

# You've done the research – now what?

By members of [SUCPRDG\[1\]](#)

## Introduction

Members of the Service User and Carer Partnership Research Development Group (SUCPRDG), sponsored by the Mental Health Research Network Cymru (MHRNC) and Involving People, facilitated a workshop at the INVOLVE 2012 conference to discuss and debate ways of disseminating research conducted by service users and their supporters.

During the workshop delegates moved between three different themed areas:

1. dissemination and social media
2. dissemination and journals dedicated specifically to service user research
3. other methods of dissemination.

They were asked to address two questions under each theme:

1. How could service users/carers/members of the public be more involved in research dissemination?
2. How could research dissemination be better achieved?

The workshop was very well attended and lively discussion ensued. Delegates' ideas were debated and refined at each work station as the discussions progressed. During the last part of the workshop everyone present discussed the ideas generated and these were ranked in importance for future research by the group.

# **1. Social media**

Delegates felt that utilising social media to disseminate research findings creates an open dialogue, with increased accessibility, but were concerned that research could lose its human element. The need for ongoing moderation was discussed, and the possibility that information may be misinterpreted necessitated clear and unambiguous dissemination via social media. Delegates felt that research should be published via all available means, including Facebook, Twitter, radio, phone apps and blogs. Other suggestions included online forums where findings could be discussed, and dedicated websites where people could study the outcomes of research. Filming research findings for those who cannot, or prefer not to, read Twitter and other similar media gathered a lot of interest. It was recognised that not everyone can use social media, and issues were raised regarding the possible negative influence of open access on those who may be vulnerable to stigmatisation and discrimination.

# **2. Dedicated journal**

Examining the issues surrounding the possibility of a journal specifically dedicated to service user research, participants highlighted the practical constraints involved: who would print such a journal and how would costs be met? In addition, delegates considered how research findings might be captured, together with questions concerning what to do about unsuccessful submissions. Ideas centred around the consideration of format and style, ensuring a journal of this kind would be appropriate and meaningful for all service users rather than to an editorial board, and verifying that reports of research findings are honest. Other suggestions included a research register that could include all service user research or a dedicated service user research portfolio with a public interface. These could include brief summaries of all research

projects with a contact address for anyone wanting more information.

### **3. Other methods**

General ideas about the dissemination of service user research were considered with delegates suggesting face-to-face meetings between researchers and research participants, with the latter being asked how they wish to be given the results. Other ideas included providing presentations, facilitating workshops and conducting seminars at meetings of service user groups, conferences and events. A newsletter could be created for active participants in research. Some delegates felt dissemination could be better achieved using charity websites and National Institute for Health Research (NIHR) web pages with links to NHS trusts. A digital TV channel devoted to research findings was also suggested, along with training on research dissemination for interested parties. Funding for dissemination was an issue which ran through all work stations. There were many questions about costs and budgets for dissemination and participants felt strongly that user involvement in funding bodies would help ensure that there is dedicated funding for this purpose. Delegates felt that funders should enquire about patient and public involvement (PPI) and dissemination at the outset, and should make suitably targeted dissemination a condition of any funding. Another suggestion included pharmacological companies funding dissemination, recognising that these should be balanced accounts and not biased. Making journal subscriptions more affordable was another popular idea.

## **Conclusion**

This workshop demonstrated a lively interest among service users and the public concerning dissemination of research. Funding is an ongoing problem that can be overcome by

ingenuity and effort.

Since the workshop the SUCPRDG has established a research writing group to ensure that service users and carers have more ownership of, and engagement with, the research writing process, including deciding how best to disseminate their work. Group members have also been involved individually in various dissemination activities, including the publication of an ibook as a new way of disseminating research findings.

The SUCPRDG would be delighted to receive other ideas and observations concerning dissemination, particularly those related to service user led research.

[www.mhrnc.org/serviceuserandcarerprdg.htm](http://www.mhrnc.org/serviceuserandcarerprdg.htm)

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