

## Invited editorial

# Spreading the word: disseminating research results to patients and carers

### Introduction

To the continuing consternation of many health scientists, their best research results, the fruits of much caring toil and labour, often appear to remain unused by health clinicians and policy decision makers. [Waddell (1), p. 3]

The dissemination of information to an audience is a vital component of research. The purpose of dissemination is to spread knowledge and, perhaps to a lesser extent, foster related research activities. In this paper, the focus will be on the distribution of information about mental illness and associated evidence-based treatments to patients and carers. As the above quotation suggests, many researchers are frustrated by the end products of their research – their research findings – not reaching interested audiences, and this audience should include patients and carers, as well as service providers and governing bodies. It is easy to imagine that patients involved in research may be particularly annoyed by a lack of feedback about the research in which they participate.

Unfortunately, most studies about the dissemination of health research findings have concerned the uptake of clinical research findings into practice by medical practitioners (1). Immediate problems arise if the results do not yield the most cost-effective or efficient treatments (2) or, further still, are inconsistent with current mental health priorities and policy directives. Dissemination obstacles include the nonpublication of results in peer-reviewed literature, variations in the quality of research and the vast amount of information available (3,4). It is therefore important to ensure that research results are customized to enable clinical improvement to be achieved (5) and it also needs to be recognized that this takes determination, time, planning and money (6). Approaches that have been taken to help address these problems, to make information more user-friendly,

include systematic reviews of the research literature and the development of ‘clinical practice guidelines’, respectively, to critically evaluate the quality of the research and condense the volume of information. One of the challenges of such initiatives is to ensure that reviews and practice guidelines are regularly updated. Indeed, the Royal Australian and New Zealand College of Psychiatrists’ (RANZCP) Clinical Practice Guidelines pertaining to six psychiatric conditions include the following important caveat:

The Guidelines are current at the time of publication, but because they are evidence-based, they will inevitably become out of date as new research emerges regarding established and novel treatments. Therefore a crucial aspect of implementing the Guidelines will be ensuring that they are reviewed on a regular basis. (7)

It is noteworthy that each of the RANZCP Clinical Practice Guidelines includes a patient and carer version.

### Dissemination beyond academic or professional journals

Dissemination beyond academic or professional journals and other academic reports has traditionally been a low priority among researchers and authors. By and large, researchers are trained in research methods and well schooled in reporting their findings in the scientific literature but not in the wider dissemination of their results. Manuscripts that are published in even major academic journals have a limited audience. Some journals promote new issues and major articles through ‘media releases’, which ensure that the wider community becomes engaged, but such practices are neither systematic nor uniform. It is also worth noting that, while some health courses and training programs continue to teach methods in research and, occasionally, scientific writing, a recent trend

has been the (additional) teaching of media skills (6,8,9), which should, at least in theory, optimize wider dissemination of results through various media outlets.

Generally, there is very little institutional incentive to disseminate beyond scientific journals. For instance, universities frequently use academic publication outputs, particularly in high-Impact-Factor journals, to guide academic promotion (10), and these publications are also influential in securing competitive research grants. In addition, time pressures often constrain the production of research findings in formats other than journal articles, particularly when this may be viewed as a lower priority. Consequently, many researchers simply assume that their 'job is done' and their work adequately disseminated when it is published in the scientific literature, and this view is rarely questioned.

It is rare for a research budget to include monies for the distribution of research results. Where budgets do take dissemination into account, resources are generally set aside to cover the expense of publication of materials but not the cost of distributing them. Other barriers relate to social, cultural and technical issues, which will be discussed subsequently.

### **Why focus on increasing patient access to research findings?**

In Australia, there has been recognition of a clear need to increase patient access to research findings in general and particularly the results of individual projects in which they were subjects (11). In all health fields, the demand for accurate and up-to-date high-quality health information for patients has increased. This growth in demand is partly a consequence of public health campaigns and increased 'health literacy' in all health fields. Mental health literacy may be defined as being able to access and utilize health information to promote good mental health (12,13). Further, it encompasses raising consciousness about a mental health condition, including knowledge about the seriousness and consequences of the problem, as well as understanding how amenable it is to treatment and how to access evidence-based treatments (13).

As mentioned, the bulk of scientific research is disseminated by publication in academic journals. Patients are obviously not the target audience in these publications, but their lack of meaningful exposure is compounded by obstacles including limited computer access, availability and skills (14), the prohibitive cost of journal access, and low comprehensibility of regular journal articles.

The growth of the Internet has resulted in increased access to information by much of the general public, including access to information regarding interventions, but problems persist with the quality of some information, issues of overload and the Internet's capacity for quickly disseminating inaccurate material (15,16). Further, it can be difficult to promote some of the better Internet sites, which inhibit access to accurate material (16). Given the apparent hurdles, what are the benefits of the broad dissemination (ie, beyond the academic sector to include patients and carers) of research findings?

### **Informed and shared choices**

Providing consumers with accurate, comprehensive and understandable information can help ensure that they are able to participate more actively in their care and treatment. [Currie et al. (17), p. 8]

The most obvious benefit of the distribution of information to patients and carers is that it facilitates making informed choices about health treatments and that these decisions are shared by patients and their health practitioners. Patients may be unaware that health advice is not always based on solid research evidence and that inaccurate health advice may even be harmful. Patients should not only be provided with a comprehensive picture about treatment options but also with the knowledge that often information on the effectiveness of a treatment and possible side-effects needs to be weighed when making decisions about treatments. These kinds of decisions are only possible when there is timely access to good research evidence.

### **Reduction of stigma**

Access to robust, evidence-based research findings, whether these pertain to disorders or treatments, may help to reduce the stigma associated with mental illness and some of the consequences of stigma, including discrimination. A large body of research indicates that the public tend to hold erroneous beliefs about the causes of psychiatric disorders, often attributing mental disorder to 'psychosocial' causes such as life events, stress or 'mental weakness', rather than to biological or disease factors (18). This may be particularly so for clinical depression (18,19). The concept of personal weakness being the cause of mental illness perpetuates the stigma and ultimately hinders treatment seeking. Access to reliable information on the

## Invited editorial

causes of mental illness and on appropriate treatments is necessary to educate the public, and counter stigma and discrimination.

### Improved research

While disseminating research to other researchers provides feedback through critical appraisal and potentially expands research networks, dissemination to patients and carers may also strengthen future research activities. For example, not only are patients and carers able to provide links to patient and carer networks to help publicize research trials (20) but they can also provide important information about those results that are of interest to them, and they can identify gaps in the information that is currently provided. Through creating a dialogue between researchers and patients and carers, these areas can be addressed. This has been most poignantly shown by the Centre for Mental Health Research at the Australian National University, which established a Depression and Anxiety Consumer Research Unit, comprising academic researchers who have experienced common mental disorders.

Often, scientific research that is undertaken is based on a need or an interest identified by a particular researcher or the institution of the researcher. This may occur in a cocoon, where a scientific hypothesis is addressed with little consideration given to the application of knowledge that will be gained. However, if the dissemination of research is planned from the outset, it provides a context for research and increases the relevance of the research for the target audience.

### Methods of dissemination

The variety of different formats and methods of disseminating health research is extensive. Each

has advantages and disadvantages, some of which are outlined in Table 1. The formats and methods include print-based (eg, postcards, brochures, posters, booklets) and web-based resources, multimedia, community forums, conferences, workplace training, outreach through existing stakeholder groups (eg, SANE), sponsorship of festivals or mental health week activities and mass media (interviews and programs on television or radio, newspaper articles).

### Ways forward in the dissemination of research findings

Researchers get caught in a “one-size-fits-all” process of dissemination, failing to tailor the content, timing, setting and format of the dissemination to the audience. [Lomas (21), p. 3]

There are two main elements to good dissemination strategies – making the information accessible and ensuring that it is comprehensible. The overriding principle is that the dissemination strategy must suit the target audience, and this can best be achieved through consultation with that audience.

### Target audience and content

Always be guided by your audience, as they are the experts in how best to communicate with their communities. [Jones (22), p. 19]

The primary step in developing a dissemination strategy is to identify the intended target audience. It is then necessary to determine what its informational needs are. When disseminating research results, this second step will be influenced by the nature and treatment of the illness in question. For instance, in the physical health arena, Barratt et al. (23) reviewed articles on patient reports of informational needs. Patients with breast cancer, benign breast disease and prostate cancer stated

Table 1. Advantages and disadvantages of dissemination methods directed toward non-health professionals

Dissemination method	Advantages	Disadvantages
Print-based material	<ul style="list-style-type: none"><li>● Easily accessible</li></ul>	<ul style="list-style-type: none"><li>● Limited by language and literacy</li></ul>
Video tape	<ul style="list-style-type: none"><li>● Easily accessible</li><li>● Engaging</li></ul>	<ul style="list-style-type: none"><li>● Expensive to produce and distribute</li></ul>
Audio	<ul style="list-style-type: none"><li>● Can be used by those with poor reading skills and/or are visually impaired</li></ul>	<ul style="list-style-type: none"><li>● Hard to remember (and possibly needs to be supported by print)</li></ul>
Internet	<ul style="list-style-type: none"><li>● Relatively inexpensive</li><li>● Inexpensive to maintain</li><li>● Easy to update</li><li>● Popular among particular target audiences (eg, youth)</li><li>● Link to other resources</li></ul>	<ul style="list-style-type: none"><li>● Daunting for some target audiences (eg, elderly)</li><li>● Expensive to establish</li></ul>
CD-ROM	<ul style="list-style-type: none"><li>● Can be interactive (and thus engaging)</li></ul>	<ul style="list-style-type: none"><li>● Expensive</li><li>● Access issues</li></ul>

that their high-priority needs were chances of cure, spread of disease, treatment options and family risk. Medium priority needs were self-care at home, impact on family and social activities, whereas the effect on sexuality was considered a low-priority need. Thus, it is important to determine what the target audience wants to know; studies of persons with mental illness (24) suggest that, not surprisingly, dissatisfaction results when information is perceived to be inadequate.

Creatively engaging patients with mental illness, such as through information workshops (25), and seeking their input about priority research areas, can result in more positive and effective outcomes for all concerned. Through patient networks, information can be readily disseminated (20). Following clarification of content, the presentation and delivery of information need to be considered, while encouraging patient feedback on these issues.

### **Presentation and delivery**

The form of the presentation will take into consideration the resources available to the target audience to receive the information (eg, is there access to the Internet?) and the optimum way to communicate with that audience. For example, research in an area mental health service in New South Wales found that almost three quarters of patients had no access to the Internet (14). Careful consideration must be given to social and cultural sensitivities, the comprehensibility of the language (eg, do technical terms require explanation?), and whether translation into other languages would be appropriate. Academic patient researchers may be more sensitive to patient needs and can actively disseminate findings within the community (26).

Format issues may include whether presentation with 'questions and answers' is suitable or whether providing broad examples, as opposed to specific facts, would be more appropriate. Other presentation considerations include layout of documents, use of diagrams and color. Finally, it is important to consider the credibility of the source of information. The research team may need to consider presenting their findings in collaboration with organizations with known experience and competence, such as an advocacy group. Thought should be given to who conveys the information (eg, patient to patient, health professional to patient). Lomas (21) and Waddell (1) both suggest we should contemplate the idea of 'knowledge brokers', people whose role it is purely to disseminate knowledge. Waddell suggests they would need an understanding of both the research and the target audience.

Other considerations include emphasizing to the audience what the research does and does not tell us. The timing of dissemination may also be pertinent – it may not always be desirable to disseminate research findings to the wider community at the time they become available. Waiting for opportunities (eg, a related news story dealing with mental illness) may be more productive. Importantly, too, while it is easy to suggest ways in which mental health research results should be disseminated to broader audiences, we also need systematic evaluation of such methods (eg, what effectively impacts on the acquisition of new knowledge, good strategies for the maintenance of knowledge and the use of knowledge in decision-making).

These considerations, and others, are well summarized by Coulter et al. (27), who asked patients and clinicians to review various information materials pertaining to their own conditions or areas of expertise. Feedback included the following: patients and clinical experts should be involved in developing the information material, which should be based on the latest research evidence; the purpose of the material should be made clear and targeted toward a particular audience, including minority groups; materials should be easily accessed and read, regularly evaluated and should include information regarding benefits, risks, further information sources and checklists for medical advice; information should be concise, with authorship explicit and include evidence regarding information sources; and distribution strategies need to be cost-effective and through the most effective gateways (eg, through targeted media sources).

Jones (22) also made recommendations for ways to overcome barriers to disseminating information. These may be summarized as follows: make effective research dissemination a priority, start small, target one small audience at a time, be flexible and creative, think cheap/free (eg, interviews, newsletter, articles), and collaborate with health care providers, governments and community groups to help absorb costs.

### **Mandating wider dissemination**

Despite the rationale for broader dissemination of research findings, as outlined, it is easy to imagine researchers' dissemination focus not extending beyond the publication of their results in the scientific literature, preferably in High-Impact-factor journals. Recent initiatives such as the *Research Quality Framework* in Australia (28), which have been developed to assess the quality

## Invited editorial

and impact of research, again do not acknowledge the issue of broad dissemination. It may therefore be desirable to ask researchers to describe, for example, in ethics submissions or grant applications, how the results will be disseminated beyond the scientific literature. Similarly, applicants for academic positions or promotions might be asked to indicate how widely their work has been disseminated, and to provide evidence for this. Indeed, akin to the development and use of citation measures such as the Impact Factor or, more recently, the 'h-index' (a measure of the highest number of papers that a scientist has produced that have had at least this number of citations) (29), the development of a measure of dissemination for research projects and researchers may be worth exploring.

## Conclusions

Broad dissemination of research findings is an essential, but sadly neglected, component of research that will enhance patient participation in treatment decisions and in mental health services generally. It has been suggested that researchers have 'intense satisfaction in making a small contribution to knowledge in a belief that this may ultimately benefit the health of others' [Joyce (30), p. 320]. How much more satisfaction will there be, and likelihood of even more positive health outcomes, if that contribution to knowledge is widely disseminated? Many factors need to be considered when developing a dissemination strategy, but the main priority must be the identification of the target audience and ongoing consultation with that audience.

*Michelle Cleary<sup>1,2</sup>, Garry Walter<sup>3,4</sup>,  
Georgina Luscombe<sup>2</sup>*

*<sup>1</sup>Faculty of Nursing and Midwifery, University of Sydney, Sydney, New South Wales, Australia;*

*<sup>2</sup>Research Unit, Sydney South West Area Mental Health Service, Sydney, New South Wales, Australia; <sup>3</sup>Discipline of Psychological Medicine, University of Sydney, Sydney, New South Wales, Australia; and <sup>4</sup>Child and Adolescent Mental Health Services, Northern Sydney Central Coast Health, Sydney, New South Wales, Australia*

*Assoc. Prof. Michelle Cleary, Research Unit,  
Sydney South West Area Mental Health Service,  
PO Box 1, Rozelle, NSW 2039, Australia.  
Tel.: (02) 9556 9100;  
Fax: (02) 9818 5712;  
E-mail: michelle.cleary@email.cs.nsw.gov.au*

## Acknowledgements

The paper was supported by an educational grant from Janssen-Cilag. We thank Tracey Davenport for her contribution to the development of the article.

## References

1. WADDELL C. So much research evidence, so little dissemination and uptake: mixing the useful with the pleasing. *Evid Based Ment Health* 2001;**4**:3–5.
2. ANDREWS G, ISSAKIDIS C, SANDERSON K, CORRY J, LAPSLEY H. Utilising survey data to inform public policy: comparison of the cost-effectiveness of treatment of ten mental disorders. *Br J Psychiatry* 2004;**184**:526–533.
3. BURNS N, GROVE SK. The practice of nursing research: conduct, critique, & utilization, 5th edn. Philadelphia: Elsevier Saunders, 2005.
4. TURER AT, MAHAFFEY KW, COMPTON KL, CALIFF RM, SCHULMAN KA. Publication or presentation of results from multicenter clinical trials: evidence from an academic medical center. *Am Heart J* 2007;**153**:674–680.
5. PINCUS HA, NABER D. Challenges in moving from evidence to quality. *Curr Opin Psychiatry* 2004;**17**:503–504.
6. National Health and Medical Research Council. How to put the evidence into practice: implementation and dissemination strategies. Commonwealth of Australia, 2000. URL [http://www.nhmrc.gov.au/publications/synopses/\\_files/cp71.pdf](http://www.nhmrc.gov.au/publications/synopses/_files/cp71.pdf) [accessed 2 April 2007]
7. Royal Australian and New Zealand College of Psychiatrists. Clinical Practice Guidelines [Webpage]. URL <http://www.ranzcp.org/publicarea/cpg.asp> [accessed 2 April 2007]
8. BROWN D. Becoming a media-savvy registered dietitian. *J Am Diet Assoc* 2006;**106**:1163–1164.
9. SUDAK HS, SUDAK DM. The media and suicide. *Academic Psychiatry* 2005;**29**:495–499.
10. BLOCH S, WALTER G. The Impact Factor: time for change. *Aust N Z J Psychiatry* 2001;**35**:563–568.
11. GRIFFITHS KM, CHRISTENSEN H, BARNEY L, JENKINS A, KELLY C, PULLEN K. Promoting consumer participation in mental health research: a national workshop. Depression & Anxiety Consumer Research Unit, Centre for Mental Health Research, The Australian National University, 2004.
12. NUTBEAM D, WISE M, BAUMAN A, HARRIS E, LEEDER SR. Goals and targets for Australia's health in the year 2000 and beyond. Canberra: Australian Government Publishing Service, 1993.
13. JORM AF, KORTEN AE, JACOMB PA, CHRISTENSEN H, RODGERS B, POLLITT P. 'Mental health literacy': a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *MJA* 1997;**166**:182–186.
14. CLEARY M, HUNT G, FREEMAN A, WALTER G. Staff and patient perceptions of research in an integrated mental health service. *Issues Ment Health Nurs* 2007;**28**:341–358.
15. CHRISTENSEN H, GRIFFITHS K. The Internet and mental health literacy. *Aust N Z J Psychiatry* 2000;**34**:975–979.
16. CHRISTENSEN H, GRIFFITHS K. The prevention of depression using the Internet. *MJA* 2002;**177** (Suppl.):S122–S125.
17. CURRIE K, SPINK J, RAJENDRAN M. Well written health information: a guide. Department of Human Services, Victoria, 2000. URL <http://www.health.vic.gov.au/consumer/downloads/dhs1074.pdf> [accessed 2 April 2007]

18. SCHOMERUS G, MATSCHINGER H, ANGERMEYER MC. Public beliefs about the causes of mental disorders revisited. *Psychiatry Res* 2006;**144**:233–236.
19. BARNEY LJ, GRIFFITHS KM, JORM AF, CHRISTENSEN H. Stigma about depression and its impact on help-seeking intentions. *Aust N Z J Psychiatry* 2006;**40**:51–54.
20. HANLEY B, TRUESDALE A, KING A, ELBOURNE D, CHALMERS I. Involving consumers in designing, conducting, and interpreting randomised controlled trials: questionnaire survey. *BMJ* 2001;**322**:519–523.
21. LOMAS J. Improving research dissemination and uptake in the health sector: beyond the sound of one hand clapping. Policy commentary C97–1. Hamilton: McMaster University Centre for Health Economics and Policy Analysis, 1997.
22. JONES S. Disseminating hepatitis C research results in the community. *Aust Health Consum* 2003–2004;**2**:18–19.
23. BARRATT A, RAGG M, COCKBURN J, IRWIG L, SWINBURNE L, CHAPMAN S. How to prepare and present evidence-based information for consumers of health services: a literature review. National Health and Medical Research Council, 1999. URL [http://www.nhmrc.gov.au/publications/synopses/\\_files/cp72.pdf](http://www.nhmrc.gov.au/publications/synopses/_files/cp72.pdf) [accessed 2 April 2007]
24. CLEARY M, FREEMAN A, HUNT GE, WALTER G. What patients and carers need to know: an exploration of information and resource needs in adult mental health services. *Aust N Z J Psychiatry* 2005;**39**:507–513.
25. CLEARY M, MATHESON S, WALTER G, MALINS G, HUNT G. Demystifying research and evidence-based practice for consumers and carers: development and evaluation of an educational package. *Issues Ment Health Nurs* (in press).
26. GRIFFITHS KM, JORM AF, CHRISTENSEN H. Academic consumer researchers: a bridge between consumers and researchers. *Aust N Z J Psychiatry* 2004;**38**:191–196.
27. COULTER A, ENTWISTLE V, GILBERT D. Sharing decisions with patients: is the information good enough? *BMJ* 1999;**318**:318–322.
28. Australian Government. Research quality framework. Assessing the quality and impact of research in Australia. Australia, Department of Education, Science and Training, 2006. URL [http://www.dest.gov.au/NR/rdonlyres/7E5FDEBD-3663-4144-8FBE-AE5E6EE47D29/14867/Recommended\\_RQF\\_Dec2006.pdf](http://www.dest.gov.au/NR/rdonlyres/7E5FDEBD-3663-4144-8FBE-AE5E6EE47D29/14867/Recommended_RQF_Dec2006.pdf) [accessed 2 April 2007]
29. PETERSON I. Science News ONLINE 2005; 168, December 3. URL <http://www.sciencenews.org/articles/20051203/mathtrek.asp> [accessed 2 April 2007]
30. JOYCE PR. The development, evolution and philosophy of a clinical research unit. *Aust N Z J Psychiatry* 2002;**36**:311–321.