Openession: asking the right questions

January 2016

EXECUTIVE SUMMARY

Identifying priorities for depression research

www.depressionarq.org



















INTRODUCTION AND BACKGROUND

Depression affects around 350 million people worldwide,¹ and roughly 1 in 10 people in the UK.² It is the leading cause of disability, greatly impacting people's daily lives, and can lead to suicide.³

Yet despite this, it is still seriously under-researched and prospects for research are under-funded. Just £1.55 per person affected by depression is allocated to depression research in the UK. This is a stark figure when compared with cancer, where research receives £1,571 per cancer patient.⁴ Whilst increased funding for depression and mental health more generally is necessary, it is vital that this is spent effectively, in areas that are of the greatest importance to those most directly affected by depression.

We know that there is often a mismatch between the things that patients, carers and healthcare professionals would like to have researched and what is actually researched (Crowe et al, 2015)⁵, and in general mental health research agenda is predominantly determined by academics and pharmaceutical companies.

This is why in 2013, MQ: Transforming Mental Health, a research-funding charity based in London, UK, approached the James Lind Alliance (JLA) to discuss working together to ensure that patient, carer and healthcare professionals voices are represented in setting research priorities for depression. This, to our knowledge, has never been done before in a systematic way.

The JLA method was originally designed to look only at questions that would result in clinical research. But mental health conditions, such as depression, have significant social factors and social interventions as well. Therefore, the Depression: ARQ project adapted the methodology to invite both clinical and social research questions and the results reveal an even spread of enthusiasm for research in both these areas.

THE PROCESS

The key stages of the JLA method were followed. An overview of the stages is detailed in Figure 1.

STAGE 1

Establishing the Depression: Asking the Right Questions partnership

- Steering group established
- Protocol agreed
- Partners recruited
- Project management and arrangements confirmed
- Project launched in 2014 at an initial stakeholder meeting

STAGE 2

Initial Survey

- Survey open May 2014July 2014
- Survey sent out by funders and partner organisations, advertised in publications and websites
- Asked "What are your questions about depression?"

STAGE 3

Data Assessment

- Data Assessment Group established and protocol agreed
- Duplicates combined to form representative questions and out of scope questions removed
- Questions grouped into two themes, "Treating Depression" and "Understanding Depression"
- Existing research checked and "certainties" removed and summarised

STAGE 4

Interim Priortisation

- Two surveys, one per theme, distributed that asked people to rate how high of a priority each question is
- Top priorities from those with depression, family & friends, and healthcare professionals identified
- Shortlist produced

STAGE 5

Final Prioritisation

- Workshop held on World Mental Health Day 2015
- Attended by patients, family & friends, and healthcare professionals
- Used nominal group technique and small group discussions, followed by full group consensus to establish

Top 10 Research Priorities

Figure 1

¹⁺³World Health Organization (2015). Retrieved 13 January 2016, from www.who.int/mediacentre/factsheets/fs369/en/

²McManus et al (2009). Adult psychiatric morbidity in England 2007. *Results of household survey.*

⁴MQ: Transforming Mental Health (2015). Funding Landscape Report. London: UK; Available at www.joinmq.org

^{**}Crowe et al (2015). Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch, **Research Involvement and **Engagement**. 1:2; Available at http://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0003-x



In summary, the JLA method has five stages beginning with the establishment of partner organisations and a steering group that ensured the project met its objectives. The group was chaired by an independent JLA advisor.

An online survey then captured approximately 10,000 questions about depression from more than 3,000 people who identified as having experience of depression, being a family member or friend of someone who has, or a healthcare professional. These questions were then analysed, formatted and grouped into two themes: Treating Depression and Understanding Depression.

Two surveys, one per theme, were then distributed online asking people to rate each question according to how important they felt it was for research. This then produced a shortlist of the combined results of both themes, which was taken to a workshop attended by a group of people who had taken part in the surveys, where they reached a consensus on the top 10 priorities.

THERE HAS NEVER BEEN A BETTER TIME, OR MORE REASON, TO EXPLORE RESEARCH PRIORITIES FOR DEPRESSION.

TOP 10 RESEARCH PRIORITIES

- What are the most effective ways to prevent occurrence and recurrence of depression?
- What are the **best early interventions** (treatments and therapies) for depression? And **how early should they be used** in order to result in the best patient outcomes?
- What are the best ways to train healthcare professionals to recognise and understand depression?
- What is the **impact on a child** of having a parent with depression and can a parent **prevent their child** from also developing depression?
- What are the best ways to inform people with depression about **treatment options** and their effectiveness in order to **empower** them and help them **self-manage**?
- What are the barriers and enablers for people accessing care/treatment when they are depressed, including when feeling suicidal, and how can these be addressed?
- Does depression impact employment?

 How can discrimination and stigma of depression in the workplace be overcome, and how can employers and colleagues be informed about depression?
- What are the best ways to help friends and family members to support people with depression?
- Are **educational programmes** on depression effective in schools for reducing stigma?
- What is the **impact of wait times** for services for people with depression?

Next Steps A CALL TO ACTION

Use the Top 10

The Top 10 list covers a wide range of topics and therefore offers a wide range of potential activities. The partnership undertook the project with the main objective of the results used to inform research projects. But there are also other opportunities for advocacy, stakeholder collaboration and influencing policy.

Tell others about the Top 10

You can help by making sure that everyone who might be interested in these results is aware of them. There is a digital copy available online at **www.depressionarq.org** and you can request printed copies by emailing **info@joinmq.org** or calling **0300 030 8100**.

Tell us how you're using the Top 10

If we know how the results are being used and who is using them, we can better coordinate our efforts as a community of interested individuals and stakeholders. Please keep in touch by using the website, www.depressionarq.org or emailing info@joinmq.org

Additionally, the questions that were deemed "evidence certainties", or those adequately addressed by existing systematic reviews, will be made available at www.depressionarq.org. These can be used to help raise awareness of existing treatments, support, symptom awareness and for policy and advocacy work.

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How to get involved

We want to make sure that the results reach those who need to know about them – research funders, policy-makers, and service providers.

You can help by sharing the report and the project website (www.depressionarq.org) and continuing to show your support for the project.



If you are part of an organisation that would like to support this work, you can still join as a partner and help disseminate the results and help them deliver real change for people who experience depression, their friends and family members, and health and social care professionals.

For more information on how to get involved, visit www.depressionarq.org or email info@joinmq.org



MQ: Transforming mental health is a company registered in England and Wales (Company number 7406055) and a charity registered in England and Wales (Charity number 1139916) and Scotland (SC046075).