editorial

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Beyond consultation: the challenge of working with user/survivor and carer groups[†]

SUMMARY
Recent years have seen increased pressures on psychiatrists to work closely with user/survivor and carer groups. We argue that although many groups are happy for this to remain at the level of consultation, there are growing demands from more radical elements of the user/survivor movement for moves towards a more collaborative framework. A number of these groups challenge some of the central assumptions of psychiatry. For productive engagement and collaboration to take place, psychiatry will have to be able to react positively, not defensively, to these challenges. We suggest that this raises questions about how we should think about the nature of science, truth and expertise.

The demands of a consumer-orientated society have resulted in the engagement of patients and carers in many aspects of healthcare over the past 10 years. In 2001, the UK Department of Health launched the Expert Patient Programme in recognition of patient expertise in the self-management of chronic illnesses such as diabetes and arthritis.[1] In 2003, the Commission for Patient and Public Involvement in Health was set up, now replaced by Local Involvement Network Links. Section 11 of the Health and Social Care Act 2001 places a duty on National Health Service (NHS) trusts, primary care trusts and strategic health authorities to involve and consult with patients in service planning and delivery. The Royal College of Psychiatrists has actively promoted service user and carer involvement in its activities through the work of the Patients' and Carers' Committee. This is a standing committee that acts as a channel of communication between the College and patient and carer organisations which inform the College of patients' and carers' views and who in turn learn about College policies. The College also pledged at its 2004 annual general meeting to involve patients and carers in psychiatric training.

All these activities have been essentially about consultation and the passing of information. However, something more fundamental has been happening in the field of mental health. Whereas most carer groups accept the medical framing of mental health problems and are in tune with the biomedical focus of contemporary psychiatry, the same cannot be said for users and survivors. It is true that many are happy to understand their problems in medical terms, but many are not. In recent years, a radical critique of the medicalisation of 'madness' and distress has arisen within the user/survivor movement. Organisations such as the Hearing Voices Network, the Paranoia Network, Self-Harm Network, Mad Pride and Mad Women have emerged. Some are better organised than others. Hearing Voices Network is now an international network with many branches in the UK and throughout Europe.

These groups have set their sights far beyond 'consultation'. They take aim at the heart of psychiatry itself – the framing of people's experiences in terms of psychopathology. They argue that by casting these experiences as morbid, psychiatrists have rendered them in purely negative terms – things to be treated, cured and eliminated. The framework of biomedical psychopathology interprets sadness, anxiety, elation, obsession, fearfulness and hearing voices as symptoms. Successful treatment involves removing or dulling them. Members of organisations such as Hearing Voices Network argue that although this makes sense within a purely medical logic, when one steps outside this logic such experiences can be encountered differently and this can lead to more positive ways of living and dealing with them. For example, the Icarus Project[2] is a US-based network of individuals who come together in different ways to talk about 'bipolar disorder and related madness'. They have been meeting, writing and campaigning since 2002. At the heart of the project is an effort to redefine the meaning of bipolar experience: 'we shared a vision of being 'bipolar' that differs radically from the narrow model put forth by the medical establishment, and wanted to create a space for people like us to articulate the way we understand ourselves, our 'disorder', and our place in the world'.[2] Rather than simply accepting their experiences as meaningless and negative, they believe that they have 'a dangerous gift to be cultivated and taken care of, rather than a disease or a disorder to be "cured" or "eliminated"'.[2] However, members of the project are not unrealistic. They know how destructive

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[†] See invited commentaries, p. 243–246, this issue.

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episodes of mania and depression can be. They seek to avoid adopting dogmatic positions and 'consistent with the Icarus vision, local groups respect diversity and embrace harm reduction and self-determination around treatment decisions, including whether to take drugs or not and whether to use diagnostic categories or not'.[2]

What is important here is the emergence of a very different way of thinking about madness, diagnosis and treatment. It is not simply a restatement of anti-psychiatry, but rather a quest to define new ways of understanding what it feels like to have bipolar disorder. The Icarus Project and other such organisations do not reject medical input and see that some prescribed drugs can be of use at times. They do not assert that psychotherapy is the answer and avoid the simplistic 'drugs – bad, therapy – good' opposition that characterised a good deal of anti-psychiatry. Crucially, they ask psychiatry to respect diversity and to be open to different ways of understanding states of 'madness' and the different interventions that follow. They want a psychiatry that can think outside the language of psychopathology and that can respect the expertise that they have gained through their personal and communal struggles.

How are psychiatrists to respond? Some will reject such ideas out of hand and simply assert that such groups are 'wrong', 'mistaken' or even 'dangerous'. Some will assert that people who experience episodes of hypomania or depression and who deny that this is caused by disease are deluding themselves. They will assert that members of these groups show a 'lack of insight'. This is understandable given that our medical training leads us to assume that psychopathology represents the unchallengeable truth about states of 'madness', rather than being simply one way of framing these experiences. However, it is hard to imagine how dialogue can take place, if this assumption remains in place and if the expertise of users/survivors is not afforded the credibility it deserves. User/survivor involvement will always be limited to consultation, if psychiatrists continue to assert that the professional position is the only 'scientific' one.

Is a different response possible? How would psychiatry have to change so that we could move beyond consultation and make genuine dialogue a possibility? We have argued for years that it is possible for us to work as doctors with those who experience 'madness' and severe distress in ways that respect the complexity of these states and diverse ways of making sense of them. 'Post-psychiatry' is an attempt to start thinking about how this might be possible.[3,4] Although there is no doubt that radical service user voices challenge psychiatrists, we believe that there are advantages for the profession, if it can engage positively with them. Before this can happen, we must consider critically how we think about science, truth and expertise.

There is a strongly held belief that in the 19th and 20th century science came to replace religion as the central reference point in Western society. However, scientific knowledge does not descend from heaven. Rather, it emerges from the struggles of human beings to cope and survive in the midst of the world. Its concepts, frameworks and explanations derive from these struggles and thus carry with them the trace of the culture and the historical period in which they emerge: its metaphysics, values and priorities. Furthermore, as Kuhn[5] argued, scientific 'facts' only exist within the context of a particular paradigm. Paradigms can and do change.

Understanding certain experiences as psychopathology is one example of a paradigm. This may be helpful for some people in a particular context, but it does not represent a fundamental truth about these experiences. A number of consequences flow from this insight. Most important for us as doctors is the question of how the insights gained from the biological sciences articulate with the diversity of frameworks used by users/survivors – how our expertise relates to theirs. If we are to engage in dialogue with users, survivors and carers about the benefits and limitations of these different approaches, we must engage respectfully with a diversity of frameworks and understand their values, assumptions and priorities. This underscores the need for a greater input from disciplines such as anthropology, philosophy and the humanities in our training. This approach to expertise also emphasises the importance of mental health professionals being comfortable with ambiguity and contradiction, and developing skills that allow them to work alongside users/survivors who reject medical frameworks. We believe that promoting 'critical thinking' in the training of professionals can play a crucial part in this.

Many psychiatrists are beginning to move in this direction. They are keen to work with different groups and are already involved in dialogue of the sort being promoted here. The growth of interest in the profession in the Critical Psychiatry Network (www.critpsynet.freeuk.com/) is evidence of this. In addition, the range of special interest groups in the College is testimony to the fact that an increasing number of clinical psychiatrists are interested in philosophy, history, transcultural issues, spirituality and religion. On an individual basis, many psychiatrists feel tension between the duties prescribed for them under the Mental Health Act and their desire to work in a negotiated way with service users. This is particularly so given accumulating evidence that calls into question the benefits of many of the treatments we use.[6]

Despite this, there remains reluctance on the part of some centres of traditional academic psychiatry to question the authority of biomedical frameworks, which works to undermine attempts to develop genuine dialogue with the user/survivor movement in all its diversity. But, in the end, real science is not a set of fixed beliefs, laws and frameworks but a process that involves, at its core, a spirit of radical doubt. In this vein, science is not something that can (or should) seek to establish 'the truth', but rather something that celebrates questioning and engages positively with diversity.

Declaration of interest

None.

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FRANK HOLLOWAY

Common sense, nonsense and the new culture wars within psychiatry. Invited commentary on . . . Beyond consultation†

In their paper on working with user/survivor and carer groups, Bracken & Thomas[1] throw down a significant challenge to mental health professionals of all disciplines, one that is rather more significant than the casual reader might believe. To fully understand this paper it needs to be read as part of a larger project, namely post-psychiatry. Relatively few readers of this journal will have read the book of this title by Bracken & Thomas[2] but perhaps more would be familiar with their articles in the *BMJ* and *Advances in Psychiatric Treatment* where they outline the tenets of post-psychiatry,[3,4] sometimes labelled critical psychiatry (although I may have missed subtle distinctions between the two constructs).

There is nothing exceptionable about the proposition that psychiatrists should engage in dialogue with users and carers. Medical managers working in England will have the various domains set out in *Standards for Better Health*[5] engraved on their hearts. The 'patient focus' domain of these standards states that: 'Healthcare is provided in partnership with patients, their carers and relatives, respecting their diverse needs, preferences and choices, and in partnership with other organisations (especially social care organisations) whose services impact on patient well-being'.[5] The ways these domains are assessed has been continually updated by the Healthcare Commission[6] and will be in future by its successor organisation, the Care Quality Commission. It is, indeed, something of a truism that psychiatrists need to be sensitive to the explanatory frameworks that our patients and their carers hold. Every day of our working lives we are engaged in a dialogue about the causes of the distress that our patients are experiencing and how this distress might be best addressed. Effective dialogue is, in fact, a core element of good medical practice for all doctors working in the UK.[7]

What is at issue is whether the dialogue that Bracken & Thomas recommend, what is now the Care Quality Commission requirement within the *Standards for Better Health* and what competent clinicians in any case engage in every day of their working life, has quite the subversive impact that the authors predict. They argue that the perspectives of groups that reject the biomedical and psychological approaches which psychiatrists are trained to adopt towards helping people experiencing particular mental health problems somehow undermine or invalidate the allegedly shaky edifice of psychiatric practice.

To support their case, Bracken & Thomas cite the influential philosopher of science Thomas Kuhn,[8] criticise descriptive psychopathology and quote the Editor of the *British Journal of Psychiatry* as providing 'accumulating evidence that calls into question the benefits of many of the treatments that we use'.[9] This is good knock-about stuff, and it is certainly thought-provoking, but is it true?

Although I could not claim the undoubted philosophical expertise that Bracken & Thomas have, there are some oddities about their programme. Kuhn did not hold the radical anti-science, subjectivist views that are ascribed to him and he tried to make this clear in the second edition of his book *The Structure of Scientific Revolutions.* Kuhnian paradigm shifts (if they really occur) do not abolish previous scientific knowledge but absorb it into a better fit with the empirical evidence.

Bracken & Thomas allude to the alleged evils of descriptive psychopathology that is rooted in the phenomenological tradition (these concerns are much elaborated on in their book).[2] It is hard to believe that they have not read the important book by Larry Davidson that uses detailed phenomenological analysis to construct an account of how people can and do recover from mental illness,[10] surely a project that Bracken & Thomas should be applauding. From an immediate practical

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†See editorial, pp. 241–243, and authors' response, pp. 245–246, this issue.