

Debate & Analysis

The role of patients in UK primary care:

from the extraordinary to the essential

THE EXTRAORDINARY

Why involve patients in primary care practice, research, or policy at all? Surely the trained health professional or policy maker knows best?

I believe that every GP, researcher, and policy maker works to improve the healthcare system and the quality of healthcare for patients. Working closely with patients and the public can help GPs, researchers, and policy makers to improve their work, and can also create a virtuous circle, leading to improved quality of care for patients.

Traditionally, the doctor 'took' a history, hardly ever admitting ignorance or uncertainty and when a test was inconclusive had a tendency to imply that the lack of diagnostic certainty was somehow the patient's fault. In her 1880s diary, Alice James sums up the effect that the medical interview could have on patients:

*'One has a greater sense of intellectual degradation after an interview with a doctor than from any human experience.'*¹

I fear things have not changed as much as doctors might believe. I have felt like this in the past and, in my years as a participant, volunteer, and employee of the Expert Patients Programme (EPP) it came up time and time again.

Patient and public involvement (PPI) in primary care research and policy began with the changes in society of the 1960s, with mental health in the forefront. Examples of PPI include the Mental Patients Union, which was formed in 1973 and became the Campaign Against Psychiatric Oppression in 1985, and the radical action group Mad Pride in the 1990s.

At the same time GPs were also thinking about patient involvement in their surgeries. Working independently, GPs began to set up patient participation groups (PPGs) in 1972 to discuss the provision of primary care.² By 1981, 19 practices in the UK had some kind of PPG. The National Association for Patient Participation was formed in 1978 as an umbrella organisation.³ A disquiet at the lack of accountability in primary care, mirrored in wider society by the growing consumer movement, also led to the formation of The

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Patients Association. Policy makers responded to consumerism by setting up the Community Health Councils in 1974, now being re-created through Local HealthWatch. Patient involvement in primary care research was very limited until the early 1990s when Involve was set up, leading the way in involving lay people in the decisions about what research should be funded.

THE ORDINARY

The battle to make patients' voices heard is not yet won, but we have come a long way. The first legislation passed to compel authorities to involve the voices of patients was Section 11 of the Health and Social Care Act 2001. Some may see this as 'political correctness,' suggesting that the patient representatives are tokenistic. There has also been the age-old problem of recruiting the 'right' people: people without a particular issue, with some knowledge, but without a detailed professional perspective; people who wouldn't be a shrinking violet, who would stand up to the

doctor, professor, or chief executive. Over the last decade, patients and health professionals also began to realise that to make health 'patient centred', patients needed to be included in research as more than the subjects of the process.

The EPP has had a significant influence on the development of PPI. The primary method behind EPP was developed in California by Kate Lorig, an American professor. Her work with people with arthritis made her realise that many with the condition have developed ways of coping and solving problems. Professor Lorig and colleagues pooled this information to develop a course that would help people manage their own arthritis. This led to the Chronic Disease Self-Management Program, on which EPP courses are based.

The EPP came to the UK when Jean Thompson (now MBE for her work with EPP) and a friend took it on themselves to go to Stanford University to train as tutors in this programme. On their return, they encouraged third-sector organisations that



The Royal College of General Practitioners' Patient Partnership Group, June 2011. Clockwise from left: Harvey Ward, Dr Tamsin Booth, Imogen Shillito, Dr Mary Selby, Saqib Ahmad, Antony Chuter, Dave Sharp, and Barbara Pendleton.

"For researchers, coproduction means researchers working with patients directly."

they worked for to adopt the programme. The then Chief Medical Officer Sir Liam Donaldson decided to fund a NHS pilot for 3 years and EPP is now widely accepted as an important part of the PPI agenda.⁴ So far over 80 000 people have attended an EPP course and 1700 people have been trained as tutors.⁵

THE ESSENTIAL

Over 40% of general practices in the UK now have PPGs.³ Although these groups have limitations and it is impossible for a PPG of 12–16 people to represent a population of several thousand, they can bring an important patient perspective to the table and connect with the seldom-heard voices in that population. They can also be a critical friend to the practice. In April this year, the Department of Health released details of the Directed Enhanced Services to improve patient participation as part of the recent changes to the General Medical Services contract for 2011/12. From April 2011 for 2 years, GP practices will be required to promote the proactive engagement of their patients through 'Patient Reference Groups' and to undertake local surveys. So PPGs may finally be moving from the extraordinary to the essential.

But such activities are still not enough. We need to work towards coproduction of services, with practices beginning to share their problems with patients, letting patients help with the solutions, and be in at the very inception of the solution. This includes controversial possibilities, such as sharing practice accounts and GP commissioning consortia being established as 'community interest' companies. For researchers, coproduction means researchers working with patients directly, both to identify and refine the research question, and also to act as part of the research team.

The UK National Institute for Health Research has helped in this process by suggesting, and in some cases insisting, that research projects ensure that patient views are a central part of the application and decision-making processes. When Directed Enhanced Services are no longer part of the fabric of primary care, will PPI

have imprinted sufficiently onto all practices that they are as essential?

Only when we have such coproduction, when we no longer have to make a special case for PPI, will the role of patients in primary care practice, research, and policy have moved from the extraordinary to the essential.

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