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**Who decides what is evidence?
Developing a multiple perspectives paradigm in mental health**

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Introduction

It has become common in the last decade for many clinicians and practitioners to believe that clinical practice should closely reflect the most firmly established and relevant evidence base (evidence-based medicine, EBM) and for some policy makers to believe that health policy should also clearly be informed by information on the effectiveness and cost-effectiveness of interventions and services (evidence-based policy, EBP). These general guiding statements, however, usually stop short of considering who defines information as evidence, and in the case of differing views over the evidence-base, whose views should predominate. These two issues are examined in this paper.

Evidence-based medicine

The recent influence of EBM reflects the maturation of systematic reviews and other meta-analytical techniques to provide overviews of the strength of scientific evidence in areas of bio-medical research. The origins of EBM lie with the birth of randomised clinical trials and the increasing recognition of the importance of scientific evidence to guide the delivery of health care interventions (Cochrane ~~AL~~, 1972) (Kassirer, 1992), which have been expressed by Light as the 'Cochrane test' (Light, 1991). This test requires clinicians and managers to respond to six challenges. (i) consider anything that works, (ii) make effective treatments available to all, (iii) minimise ill timed interventions, (iv) offer treatment in the most effective place, (v) prevent only what is

preventable, (vi) diagnose only if treatable (L'Abbe *et al.*, 1987) (Chalmers, 1993) (Sackett *et al.*, 1996) (Calman, 1994) (Knapp & Beecham, 1990).

Evidence-based policy (EBP)

In comparison with EBM, EBP is a relatively neglected topic in the literature. Early commentators used data from epidemiological research to inform national level decision making (Sartorius, 1982), but it is really only in the last decade that politicians and officials in some countries have begun seriously to pay attention to the scientific literature when forming health policies (Tunis *et al.*, 2003). In England, for example, current mental health policy for adults of working age is encapsulated in the National Service Framework for Mental Health (Department of Health, 1999), which is explicit in stating which of the standards set are based on published scientific evidence, and the strength of that evidence in each case, using the following classification system (Geddes & Harrison, 1997):

- Type I at least 1 good systematic review, including at least 1 RCT
- Type II at least 1 good RCT
- Type III >1 well designed intervention study without randomisation
- Type IV >1 well designed observational study
- Type V expert opinion, including the opinion of service users and carers

In the U.S.A., the Surgeon General's report on mental health (Satcher, 2001) set out eight necessary actions to close the gap between science and practice: continue to build the science base; overcome stigma; improve public awareness of effective treatments; ensure the supply of mental health services and providers; ensure delivery of state-of-the-art treatments; tailor treatment to age, sex, race, and culture; facilitate entry into treatment; and reduce financial barriers to treatment (Goldman *et al.*, 2001). This report built upon

careful literature reviews leading to consensus-~~building-based~~ statements ~~for-about~~ good clinical practice, from which guidelines and protocols have been developed (Lehman & Steinwachs, 1998).

Another approach to EBP is to subject current policies to evaluation, which can then inform decisions about whether these policies should continue. An example of this in England concerned the Supervision Register, a procedure to document and list patients deemed to be at higher risk of harm to others (Bindman *et al.*, 1999) (Bindman *et al.*, 2000). This evaluation found that the policy was widely regarded by practitioners as adding no value to their work, and the policy was discontinued shortly after this report.

Multiple perspectives on evidence

Despite such attention to the question of *what* evidence exists to guide policy and practice, fewer publications address *who* decides what is evidence, or more precisely, whose versions of evidence are given priority? One can consider a series of stakeholders who may have differing perspectives on evidence, including: service users, families and informal carers, professionals, and policy makers [tax-payers is the normally neglected member of this list!].

Perspectives of service users

There has been a rapid recent growth in the involvement of service users in the conduct of research and in the debate over what constitutes evidence (Trivedi & Wykes, 2002). It has been estimated (Wallcraft *et al.*, 2003) that the user movement in the UK, for

example, has grown from some 15 groups in the mid-1980s to over 700 today. Over the past five years, service user research has ‘grown wings and begun to fly’ (Strategies for Living, 2003). One example of such research is the Review of Consumers’ Perspectives on Electro-Convulsive Therapy (Rose *et al.*, 2003). This was commissioned by the Department of Health alongside a meta-analysis of trials of the effectiveness and safety of ECT. The two empirical researchers on the Consumer project had themselves experienced ECT. The team also included a psychiatrist and a psychologist, and their role was to help with the analysis and reporting.

The review relied upon existing materials, and used 26 papers written by clinical academics and 9 authored by consumers or written in collaboration with consumers. In addition 139 ‘testimonies’ or first-hand accounts of receiving ECT were gathered, ~~and~~ most of these were in electronic form, ~~for example, mainly~~ from the Internet. The scientific papers reported much higher levels of satisfaction with ECT than did either the user-led research or the testimonies. The standard response to this proposition is that the user-led research and the testimonies relied on biased sampling. However, because the user researchers on the project had experienced the treatment and also experienced being in hospital and being interviewed as to whether this treatment had helped, it seemed to them that other explanations were at least as plausible. The academic articles that reported the highest levels of satisfaction had a very particular methodology. Satisfaction interviews were conducted as soon as treatment ended, or even during it, and the interviewer was the treating doctor who asked a few simple questions. From the personal experience of the researchers, they considered that, under these circumstances, users

would not want to complain or might not tell the truth in order either to avoid more treatments or simply to get rid of the doctor who was asking yet more questions! It was therefore argued that these academic papers were over-estimating user satisfaction with ECT. This use of personal experience led to novel results, in contrast to the previously received psychiatric wisdom

One particular finding of this study by Rose et al was that even where people signed a consent form for ECT, up to a third felt there was pressure to do so and so they did not freely choose to have the treatment. Another important finding was that according to a significant number of users, persistent memory loss is a very detrimental side-effect of ECT. This study has also had policy implications, as the UK National Institute for Clinical Excellence (NICE) has referred to the study findings in its guidelines on good clinical practice in the use of ECT.

Perspectives of carers

The research reviewed above was conducted by service users themselves. There is no comparable research conducted by carers and little literature on what kind of evidence they favour or how they would prioritise the content of research. However, carers and their priorities have been the subject of research by professionals. Even compared with information from service users and their advocates, there is little published on the views of family members and other informal carers, either on the type of evidence they value or on the content of research they favour. Where studies have been made of the issues most salient to carers, several recurrent themes have emerged (Berry *et al.*, 1997) (Szmukler *et al.*, 2003) (Szmukler & Bloch, 1997) (van Wijngaarden *et al.*, 2003), namely: a sense of

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loss of expected future of the affected relative, concerns for their own mental health in terms especially of anxiety and depression, financial worries, the need for respite breaks, a clear requirement for information and advice on the psychiatric condition, its cause and future treatment and care options, and fear for future when they can no longer provide care. Because of this expressed need for more widely available information for carers, a website now provides evidence especially for carers of people with mental disorders at www.mentalhealthcare.org.uk.

Perspectives of professionals

Most of the literature published concerning mental health policy and the relevant evidence-base is written from a professional perspective: from the viewpoints of either practitioner or researchers. This has perhaps been best expressed by Bradford Hill when he wrote, ‘The physician’s first duty is to his patient –to do all in his power to save the patient’s life and restore him, as rapidly as possible to health. That fundamental and ethical duty must never be overlooked... the onlooker may perhaps with good reason sometimes ask the clinician, ‘Are you sure you know where that duty lies? It seem to me sometimes to be unethical not to experiment.’ (Doll, 1992).

One example of work with this provenance is a recent review published by the Health Evidence Network of the World Health Organisation, which gives an overview of evidence on community-based mental health care (Thornicroft & Tansella, 2003). The review goes on to propose a ‘balanced care model’ (i) for services in low resource countries, with both primary care services and limited specialist provision, (ii) in medium

resource countries which includes (i) and also has mainstream mental health care in five categories: out-patient/ambulatory clinics, community mental health teams, acute in-patient care, long-term community-based residential care, and occupation/day care. (iii) High resource countries may be then able to afford specialised/differentiated types of service in some of these five categories.

Perspectives of policy makers

A series of issues have been described by Sartorius (Sartorius, 1982) which may affect how far policy makers can directly access or use relevant evidence when they formulate policy. Many will have had no mental health training and may need to have basic concepts and terminology explained clearly to them. They may think that scientists do not appreciate how gruelling it is to administer health services. They may not have had evidence reach them as scientists forget that most people need to hear the facts frequently to believe them. Policy makers often need results within 2 years. At the extreme, some decision makers often think there is no evidence based in mental health and so action may be wasteful, or psychiatrists are seen as contemplators, not people of action. Decision makers by nature react to change and emergencies, while mental illness is rarely news. Finally, decision makers see mental health as competing with other health problems, rather than as complementary, and often as less of a priority than most other categories of health expenditure (World Health Organisation, 2001).

Developing a multiple-perspectives paradigm

What emerges from the preceding discussion is not so much that these stakeholder groups

take differing views on which evidence to priorities, but rather [that](#) the epistemological status of evidence is now often disputed. Service user-led or user-controlled studies are more often within the qualitative scientific traditions, and practitioner-led research more often quantitative. In part this reflects [a](#) long-standing ambivalence about the nature of evidence which is reflected in its very definition, being both (i) ‘evidence available facts, circumstances, etc. indicating whether or not a thing is true or valid’ (that is permanently true), and (ii) ‘in law, information tending to prove a fact or proposition, (b) statements or proofs admissible as testimony in a law court’ (that is, contestably and contingently true). Indeed it is this contestability and this contestation which is progressively introducing the need to develop an integrative paradigm that can inter-relate differing forms of knowledge to contribute to a more satisfactory evidence-base.

Even within an empirical paradigm, approaches are available which directly incorporate more than one perspective. Partly randomised preference trials, for example, can compare two or more treatment conditions when service users’ treatment preferences are taken into account (Brewin & Bradley, 1989). They make provision for preferred treatment options to be provided, and randomisation is then only applied to those people who have expressed no clear treatment preference. This allows both treatment effects and preference effects to be estimated in the analyses (Jadad, 1998) (McKee *et al.*, 1999) (Haynes *et al.*, 2002).

[A](#) related approach within the empirical tradition is to separately rate the views of staff and service users and to make explicit comparisons, for example on how far needs are met or unmet. In one study in London, for example, an epidemiologically representative

group of 137 service users with an ICD-10 diagnosis of a functional psychotic disorder was assessed cross-sectionally by users themselves and by staff (Slade *et al.*, 1998), using the Camberwell Assessment of Need (CAN) (~~Slade *et al.*, 1998~~) (~~Slade *et al.*, 1996~~) (Slade *et al.*, 1999). The results showed that staff rated service users as having on average 6.1 needs, while users rated themselves as having an average of 6.7 needs ($p = 0.011$), with staff ratings of 1.2 unmet needs, compared with users rating of 1.8 unmet needs ($p < 0.001$). There was moderate or better agreement on the presence of a need for 13/22 domains of the CAN. The following needs were more often rated by staff: psychosis, and harm to others, while service users more often identified needs for: information on treatment, company, welfare benefits, transport, and sexual expression.

Another view is to strengthen research conducted within a post-modern paradigm, a counterpoint to empiricism/modernism, which it characterises as rationalist, materialist, and reductionist, namely the approach which has so far underpinned EBM and EBP. This view attaches value to the relative realities of participants, uses both meta- and micro-narratives as its source material, and pays attention to the uncertainties, experiences, differences in views, and multifaceted perspectives of the realities of those whom it studies (Laugharne & Laugharne, 2002).

The work described as post-psychiatry is conducted within this tradition, and it is based upon a profound doubt about the ability of science and technology to resolve human and social problems. It proposes a need to actively engage with the interests and contributions of users, it emphasises social and cultural contexts, it seeks to minimise medical control and

coercion, and it encourages doctors to redefine their roles/responsibilities (Bracken & Thomas, 2001) (Faulkner & Thomas, 2002).

There is also the question of how knowledge relates to power. According to Foucault (1977) this relation always exists and he calls it the 'knowledge/power axis'. In the context of this paper, the Cochrane test would assign to EBM the status of universally true knowledge. The focus on experience in user research means that it would be relegated to the bottom of the hierarchy and so accorded less power in the fields of knowledge, policy and practice. It should be noted that for some authors (Harding, 2004) universal knowledge is a myth as all knowledge is situated and contingent. If this were accepted then it would reduce the knowledge/power relation between practitioners and policy makers and users and carers. However, the power of the dominant paradigm in EBM means that such an argument would probably be refused.

How can these tensions and contradictions be managed if not resolved? We propose that work continues to build what can be referred to as a multiple perspectives paradigm to integrate such varied sources of evidence. In the meanwhile we propose increasing service user access to setting research questions, developing a wider range of interventions assessed, creating and consolidating structures to develop service user and carer research, and using research designs which actively include service user preferences. These steps can be taken within a context where it is necessary to admit that the overall evidence base is relatively weak in mental health, where there is a predominance of quantitative over qualitative evidence, where research questions are

usually set by researchers and policy makers, and where there is rarely qualitative-quantitative cross-fertilisation of ideas or research methods. Meanwhile conceptual and methodological work is now timely to extend current early approaches to multi-methods research to more firmly ground it in a nascent paradigm that values multiple perspectives on evidence in mental health (Thomas *et al.*, 2004).

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