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CHANGING RELATIONSHIPS

Findings of the Patient Involvement Project

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Changing Relationships: Findings from the Patient Involvement Project

ROSEMARY GILLESPIE, DOMINIQUE FLORIN AND STEVE GILLAM

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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.

Introduction

The exchange and provision of information is at the core of an open and honest relationship between healthcare professionals and patients.

(www.bristol-inquiry.org.uk)

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. The recommendations following the inquiry into children's cardiac services at the Bristol Royal Infirmary include wider involvement and access to information by patients and their families, and increased partnership, honesty, transparency and openness with patients, carers and the public. There is a growing momentum for change in the way that health professionals, particularly those in the medical profession, engage with patients and the public.

During the late 1990s and early 2000s, the Government outlined various policies that were designed to facilitate increased public and patient involvement in the NHS, and to make it more responsive, inclusive and accountable to the needs of those who use it (Department of Health 1999, 2000, 2001).

Similarly, many health professionals have been instrumental in the promotion of increased patient involvement in decision-making, which is seen as pivotal to improving the quality of care (Elwyn *et al.*, 1999a; O'Connor and Edwards, 2001).

These social and policy changes have, in turn, affected relationships between groups of health professionals, on the one hand, and between providers and consumers of health care, on the other. The public and patients are becoming increasingly involved in partnerships at the level of policy, planning and delivery of services. The term 'patient-centred' care has come to be used widely by those in government, policy analysis and service delivery. Yet what does the term 'patient-centred' mean? In what ways might relationships with health professionals and services change, and how might we evaluate these changes as an approach to patient care and service delivery?

This paper reports on a King's Fund project that focused on changing relationships between health professionals and patients/clients in a changing health environment. Part one provides an analysis of the social, policy, professional and organisational context for wider patient choice, shared decision-making and patient-centred care. Part two presents the findings of an empirical study that considers the extent to which key stakeholders are taking a patient-centred agenda in health care forward.

Finally, the report provides recommendations that it is hoped will contribute to the promotion of an increasingly patient-centred approach to patient care in the health service.

Part one: policy analysis

Medical sociologists have used the terms 'deprofessionalisation' and 'proletarianisation' to describe the effects on medicine of wider social trends that have affected occupations which enjoyed privileged status on the basis of their technical expertise in late twentieth century societies (Haug and Lavin, 1983; McKinlay and Arches, 1985; McKinlay and Stoeckle, 1988; Weiss and Fitzpatrick, 1997; Barnett *et al.*, 1998). However, whereas proletarianisation places most emphasis on the changing working conditions of doctors in terms of salaried practice and management control, deprofessionalisation stresses the changing relationships between doctors and patients (Elston, 1991). Although this literature focuses predominantly on health care in the USA, to some extent both these processes can also be seen to be occurring in health care in the UK.

Social change

Significant social change in recent years has had a major impact on the way that the public views health professionals, particularly the medical profession. This process of deprofessionalisation is linked to wider social transformations, as a result of which, some writers argue, medical knowledge is becoming increasingly demystified and the power of the medical profession diminished (Hardy, 1999).

An increasingly critical media, an improvement in general levels of education, and the increased availability of information technology, particularly the Internet, have made information about health issues, illness and disease readily available to a growing number of individuals and have contributed to challenges to medical power. Although not all Internet sites provide high quality information, and wider knowledge is often necessary to enable individuals to interpret material objectively, specialist knowledge that was previously accessible only to specific, hegemonic professional groups through academic databases and professional journals has become more widely available. Evidence of the impact of this on individual clinician-patient relationships is currently sparse, but, as Hardy (1999) suggests, the potential for the Internet to transform these relationships may be significant.

Challenges to medical dominance by self-help groups and patient organisations can be traced back as far as the 1960s, and have come to be a catalyst for change in the relationship between providers of care and service users, promoting self-help, independence and taking control of health and illness. For example, in the 1990s, increasingly empowered and articulate young, male homosexuals challenged their prejudiced status and articulated their demands for the treatment of HIV and AIDS (Squire *et al.*, 1991; Johnson *et al.*, 1993).

Other challenges to medical paternalism have come from a feminist critique challenging medical control over female sexuality, fertility, reproduction and mental health (Ehrenreich and English, 1976; Savage, 1986; Miles, 1988; Ussher, 1991; Oakley, 1993).

Similarly, the rise in the number of patients seeking complementary therapies has helped to generate a climate of demand for more patient-focused services (Gordon, 1995; Trevelyan, 1998). In addition, patients have become more litigious, with a consequent increase in medical negligence claims: the number of claims rose by 72 per cent between 1990 and 1998, and 10,000 new claims were received during the year 1999–2000 (National Audit Office, 2001).

Finally, several high profile inquiries have highlighted the failure of some within the medical profession to live up to the standards expected by the general public. These include the inquiry into children's cardiac surgical services at the Bristol Royal Infirmary between 1984 and 1995, and into the removal, retention and disposal of patient organs at Liverpool's Alder Hey Hospital in 1999. The extent of public disquiet and long-term damage to individual relationships between clinicians and patients that these have caused is difficult to measure. Nevertheless, the recent lack of public confidence over the MMR (measles, mumps and rubella) vaccine shows that such failures in the partnership between professionals and patients can have repercussions in the arena of public policy. The effect of this has been for policy-makers to place patient and public involvement high on the political agenda, and has led the way for a more open, honest and informed approach to the consumption of health care services.

Policy framework for wider patient choice

Traditionally, the provision of health care was based on medical paternalism, under which doctors were the key decision-makers and patients were passive recipients with few opportunities to participate in decisions about policy or treatment, or the planning of services (North, 1997).

Through their privileged position in the professional and organisational hierarchy, doctors have had the power to influence the organisational culture, professional practice and ethos in the NHS since its inception in 1948. The profession's close and influential association with policy-making resulted in doctors being able to influence resource allocation and define as 'professional issues' areas that they alone were qualified to manage (Klein, 1989). Nursing, midwifery and other allied semi-professions (Etzioni, 1969) remained subordinate and weak against medical dominance and paternalism. However, in the 1980s, a political climate of strong Conservatism, demands for greater accountability and control emerged.

The Thatcher and Major governments of the 1980s and early 1990s articulated commitment towards a more consumerist service through policies such as the quasi-consumerism of the internal market, wider scrutiny of the medical profession through medical audit, and the *Patient's Charter*, designed to make services more responsive to patients' needs and for the first time set out patients' rights. Similarly, Local Voices (Department of Health, 1992) required health authorities to take account of the views of local people in the planning of services.

However, although these reforms were radical and wide-ranging for their time, they were mostly concerned with improving efficiency and value for money. Tensions remained between what was still a predominantly 'top down' approach to policy-making and an expressed commitment towards a more consumer-oriented service. Little was done to address underfunding, or to provide consumers with a real choice of services or access to them (*Health Care UK*, 1990).

In comparison with many other developed countries, the British health service has traditionally been a relatively 'low choice' system (Florin and Coulter, 2001). Patients register with one general practitioner (GP), who then acts as 'gatekeeper' to specialist services, rather than being able to enjoy open access to specialist services. Similarly, secondary health care is provided on the basis of local contractual arrangements whereby patients do not generally choose either the specialist or the hospital at which they receive their treatment.

The idea that patients and the public should be more fully involved in the service and that it should be more responsive to patients has gained support and has increasingly come to dominate political and policy discourse on health care. In addition, since the election of the Labour Government in 1997, terms such as 'public involvement' and 'patient-centred care' are increasingly common in political speeches and policy processes. The precise meaning and extent of these terms, however, has not been made clear.

Prior to the general election, the Labour Party had articulated in its manifesto a commitment to a wider scrutiny of the service and increased public involvement. Since coming to power in 1997, a range of initiatives has been rolled out. *The New NHS* (Department of Health, 1997) and *The NHS Plan* (Department of Health, 2000) set out plans for increased access to information and greater transparency over performance and quality of local services through the National Performance Assessment Framework (NPAF) and the Commission for Health Improvement (CHI).

Similarly, the yearly National Patients' Survey was set up to evaluate patients' experiences of the NHS. In 1998, clinical governance was introduced to provide a systematic approach to the delivery of high quality care with 'patient-centred care at the heart of every NHS organisation' (www.cgsupport.org). A new system for complaints is currently being established that will work closely with the new Patient Advice Liaison Services. Since 2002, trusts have been required to produce patient prospectuses that include information on services, performance, and their response to issues raised locally by patients.

Central to the Government's agenda to facilitate wider public involvement has been its expressed commitment to increased patient choice. This was one aim of developments such as NHS Direct and Walk-in Centres. However, although these services have generally been well evaluated by those who use them, and can provide access to services for patients not registered with a GP, evidence also suggests that these services may not reach those in greatest need (Appleby and Coote, 2002).

Further measures to promote patient-centred services and increased choice have included *The Expert Patient* (Department of Health, 2001), which established a range of self-managed programmes designed to draw on patients' own skills and knowledge in the management of chronic illness. The proposed establishment of the Commission for Patient and Public Involvement in Health, a new public body charged with the task of empowering individuals and communities, is designed to ensure the NHS listens and responds to patient needs.

Since 1997 there has been an escalation of rhetoric and the introduction of policies designed to increase public involvement and extend patient choice. However, in reality they do little to challenge the dominance of the medical model or offer alternatives to existing provision. In addition, tensions exist between the

development of new structures for public participation and existing organisations. For example, the proposed abolition of the independent and often highly critical Community Health Councils and their replacement with potentially less independent groups located within the health service itself, such as Patient Advice Liaison Services, has caused widespread debate and disagreement. Although the Government has emphasised that levels of public participation and patient choice will be significantly increased, so far it has relinquished little control.

Organisational change

Organisational change has been a feature of the NHS since its inception in 1948, but the focus has been primarily on changing organisations and structures rather than on face-to-face relationships. Since the late 1980s, however, the pace of change has increased in ways that place huge pressures on health professionals, requiring them to play a greater part in management and in running health organisations, while also carrying out their professional roles.

The advent of new primary care organisations – Primary Care Groups (PCGs) and Primary Care Trusts (PCTs) – the reconfiguration of trusts, and the development of partnerships between health care providers and social care services, all offer new opportunities to professionals and patients alike for increased partnership and democratisation. The additional responsibilities associated with these new structures provide new challenges as well as potential distractions from the business of improving the way that individual practitioners engage with patients.

Changes to the contractual arrangements and working practices of health professionals, particularly the new GP contract, might impact on professional hierarchies, and in particular medical power, by removing practitioners' autonomy over the way they provide services and share roles with other health workers. In addition, clinical governance increasingly determines and restricts what individual practitioners are able to do by placing responsibility for quality on individuals and teams providing care, making them externally accountable for the care they provide.

Clearer lines of responsibility and accountability for the quality of care provided should be welcomed. Yet locating these responsibilities in provider organisations, rather than, as in the past, for example, in the Royal Colleges, provides a challenge to professional power, and is seen by some as undermining the privileges of professional status or 'traits' of self-regulation and autonomy traditionally enjoyed by professional groups (Greenwood, 1957).

Similarly, recent Department of Health initiatives to improve performance include a 'star rating' system of measuring, rewarding and punishing those parts of the NHS perceived to be doing well or badly. However, these may be a blunt instrument for measuring quality and can serve to undermine professional morale.

In recent years, professional organisations, partly in response to public criticism and pressure and a more democratic ethos, have embraced wider public involvement and greater transparency in their affairs. Increased consultation with patients and the involvement of consumer groups in the affairs of professional bodies have resulted in the growth of public involvement through, for example, patient liaison groups within Royal Colleges and the British Medical Association (BMA). In addition, modernisation and wider transparency in regulatory bodies

such as the Nursing and Midwifery Council (formerly the United Kingdom Central Council for Nursing and Midwifery) and the General Medical Council (GMC) have included a greater role for lay members and lay participation. Other examples include the constitution of the Commission for Health Improvement (CHI), which requires at least eight of its 14 commissioners to be lay members.

Further changes in the organisational culture of the service have recently helped to transform doctors' relationships with other health care practitioners. Traditionally located at the apex of the medical occupational hierarchy, doctors have seen their roles transformed by changes or 're-engineering' of the roles of other health care workers. Examples include the extension of the role of the nurse into traditional areas of medical practice such as nurse prescribing and patient consultation, the latter in NHS Direct and nurse-led walk-in centres. Although on the one hand these types of service provision may be seen to provide wider patient choice of the style of consultation, they are seen by some professionals as undermining the traditional doctor-patient relationship and being disruptive to continuity of care (Jones, 2002).

Barnett *et al.* (1998) highlight that the waning of professional autonomy may result from medicine being more regulated than ever before, through, for example, clinical governance and performance indicators. Treatment protocols, national service frameworks and evidence-based decision-making all seek to reduce variations in performance and promote good practice, but they can also impede patient choice. They also restrict professional autonomy and risk a lack of engagement by health professionals with the Government's modernisation agenda.

Professional developments

Meanings of public involvement and patient-centred care are often conflated by government and policy-makers. An approach that placed patients and their experience at the centre of the consultation process dates back to the work of Michael Balint (1957), and is not therefore new. Throughout the 1970s and 1980s, understandings of the lay-professional interface drew on analysis of the way in which professionals and patients related to each other and the roles each adopted in the clinical encounter.

Byrne and Long (1976), in a study of behaviour between doctors and patients, identified a range of clinical practice styles that polarised into those that were doctor-centred and those that were patient-centred. Doctor-centred clinical practice styles were defined as tightly controlled, using closed questioning techniques, and with patients' problems being defined in biomedical terms. Patient-centred styles, on the other hand, were seen as much less authoritarian and paternalistic, giving greater attention to patients' own accounts and to the holistic and psychosocial aspects of patients' problems.

Stewart and Roter (1989) also highlighted a range of clinical practice styles, as determined by the amount of control exerted by both patients and professionals. Clearly, different styles of encounter between health professionals have been shown to be suited to different patients, groups or specific health needs. However, while health professionals may claim to be practising patient-centred care, little is really known about what really goes on between health professionals and patients in individual face-to-face encounters, and further research is needed in this underdeveloped area.

A patient-centred model of care requires a shift from the traditional notion of the health professional (traditionally the doctor) being the dominant participant, with the patient passive, to one in which power and control are shared. Attention is paid to the patient's personal experience of illness and disease (Brown *et al.*, 2002), and treatment provided as a result of a 'therapeutic alliance' between health professional and patient (Mead and Bower, 2000). Changes in professional-patient relationships can have significant implications for health professionals in terms of training, professional culture and the acceptance of new roles and responsibilities.

A growing body of research has begun to explore the range of strategies that can be used in the consultation, and to define when approaches such as shared decision-making are appropriate (McKinstry, 2000). Terms such as 'evidence-based patient choice' (Elwyn and Edwards, 2001) and 'evidence-informed patient choice' (Entwistle *et al.*, 1998) have been used to describe approaches in which patients are provided with research-based information about the effectiveness of treatment options. However, as Stewart (2001) argues, it is a misconception to suggest that patient-centredness means sharing all information and all decisions. Rather, it involves taking account of patients' desire for information and responding appropriately to them in a holistic manner.

Stewart and Brown (2001) suggest this approach has much in common with other professional models of care delivery, such as the psychotherapeutic concept of client-centred therapy (Rogers, 1951) and Newman and Young's total patient approach in nursing (1972). Increasing moves to break down professional boundaries through education and training and the extension of the professional roles of nurses – through, for example, NHS Direct – provide opportunities for the re-engineering of professional roles in ways that offer the chance to draw on interdisciplinary models of care.

Nevertheless, while acknowledging that patient-centred care and shared decision-making are highly complex, evidence also suggests that patients do desire more information and more control (Guadagnoli and Ward, 1998; Little *et al.*, 2001).

Researchers, themselves based in clinical practice and in the teaching of health professionals, have been working to promote more equal and participatory relationships with patients (O'Connor and Edwards, 2001; Elwyn *et al.*, 1999b). Towle and Godolphin (2001) have proposed a set of competencies for the practice of informed shared decision-making by physicians and patients. Elwyn *et al.* (1999b) concluded that moving towards enhancing patient involvement in decision-making in the future will depend on developing both the skills and attitudes of professionals. Similarly, Elwyn *et al.* (1999a) argue that future developments in shared decision-making will depend on increasing the time available for consultations, and on developing skills for communicating with patients.

Entwistle *et al.* (1998) suggest that the rationale for evidence-informed patient choice (EIPC) is based around two concepts: that there is a moral obligation to provide individuals with choices about their health care; and the assumption that EIPC will have beneficial outcomes. These include:

- greater clinical effectiveness as patients may demand the most effective treatments
- individually appropriate health care suited to individual needs

- direct health utility gain as a result of patients' direct involvement
- reduced health expenditure on ineffective or inappropriate decisions
- reduced litigation against health professionals.

Nevertheless, Entwistle *et al.* (1998) further argue that the promotion of individual patient choice may not necessarily lead to the equitable distribution of resources, since those used for one individual cannot be used for another. They question whether, when choices are to be restricted or resources rationed, patients should be presented with information about options they are unable to access. They suggest that alternative approaches might include the provision of information in the context of a public health perspective, as well as according to patients' own needs, in terms of both costs and the effectiveness of treatments. Individuals already on occasion act in an altruistic manner, for example blood, organ or egg donation. However, as Sculpher (1999) suggests, individuals are unlikely to choose cheaper treatments in order to maximise resources in ways that improve the overall health outcomes for society, if they result in less likelihood of a favourable outcome for themselves or their families.

Tensions arise over whether clinicians should explain all treatment options to patients, even if some are not available to them under current policy guidelines within a publicly-funded health care system. These tensions are outlined in the light of recent disparity in treatment provision in different geographical areas, the so-called 'post code' health lottery, in which treatment or drug availability is dependent not on patients' levels of need but on the area in which they live.

Conclusion

Social changes, organisational changes and changes within professional groups have started to challenge traditional relationships in health care, and in particular medical power. Throughout the 1980s and 1990s, governments set out policies designed to facilitate an increasingly consumerist approach to health services. This process has gained momentum since 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 relationships between patients and clinicians. This has led to higher expectations for the provision of information and sharing of power and decision-making in individual clinical encounters and has put the spotlight on face-to-face relationships in health care services.

Developments have so far focused predominantly on macro-level public participation. Although face-to-face relationships are difficult to measure, progress towards empowerment, sharing of power, increased patient choice and patient-centred care appears to have received less attention.

The extent to which the service will really become more democratic, and to which the Government will relinquish central control, remains to be seen. In addition, unresolved moral questions remain over equity of resources and how far choice might reasonably be devolved to service users in an environment of finite resources. There is little research to tell us what goes on in individual, face-to-face, clinical encounters. Further work in this underdeveloped area is needed to explore the extent to which stakeholders are taking forward an agenda of patient-centred

care and the sharing of power in clinical encounters, as well as the extent to which attitudes and culture are changing within the service in accordance with public expectations. Part two of this report sets out the findings from an empirical study designed to contribute towards this.

Part two: the study

Many aspects of wider participation and public involvement at the macro-level are already being addressed (Anderson and Florin, 2000). Similarly, research at the clinical interface drawing on patient experience, such as the annual National Patients' Survey, has begun to build up a body of knowledge on patients' views of the NHS. However, if the service is to become more patient-centred and if providers are to embrace the changes in culture, attitude and behaviour that are needed to transform face-to-face relationships at the clinical interface, these relationships need to change. More information is needed to inform what goes on in clinical encounters between practitioners and patients.

Drawing on the social, political, policy and professional context highlighted in the previous section, and on the principles set out after the Bristol Inquiry, the second part of the King's Fund Patient Involvement Project involved a study designed to contribute to a fuller understanding of patient-centred care in the context of face-to-face relationships between practitioners and patients. Part two of this report sets out the findings from the study designed to explore the changing relationships between health care professionals and patients.

The study considered the extent to which stakeholders in health care are forwarding a patient-centred agenda. In particular, it set out to examine the meanings of patient-centred care and shared decision-making, and the extent to which they inform professional practice and user group experiences of face-to-face clinical encounters. The study also formed a backdrop for the development and wider dissemination of ideas and innovation.

Methods

In order to provide a focus for the work, a small number of informal interviews were initially carried out with five health practitioners, researchers and academics working in the areas of patient-centred care and shared decision-making. This formed the basis for an information-gathering exercise and a series of pilot interviews.

The rationale for the work was to consider the extent to which a patient-centred agenda is being promoted. It set out to achieve these aims by exploring the understanding and practice of these stakeholders. In order to achieve this, respondents for the main study were drawn from a range of different health stakeholder groups, including policy-makers, those involved in the education, development and regulation of health professionals, consumer groups and patient/client organisations.

The preliminary analysis obtained from the initial interviews provided the key questions to be addressed in the study, and helped to shape the interview schedule. The main study used semi-structured interviews with a range of key stakeholders to address the research questions. These 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 among these groups to forward this agenda?
- What are the barriers to the provision of patient-centred care?

Forty-five semi-structured interviews were carried out during the early part of 2002 with participant stakeholders drawn from:

- the Department of Health
- health policy agencies including CHI, the Modernisation Agency and the National Institute for Clinical Excellence (NICE)
- senior officers from the Royal Colleges and professional organisations
- regulatory bodies
- patient/user groups
- consumer organisations.

It was hoped that the stakeholders would provide informative accounts of policy and governance, as well as educational, organisational and regulatory approaches to professional practice in face-to-face encounters with patients. They would also, it was anticipated, provide accounts of their own clinical experience.

The semi-structured interviews lasted on average an hour and a half. Interviews were then transcribed and a field diary was kept in order to create as full and accurate a record of the accounts as possible. Data analysis involved reflection, looking for patterns and categories in respondents' accounts. A range of key themes emerged from the data analysis. These are set out and discussed in the next section.

Findings

Meanings of patient-centred care

The previous section highlighted that the term 'patient-centred' is frequently used but underexplained by ministers and policy makers. Moira Stewart (2001) has also argued that patient-centredness is a widely used yet poorly understood term, with a wide range of definitions. Findings here support this view where a considerable disparity in understandings of patient-centred care emerged. Respondents used the term in a variety of different ways. Several articulated the notion of placing the patient/client at the centre of the care process, but what this meant was not well articulated and no clear or common understanding emerged.

Patient-centred care. Yes, what does it mean? I think my role is to try to find that out.

CHI officer

Several strands of a patient-centred approach emerged. These tended to vary depending on which group respondents belonged to. Groups were largely at variance and at times in conflict with each other.

Health care relationships as partnerships

Several highlighted a need for information, for partnership, and for creating an environment that was conducive for patients to participate, or not, as they wish.

If it's not a relationship, if it's not a partnership between professional and patient, it's not going to work, the patient is not at the centre ... the professional brings the technical expertise, and what the patient brings is the individual experience. You need both to be acknowledged to make it successful for the patient.

Patients' organisation officer

Empowering them, giving them the tools ... power should be with the person who is receiving the care. It is easy to say choice, but that is too simplistic. It needs to be informed choice. If you do not have the information on which to base choice, choice becomes meaningless.

Independent midwife

Our biggest challenge is around relationships: changing relationships and how you change the culture.

Senior officer in the Department of Health

One respondent described familiarity with the rhetoric of patient-centred care, but outlined his ill-preparedness to incorporate this into practice, as well as his paucity of knowledge about a social model of health.

Putting the patient at the centre – but where is the centre? ... We were taught about the body, not the Black Report, not the person.

Senior BMA officer and GP

Professional groups/biomedical model

Perhaps not surprisingly, stakeholders drawn from professional groups generally adopted a medical model of patient-centred care, with medical priorities determining patients' needs. For example, definitions were often based on a medical perception of priorities such as:

I keep them informed.

Senior officer of a Royal College

Patient-centred care involves engendering confidence in me and having a relationship with a patient.

Senior officer of a Royal College

Some health professionals considered patient-centred care to be part of a wider sharing of responsibility for decision-making and outcomes of care. For example, some coupled the idea of patients' rights (to information, choices and care provision) with the idea that they also had, in an increasingly litigious society, responsibilities. These responsibilities were reflected, some felt, in the need for patients to share the burden of decision-making with doctors.

If people are going to turn around and sue, they have to be prepared to share in the doubt and uncertainty.

Senior officer of a Royal College

User groups/social model

Respondents from user groups often described patient-centred care in the context of a social (whole person) model of health. However, often what they described

were ideas for planning and delivery of services rather than individual face-to-face encounters.

You need to ask people. Care may be provided with the patients' best interests in mind, and with the best will in the world, but if you don't ask them how do you know?

User group organisation officer

They have to be able to tell their story. The system needs to be designed around the people, not around professionals or organisations.

Patients' organisation officer

I think the service might learn from our model. The reason we are here is the individual: improve the quality of their life, keep them independent. We never direct, we always offer advice.

Officer of user group organisation

One member of a client organisation highlighted a more radical perspective: that the whole way in which we approach patient-centred care may be flawed.

Rather than start with the service providers and think about how we can transform existing structures and institutions with all their history and baggage, we need to create a system that starts from the service user, and ask what are your needs? How might services be designed to promote/restore your well-being?

Senior officer of patients' organisation

The previous section set out the paucity of direction or lead from policy-makers despite wide use of the term, so this lack of shared understanding is therefore unsurprising. There is a need for clear leadership and clearer ideas in order to promote common understanding. The findings here highlight a gulf between the increasing literature on shared decision-making and concordance (Robson, 2002), and respondents' understanding. There is a need for wider dissemination of knowledge, drawing on the growing literature on patient-centred care and shared decision-making. There is also a need to draw more fully on the views of patients and carers in designing services. These approaches are essential in order to inform wider understandings or benchmarking of a patient-centred approach to service delivery.

Re-branding existing activities as patient-centred care

The second area of findings to emerge from the study was the re-branding of existing activities within professional training and service delivery as 'patient-centred'. Given the confusion surrounding the meanings of patient-centred care, it is perhaps not surprising that different groups within the service focus on their own area and redefine this as patient-centred care. The first of these areas was the teaching of communication skills.

Communication skills

Thomson *et al.* (2001) emphasise that good quality health care involves patients in decisions about their care, but, they argue, the changes needed in clinical practice to make this a reality have yet to be made. Respondents in this study whose roles involved facilitating the professional education of nurses and doctors

predominantly discussed patient-centred care in the context of communication skills and consulting skills. Undoubtedly, a patient-centred approach is not possible without well-developed communication skills on the part of the health practitioner. Communication skills form a vital part of the education and training of these groups. Nevertheless, the skills required to facilitate a patient-centred approach go further than what many describe in the context of teaching communication skills, as informing patients or obtaining information from them.

Respondents emphasised the importance of imparting a patient-centred approach to their students. However, when asked to describe the ways a patient-centred approach was taught, assessed and evaluated, often they crossed over into talking about communication in traditional ways. Some for example, described teaching communication in the context of breaking bad news or explaining procedures to patients.

Common to their accounts were descriptions of their own practice. Often their approach to communication was based on an exchange of information geared to obtaining information from the patient.

I always try to make sure they understand what is being said to them.

Medical teacher and consultant

When I was a medical student we were not taught communication skills, we were taught how to extract a history ... The idea that there is a case of type 2 diabetes in bed 3 is wrong now – I mean there is a patient with diabetes.

Dean of a medical school

This approach was also evident in the way that students were taught. A lot of the marks go on how they interacted ... how they extracted the information.

Dean of a medical school

It is taught in groups, with patients or actors ... communication skills are taught right through the course and culminate in the final examination.

Dean of a medical school

Typical would be: Mrs So-and-so is about to have a hip replacement; she's very concerned about the anaesthetic; explain to her what the anaesthetic would be like. Or: Explain to Mrs X about pain post-operatively, explain to her how you will manage the pain ... The assessment is as rigorous as it can be in something as subjective as communicating.

Dean of a medical school

Clearly, communication skills form a key part of a patient-centred approach and this is particularly evident in the field of general practice. An innovative approach to teaching and learning communication skills is essential in order to equip health workers to deal with the sharing of power in relationships in clinical practice.

A great deal of commitment to a patient-centred approach was discernible among some respondents, and many were working towards embracing a more participatory approach. For example, one school of nursing was in the process of appointing a senior academic whose role would involve assimilating a patient-centred approach into the nursing curriculum. Although this innovation was in its early stages and the school was still unclear about how it would be achieved, it

nevertheless highlighted a readiness to change the way in which nurses are educated and ultimately practise.

Similarly, some of those in clinical practice emphasised their enthusiasm and commitment to a patient-centred approach. However, most from educational environments discussed teaching communication skills in traditional ways, rather than in ways that challenge power relationships and change attitudes. As Elwyn *et al.* (1999a) highlight in their study of general practice registrars, despite the emphasis on communication skills in the general practice curriculum, registrars were not being adequately trained in the skills required to involve patients in clinical decisions. Consequently, a disparity persists between perceptions of communication and communication skills, and facilitation of patient choice and concordance at the lay professional interface inherent in a patient-centred approach.

Quality assurance

A further example of patient-centred care collapsing into existing practices was the re-branding of quality assurance as patient-centred care. Bechel *et al.* (2000) argue that as stakeholders demand more accountability and value from providers of health care services, treating the patient as customer has led to a wider discourse associated with patient-focused, patient-based and patient-centred care.

Traditionally, measurement of quality has been through patient satisfaction surveys, focusing on elements of service delivery such as privacy, amenities and cleanliness. Although, as Staniszewska and Ahemed (1999) have argued, methodological problems associated with the measurement of satisfaction, cast doubt on the validity of these studies, a better understanding of expectations and satisfaction is based in patient experience.

However, for those involved in health policy, management of services and clinical governance, meanings of patient-centredness were often vague and distinct from shared decision-making in the clinical encounter.

Perhaps as a result of the lack of clarity by those leading the service, and the need for wider research and benchmarking, data obtained through patient satisfaction and patient experience surveys gave rise to perceptions of patient-centred care grounded in quality assurance. For example, the Modernisation Agency describes its function as: 'seeing through patients' eyes' and 'to put patients at the centre of everything we do' (NHS Modernisation Agency, 2000/2001). Similarly, the principles that CHI aims to work within include: 'the patient's experience is at the heart of CHI's work'.

Respondents from policy and service delivery focused on issues of quality assurance. In particular, these included cleanliness of wards, courtesy of staff, food quality, and the time spent waiting for procedures – factors of quality that could be measured and produced in a format that could be published in relation to measurable targets.

Patient-centredness is about outcomes of care, the humanity of care, the quality of care, the patient's experience – all those things that matter to patients.

CHI officer

A further example of quality assurance branded as patient-centred care was one health authority's toolkit for measuring patient-centred care: the Patient Centreometer. This was developed:

[to assess] how 'patient-centred' NHS services are now, identify areas for attention and improvement, and subsequently measure how services improve in the future.

NHS Trent Regional Office, 2002

The toolkit contained benchmarks for four key areas of the patient's experience of NHS services. These included:

- patients in control of their care
- service integrated across agencies and professions
- services that do the small things that matter well
- services that are sensitive, equal, fair, listen and act.

The team that produced the toolkit described it as: 'probably the single most important development in addressing the quality and public/patient involvement agenda in practice'.

There is no doubt that quality in these areas is a high priority for the service and that all these factors impact on patients' experiences of health care services. In doing so, they are all part of what might be conceptualised as patient-centred services. Nevertheless, the quality assurance model of patient-centred care is far removed from that based on shared decision-making, concordance and evidence-based patient choice.

Tools like the Patient Centreometer risk limiting understandings of patient-centred care to elements of quality, in particular those that can be measured easily. This oversimplification of what patient-centred care means fails to encapsulate the complexity of meanings highlighted in published literature and by respondents in this study. It risks fragmenting aspects of the patient's experience in ways that inhibit the wider potential for individual choice.

Public participation and patient-centredness

Part one of this report highlighted the Labour Government's programme of change for the NHS, which is designed to make the service more democratic through giving patients, carers and the public a greater say in the design, planning and delivery of NHS services. This agenda is set to be implemented through a range of initiatives including: patient advocacy, patient advice and liaison services, and patients' forums in NHS trusts and PCTs.

Patients and the public will have increasing opportunities to become involved in partnership and in influencing decisions about the service. In addition, a Commission for Patient and Public Involvement in Health has been planned to promote further public participation and help guide the NHS towards creating a more patient-centred service.

However, although the notion of a more patient-centred service includes increased choice and control within individual face-to-face relationships between professionals and patients, in reality the focus is predominantly on public involvement in policy, planning and delivery of services. Although public involvement is crucial for a

more democratic service, and may potentially lead to increasingly patient-centred approaches to service delivery, it remains distinct from what goes on in face-to-face encounters between clinicians and patients.

In the study, the final example of the re-branding of existing activities was the reconfiguration of patient-centred care into public participation. This report has already emphasised that government-led changes to the service since the late 1990s have predominantly been at the macro-level of public participation in planning and service delivery. It is therefore not surprising to find that this is reflected in stakeholders' accounts.

I have highlighted above that increased public involvement may ultimately impact services in ways that make them more patient-centred. However, the two are not synonymous, although respondents often spoke of them as though they were. In conflating the two, the harder task of changing attitudes, culture, and the way practitioners engage with individual patients tended to be lost.

For example, when asked about what impact a Royal College Patient Liaison Group has on clinical practice and patient experience, responses from senior officers within the Royal Colleges were often vague.

Quite a lot of college business is not something that desperately needs a lay perspective ...

Senior officer of a Royal College

Some of the those interviewed saw patient-centredness as public involvement in the context of letting people know what the college was doing. The emphasis was firmly focused on the college agenda:

We would involve patients in drawing up our guidelines.

Senior officer of a Royal College

We work with them to set standards ... The two pillars of our business [Royal College] are standards of clinical care and education ... patients' wishes, patients' rights, patients' involvement should be working right through.

Senior officer of a Royal College

At times an element of tokenism was discernible in their response:

We had a [Royal College] Council meeting yesterday and there was a user/carer present ... they have access to all Council notes and can make suggestions.

Senior officer of a Royal College

One example ... about the Lay Advisory Committee: a debate was sparked by someone, a doctor who wanted their own lab results, despite this being against policy, so we floated it past them [the Lay Advisory Group].

Senior officer of a Royal College

Some even perceived the lay advisory group to be a useful tool to forward particular professional agendas:

I am quite keen to get their views on the latest consultation document from the government on the medical education standards board, because as it is it is

implicitly threatening to colleges because it is going to disempower and marginalise us and take over state control of postgraduate education. If they [the Patient Liaison Group] come up with a negative view to the proposals, quite spontaneously, and if it is echoed in other lay groups, then it is a more powerful argument to make the government think again than if the colleges say we don't like it.

Senior officer of a Royal College

Similarly:

There is another aspect of patient-centredness which we have ignored in the past. These sorts of things [organ retention] are for research and teaching, are done for patients, not for doctors, for patients ... Patients' groups have the responsibility to inform the public at large ... and we should use them extensively for that.

Senior officer of a Royal College

Perhaps as a result of the paucity of understanding of the meaning of patient-centred care and uncertainty about how to achieve and evaluate it, it was frequently conflated with existing activities within health care services.

There is no doubt that professionals' ability to communicate, the quality of services and public voices in the running of the service can all contribute in a positive way to patients' individual experiences and are therefore all components of patient-centred care. Although a patient-centred approach needs to draw on each of these, there is still little evidence that the nature of the face-to-face encounter has changed.

Barriers to change

The final theme to emerge from the study were factors that respondents described as barriers to patient-centred care. Although this study is not representative of professional and user groups, and the findings therefore need to be taken with caution, what emerged from the accounts of these key individuals was valuable qualitative insights into their experiences of working in the service. The first of the barriers highlighted by respondents was attitudinal change.

Attitudinal change

In what may be termed a post-Bristol climate, there was evidence of reflection on practice in ways that did challenge traditional attitudes and facilitated a more participatory approach, as well as a willingness to change among many individuals. Although recent developments in professional education and the re-engineering of professional roles may help to transform professional cultures, attitudinal change among occupational groups is extremely difficult to bring about (Wallace *et al.*, 2001). Nevertheless, attitudinal change among many health professionals towards a more equal approach to power in the clinical encounter and in decision-making is needed in order to empower patients and provide a more patient-centred service.

Attitudinal change represents one of the key challenges for stakeholders in a new post-Bristol health environment. Although the findings from this small qualitative study cannot be seen to be representative, nor to provide a comprehensive account of professional attitudes, the accounts of stakeholders nevertheless provide useful insights into this key issue.

Evidence of attitudinal change

New departments within the Department of Health, such as the Modernisation Agency, have been put in place to develop leadership in the service and are key instruments for change in 'supporting the NHS in making radical and sustainable changes to services for the benefit of patients' and 'as the catalyst for a modern movement' (NHS Modernisation Agency, 2000/2001).

In addition, other government health agencies such as NICE and CHI, each have independent functions but work in partnership with each other to provide a new, contemporary approach to the provision of health care services. These institutions seek to challenge outdated practices and attitudes and promote change within the service.

In addition, the newly formed Nursing and Midwifery Council and recently modernised GMC both acknowledge a need to deliver a new, open and modern approach to the education, practice and conduct of the professional groups they regulate. However, the extent to which they will achieve real change in the way services are delivered, particularly what goes on in face-to-face encounters, remains to be seen.

[Post-Bristol] we will never go back to that state where there was unrivalled trust in medicine.

Nursing and Midwifery Council officer

Some of those within professional groups also embrace change:

Barriers are beginning to break down: nurse prescribing, nurses taking a greater role in, for example, NHS Direct, Walk in Centres.

GP and BMA officer

Students are aware that medicine is not just a biomedical science for humans, but there is a major ethical dimension to it. There is a very active student ethical group here.

Dean of a medical school

[Nursing] professionals who have been trained recently, or in the last few years, I think have a sense of working with clients. They are not within that paternalistic mould, they are much more collaborative.

Head of School of a school of nursing

Persistence of medical paternalism

Nevertheless, some from patient/client organisations felt there was intransigence among professional groups, and a continuing need for a change in attitude, particularly in medicine and nursing. This was described in terms of resistance to change, reluctance to share power, and protection of professional boundaries.

I see this on the various agencies and boards that I belong to. Health professionals have changed very little, even after Bristol. Doctors and nurses, their agenda is to hold on to their power base.

Senior officer of a user group

One independent midwife talked about the way doctors, nurses and midwives were encouraged to think that they 'knew best'.

We may now teach 'communication' in new ways, but do we still instil in health professionals a sense that they know better than the patient?

Independent midwife

In addition, some senior members of Royal Colleges articulated a more intransigent approach to change:

Professionals have to make a judgement about what people can handle and what they can't handle.

Senior officer of a Royal College

We always groan inwardly when we get very intelligent parents, because they're terribly time consuming and they torture themselves trying to cope with things ... Teachers and social workers are always difficult too.

Senior officer of a Royal College

I personally think you should pay heed when allocating places in medical schools to whether a person comes from a medical family or not. It would prepare you for some of the problems you come across ... We are light-years away from the French in this area that you have called patient-centred care. We have been shaken into this by Bristol. We all have a sneaking feeling that there but for the grace of God I might have been ... In the past it wasn't an issue because the patient explanation was well we know that you don't always come out of this hospital alive, but now the expectation is very different.

Senior officer of a Royal College

As Klein (2001) emphasises, attitudinal change is not easy to bring about. Nevertheless, it is pivotal if the objectives of a more patient-centred service are to be met.

Resources and structures

A further area that constituted a barrier to change was resources and structures. Some commentators have suggested that in the contemporary era doctors are experiencing declining morale (Smith, 2001; Edwards *et al.*, 2002). The accounts in this study highlighted a strong sense that the changes needed to promote a patient-centred service would not be possible in the current climate of underfunding, low staffing levels and low morale.

Since the inception of the NHS in 1948 arguments that the service has been under-resourced have been well rehearsed. Nevertheless, respondents felt that in order to bring about the wider changes needed to transform the service into a more patient-centred one, and to facilitate increased sharing of decision-making, more significant changes were needed. These, it was felt by many, would not be possible without greater resources. More specifically, resources were described as: more doctors; more nurses; more clinic appointments; and more time to spend with patients.

We can talk and talk about how to provide a more patient centred-service, but then I have to get through a clinic bursting at the seams with patient appointments, and the best I can do is simply get through them.

Senior officer of a Royal College

We have about 25,000 asylum seekers, we have tuberculosis levels which are the same as Ethiopia, we are 150 GPs down – patient-centred care in the east of London, it's a laugh! Basically, it's just crisis management.

Senior consultant

We can tweak the margins, but in essence we need more nurses, more doctors, more clinics, more time to spend with patients.

Senior consultant

Several respondents were critical of what they described as the copious and often unhelpful material emanating from the Department of Health, designed, one person believed, to shift responsibility for failure from the Government on to the professionals.

We received a directive from the Department of Health saying patients will no longer wait on trolleys. No support, no ideas, no funding, just get on with it.

Senior officer of a Royal College

In terms of their own and colleagues' practice, stakeholders generally spoke of low morale, poor pay and low staffing levels as barriers to the enthusiasm needed to place the patient at the centre of care.

I do the best I can, so do my colleagues, but it is often just not good enough, I know that.

Nurse

Some did highlight small but effective measures for improving the service that involved minimal costs and few resources. One example was to ensure that computer screens did not impair communication by blocking the patient or the practitioner's line of vision. Others included more innovative use of appointment or clinic time. Although simple measures such as these can help to facilitate better communication between health professionals and patients, they may not be cost neutral. For example, better communication may involve longer consultations as lines of communication are opened up. Nevertheless, simple ideas can often bring about considerable improvements to services at minimal cost.

Social divisions and social exclusion

Social divisions and social exclusion serve to reinforce disadvantage and powerlessness in the context of health. A large body of literature has established the ways poverty, class, race, gender, level of education, sexuality, ethnicity, (dis)ability and language can all impact on health and the individual's experience of health care services, and patients' experience can be mediated by their social location. In addition, children are often excluded from decision-making even when the consequences for them are grave or enduring.

Similarly, Doyal (2001) highlights that there is still evidence that women experience demeaning attitudes and unequal allocation of resources. For women,

patient-centred care may represent a double jeopardy as gender inequalities may be combined with wider inequalities. Conversely, despite the apparent privileges maleness conveys, there is a direct relationship between masculinity and some behaviours that place health at risk, especially in certain groups of young males, as well as a greater susceptibility to certain illnesses such as heart disease.

It is difficult to imagine where control over decision-making and sharing of power, could be more appropriate than at the end of life, in the context of the terminally ill.

Terminal care is a huge area. I am not sure, in all honesty, we really always provide a patient-centred service to dying patients.

Nurse

Respondents emphasised the ways poverty went hand in hand with disempowerment. Often those in the greatest need were in areas where resources were most scarce.

How can you provide a patient-centred service, and spend as long as you need to with patients, when there is such a shortage of doctors in the East End of London?

Senior officer of a Royal College

Patient-centred care is very sporadic when you are dealing with individuals who are disempowered in every other aspect of their lives – financially, educationally, and especially if they are women. How do patients assert themselves, or take control? They can't.

Midwife

Some respondents saw language as a barrier to patient-centred care:

How can we provide patient-centred care if we cannot even speak directly to our patients? I feel that language is such a barrier to nursing, even if an interpreter is present.

Nurse teacher

If an interpreter is used, a huge amount of reliance may be placed on the language and wider communication skills of the interpreter. Inaccuracies due to the complexity of clinical interactions and poor communication can lead to detrimental outcomes, as well as compromising privacy (Ebdon *et al.*, 1988; Cohen *et al.*, 1999).

Language can be problematic. Users of interpreters can also be a problem. How do you know the patient has understood?

Doctor

Finally, one senior nursing lecturer expressed concerns about the effect of social and cultural barriers on patient-centred care and shared decision-making. She highlighted that patient-centred care and shared decision-making and their associations with 'individualism' and 'choice' are Western philosophical constructs. She suggested that notions of choice and the individual may differ among some in other cultures where a more fatalistic approach may prevail, and choice is based on collective or community ideas. In these circumstances, differential choices that may be at variance with those professionals might themselves make need to be

recognised and accommodated as part of the wider range of ways in which patients may choose to engage with health care services. Some patients may not wish to actively engage in decisions or take responsibility, or do not feel able to do so.

Key challenges remain in seeking to promote patient-centred care among different groups. How do we ensure real choice within routine practice or packages of care? A patient-centred approach needs to recognise these key challenges and health professionals need to be equipped with the necessary communication skills in order to meet these challenges. These examples constitute differential ways of sharing power in clinical encounters. Clearly, although wider research is needed in this area, failing to take into account differing explanatory models can be ethnocentric and inadequate and fail to meet the patient-centred needs of patients in certain minority groups.

In the 2002 budget, the Government increased health spending to reach 9.4 per cent of GDP (gross domestic product) by 2008. It also set out the changes to the service that it expects to be implemented alongside this (Department of Health, 2002). These include the introduction of national standards, increased plurality of service providers, and modernisation of professional practice. The roles of agencies such as the Modernisation Agency, CHI and NICE are central to the management of change in these areas. It remains to be seen whether these perceived barriers may be overcome, and whether the increases in resources and programmes of change will be enough to generate the wider transformation of the service needed to impact on individual clinical encounters.

Conclusion

The first section of this report comprised a policy analysis that examined the social, policy, organisational and professional changes that have impacted on relationships between health professionals and patients. The effects of these changes have been to create a drive for consumerism in health care whereby patients may increasingly gain greater control over decisions about their care, and where power in the clinical encounter may increasingly become shared between professionals and patients.

In addition, the impetus for change articulated by government and professional groups since the inquiry into children's cardiac surgical services at the Bristol Royal Infirmary have made creating a service that meets patients' expectations in terms of information and quality a timely priority.

The empirical part of the project set out to evaluate progress towards shared decision-making and patient-centred care. Three key findings emerged from the study. First, despite much rhetoric from ministers and policy-makers surrounding patient-centred care, and the growth of a body of literature into patient choice, shared decision-making and concordance from academic and professional sources, these ideas have failed to penetrate, to any great extent, the understanding of those who work in the service.

A lack of direction from the Government, a wide and yet confused use of the terms among policy-makers and managers, and lack of leadership on the issues have given rise to a general paucity of understanding. In raising expectations about patient-centred care without providing clarity about its meaning, the Government may have created a hostage to fortune. In a climate of high public expectations and an increasingly critical media it may be unable to meet the differential expectations of patients and the public. In addition, although the literature may help us to understand the issues, it does not tell us how to achieve it. Similarly, if a lack of understanding and consensus exists between what stakeholders understand by patient-centred care, difficulties arise in terms of the teaching of professionals, clinical governance and service evaluation. Strong leadership is needed to disseminate knowledge and set and maintain standards.

Secondly, the study highlighted that stakeholders re-configured existing approaches and familiar activities as patient-centred care. This 're-branding' was exemplified in the education of professional groups as communication skills; as quality assurance in service delivery; and public participation across the service. Clearly, all of these may be key components of a patient-centred service and need to be developed further. However, each in isolation does not encapsulate the totality of patient-centred care in terms of providing information to patients, sharing decision-making and providing quality services. A shared decision-making, concordance model of patient-centred care is far removed from quality issues such as waiting times and cleanliness of wards. A fuller understanding and

better co-ordination across different functions of the service is needed in order to facilitate a coherent, more effectively patient-centred, approach.

As a result, there exists much rhetoric about patient involvement and patient-centred services, yet little consensus about what these terms mean. Policy initiatives to democratise the service and to make it more patient-centred have focused predominantly on public participation and lay involvement and less on changing the culture, attitudes and behaviour of professionals in ways that can impact on face-to-face encounters between health professionals and patients. Despite increasing lay involvement in professional regulatory bodies and the Royal Colleges, their role within these organisations is still relatively weak, with lay members frequently being unable to vote, and at times being unable to speak at the very committees on which they serve.

Finally, the study highlighted the barriers to patient-centred care. These included the culture and attitudes of those working in the service, and the limitations of current resources and inflexible structures. Despite the methodological limitations of a small, qualitative study such as this one, the insights provided highlighted that although there was evidence of intransigence among some respondents, there was also evidence of enthusiasm, self-reflection and innovation among others.

Clearly, additional resources are crucial if the NHS is to meet present and future needs, and the extent to which these resources will be forthcoming remains to be seen. The continuing grip of central Government and professional groups on services, however, casts doubt on the extent to which power and control will in reality be shifted to patients. The extent to which these changes will impact on the culture, attitudes and behaviour of those working in the service, and transform power relations in face-to-face relationships between professionals and patients remains to be seen.

Central to achieving the essential aims of modernisation and structural change is transforming the way services are provided. It may, however, also be necessary to manage patients' changing expectations of health professionals, and to modify the way that patients use services.

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 professions 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.

References

- Anderson W, Florin D. *Involving the Public – One of Many Priorities: a survey of public involvement in London's primary care groups*. London: King's Fund Publishing, 2000.
- Appleby J, Coote A. *Five-Year Health Check: A review of government health policy 1997–2002*. London: King's Fund Publishing, 2002.
- Balint M. *The Doctor, His Patient and the Illness*. London: Pitman, 1957.
- Barnett J R, Barnett P, Kearns R A. Declining professional dominance? Trends in the proletarianisation of primary care in New Zealand. *Social Science and Medicine* 1998; **46**(2): 193–207.
- Bechel D L, Woodrow M A, Smith D G. Does patient-centred care pay off? *The Joint Commission on Accreditation of Healthcare Organisations* 2000; **26**(7): 400–9.
- Brown B J, Stewart M, Tessier S. *Assessing Communication Between Patients and Doctors: A manual for scoring patient centred communication*. London: Thames Valley Family Practice Research Unit, 1995 (Working Paper Series 95–2).
- Byrne P S, Long B L. *Doctors Talking to Patients*. London: HMSO, 1976.
- Cohen S, Moran Ellis J, Smaje C. Children as informal interpreters in GP consultations: pragmatics and ideology. *Sociology of Health and Illness* 1999; **21**(2): 163–86.
- Department of Health. *Local Voices: The views of local people in purchasing for health*. London: NHSME, 1992.
- Department of Health. *The New NHS: Modern, dependable*. London: London Stationery Office, 1997.
- Department of Health. *Shifting the Balance of Power*. London: Department of Health, 1999.
- Department of Health. *The NHS Plan: A plan for investment, a plan for reform*. London: Department of Health, 2000: Cm 4818–I.
- Department of Health. *The Expert Patient: A new approach to chronic disease management for the 21st century*. London: Department of Health, 2001.
- Doyal L. Sex, gender and health: the need for a new approach. *BMJ* 2001; **323**(7320): 1061–3.
- Ebden P, Bhatt A, Carey O J, Harrison B. The bi-lingual consultation. *Lancet* 1988; **8581**: 347.
- Edwards N, Kornacki M J, Silversin J. Unhappy doctors: what are the causes and what can be done? *BMJ* 2002; **324**: 8835–8.
- Ehrenreich B, English D. *Witches, Midwives and Nurses*. London: Writers and Publishers Press, 1976.
- Elston M. The politics of professional power. In: Gabe J, Calnan M, Bury M editors. *The Sociology of the Health Service*. London: Routledge, 1991.
- Elwyn G, Edwards A. Evidence-based patient choice? In: Edwards A, Glyn E, editors. *Evidence-Based Patient Choice: Inevitable or impossible?* Oxford: Oxford University Press, 2001.
- Elwyn G, Edwards A, Kinnersley P. Shared decision making in primary care: the neglected second half of the consultation. *British Journal of General Practice* 1999a; **49**(443): 477–82.
- Elwyn G, Edwards A, Gwyn R, Grol R. Towards a feasible model for shared decision making: focus group study with general practice registrars. *BMJ* 1999b; **319**(7212): 753–6.
- Entwistle V A, Sheldon T A, Sowden A, Watt I S. Evidence-informed patient choice: practical issues of involving patients in decisions about health care technologies. *International Journal of Technology Assessment in Health Care* 1998; **14**(2): 212–25.

- Etzioni P. *The Semi-professions and their Organization*. New York: Free Press, 1969.
- Florin D, Coulter A. Partnership in the Primary Care Consultation. In: Gillam S, editor. *New Beginnings: Towards patient and public involvement in primary health care*. London: King's Fund, 2001.
- Gordon S. Complementary Medicine in Europe. *Eurohealth* 1995; 1(3): 19-21.
- Greenwood E. Attributes of a Profession. *Social Work* 1957; 2(3): 44-55. (See North, 1997.)
- Guadagnoli E, Ward P. Patient participation in decision-making. *Social Science and Medicine* 1998; 47(3): 329-39.
- Hardy M. Doctor in the House: the Internet as a source of lay health knowledge and the challenge to expertise. *Sociology of Health and Illness* 1999; 21(6): 820-35.
- Haug M, Lavin B. *Consumerism in Medicine: Challenging physician authority*. Beverly Hills: Sage, 1983.
- Health Care UK. NHS reforms: an unfinished revolution (editorial). *Health Care UK* 1990: pp. 5-10.
- Johnson A M, Shergold C, Hawkins A, Miller R, Adler M W. Patterns of Hospital care for patients with HIV infection and AIDS. *Journal of Epidemiology and Community Health* 1993; 47(3): 232-4.
- Jones M. Walk-in primary medical care centres: lessons from Canada. *BMJ* 2000; 321(7266): 928-31.
- Klein R. *The Politics of the NHS*. London: Longman, 1989.
- Klein R. Hospital inquiries: no quick fix. *Health Service Journal* 2001; 111(5770): 28-30.
- Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C. Preferences of patients for patient-centred approach to consultation in primary care: observational study. *BMJ* 2001; 322: 468-72.
- McKinlay J, Arches J. Towards the proletarianisation of physicians. *International Journal of Health Services* 1985; 15: 161-95.
- McKinlay J, Stoeckle J. Corporatization and the social transformation of doctoring. *International Journal of Health Services* 1988; 18: 191-205.
- McKinstry B. Do Patients wish to be involved in decision making in the consultation: a cross sectional survey. *BMJ* 2000; 321(7265): 867-71.
- Mead M, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine* 2000; 51: 1087-1110.
- Miles A. *Women and Mental Illness*. London: Harvester Wheatsheaf, 1988.
- National Audit Office. *Handling Clinical Negligence Claims in England*. London: HMSO, 2001.
- NHS Modernisation Agency. *The Work of the Agency: Information for NHS Organisations*. London: NHS Modernisation Agency, 2000/2001.
- NHS Trent Regional Office. *Patient Centrometer: Delivering patient centred care*. NHS Trent Regional Office, 2002.
- Newman B, Young R J. A model for teaching total person approaches to patient problems. *Nursing Research* 1972; 21: 246-9.
- North N. Policy processes. In: North N and Bradshaw Y, editors. *Perspectives in Health Care*. London: Macmillan, 1997.
- Oakley A. *Essays on Women, Medicine and Health*. Edinburgh: Edinburgh University Press, 1993.
- O'Connor A, Edwards, A. The role of decision aids in promoting evidence-based patient choice. In: Edwards A, Glyn E, editors. *Evidence-Based Patient Choice: Inevitable or impossible?* Oxford: Oxford University Press, 2001.
- Robson, J. How concordance challenges us to rethink our attitudes. *Pharmaceutical Journal* 2002; 268(7202): 836.
- Rogers C. *Client-centred Therapy: Its current practice, implementations and theory*. Cambridge, MA: Riverside, 1951.

Savage W. *A Savage Inquiry: Who controls childbirth?* London: Virago, 1986.

Sculpher M. Shared decision making in a publicly funded health care system. *BMJ* 1999; **319**: 725-6.

Smith R. Why are doctors so unhappy? *BMJ* 2001; **322**: 1073-4.

Squire S B, Elford R, Bor R, Tilsed G, Salt H, Bagdades E K, Janossy G, Griffiths P D, Johnson M A. Open access clinic providing HIV-1 antibody results on day of testing: the first twelve months. *BMJ* 1991; **302**(6789): 1383-6.

Staniszewska S, Ahemed L. The concepts of expectation and satisfaction: do they capture the way patients evaluate their care? *Journal of Advanced Nursing* 1999; **29**(2): 364-72.

Stewart M. Towards a global definition of patient centred care. *BMJ* 2001; **322**: 444-5.

Stewart M, Brown J B. Patient-centredness in medicine. In: Edwards A, Glyn E, editors. *Evidence-Based Patient Choice: Inevitable or impossible?* Oxford: Oxford University Press, 2001.

Stewart M, Roter D. *Communicating With Medical Patients*. New York: Sage, 1989.

Thomson R, Bowling A, Moss F. Engaging patients in decisions: a challenge to health care delivery and public health. *Quality in Healthcare* 2001; **1**(3): Supplement 1: 1.

Towle A, Godolphin W. Education and training of health care professionals. In: Edwards A, Glyn E, editors. *Evidence-Based Patient Choice: Inevitable or impossible?* Oxford: Oxford University Press, 2001.

Trevelyan J. Complementary options. *Nursing Times* 1998; **94**(13): 28-9.

Ussher J. Women and Madness: *Misogyny and Mental Illness*. Hemel Hempstead: Harvester Wheatsheaf, 1991.

Wallace L M, Freeman T, Latham L, Walshe K, Spurgeon P. Organisational strategies for changing practice: how trusts are meeting the challenges for clinical governance. *Quality in Health Care* 2001; **10**(2), 76-82.

Weiss M, Fitzpatrick R. Challenges to medicine: the case of prescribing. *Sociology of Health and Illness* 1997; **19**(3): 297-327.

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CHANGING RELATIONSHIPS

FINDINGS OF THE PATIENT INVOLVEMENT PROJECT

In recent years, rapid and significant changes in the social, political and policy context of the relationship between health professionals and patients have put the concept of 'patient-centred care' increasingly in the spotlight. Society is challenging traditional perspectives – particularly the patient-clinician relationship – and the Government is pushing the NHS to provide a more open, accountable and democratic service for health 'consumers'.

But what does being 'patient centred' really mean? And can it produce measurable improvements? Policy initiatives to democratise the NHS have, to date, largely focused on formal public representation mechanisms – rather than the more complex and less quantifiable issues of patient choice, distribution of power, and the dynamics between patient and practitioner.

Changing Relationships shows how the policy framework has shifted in response to wider cultural changes and high-profile investigations such as the Bristol inquiry. It presents the results of the King's Fund Patient Involvement Project, which examined what patient-centred care means on the ground through 45 interviews with a wide range of stakeholders, including representatives of regulatory, teaching and professional bodies, medical practitioners, and patient and consumer groups.

The research found that there were widespread disparities in understandings of what patient-centred care is and how to achieve it, alongside a tendency to re-define existing activities to fit the concept. It suggests that patients, users and carers must play a central role in shaping and evaluating what it means in the future, if clinical encounters are to be transformed, and more power and control devolved to them.

With a wealth of quoted material from clinicians and stakeholders, this paper will be invaluable to a wide range of health professionals involved in health delivery, education and communications; managers and purchasers of services; policy-makers; and patient and user groups. It will also be of interest to academics and social policy commentators interested in health policy.

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