EDITORIAL

Service user and carer priorities in a Biomedical Research Centre for mental health

Dan Robotham, Til Wykes, Diana Rose, Lisa Doughty, Sally Strange, Joanne Neale, and Matthew Hotopf

Institute of Psychiatry, Psychology & Neuroscience, King's College London, UK

The term ''service user involvement in research'' implies that service users are stakeholders in the research process, rather than mere participants. The principles of involvement have long been recognised in this journal (Callard & Rose, 2012; Callard et al. 2012; Evans et al., 2012; MacInnes et al., 2011; Rush, 2008; Thornicroft et al., 2002; Townend et al., 2008; Trujols et al., 2013; Ward & Bailey, 2013). Involvement helps prioritise research questions and direct funding into research areas valued by service users (Trivedi & Wykes 2002). One example of this process in action is the recent Roadmap for Mental Health Research in Europe (ROAMER), funded by the European Commission. This exercise included service users, carers and their organisations alongside scientific experts developing mental health research priorities (Fiorillo et al., 2013; Wykes et al., 2015). Nonetheless, service user voices are not always present in setting research agendas. Discussions about ''important research areas'' can become dominated by the voices of researchers, who may have vested interests in perpetuating their own funding rather than prioritising areas valued by service users.

Much has been written about the difficulties of translating findings from basic ''discovery'' science into something clinically useful; it takes an average of 17 years for research findings to have clinical impact (Butler, 2008; Morris et al., 2011), with 85% of the effort being wasted along the way (Chalmers & Glasziou, 2009). ''Translational'' research is intended to adapt findings from basic science for clinical use. For translational research to be effective, researchers should keep clinical application in mind, as described in the RAND Retrosight report into schizophrenia research (RAND Europe, 2013). Basic/discovery research may generate academic

This article was originally published with errors. This version has been corrected. Please see Erratum (http://dx.doi.org/10.1080/09638237.2016.1181299).

Correspondence: Dan Robotham, Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, De Crespigny Park, Camberwell, London, SE5 8AF London, UK. E-mail: Dan.Robotham@kcl.ac.uk

impact through publication citations but applied research is more likely to impact on clinical care (Wooding et al., 2014). A challenge for translational research is ensuring that researchers focus on clinical impact in addition to academic impact.

The importance of patient/service user involvement in priority setting for translational research is obvious in this context. It ensures that the focus remains on translation rather than on discovery or academic curiosity. The work of the James Lind Alliance (JLA) provides a framework for achieving this. The JLA has developed methodologies for convening ''priority setting partnerships'' between patients, carers and clinicians in order to identify gaps in research and knowledge. Research questions of potential interest are generated; then the scientific literature is reviewed to see which questions have not yet been answered. Unanswered questions are arranged into ''top ten'' (Barnieh et al., 2015). If academic researchers need further incentive to embrace this type of priority setting then perhaps it is worth highlighting that research applications based on JLA priorities are more likely to be funded (Fight for Sight, 2014).

At the time of writing, the JLA had completed two priority setting partnerships in mental health (schizophrenia and depression) with others underway for bipolar and eating disorders. Priorities overwhelmingly emphasise applied and/or clinical research. Basic/discovery science is conspicuously absent, even for research into pharmacological treatment, where priorities focus on reducing adverse effects rather than on developing new compounds (''Do the adverse effects of antipsychotic drugs outweigh the benefits?''; ''How can sexual dysfunction due to antipsychotic drug therapy be managed?''). Similar findings were shown in ROAMER and other exercises which have sought service user views. Service user priorities are more likely to emphasise social instead of biomedical interventions; for example, the quality of mental health services, and the development of alternative treatments (Fiorillo et al., 2013; Rose et al., 2008; Thornicroft et al., 2002).

Research organisations such as the National Institute for Health Research (NIHR) Biomedical Research Centres (BRCs) were specifically set up to conduct translational, early phase clinical trials and experimental medicine studies. Our NIHR BRC at the Maudsley is the only one dedicated to

mental health. Although biomedical research must remain a focus, a mental health BRC should also include research into translatable social and psychological research (Cella et al., 2015; Masson et al., 2015; Robotham et al., 2015). Our BRC has always emphasised the role of service users in our research, but many of the research ideas were not originally generated by service users. Without user involvement in setting research agendas we may end up with research of no translatable value.

The exercise

We have described the consultation process to ensure that it can be replicated, but this is not rocket science. Service users are empowered to provide their views, and those receiving these views commit to assimilating priorities into their research strategy. We have not replicated the JLA priority setting partnership methodology, because these exercises focus on particular illnesses/conditions whereas we focused on a broader topic of ''mental health research in a Biomedical Research Centre''. This was a new venture and we decided to begin with service users and carers, thus clinicians were not involved at this stage. This was particularly important because we know that clinicians' views have conflicted with service users' views in the past (Fiorillo et al., 2013). The process was led jointly by service users and researchers (who also had experience of using mental health services themselves).

We conducted an initial survey/consultation stage between November 2014 and February 2016 to collect research priorities from service users and carers. This exercise involved visits to service user-led organisations, open space events in venues frequented by service users and small-group consultations with targeted communities; young people, people aged ≥ 65 years, people from black and ethnic minority backgrounds, people with a history of substance misuse, families/carers/supporters. At the end of the consultation, priorities were formulated into a list of possible research questions and grouped into themes, with similar and duplicate questions being combined where appropriate. Eighty-three individuals were included in the initial consultation. Then, in February 2016 we convened a half-day workshop with 23 individuals to discuss and rank the priority research questions.

The priorities

Many themes are similar to those arising in previous priority setting exercises, although the emphasis may differ. The continuity of themes reinforces their importance to mental health service users.

Early diagnosis and intervention

The early detection, management and prevention of mental health problems was stated in ROAMER (Wykes et al., 2015) and concerns about the mental health of young people have recently been a major focus for the public too (BBC News, 2014). In this exercise, the emphasis was on ensuring effective mental health services at an early stage. Possible research questions included: what are barriers to early diagnosis and early intervention? How do we educate people in schools about mental health and illness? How do we recognise early warning signs prior to crisis? How can we improve mental health awareness in young people? How can we encourage people to seek help before an illness becomes more severe?

Reducing the burden of medication

One of the most common complaints by service users was the burden of medication. This reflects similar findings of previous consultations (Rose et al., 2008). The following specific research questions were suggested: is maintenance medication necessary? What were the long-term effects of polypharmacy? How can medication review processes be reviewed? How can the cessation of medication be managed? In particular, service users noted that side effects profiles vary, so more information is needed about what works for individuals, rather than what works for people ''in general''.

The interface between physical and mental health

Priorities emphasised the importance of research into mental health and mental illness in relation to wider health concerns, particularly in relation to physical health. Indicative questions included: What is the impact of poor physical health on mental health (and vice versa)? What are the effects of nutrition, alcohol and exercise on mental health and well-being? Does long-term medication produce reversible or irreversible physical effects? Similar priorities appeared in ROAMER.

The importance of socio-environmental factors

Socio-environmental factors such as social inclusion and the impact of the physical environment arose in previous exercises (Barr et al., 2015; Fiorillo et al., 2013; Thornicroft et al., 2002; Wykes et al., 2015). In this exercise the important research questions were framed in the following terms: What are the effects of financial insecurity on mental ill health? What contribution do support networks and peer support have on mental health? There has been an explicit focus on social, welfare and basic needs reflected in service user priorities for over a decade (Thornicroft et al., 2002).

The development of new therapies and interventions

The development of new (or better) psychological therapies and complementary/alternative therapies arose in previous consultations (Fiorillo et al., 2013; Rose et al., 2008; Thornicroft et al., 2002; Wykes et al., 2015). Important research questions included: How effective are creative therapies, complementary therapies & mindfulness? How can the relationships between primary and secondary care be managed and can we use Big Data to provide some solutions and insights?

Ranking of priorities

(1) Can physical and mental health physicians work better together to improve care?
(2) Barriers to early intervention/early diagnosis of mental health conditions.
(3) Effectiveness of aftercare and follow-up services.

(4) Understanding whether (and how) individuals will respond to medications.
(5) Understanding how people can be best supported during transition between services.

For future consideration

The top ranked priorities represent a range of ways in which the mental health care process could be improved, from early intervention, transition, links to other services, treatment and aftercare. The predominance of service delivery priorities over biomedical ones is perhaps unsurprising, particularly considering the results of previous exercises. There was overlap with earlier consultations in mental health, which have emphasised early intervention, social and economic contexts of mental illness, financial problems, peer support and employment. The importance of contextual and societal factors no doubt reflects their importance in service users' (and carers') lives.

Nonetheless, many of the areas complement the translation of basic biomedical research into clinical practice. Understanding who will respond to treatment, and improving early diagnosis and intervention are achievable under the promise of ''precision medicine''. This refers to individually tailoring treatments to service users' unique circumstances, and so reducing the ''trial and error'' element of care, and reducing the number of unnecessary treatments prescribed.

Reducing the burden of medication is a priority. Many medications have unwanted side effects and precision medicine potentially reduces the number of medications an individual tries before finding the most acceptable regime. In the long-term, these discoveries may improve medication review processes, help service users and clinicians assess the risks of taking multiple medications, and reduce the burden of harmful side effects. Identifying factors predictive of response may allow a nuanced approach to evaluating whether treatments are working. In the longer term this will provide a mechanism for clinicians and service users who want to understand whether existing drugs are worth prescribing (or worth taking).

Above all, this exercise confirms that a BRC in mental health should conduct translational research not just in biomedical, but also in social and psychological contexts. Clinical decisions (particularly in mental health) are made based upon social, environmental and psychological information. Databanks collect wider information than genetic variables; they include contextual variables that can aid clinical decisions. Although a holistic approach is well established in mental health, these lessons could later be transferred to general health contexts, where ''all the evidence suggests that we [...] are far from recognizing that our collective health is shaped by factors well beyond clinical care or our genes'' (Bayer & Galea, 2015).

The future of translational research has much to offer service users and clinicians, but researchers should find ways of translating their research ideas to fit practical problems experienced by service users. This will improve the likelihood that people will participate in research, and become more involved in its development. The exercise shows that the needs of service users, carers and researchers do not differ hugely, but the emphasis of the research needs to focus on practical solutions and treatments.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

References

Barnieh L, Jun M, Laupacis A, et al. (2015). Determining research priorities through partnership with patients: An overview. Semin Dialysis, 28, 141–6.

Barr B, Kinderman P, Whitehead M. (2015). Trends in mental health inequalities in England during a period of recession, austerity and welfare reform 2004 to 2013. Soc Sci Med, 147, 324–31.

Bayer R, Galea S. (2015). Public health in the precision-medicine era. New Engl J Med, 373, 499–501.

BBC News. (2014). Child mental health issues 'missed'. London.

Butler D. (2008). Translational research: Crossing the valley of death. Nature, 453, 840–2.

Callard F, Rose D, Wykes T. (2012). Close to the bench as well as at the bedside: Involving service users in all phases of translational research. Health Expect, 15, 389–400.

Callard F, Rose D. (2012). The mental health strategy for Europe: Why service user leadership in research is indispensable. J Ment Health, 21, 219–26.

Cella M, Reeder C, Wykes T. (2015). Lessons learnt? The importance of metacognition and its implications for Cognitive Remediation in schizophrenia. Front Psychol, 6, 1259. doi:10.3389/fpsyg.2015.01259.

Chalmers I, Glasziou P. (2009). Avoidable waste in the production and reporting of research evidence. Lancet, 374, 86–9.

Evans J, Rose D, Flach C, et al. (2012). VOICE: Developing a new measure of service users' perceptions of inpatient care, using a participatory methodology. J Ment Health, 21, 57–71.

Fight for Sight. (2014). Fight for Sight grants that address the research priorities identified by the Sight Loss and Vision Priority Setting Partnership. London.

Fiorillo A, Luciano M, Del Vecchio V, et al. (2013). A survey among national stakeholders' associations within the ROAMER project. World Psychiatry, 12, 165–70.

MacInnes D, Beer D, Keeble P, et al. (2011). Service-user involvement in forensic mental health care research: Areas to consider when developing a collaborative study. J Ment Health, 20, 464–72.

Masson M, Wykes T, Maziade M, et al. (2015). Top–down computerized cognitive remediation in schizophrenia: A case study of an individual with impairment in verbal fluency. Case Rep Psychiatry, 2015, 242364.

Morris ZS, Wooding S, Grant J. (2011). The answer is 17 years, what is the question: Understanding time lags in translational research. J Roy Soc Med, 104, 510–20.

RAND Europe. (2013). Mental Health Retrosight: Understanding the returns from research (lessons from schizophrenia). Cambridge, UK.

Robotham D, Mayhew M, Rose D, Wykes T. (2015). Electronic personal health records for people with severe mental illness; a feasibility study. BMC Psychiatry, 15, 192. doi:10.1186/s12888-015-0558-y.

Rose D, Fleischman P, Wykes T. (2008). What are mental health service users' priorities for research in the UK?. J Ment Health, 17, 520–30.

Rush B. (2008). Mental health service user involvement in nurse education: A catalyst for transformative learning. J Ment Health, 17, 531–42.

Thornicroft G, Rose D, Huxley P, et al. (2002). What are the research priorities of mental health service users? J Ment Health, 11, 1–5.

Townend M, Tew J, Grant A, Repper J. (2008). Involvement of service users in education and training: A review of the literature and exploration of the implications for the education and training of psychological therapists. J Ment Health, 17, 65–78.

Trivedi P, Wykes T. (2002). From passive subjects to equal partners – Qualitative review of user involvement in research. Brit J Psychiat, 181, 468–72.

Trujols J, Portella MJ, Iraurgi I, et al. (2013). Patient-reported outcome measures: Are they patient-generated, patient-centred or patient-valued? J Ment Health, 22, 555–62.

Ward J, Bailey D. (2013). A participatory action research methodology in the management of self-harm in prison. J Ment Health, 22, 306–16.

Wooding S, Hanney SR, Pollitt A, et al. (2014). Understanding factors associated with the translation of cardiovascular research: A multi-national case study approach. Implement Sci, 9, 47. doi:10.1186/1748-5908-9-47.

Wykes T, Haro JM, Belli SR, et al. (2015). Mental health research priorities for Europe. Lancet Psychiat, 2, 1036–42.