve communication of both what the site was about, and how people could use it, to best support changes to mental health and wellbeing within their local community. The recommendations are themed into three sections, following the structure of the consultation sessions.

Suggested changes to improve the MHIN introductory pages

We first considered the website home page and the concept of the MHIN. Our consultation recommended MHIN:

1. **Justify use of the term intelligence in the site title** (Mental Health *Intelligence* Network); it has meanings linked to IQ and spying that need separating from the purpose here which was felt to be intelligent use of available data and information.

2. **Change the strapline** for the site along the lines of *Making data and information accessible to improve the mental health of your community*.

3. **Edit the home page** to ensure that visitor's first experience of MHIN is inclusive and reflective of a broad understanding of mental health and wellbeing. Ensure lay public are welcomed to the site by naming them as one of the intended audiences.

4. **Ensure the tone and focus of the site is recovery focused**, avoiding unnecessary jargon and ensure the social aspects of wellbeing as well as a medical approach feature on the site.

5. **Add a glossary** to help users understand technical terminology, both mental health and statistical terms.

6. **Improve the site by simplifying it** (it should not be too text dense) and adding in interactive elements

Community health data profiles

In order to introduce participants to the type of data they would find on the MHIN we provided copies of local community health profiles which are available for every county and metropolitan borough across England. By looking at these 'data pictures' of a locality our consultation participants recommended MHIN:

1. Pay attention to the design of data presentation to **help lay users engage with this information**.

2. **Provide guidance for people who are unfamiliar with data profiles**, on what the information may mean and how it might be used.

3. **Provide tools for data manipulation** to increase the value and use of the data on the site for commissioners and lay public. Address data quality issues in the process.

4. **Broaden data to further capture wellbeing.** Use identified gaps in available data to make the case for routine collection of additional local indicators.

Encouraging access and use of the data

The consultation discussed how the data might be used by the lay public. There was recognised value in bringing data together to explore on an area by area basis.

1. **Demonstrate the value of the data for the end users.** People may be either unaware or sceptical of the value of having data of this sort available to commissioners, service leads and front-line staff or managers. Providing case studies in an engaging, accessible format, demonstrating real-life changes through use of data could help the public to see the purpose of the site and, more broadly, the purpose of their health data being recorded and shared in this way.

2. **Show examples of how people can use the data, and what use of the data can achieve for their community.** Participants found it hard to imagine how and when they might access this type of data. We believe there is real value in trying to find ways in which local groups, individuals and collectives can make this data work for them. We therefore recommend a targeted piece of work to fund and evaluate some pilot groups who could, with minimal support, use the data in a specific campaign or other project. These pilots could then be made available on the MHIN site as case studies, to illustrate for other visitors how they might use the data for their own ends.

Next steps

Finally the McPin Foundation considered what "next steps" could be undertaken by Public health England, and we will engage in conversation with them about taking ideas forward.

1. Consider and action recommendations and Public Health England / the MHDNIN executive board to respond where recommendations are not taken up.

2. Create a stakeholder advisory panel which will include all end users of the site including commissioners, policy makers, clinicians and the lay public. Adopt co-production principles in sustaining the MHIN – bring lay public and commissioners together.

3. Develop "how to use guides" to help lay public navigate and use data profiles contained within the MHIN.

4. Evaluate the impact of MHIN – particularly within pilot regions and use material generated as case studies for the website to demonstrate how data and information can improve community mental health and wellbeing.

About the McPin Foundation

We are a charity dedicated to improving the quality of mental health research by increasing involvement of people with lived experience of mental health problems. Set up in 2007, the charity expanded in 2013 to create a team staffed by people committed to:

- Developing collaborative and user-focused mental health research with individuals, families, and carers who have experience of mental health problems.

- Encouraging and supporting individuals, families, and carers who have experience of mental health problems to get involved in research.

- Partnering with organisations to deliver public and patient involvement in research studies.

- Collaborating widely with individuals and organisations to ensure our work benefits everyone affected by mental health problems particularly delivering practical resources based upon research insights.

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