

King's Fund

Executive Summary

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CHANGING RELATIONSHIPS

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changing relationships

Findings from the Patient Involvement Project

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Executive Summary

In the past few years, rapid and significant changes have taken place in the social, political and policy environment in which health professionals and patients interact. This paper reports on the Patient Involvement Project, a King's Fund study that assessed changing relationships between health professionals and patients/clients in a changing health environment.

Part one of the report constitutes a policy analysis that sets out the context for changing relationships. Part two reports on an empirical study designed to contribute towards a fuller understanding of changing relationships and patient involvement in health care.

Part one: policy analysis

Social changes, organisational changes and changes within professional groups have started to challenge traditional relationships in health care, in particular the power of medical professionals.

Throughout the 1980s and 1990s, governments set out policies designed to facilitate an increasingly consumerist approach to health services. This process gained momentum in 1997 when the Labour Government came to power with a commitment to provide a more open, accountable and patient-centred service.

Several high profile inquiries in the past few years have also provided a catalyst for changing the relationship between patients and clinicians. This has led to higher expectations for the provision of information and the sharing of power and decision-making in individual clinical encounters, and has put the spotlight on face-to-face relationships in health care services.

So far, developments have focused mainly on macro-level public participation, and although the quality of face-to-face relationships is difficult to measure, progress towards empowerment, the sharing of power, increased patient choice and patient-centred care appears less well advanced. The extent to which the service will become truly more democratic, and to which the Government will relinquish central control, remains to be seen. There also remain unresolved moral questions about equity of access and how far choice might reasonably be devolved to service users in an environment of finite resources.

Further work is needed to establish what goes on in individual, face-to-face clinical encounters, and the extent to which stakeholders are taking forward an agenda of patient-centred care and the sharing of power in clinical encounters. In addition, the extent to which attitudes and culture are changing within the service in accordance with public expectations needs to be considered. Part two of the report sets out the findings from an empirical study designed to contribute to this.

Part two: the study

The empirical part of the project assessed changing relationships and the meaning of patient-centred care. Forty-five semi-structured interviews were carried out with stakeholders drawn from a range of key areas. These included:

- the Department of Health and health policy agencies, including the Commission for Health Improvement, the Modernisation Agency and the National Institute for Clinical Excellence
- medical and nursing schools
- regulatory bodies
- patient/user groups
- consumer organisations
- senior officers from the Royal Colleges and professional organisations.

The key questions addressed

The key issues addressed in the study emerged from a small series of pilot interviews that helped to shape the main research and highlighted areas of particular concern to the stakeholders involved. The key questions included:

- What is meant by patient-centred care?
- How well is patient-centred care understood by key stakeholders?
- Is there commitment among stakeholders to forge a patient-centred agenda in health care?
- What is currently being done in these groups to forward this agenda?
- What are the barriers to the provision of patient-centred care?

Findings

Analysis of the data involved looking for patterns and categories in respondents' accounts. A range of key themes emerged:

Considerable disparity in understanding of patient-centred care

There is a wide gulf between the published literature on shared decision-making and patient-centred care, and respondents' understanding of these.

Although respondents often described the need for partnership and placing patients 'at the centre', different groups described patient-centred care in different ways:

- **Biomedical approach** Health professionals generally adopted a biomedical approach to patients' treatment decisions
- **Social model** Members of user groups more often adopted a social model, drawing on their whole life experience of illness, disease and disability.

Tendency to re-brand existing activities as patient-centred care

Given the lack of clarity surrounding the meaning of patient-centred care, and therefore how to achieve and evaluate it, it is not surprising that different groups within the service tended to focus on their own area and redefine this as patient-centred care. This was particularly apparent in three areas:

- **Communication skills** Conflating the teaching of communication skills with patient-centred care in the professional education of health professionals
- **Quality assurance** Reconfiguring quality assurance as patient-centred care
- **Public participation** Collapsing patient-centred care into public participation.

Barriers to change

The barriers to providing a patient-centred service highlighted by respondents were:

- **Attitudinal change** Although there was evidence of attitudinal change among some respondents, there was also evidence of intransigence and the persistence of medical paternalism.
- **Resources and inflexible structures** Although there was evidence of some innovation, respondents emphasised that the changes needed to promote a patient-centred service would not be possible without access to adequate funding and staffing levels, and in a climate of low morale.
- **Social divisions and social exclusion** Respondents highlighted the difficulties in delivering a patient-centred approach amid social divisions, social exclusion and among different cultural groups.

Conclusion

A lack of direction from the Government and service leaders, and a lack of clarity in the use of the term among stakeholders, has given rise to confusion about the meaning of the term 'patient-centred care'.

A fuller understanding and better co-ordination across different functions of the service is needed in order to facilitate a coherent approach.

Policy initiatives to democratise the service and to make it more patient-centred have focused predominantly on public participation and lay involvement at the macro level. They have focused less on changing the culture, attitudes and behaviour of professionals – approaches that are necessary to affect face-to-face encounters between individual health professionals and patients.

Although there was evidence of intransigence among some respondents, there was also evidence of enthusiasm, self-reflection, and innovation among others.

It remains to be seen whether barriers can be overcome, and whether recent increases in resources will be enough to generate the wider transformation of the service needed to affect individual clinical encounters.

The continuing grip on services exerted by central Government casts doubt on the extent to which power and control can really be shifted to patients. Crucially, the extent to which

these changes will affect the culture, attitudes and behaviour of those working in the service, and transform power relations in face-to-face relationships between professionals and patients, also remains to be seen.

Recommendations

- Patient-centred care has a wide spectrum of meaning. Greater clarity and leadership is needed from all stakeholders including ministers, policy-makers, senior managers and health professionals in relation to the widely used yet poorly understood concept of patient-centred care. Patients, users and carers also need to be central in defining and evaluating patient-centred care.
- In order to help health professionals design, plan and deliver patient-centred care, there is a need for wider research that draws on and explains face-to-face relationships between professionals and patients.
- The Government and taxpayers need to understand that adequate resources will be needed to transform face-to-face encounters as patient-centred services will almost certainly be more costly in terms of time, manpower and wider resources.
- Patient-centred care, shared decision-making and patient information all need to be recognised as separate from the macro-issues of public participation. Greater clarity is needed on how these might affect each other. For example, a more democratised service might lead to greater choice for individual patients, but public participation is distinct from patient-centred care.
- Patient-centred care means different things to different professional groups within the service. Each of these is an important component. There is a need for better co-ordination across the service in order to encompass the full spectrum of patient-centred care.
- Challenges for the future include the need to change practice, attitudes, structures and philosophy in order to promote a modern approach to health care delivery in which power and decision-making are shared and face-to-face relationships are more equal. Health professionals need to be equipped with new skills in order to meet these challenges.
- Professional bodies need to take a proactive position in transforming face-to-face relationships with patients. For example, their role in self-regulation and maintaining standards needs to include promoting patient-centred care and monitoring face-to-face clinical encounters with patients.
- Increased access to information for patients is a key aspect of patient-centred care. The Internet has already transformed communication and access to information for many. New technologies are already opening up opportunities for new and different relationships between health professionals and patients, and the scope for this is set to increase. Opportunities for quick and easy access to information for professionals and patients alike need to be grasped, as well as opportunities for innovative ways of delivering services through, for example, teleconferencing.

- There is a need to change the culture, attitudes and behaviour of those providing the service. In addition, changes are needed in the way that consumers use services that extend beyond the role of health services. Other agencies – such as education services, local authority library services, social security and immigration services – all need to work together to enable citizens to make appropriate choices in their health care. In addition, in an increasingly litigious society, individuals need to develop the knowledge and skills to enable them to share the burden of responsibility for treatment choices.