

# update

## USER INVOLVEMENT IN HEALTH AND SOCIAL CARE

### Patient and Carer Participation in Medical Education

**Doctors may know a great deal about diseases, but only the patients who have those conditions or the parents who care for them know what it is like to cope with them day in and day out. The patients have the potential to teach medical students – and maybe even qualified doctors – an enormous amount.**

Perhaps surprisingly, however, most patients who took part in a medical education programme that involved being interviewed by medical students about their illnesses did not see themselves as teaching the students, even though most were adamant that they were the experts about their illness.

Ann Jackson, Community Coordinator at Coventry Primary Care Trust and Associate Fellow of the Institute of Health, Loraine Blaxter, Lecturer at the Institute of Education and Gillian Lewando-Hundt, Director of the Institute of Health, all at the University of Warwick, carried out a study to find out what patients and carers living in deprived areas thought about their participation in medical education.

#### **Patient interviews by students**

The medical students conducted their interviews with patients as part of a module looking at inequalities in health, so by definition their subjects lived in relatively deprived areas. They began by visiting each locality in groups, armed with a vignette that challenged them to imagine what it was like to live there while suffering from a particular illness or needing to seek healthcare. So, for example, they might imagine that they were a pregnant mother with three children under five living in a first floor maisonette: how easy would she find it to get to the health centre, buy healthy food or visit the hospital for antenatal appointments?

Jackson, working at Leicester Medical School with Dr Angela Lennox and Dr Liz Anderson, had already noticed that patients who had been visited by medical students as part of a similar module seemed to change as a result. She said: 'These patients tended to be very anxious before the students came but gradually they became more confident. It was as though they became empowered – it was lovely to see and it happened to patients of all ages.'

At Warwick, with Loraine Blaxter and Gillian Lewando-Hundt, she decided to examine what was happening during this process in

more detail. The paper describing their findings has been accepted for publication in *Medical Education* and will appear later this year.

Warwick students go out to 10 community sites, where groups of four interview individual patients. Between October and December 2000 they interviewed 54 patients, 9 at each of 6 sites. Of these 9, 3 were children (the interviews were with their carers), 3 were adults in mid-life, and 3 were older adults. Each interview lasted an hour, with students encouraged to ask the patients about their views on the strengths and weaknesses of the services involved in their care. All patients interviewed had to have at least three agencies involved in their care, such as a general practitioner, a district nurse and a carer.

#### **Patients' views of their participation in medical education**

Following these interviews, 3 patients from each site were asked if they would take part in a further research study to ask them how they had felt about the student interviews, and how they had understood their role in medical education.

Jackson, who carried out these interviews, believes it is particularly important to seek the views of patients from deprived backgrounds in a study such as this, because, she says, their voice is less likely to be heard than those from more affluent backgrounds.

She and her colleagues found that a key theme in what patients told her was the importance of good communication between patient and doctor. She says: 'In some cases, patients talked about how they had been told of their diagnosis, which may have been a negative experience, perhaps because a nurse or a doctor had been abrupt or left them – in their words – hanging "in mid air" without putting them in contact with someone who could help them. This was, however, usually balanced with descriptions of other staff who had been very understanding or helpful. They talked very favourably of doctors who would sit and explain everything to them, answer their questions, and listen to them.'

#### **In partnership with doctors**

It was also clear from what patients said that they did not want to challenge doctors' expertise or be left on their own to deal with their diagnoses: rather, they wanted to be in partnership with their doctors, and to be listened to.

Most patients (and all the parents) interviewed for this study considered that they were the best judge of their illness (or their child's illness). Yet very few had regarded themselves as teachers

of medical students. Jackson says this is perhaps unsurprising given the negative experience that many of her sample of patients may have had of the education system.

'Clearly it all comes down to good communication,' says Jackson. 'That is the challenge – to equip today's medical students to meet the needs of patients through good communication, in a clinic or general practice consultation where there will be a penalty for keeping other patients waiting.'

## The Interaction Between Service Users and Health Care in Tackling Inequalities in Health



**Users of medical services can also have important messages for other types of care, including social work. Eileen McLeod, Reader in Social Work at the School of Health and Social Studies at the University of Warwick, has explored some of the roles that service users can assume, and the ways in which these roles can help to reduce inequalities in health.**

Eileen McLeod

She says: 'Service users can be "key workers", "expert witnesses" or "researchers" who help to design and deliver research.'

McLeod has examined these aspects of the interaction between service users and healthcare in the context of how social work can contribute to tackling inequalities in physical health.

As she explains in her book *Social Work, Health and Equality* (Routledge, 2000), the 'unjust, unnecessary suffering resulting from socially-constructed inequalities in physical health should be a cause of concern to social workers'; social work is 'implicated in processes which produce and maintain such inequalities'; and can contribute to tackling inequalities in health.

### Service users as key workers

A study by McLeod, funded by the charity Age Concern, exemplifies for her how service users can take on the role of key workers. Her findings are summarised in the report *Facing it Together* (Age Concern, 2000).

This study involved analysing what older women with secondary breast cancer, where cure is no longer possible, found helpful or unhelpful about their involvement with a self-help support group. Such groups were pioneered by C4Ward, an alliance of women with secondary breast cancer, volunteers and professionals, who all realised that support groups that focused primarily on recovery had little to offer those women with secondary disease.

The group that McLeod examined was set up by social workers at a hospice, and facilitated by one of them, and by a volunteer. It has met fortnightly since its start in 1998, and is open to any woman over the age of 60 with secondary breast cancer who is using any of the hospice's services.

An account of the analysis also appears in McLeod's chapter 'Grouping together for equality in physical health', in *Gender and Groupwork* (Routledge, 2003). She writes: 'All members were coping with daunting physical, emotional and social demands associated with their illness. However, their experience also reflected the imprint of gendered, ageist/disablist social relations and relative poverty on ill-health.'

Although this was a small-scale, qualitative study, feedback from the group indicated that groups such as this may improve members' chances of well-being despite their ill health. Group members viewed each other as 'key workers' who could help each other to express their anxieties and concerns more freely. They gained a sense of solidarity from realising that other people were in a similar situation.

The ability to share information benefited the group greatly. For example, group members encouraged some women to ask for more effective pain relief rather than suffering in silence and being unwilling to 'trouble the doctor'. They also encouraged each other to apply for financial benefits to which they were entitled.

McLeod did, however, identify ways in which the group could act to reinforce existing discrimination. All women in the group described themselves as 'white, English' and some discussions among them showed racist undercurrents. McLeod concluded that if any women from ethnic minorities had joined the group, they could have been subjected to discrimination. Similarly, in group discussion it seemed to be assumed that all group members were heterosexual.

### Service users as expert witnesses

Turning to the service user as 'expert witness', McLeod uses this term to describe how older people admitted to emergency units can give their views on the service provided by social workers linked to these units.

Internationally, McLeod says, there has been interest in whether social workers attached to emergency units can help to avoid 'unnecessary' admission of older people to acute hospitals by putting additional social care in place. As yet, however, little attention has been paid to service users' own evaluation of services. Together with Birgitta Sanden Eriksson of Stockholm University (McLeod and Sanden Eriksson, 2002), McLeod concluded that the results pointed towards hospital social work being able to lessen the risks to health that socially disadvantaged service users faced.

They write: 'So, for example, more comprehensive home care for older patients for a matter of weeks following discharge from hospital, can find them a year later more likely to still be living at home and without having had to suffer the trauma of a breakdown in health, necessitating emergency hospital admission in the interim.'

McLeod has explored in greater depth what the service users as 'expert witnesses' thought of this type of service, as part of an initial evaluation of a pilot social worker attachment to an emergency unit at a local hospital (McLeod, 2001). For this study, as well as seeking the views of service users and healthcare staff about the service, she sought written feedback from an older people's forum on both the aims and design of the project.

She says: 'The key finding two or three weeks after discharge from hospital was that while service users identified a range of benefits from the services of the social worker based in the emergency unit, major shortcomings in service provision were already evident due to problems of funding and organisation of social and health care in the community.' This undermined the good work of the hospital social worker. The services put in place were frequently cancelled or terminated by the users because, for example, they were not punctual enough, or, in some cases, had not started.

### Service users as researchers

McLeod is broadening such feedback on her studies to allow her to include service users in their role as 'researchers'. She and Mariann Olsson of the Karolinska Institute in Stockholm are conducting an Anglo-Swedish pilot study, which aims to evaluate what older people who frequently attend hospital emergency units think of the input from the social workers attached to such units. She says: 'Our plan is that an older people's forum will review, on an anonymised

basis, our draft results and their feedback on those will be incorporated into the conclusions of our final report. It is not just the views of the research workers that will count towards our findings.'

## Understanding People's Experience of Cancer



Jonathan Tritter

**If people with cancer are to receive care that is individually tailored to their needs, it is crucial to understand the many and varied ways in which the diagnosis of this disease affects them. The research of Jonathan Tritter, Lecturer in Sociology at the University of Warwick, has focussed for the past seven years on trying to better understand people's experience of cancer and the impact it has on their lives.**

He notes that medical and public health literature has explained the effects of cancer on patients in psychological terms, and applied models of chronic conditions. Yet Tritter argues, that according to his empirical work with patients, carers and health professionals, the experiences of people diagnosed with cancer are – on many levels – different to those with other chronic illnesses.

He says: 'It is important to classify cancer correctly because a diagnosis of cancer brings with it a huge set of issues that are not part of most chronic illness trajectories, but which are essential to understanding how people make sense of having cancer, and how they manage their lives after diagnosis and their treatment.'

### Developing a social model of cancer

Tritter is founder and convenor of the Cancer Study Group within the Medical Sociology Group of the British Sociological Association. The group seeks to promote research on the broader social impacts of cancer on all those affected by the disease. He presented his case for creating a distinct sociology of cancer at the XV World Congress of Sociology in Brisbane, Australia, in July 2002. He has also outlined his thoughts, jointly with Michael Calnan, of the Department of Social Medicine at the University of Bristol, at a workshop sponsored by the Medical Research Council, which was published in a special edition of the *European Journal of Cancer Care* (Tritter and Calnan, 2002).

Although he recognises that cancer has some features in common with chronic illnesses, he believes that, on the whole, it has distinctive characteristics. He says: 'Chronic illnesses have a lower status in healthcare, and the classification of cancer as chronic diminishes the way it is viewed and treated. Most people with chronic illnesses don't have to face the threat of imminent mortality, whereas this is an integral part of a diagnosis of cancer – and it continues to be part of the identity of someone who has had cancer.'

He has identified other distinctions, too. First, most patients with chronic conditions can manage these medically themselves, whereas the treatment for people with cancer relies on complicated medical and surgical interventions and investigations which patients cannot perform on their own.

Secondly, most chronic conditions have a gradual onset, whereas many patients with cancer find out about their illness at a time when they still feel quite well; the diagnosis is often very sudden, and frequently it is the treatment that makes them feel very ill.

## Recognising the broader social impacts of cancer

Tritter adds that an acceptance that cancer is not a chronic condition could act to improve the extent to which cancer is treated in a holistic way. He says: 'Anything that moves away from the definition of chronic illness is likely to improve health workers' appreciation of how that diagnosis affects somebody's life. It also makes it seem less like the responsibility of the individual and more of a joint responsibility together with those who are responsible for his or her care.'

Tritter argues that a sociology of cancer is essential if researchers are to understand the broader social impact of the disease. For patients, such an approach provides a useful counterpoint to the dominant model of the cancer patient, which is heavily reliant on psychosocial oncology and tends to treat patients as passive objects rather than as people taking an active part in their own care. 'This traditional view seems to miss out the way in which being diagnosed with cancer changes people's identity, how it transforms their sense of the future and how, when faced with it, people make active choices about how to live with cancer, and the huge implications that these choices have for their families and friends,' he says.

### References

Jackson A, Blaxter L, Lewando-Hundt G. "Participating in medical education: the views of patients and carers living in deprived communities". *Medical Education* (in press).

McLeod E and Bywaters P. *Social Work, Health and Equality*. London: Routledge, 2000.

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McLeod E and Sanden Eriksson B. "Hospital social work in Sweden and the UK: access to chances of physical health and well-being". *European Journal of Social Work*. 2002: 5(2); 159–169.

Tritter J and Calnan M. "Cancer as a chronic illness? Reconsidering categorization and exploring experience". *European Journal of Cancer Care*. 2002: 11; 161–165.

### Selected Current Research at the University of Warwick in the Area of User Involvement

Dr David Heney (Leicester Warwick Medical Schools, Division of Medical Education). *User Involvement in Childhood Cancer*. Funded by Ward 27 Fund

Dr Janet Read (University of Warwick) Ms. Clare Blackburn (University of Warwick) and Nathan Hughes (University of Warwick). *CARERS online. Evaluation*. Funded by ODPM

Dr Jackie Sturt (University of Warwick, Centre for Primary Health Care Studies) and Dr Hilary Hearnshaw (University of Warwick, Centre for Primary Health Care Studies). *The contribution to research by people living with diabetes*. Funded by Warwick Diabetes Care

Ms. Rose Ruddick (University of Warwick). *Ongoing research literature review on behalf of 'Making Research Count' initiative, for annual regional conference on 20 November 2003*

## Forthcoming Events

The Institute of Health, University of Warwick  
*Series of Three Seminars on the use of Randomised Control Trials in Public Health.*  
 Monday 28th April, Wednesday 4th June and Wednesday 15th October  
 2003, Warwick University  
 For further details please contact Cecilia Olivet:  
 E-mail: Cecilia.olivet@warwick.ac.uk Tel: +44 (0) 24 7657 23164

Department of Health Management & Food Policy, City University  
*ESRC Gene Seminar Series. Cultures of the Gene: Discourses, Dialogues & Debates: Consumption and the Gene: the GM Food Debate.*  
 Wednesday 14th May 2003, City University London.  
 For further details please contact Cecilia Olivet:  
 E-mail: Cecilia.olivet@warwick.ac.uk Tel: +44 (0) 24 7657 23164

Centre for Research into Sport and Society (CRSS) (University of Leicester)  
 Warwick Centre for the Study of Sport in Society (WCSSS) (University of Warwick)  
*Health, Illness and Sport.*  
 16th May 2003, University of Warwick, Coventry, UK.  
 For further details please contact Dr Andrew Parker  
 Tel: +44 (024) 765 23065 Fax: +44 (024) 765 23497  
 E-mail: andrew.parker@warwick.ac.uk

Institute of Medicine, Law and Bioethics, University of Liverpool  
*ESRC Gene Seminar Series. Cultures of the Gene: Discourses, Dialogues & Debates: The Regulated Gene: New Legal Dilemmas.*  
 Wednesday 2nd July 2003, Warwick University.  
 For further details please contact Cecilia Olivet:  
 E-mail: Cecilia.olivet@warwick.ac.uk Tel: +44 (0) 24 7657 23164

'Making Research Count', School of Health & Social Studies, University of Warwick  
*Engaging with Service Users in the Development of Knowledge-based Research and Practice: Issues and Examples from Social Care and from its Inter-face with Health and with Lifelong Learning.*  
 20 November 2003, Rootes Social Building, University of Warwick.  
 For further details please contact Sylvia Moore:  
 Tel: 024 7657 4136 E-mail: Sylvia.Moore@warwick.ac.uk

The Institute of Health, University of Warwick  
*Inequalities in Health: The Acheson Inquiry - Five Years On Evidence, Impact and Future Challenges.*  
 15 December 2003, Warwick Medical School, University of Warwick.  
 Convenors: Sir Donald Acheson, Dr Elizabeth Dowler and Prof. Gillian Hundt.  
 For further details please contact Nihid Iqbal:  
 Tel: 024 7657 4098 E-mail: nihid.iqbal@warwick.ac.uk

## Forthcoming Continuing Professional Development

2 September & 9 December	Initiating Insulin
31 March – 4 April	Applied Pharmacology
31 March – 4 April	Masters in Medical Education – What is Learning?
1 April	PGA Principles of Dermatology
7–11 April	Diploma in Occupational Health – Safety & Hygiene
7–11 April	Management Issues
1 May	Introduction to Research
1–2 May & 3–4 November	Diabetes and Retinopathy
8 May	PGA Principles of Dermatology
9–13 May	Diabetes and the Older Person
12–16 May	Diploma in Occupational Health – Management
14–16 May	PGA in Medical Education
19–23 May	Further Principles of Diabetes Care
5 June	PGA Principles of Dermatology
9–13 June	Diabetes and the Older Person
10–11 June & 2 days tba	Hypertension and Nephropathy
16–20 June	Diploma in Occupational Health Management
23–27 June	Masters in Medical Education – Becoming an Effective Teacher
24–27 June	Counselling Skills for Health Care Professionals in Diabetes
July	Principles of Diabetes Care

4–5 September	An Introduction to Bioinformatics: a practical approach
11 September, 13 November, & 15 January, 12 March, 13 March 2004	Certificate in Diabetes Care Programmes – 5 day programme (September start)
15–19 September	Principles in Diabetes Care module/PGA
23–24 September & 9–10 December	Advanced Leaders Programme – 2 day programme trains leaders to run Certificate in Diabetes Care programme across UK
29 September – 1 October	PGA in Medical Education
30 September, 1 October, 4 February & 17–18 June 2004	Management of the Menopausal Years
15–19 October	Principles of Diabetes Care
17–21 November	Nutritional Managements in Diabetes module/PGA
19–21 November	PGA in Medical Education
4 December & 5 February, 8 April, 3–4 June 2004	Certificate in Diabetes Care Programmes – 5 day programme (December start)
8–12 December	Metabolism and Therapeutics of Diabetes
8–11 December	Techniques and Applications of Molecular Biology

## NEW MASTERS LEVEL CPD COURSES

Social and Health Care Law in Practice and Advocacy Studies  
*Applications being taken now for a September 2003 start.*  
 For further information please contact, Nihid Iqbal, School of Health and Social Studies, University of Warwick, CV4 7AL, Tel: 024 7657 4098, Fax: 024 7657 4101 or E-mail: [Nihid.Iqbal@warwick.ac.uk](mailto:Nihid.Iqbal@warwick.ac.uk)

Postgraduate Certificate in Contemporary Mental Health Practice  
*The Sainsbury Centre for Mental Health & The University of Warwick in collaboration with West Midlands South, NHS Workforce Development Confederation.*

*Applications being taken now for a September 2003 start.*  
 For an application pack contact: Nihid Iqbal, Institute of Health, University of Warwick, Coventry CV4 7AL, Tel: 024 7657 4098, Fax: 024 7657 4101, E-mail: [nihid.iqbal@warwick.ac.uk](mailto:nihid.iqbal@warwick.ac.uk) – [www.warwick.ac.uk/healthatwarwick/](http://www.warwick.ac.uk/healthatwarwick/)

For any other enquiries contact: Mark Hemming, Sainsbury Centre for Mental Health, 134–138 Borough High Street, London SE1 1LB, Tel: 020 7403 8790, Fax: 020 7403 9482, E-mail: [mark.hemming@scmh.org.uk](mailto:mark.hemming@scmh.org.uk)

The Department of Philosophy  
 Postgraduate Awards in Philosophy and Ethics of Mental Health  
 Concepts of Disorder in Psychopathology and Mental Health Practice  
 Case Studies in Philosophy and Mental Health

*Applications being taken now for 28th April 2003 start.*  
 For further details of the programme and an application pack please contact: Dr Tim Thornton, Department of Philosophy, University of Warwick, Coventry CV4 7AL. Tel: 024 7652 3523 ext 22421 Fax: 024 7652 3019

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