

Patient involvement in primary care mental health: a focus group study

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ABSTRACT

Background

Patient involvement in health care is a strong political driver in the NHS. However in spite of policy prominence, there has been only limited previous work exploring patient involvement for people with serious mental illness.

Aim

To describe the views on, potential for, and types of patient involvement in primary care from the perspectives of primary care health professionals and patients with serious mental illness.

Design of study

Qualitative study consisting of six patient, six health professional and six combined focus groups between May 2002 and January 2003.

Setting

Six primary care trusts in the West Midlands, England.

Method

Forty-five patients with serious mental illness, 39 GPs, and eight practice nurses participated in a series of 18 focus groups. All focus groups were audiotaped and fully transcribed. Nvivo was used to manage data more effectively.

Results

Most patients felt that only other people with lived experience of mental illness could understand what they were going through. This experience could be used to help others navigate the health- and social-care systems, give advice about medication, and offer support at times of crisis. Many patients also saw paid employment within primary care as a way of addressing issues of poverty and social exclusion. Health professionals were, however, more reluctant to see patients as partners, be it in the consultation or in service delivery.

Conclusions

Meaningful change in patient involvement requires commitment and belief from primary care practitioners that the views and experiences of people with serious mental illness are valid and valuable.

Keywords

consumer involvement; mental health; primary health care.

INTRODUCTION

Patient involvement in health care has become an increasingly important issue in many countries. In the UK it is driven by a number of different agendas including democratic rights as tax-paying citizens, the desire to increase accountability throughout the health service and, above all, consumerist principles and the patient choice agenda. This last one has generated a 'Patient Tsar' and a Command Paper, *Building on the Best*,¹ which sets out a series of measures to extend patient choice across primary, secondary, and community care.

In spite of this policy prominence, there has been relatively little previous work exploring aspects of patient involvement for people with serious mental illness in primary care. This is significant since serious mental illness affects 3% of the population in the UK,² patients consult more frequently,³ and they are in contact with primary care services for a longer cumulative time than patients without a mental illness.^{4,5}

Although patients with serious mental illness have expressed a desire for greater involvement in their care and in the decision-making process within the consultation, the limited literature in this area suggests these goals have seldom been achieved.^{6,7} Indeed, other recent policy shifts, including the proposed Mental Health Bill,⁸ have intensified the focus on risk management and the safety of the

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How this fits in

Patient involvement is one of the central tenets of the NHS. The relatively limited work exploring aspects of patient involvement for people with serious mental illness in primary care suggests a desire for greater involvement in care that has seldom been achieved. People with lived experience of serious mental illness may be able to offer a range of services to patients in primary care including helping them to navigate the health- and social-care system, and offering advice and support at times of crisis. Employing, in primary care, patients with lived experience may also help address wider issues of poverty and social exclusion for people with serious mental illness.

general public rather than the rights of patients as consumers to choose and be actively involved in their health care.

This article reports the findings of a qualitative study on the provision and receipt of primary care that describe the views on, potential for, and types of patient involvement in primary care from the perspectives of both primary care health professionals and patients with serious mental illness.

METHOD

Participants and methods

Focus groups have been widely used to examine people's experience of disease and health services.⁹ Compared with individual interviews, they are also a potentially more enabling setting for vulnerable people to express their views.¹⁰ The dynamic interaction of the group can also provide insights into attitudes, perceptions, and opinions,¹¹ and dissent between participants can clarify beliefs and reveal underlying assumptions. Eighteen focus groups with between five and 12 people were convened in six primary care trusts (PCTs) between May 2002 and January 2003.

PCTs were purposively sampled to reflect differing levels of deprivation and population density. Patients were broadly defined to include people with recurrent severe depression as well as psychosis such as schizophrenia and bipolar disorder. They were recruited through a wide range of existing community-based patient networks. In each PCT, contact was made with the largest local non-statutory mental health service user group to explain the methods and rationale of the research. The help of that group leader was then enlisted in disseminating information about the study locally and in recruiting other patients using a snowballing technique,¹² (that is, each leader contacted other patients who in turn nominated friends, colleagues, and other contacts).

All GP principals and practice nurses in each PCT were invited to attend a focus group by a

personalised joint letter from the research team and PCT's mental health lead; locum expenses were offered for time away from surgery. This sampling method was used to encourage participation from health professionals with a spectrum of interests in mental health.

Procedure and topic guide

Focus groups were held in non-clinical settings with one of the authors and co-facilitated by another team member who ensured that all responders had sufficient opportunity to air their views and that non-verbal group dynamics were noted. Discussions lasted 60–90 minutes. Separate patient and health professional focus groups were followed, usually 1 week later, by a combined self-nominated group of approximately half of the patients and health professionals who had attended the separate groups. This enabled a more in-depth discussion of ideas that were felt relevant and of value by patients and deliverable by health professionals. No patient was registered at a participating health professional's practice.

The topic guide was developed from a literature review and piloted with patients and health professionals in Birmingham. Patient pathways and healthcare responses were mapped by exploring perceptions of ideal care and current issues in receiving/providing care. Critical incidents¹³ on patients' journeys through the health system from all perspectives were sought. Combined groups additionally explored the roles and responsibilities of patients and health professionals and ideas to improve services. Participants also completed a brief demographic questionnaire; results of these are detailed in Table 1.

Analysis

Focus groups, data collection, and analysis were concurrent and focus groups were continued until data saturation was felt to be complete. The final set of three focus groups was used to explore emergent themes. All focus groups were audiotaped and fully transcribed and two authors each read the 18 transcripts and contemporaneous field notes independently several times and constructed a preliminary thematic coding framework. Disagreements during this process were discussed until a consensus was achieved. Deviant cases, that is, pieces of data that differed from the norm, were actively sought throughout the analysis and emerging ideas and themes modified in response.¹⁴

The Nvivo (QRS release 2.0) computer package was used to manage data more effectively and transparently; data was organised into initial and

then higher codes that provided insight into identified themes. This process was aided by seeking issues with strong group-to-group validation and 'sensitive moments' within group interactions that indicated difficult, but important, issues.

Trustworthiness of the findings was further enhanced through responder validation of the findings at the start of each combined focus group¹⁵ and by sending a summary of each group discussion to all participants for comments on content and emphasis. Two-thirds of the participants replied, all of whom confirmed that they agreed with the findings.

RESULTS

Eighteen focus groups involving 45 patients, 39 GPs, and eight practice nurses were held in six PCTs with Townsend Deprivation Scores ranging from -3.35 to 6.00¹⁶ and population densities per hectare from 1.25 to 36.49 people per hectare. Most participants were white British with an approximately equal distribution of men and women. Patients were aged between 19 and 61 years (mean = 38 years) and health professionals were aged between 31 and 61 years (mean = 46 years).

The most common patient diagnoses were schizophrenia and recurrent depression, with a mean duration of illness of 8.8 years (range = 1–32 years). The mean duration of practice for the health professionals was 21.7 years (range = 7–36 years) for GPs and 23 years (range = 14–34 years) for practice nurses. All patients had seen their GP within the past 12 months and 38 (84%) were in receipt of shared care.

Quotations from the focus groups have been chosen on grounds of representativeness, with only sex, background, and PCT indicated to preserve anonymity. The major and inter-related themes that appear key to understanding patient involvement in primary care were:

- the value of lived experience;
- decision making in the consultation; and
- the importance of paid work.

The value of lived experience

A strong and consistent theme throughout each patient group was the particular experience of living with serious mental illness. The majority of patients felt that the emotions and consequences of mental illness set them apart from the rest of society and meant that only someone with lived experience of mental illness could really understand what they were going through. Assumptions about the relative affluence of GPs was occasionally contrasted with the often financially difficult situations that many

Table 1. Participant demographic details.

	GPs (n = 39)	Practice nurses (n = 8)	Patients (n = 45)
Sex			
Male	25	0	21
Female	14	8	24
Age range (years)			
15–29	0	0	8
30–49	28	5	30
50–70	11	3	7
Ethnicity			
White British	31	7	37
African Caribbean	0	0	2
Asian	6	1	2
Other	2	0	4
Diagnosis			
Schizophrenia			15
Bipolar disorder			4
Recurrent depression			15
Dual diagnosis			3
Anxiety			4
Obsessive compulsive disorder			2
Substance abuse			2
Average duration of illness in years (range)			8.8 (1–32)
Average number of visits to primary care in the last 12 months (range)			7.2 (1–24)
Number of patients currently receiving treatment from secondary care			38
Number of patients who have had in-patient admissions (ever)			35
Number of patients who have had in patient admissions in the last 2 years			20
Number of patients sectioned (ever)			10

patients found themselves in, and made it appear even harder for GPs to appreciate the lifestyle and opportunities available to a person with mental illness:

'The things, the experiences, the emotions, the feelings that we as people suffering from mental distress go through simply aren't experienced by people in good health. The vast majority of doctors probably go through their entire life without ever feeling half of the feelings that we go through. And therefore trying to get that across to somebody who hasn't ever felt like that, you know, the Sword of Damocles is hanging round your neck for no apparently good reason, you know you can't do it. It's like trying to explain colours to a blind man. You're trying to explain an emotive language, a set of emotions, which you know you shouldn't have and normal people don't have, and trying to get these across is an almost impossible task.' (Patient 1, M, Coventry.)

Living with the side-effects of medication was a focus of four of the six patient groups. The meaning of medication, both in terms of the effects on quality of life and the symbolism of 'a life sentence', was a frequent topic of conversation for patients, but appeared rarely to be discussed by the GPs who dispensed medication:

'I'd have to be in bed for certain and I'd need 13 hours sleep and I'd wake up at 10.00 in the morning and I'd have blurred vision and felt like a zombie and then I'd have to lie back down and fall back to sleep or I'd have to have a 2-hour nap in the afternoon because it was knocking me out.' (Patient 2, M, Cannock.)

'I went to see him and I felt lousy and he never said "do you want any help?" he just put me on medication. I said "I don't want medication. I want to keep my brain ticking in its own way" [laughter and clapping from the group]. I'm sorry as I've said before I've seen other people on these medications and it's wrong and I've said no I'm not going to go through that.' (Patient 3, F, Birmingham.)

Patient-run day centres and groups in the voluntary sector were frequently mentioned as an important and reliable source of information about services and alternative treatments, and an important source of vital peer support. In contrast, although the positive value of the peer support available in the voluntary sector was mentioned — GP 1 (F, Cannock) commented that *'I think MIND [a mental health charity] in Cannock is great and I try to get people to go and I talk to them about it a bit and I give them a leaflet'* — it was only discussed by two GPs.

Based on their experience of patient-led initiatives in the voluntary sector, many patients felt that talking to someone with lived experience of mental illness might lead to a number of benefits for patients within the NHS. Talking with someone who had been through the system at the beginning of an episode of ill health might help patients navigate the health- and social-service system more effectively. Patients could also talk through the potential side-effects of different medications and effects on quality of life:

'It's important that users are involved because it's not the doctors that are taking the pills or injections so they should listen to the people when they talk to them. I've been on medication for years and young, black men like me, we stay on it for years. We don't ever come off it.' (Patient 5, M, Birmingham.)

'I mean I would have found it very useful to have spoken to somebody who's been in the system or through the system who could say, "... well OK, you know this is happening to you, you're going to go through this and this and this, well that's probably caused by this. You know I've been through it. I know what's happening and you're probably very confused", and so on and so forth. Now I could accept that coming from another patient but I'm damned if I could accept that coming from a doctor or a nurse.' (Patient 6, M, Coventry.)

'I found that C ... taught me relaxation and how to manage stress, and that actually helps you to manage the symptoms and actually move on which the doctors didn't do.' (Patient 1, M, Coventry.)

'You can offload and then get your head around anything that you might need to get sorted.' (Patient 6, M, Coventry.)

At times of great stress, admission to patient-led alternatives, such as a crisis house, might avert an inpatient admission:

'I think it would be ideal not to send you to hospital or anything but to a crisis house somewhere just nice you know, that you can go and feel safe. You'd be able to talk to someone about what's going on in your head and you'd have an idea that somebody's looking after you not just that you're left on your own.' (Patient 8, F, Birmingham.)

Decision making in the consultation

Few examples were given, by either health professionals or patients, of a 'partnership' approach to the doctor-patient relationship, where patients and GPs shared decision making and appeared to view each other as equals. Indeed, most patients described decisions about medication and referral being made only by the health professional. Most felt unable to challenge the GP because of a lack of information about alternatives and, occasionally, fear of being misinterpreted as difficult and removed from the surgery list:

'When I first went to him, he said "You should have medication". But I didn't want that. And he said he wouldn't be able to treat me if I didn't have medication. His way or no way, you know what I mean. That's when I felt the control had been taken out of my hands.' (Patient 9, M, Worcester.)

'So when he says he'll give me such and such treatment, I don't turn round and say "well, that's rubbish" do I? Um, you know, you can say all these things about saying it, but your doctor can take you off the list. You hear bad cases where people stop going but are desperate for help. So you have to learn not to say boo to a goose. Because you know, if my lifeline is stopped, where do I go from there?' (Patient 2, M, Cannock.)

The few positive examples of mutual decision making from the patient perspective included time to discuss options, provision of information, and exploration of underlying reasons for feelings and behaviours:

'But these days I've got a more relaxed relationship with my doctor and we discuss things and he said you know clearly there's a choice and its got to be your choice. He's put me very much in the driving seat, gives me time and he said he's quite happy to take my word when I'm fit enough to come off the drugs and go back to work but certainly in other surgeries that's not been the case ... when I go and see him, it's an equal relationship. He respects my knowledge of my personal situation and I obviously respect his medical qualifications. And it works very well now. He's done a lot of work and I must give him credit for all that. He did an awful lot of work establishing a proper working relationship between us.' (Patient 1, M, Coventry.)

Many health professionals felt that the opportunity for patients to influence decision making in the consultation was limited by the lack of treatment options, other than medication, they had to offer patients with serious mental illness:

'I mean I know we talk about treatment and we mean medical treatment often, but last week I saw somebody whose parents had separated, who's lost their grandma that she's close to, and lost her job, and she's obviously depressed but obviously tablets aren't going to alter the circumstances. But often in primary care there's little else you can do other than give tablets to feel that they might be able to help them, to help them to cope under circumstances but it doesn't alter the circumstances.' (GP 6, M, Birmingham.)

'It doesn't really deal with the issues does it really?' (Patient 7, M, Birmingham)

'Yeah but there's a lack of resources to help patients come to terms, lack of counselling and

support group, there's just a lack of resources.' (GP 6, M, Birmingham.)

Most also felt that generic pressures on their consultation time together with the lengthy consultations they felt many people with serious mental illness required, meant there was little time left to involve patients in decision making:

'It would be good to give patients a bit more choice, but you know again it's resources, and time and there are not enough bodies!' (Practice nurse 1, F, Cannock.)

'I think certainly sometimes you do get elements where you think "oh thank God it's a sore throat, we'll deal with it, we'll get them out the door and they might not mention the blue cats walking around".' (GP 4, M, Solihull.)

Several patients felt that their lack of involvement also reflected the negative way in which they were often viewed, a factor acknowledged by many health professionals in the combined groups. Most patients reported feeling perceived as malingerers or time-wasters:

'In advance of the consultation I feel I'm wasting their time although I think that's probably inside of me because that isn't really the impression I get from my GP. It's just that each consultation that's what's going on in my mind.' (Patient 10, F, Worcester.)

'That's right, I think that they think that I'm a malingerer. I think they think "oh no not him again".' (Patient 12, M, Worcester.)

'I think that I'm not taken seriously.' (Patient 11, F, Worcester.)

Some health professionals shared negative patient stereotypes of irrationality, poor intellect, and bad time-keeping, which influenced their perception of patients' capabilities to make informed choices. Indeed, the issue of malingering expressed by one GP in a combined group led to a series of argumentative dynamics and revealed the depth and intensity of some GPs' negative stereotypes:

'They don't respond to authority. They will always be chaotic and inadequate.' (GP 2, M, Birmingham.)

'They are notoriously bad at keeping appointments or turning up, you know, so if you

say you want to see them on a regular basis they probably won't keep the appointment and they'll turn up when you're not there.' (Practice nurse 2, F, Birmingham.)

'A lot of them are very poorly educated, so they don't learn about the system in the surgery and they just come whenever they want. And they don't turn up even though they make an appointment. So it's very difficult you know to deal with them.' (GP 3, M, Cannock.)

A further interesting, but more subtle, influence on involvement was a fear of violence, expressed by a minority of health professionals. This may also have had an impact on their ability to see patients with mental illness as partners in care:

'I think there is always a fear of violence, especially when you are on your own in the surgery and it's a one-to-one consultation.' (GP 5, F, Worcester.)

The importance of paid work

Patients in most groups talked about paid work within surgeries as a way of increasing their involvement in their health care. This would enable them to use their lived experience in a positive way by facilitating other patients' pathways and to discuss treatment options and consequences. It might also, in the longer term, be able to help reduce healthcare costs through fewer referrals to outpatients:

'You could actually create another job really by giving somebody who's come on with a mental health problem, somebody who has been a service user and they could probably work in the surgery and deal with people with mental health problems if they were stable enough to do that, because there's no-one better than someone who has been there and done it and knows what you're going through and could probably show you some of their ways of coping, how they coped with it you know what I mean?' (Patient 5, M, Birmingham.)

'... it would actually break down the barriers — there's basically a commonality there — and it might be a way of actually welcoming people into the surgery. It might also be a way of screening people as well as giving information and advice on where to go for tests and things. It could be a number of things really. It might also be a way of actually lessening the load on GPs themselves ["yes" throughout the group].' (Patient 8, F, Birmingham.)

Many also felt that paid employment would help address wider issues of poverty and social isolation. A minority of patients, however, recognised that being accepted as part of the primary care team would require more than a name badge, and that, for example, professional hierarchies would create additional difficulties for patients in terms of being accepted as part of the healthcare system.

'I think it would be a very good idea especially if you're coming out of your mental health problem and you're looking for some kind of employment. To just know that I'm helping taking a load off GPs and helping the GPs to do their job better would be good.' (Patient 6, M, Cannock.)

'... when you phone up and say this person does need to see you, you wouldn't necessarily get listened to as a professional would you, so there's a bit of bridge-building that needs to be done.' (Patient 4, M, Cannock.)

'I mean how long have you got to be stable for, to prove that you've been stable before you're good enough to get real work because I mean we are good enough to do voluntary work you know [agreement]. I mean that's the big thing. I did volunteer there and I helped there 3 days a week and I'm good enough for paid work you know ... It's a problem because I'd love to get a job within the NHS around mental health issues because I've suffered myself and so I can relate to people and I can offer a shoulder a cry on, but nobody seems to want to know me.' (Patient 7, M, Cannock.)

Two combined groups discussed the potential value of employing someone with lived experience of mental illness within the surgery. However, although this was seen as positive in theory, practical barriers, such as a lack of sustainable funding for such a post, were always raised by health professionals. As explained by GP 8, F, Birmingham:

'I like the idea of someone being attached to the practice who's a mental health service user who might well be able to bridge some of the gaps at the present. But how do you move on from an idea to making it something in reality. It's much harder isn't it?'

Another barrier included the unpredictable nature of patients with serious mental illness. Some health professionals felt that such factors might make voluntary work more appropriate than paid employment.

DISCUSSION

Summary of main findings

This study suggests that patient involvement in primary care mental health is not well developed. Although acknowledging that involvement is important for many patient groups, not just those whose members have a mental illness (www.expertpatients.nhs.uk), this is a group of people who have little choice or voice in social life and for whom the consequences of illness in terms of unemployment, poverty, and social exclusion have a greater impact than those with many other conditions.¹⁷ Involvement, we would argue, is therefore particularly important for people with serious mental illness.

The study highlights the potential of people with lived experience of mental illness in terms of improving patient pathways in primary care and patients' desire for greater involvement in their care. It also suggests that many health professionals are resistant to the idea of greater patient involvement both within the consultation in terms of treatment choices and as part of the wider practice team.

Comparison with existing literature

This study supports previous work that suggests that patient involvement in primary care mental health is often acknowledged as a 'good thing,' but is relatively rarely acted upon in practice.⁷ It further reinforces the pervasive influence of negative stereotypes of serious mental illness on health professionals' attitudes and behaviours.⁶ It also echoes the findings of relatively limited patient involvement in secondary care mental health.¹⁸ Some of the data, around the practical value of lived experience and ways in which it might be effectively utilised in primary care are, however, significantly different from previous work.

Peck *et al*¹⁹ have constructed a useful schema in the context of secondary mental health care, with three distinct concepts of patient involvement as recipients, subjects of consultation, or agents in control. At the same time, they suggest patient involvement within mental health services operates at four levels:

- the interaction between patients and the form of self help;
- the interaction between individual patients and professionals working with them;
- the management of local services; and
- the planning of overall services.

Peck *et al* argue that if these two frameworks are combined, it is possible to construct a matrix for patient involvement (Box 1). They suggest that although the matrix illustrates the sheer diversity of mental health patient involvement activities in the UK at the present time, many initiatives are clustered in the consultation category with the 'patient control of

the overall service' planning box significantly empty.

The results of this study suggest that in the context of primary care, although there are a number of positive examples of 'interactions between patients' — particularly in terms of support and advice in the voluntary sector — interactions with primary care health professionals appear to mostly consist of patients being recipients of care, as opposed to partners in the management of it. However, the matrix also usefully highlights practical ways in which patient involvement from a secondary care perspective could be used to improve involvement in primary care mental health.

Strengths and limitations of the study

There has been relatively little previous work that addresses the views of people with serious mental illness from a primary care perspective, and almost none that encompasses the dual perspectives of recipient and provider.²⁰ The success of the study methodology, particularly the use of mixed focus groups, where health professionals and patients were able to share their views in a largely constructive manner, also strengthens the notion of greater patient involvement in primary care mental health.

A number of limitations affect the utility of the results. Although all GPs and practice nurses within

Box 1. Examples of patient involvement in England (Peck *et al*¹⁹).

LEVELS OF INTERACTION	CONCEPTIONS OF PATIENT INVOLVEMENT		
	Recipient of communication	Subject of consultation	Agent in control
INTERACTION BETWEEN PATIENTS	Newsletters Periodicals	Advocacy schemes	Hearing voices Newsletters Periodicals
INTERACTION BETWEEN PATIENT AND PROFESSIONALS	Receiving care plans^a	Agreeing care plans	Direct payments
MANAGEMENT OF LOCAL SERVICES	Receiving information services	Patient councils Patient surveys 'User-focused monitoring'	Patient-run crisis houses Social firms
PLANNING OF OVERALL SERVICES	Community care plans	Mental health taskforce membership Stakeholder Conferences Patients on local implementation teams	

^aThe area in bold shows that patients' interactions with primary care health professionals appear to be predominantly in terms of their being recipients of, rather than partners in, care.

the six PCTs were invited to participate, only about 8% agreed to. However, comparisons with UK national statistics suggest that the age range, sex, and ethnicity of the GPs were representative of GPs across England and Wales.²¹ Patients were also self-selected but represented a broad range of age, ethnicity, and self-perceived diagnoses. Practice nurses, however, were poorly represented and their voices and opinions were rarely heard in the focus groups. This may reflect the professional hierarchy within many practices and perhaps their relative lack of involvement in the care of people with serious mental illness.

Implications for clinical practice and future research

As the recent Chief Executive's Report to the NHS suggests, the challenge for the future NHS is to:

*'move from being a service that simply does things to or for people to one which works with them in supporting them to make decisions about their health and about the services they will use.'*²²

Utilising patients' lived experience through paid employment in primary care is one way of turning such policy aspirations into practical reality. Employing patients who understand the realities of living with mental illness could not only provide a range of services that patients have been highlighted as important, but also begin to address the significant problem of social exclusion.²³ This is already beginning to occur with the advent of support time and recovery workers for whom lived experience of mental illness is key, and in the broadening of the criteria for graduate primary care mental health workers to include this as a desirable requirement.

Enabling such positive contact between patients and health professionals could also challenge some of the negative stereotypes of violence and irrationality that appear to act as a barrier to greater involvement,²⁴ and perhaps also encourage a partnership approach to decision making in the consultation. However, strategies for greater patient involvement also have significant implications for funding primary care, both in terms of employing patients in new roles and addressing the consequences of potentially longer consultation times required for shared decision making. In a world of performance-related targets and practice-based commissioning, patient involvement may not be a high priority. Perhaps, above all, a meaningful change in patient involvement, therefore, requires an attitudinal shift towards a commitment and belief from primary care practitioners that the views and experiences of people with serious mental illness are valid and valuable, and need to be listened to at a consultation and practice level.

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Ethics committee

Ethical approval for this study was granted by the West Midlands Multicentre Research Ethics Committee (MREC/01/7/32)

Competing interests

The authors have stated that there are none

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