HEALTH POLICY FUTURES

ENGAGING WITH CARE: A VISION FOR THE HEALTH AND CARE WORKFORCE OF ENGLAND

Background paper 8:

The Lay/Professional Relationship in Health: Trends and Policy Implications

Prepared by Will Erickson

Edited by Sandra Dawson, Beth Altringer and Zoë Morris

March 2007

Available at: http://www.jbs.cam.ac.uk/research/health/polfutures/restricted

NOT TO BE QUOTED WITHOUT PERMISSION OF THE AUTHOR.

The editors and author acknowledge the support of the Nuffield Trust in funding this work as the final part in a series of projects concerned with Policy Futures for Health. We are indebted to the Nuffield Trust's trustees and officers for their help, guidance and support, and to members of our expert group, who have shared their insights, experience and evidence with us. We would also like to thank Jenny Ridgeon for her administrative support. Whilst indebted to many the authors stand responsible for the content.
Preamble
This is one of 10 web published background papers which provide detailed analysis and support for the Report: Engaging With Care: A Vision For The Health And Care Workforce Of England, which will be published in September of 2007. The report together with the set of background papers provides an analysis of current policies and trends and identifies routes for future action. The report identifies trends and challenges that can help define the common ground in health and care policy, while allowing for different policy directions at national and local levels. The intention is that all those involved in health, in their various roles as paid, informal or self carers, patients and clients, educators, service providers and citizens will be able to understand their roles and contributions and, together with the policy makers, feel empowered to influence health and care policy and practice.

Contents:

1. Introduction and Methodology 3
2. Summary of the Literature on the Lay/Professional Relationship 4
   1. Trends 5
   2. Issues 5
   3. Options for Action 7
3. Annotated bibliography 9
   1. The patient/professional relationship in patient-centred care 9
   2. Continuity of Care 13
   3. Patient Participation in Care 16
   4. Expert patients 23
   5. The challenge of evidence-based medicine 25
   6. Informal carers and Professional carers 27
4. Conclusion and Recommendations 29
5. References 35

1 Available at: http://www.jbs.cam.ac.uk/research/health/polfutures/restricted
1. Introduction and Methodology

This paper begins with a discussion of aims and the methodology used. Section two summarizes the trends and issues raised in this literature search. Section three, the bulk of this paper, is an annotated bibliography of the literature reviewed. The paper concludes with a section detailing conclusions and recommendations based on this literature review that will inform the scenario planning exercise of the broader Health Policy Futures project.

The aim of this literature review was to:

- Review how patients’ relationships with their health professionals has changed and will change, in such areas as decision-making, educating about illness and health, and maximising opportunities for self-care.
- Understand the importance of the professional/patient relationship to the patient as they manage and live with (increasingly chronic) illness.
- Assess what health professionals think this relationship should be like, and what measures they have taken in their attempts to shape it.
- Predict impact of trends toward better informed, active and consumerist patients able to access information and advice from multiple expert sources on the professional-patient relationship.
- Examine interactions between informal carers and professional carers, and assess how the two might best support each other in their complementary roles in the future.

Keyword searches were performed using Web of Knowledge, culling by title, then by abstract. Keywords used were doctor-patient relationship/communication, nurse-patient relationship/communication, professional-patient relationship/communication, patient participation, and expert patient. Citations from selected articles were then mined, and the citations in those articles which met criteria were mined, and so on. “Cited by” lists were used in this way even more. Articles were selected based on the relevance of their conclusions to thinking about the future (though almost none were explicitly futures-oriented) and the ease with which policy implications could be drawn from them (or were drawn explicitly by the authors). Newer (post-2000) literature was strongly privileged over older work, in light of the major changes that have taken place in the organisation of formal health and social care.

Most of the literature is written for and by a medical sociology audience, though studies in medical journals, especially the popular ones, like BMJ, were very plentiful, and often relevant. The vast majority of the medical literature is written for and about GPs. The UK seems proportionally more interested in this topic than other countries, though in raw numbers most literature comes out of the US. Holland, Canada, Australia, and Scandinavia are also well represented in the English-language literature. By privileging UK studies, I hope to have created a more accurate snapshot of the country with an eye toward future policy. On the other hand, in doing this I have excluded important international contributions, as well as undoubtedly missed important trends in other countries that may be coming our way, such as the role of litigation in the US doctor/patient relationship. I was able to find very little within the scholarship relating to social care on this topic – this is clearly an angle that requires much more research.

Though most of the articles included in this sample literature are patient-centred in their
attitude, relatively few focus on the measures patients do take and could take to manage their relationships with their health professionals. This literature exists in the wider popular press, but not in online academic search databases. Though much of the data in the academic literature presented here describes patients’ attitudes, expectations, and perceptions, it is used by professionals seeking to understand and improve encounters and relationships with their patients and thus improve their therapeutic benefit.

Limitations of Study:
For time reasons (a limit of approximately 70 hours), the search was restricted to academic articles, including both qualitative and quantitative studies. A good proportion of the articles included here were read, others were skimmed, and those with detailed, straightforward abstracts (and no online viewing privileges) were often simply mined for references and summarised from the abstract. Where relevant, earlier reviews of the literature were relied on so as not to replicate the work of others, and to draw on their conclusions. That this list is fully inclusive of all of the highest quality work on this topic cannot be assured, as I often skimmed down a page to the ‘methods’ section and read no further if the data came from outside the UK, unless the topic was relatively uncovered in the domestic literature or seemed to be a particularly unusual contribution. Because this literature is so voluminous, and thus varies in quality, scope and ambition, I would like to have spent more time appraising methods and data employed than I was able to do. Where there is disagreement in the field I have tried to highlight it, though with sensitivity to the proportional dominance of one side or another of the dispute.

With more time, the review would have been widened to include books, as well as the literature surrounding what seem to be further key questions in thinking about professional/lay relations in the future: whether age preferences for a longitudinal and meaningful relationship with one’s health professional will stick or will evolve as those people age; the effect of patient groups, and patient participation through committees in the larger design of care or research strategy; whether legal issues/litigation concerns will play a greater role in the future, as they do to startling degree in the US; whether choice will catch on and the effect it will have on health relationships; and efforts at educating expert patients among those who use GPs the most: minorities and the poor, perhaps partly because they are the least expert. Also, an interesting perspective might come from a Lexis-Nexis search of newspaper and popular magazine articles from the burgeoning health journalism advising readers on how to talk to health professionals.

2. Summary of the Literature on the Lay/Professional Relationship

This section reviews issues and trends in the way patients experience the care they receive as well as the system through which it is delivered. It also explores their relationships with health professionals, and how they and health professionals view those relationships.

There are two distinct and important medical traditions influencing the lay-professional relationship today: biomedicine and psychosocial medicine. Evidence-based medicine, technical knowledge and professional authority come out of the first, while patient-centred care and patient involvement in decision-making have their roots in the second. While the goal of psychosocial medicine is to provide individualised care based on the unique circumstances and preferences of the patient, biomedicine aims to know and to apply the best odds, based on trials of various possible treatment options.
Practitioners are not always motivated primarily by the first movement, or patients by the second: biomedicine and psychosocial medicine do not represent a top-down approach or a bottom-up approach, respectively. Most practitioners, policymakers and patients instead share goals of both movements simultaneously. The directive to treat the patient rather than the illness has existed for a long while among health professionals in the UK, particularly those in general practice, but gains salience and complexity in the context of the tension between evidence-based medicine and individualised care.

2.1 Trends

- The importance of patient-centred, individualised care to patients and within health and social care continues to grow, and at least some patients still prefer it to access (Roberts 2004).
- There is a trend away from interpersonal continuity (Freeman, Olesen et al. 2003). Though young people appear not to mind this much, valuing continuity less than ease of access, we cannot be sure that this is a cohort effect and not a life-cycle effect (Guthrie 2002). The answer to this question, as well as that of whether informational continuity can replace interpersonal continuity, has powerful implications for the future.
- Far more patients desire greater involvement in their care decisions than experience it, and those who would prefer for the health professional to make a decision for them nevertheless often desire more information about their care than they receive (Caress, Beaver et al. 2005; Say, Murtagh et al. 2006; Vick and Scott 1998). Efforts to implement shared decision-making in practice have had very limited success (Edwards and Elwyn 2006).
- The importance and practice of evidence-based medicine (EBM) is on the rise, and potentially in conflict with the countervailing trend toward patient-centred, individualised care which invites patient participation. Efforts to combine the two in the consultation have thus far proven difficult (Ford, Schofield et al. 2003).
- Barriers between social and health care continue to flummox patients as well as staff (Nies 2006).

2.2 Issues

**Patient-centred care:**
Care which can be described as ‘patient-centred’ is designed to elicit more participation from the patient, which is individualised to the particular needs and preferences of the patient, and which employs open rather than closed questions and strong listening skills (Morgan 2003). Health professionals would likely improve their relationships with their patients further by seeking to understand better their role in their patients’ larger experiences of living with and managing illness (Haidet, Kroll et al. 2006). Nurse practitioners (NPs) appear better able to meet patients’ expectations of a warm, empathetic medical encounter, both because of their professional culture and training and their longer consultation times that allows for more listening, discussion, and informal interactions (Seale, Anderson et al. 2006; Williams and Jones 2006).

Some argue that in focusing too much on maintaining good patient relations, professionals may become reluctant to challenge patients’ strategies for managing their health and illnesses (Butler, Rollnick et al. 1998; Chew-Graham, May et al. 2004).
Continuity of care:
Interpersonal continuity of care is highly valued by patients, particularly those with life-threatening, chronic and mental illnesses (Guthrie 2002; Love, Mainous et al. 2000). It is also valued by health professionals (Kearley, Freeman et al. 2001; Ridd, Shaw et al. 2006). It is associated with many positive health outcomes, including increased patient satisfaction, better prevention, more adherence, and fewer hospitalisations and A & E visits (Cabana and Jee 2004; Freeman, Gray, Evans et al. 2003; Horder et al. 2002). It may also be cheaper (Saultz and Lochner 2005). It is, nevertheless, less available to patients who desire it than in the past (Freeman, Olesen et al. 2003).

Whether larger general practices and the policy of assigning patients to practices rather than to GPs must necessarily beget less interpersonal continuity is not entirely clear (Guthrie 2002). Evidence appears to suggest that some interpersonal continuity is better than none, and that team continuity and information continuity can yield positive benefits as well (Tarrant, Windridge et al. 2003). These types of continuity have their own organisational challenges, however, and it is not clear that they are effective substitutes.

Patient participation in care:
Health professionals could be more attentive to their patients’ preferences for decisional control, even over the course of a single illness or consultation (Cohen and Britten 2003; Say, Murtagh et al. 2006). There need to be clearer ways to inform patients of the existing evidence for different treatment options while at the same time allowing them the freedom to make the best choice for them, as patients who assist in choosing their treatment are more likely to follow it through than those who reluctantly follow their doctor’s advice (Montori, Gafni et al. 2006). While tools such as decision aids may help convey information to the patient more quickly and completely (Elwyn, O’Connor et al. 2006), a significant transformation in the way health professionals conduct consultations may be required, as grafting shared decision-making practices onto existing practices seems not to work well and ingrained habits are of both patients and professionals are difficult to change (Towle, Godolphin et al. 2006).

Evidence-based medicine:
EBM is a movement with significant potential to improve health outcomes, as it seeks to apply the best scientifically-derived evidence to a patient’s care, but the assumption of a single best solution seems at odds with the counterveiling trend toward increased patient involvement and individualised care. ‘Evidence-based patient choice’ (Ford, Schofield et al. 2003) and the “informed patient” (Entwistle et al. 1998) represent potentially useful models which seek to capture the best aspects of both trends. However, it is difficult to conceive of applying models such as this one in practice because of the increased consultation time required.

Many practitioners choose to defer to their patients’, or their own, judgement, rather than follow EBM protocols. They would likely increase their use of evidence-based medicine, however, were the evidence to appear more suited to various individual cases: it remains easy for doctors to argue that the details of their individual patient’s health might respond better to a treatment that differs from that appropriate for the general population (Freeman and Sweeney 2001; Summerskill and Pope 2002).

Expert patients:
Patients who are fully engaged with their health and care are a central plank of present health policy. Some who are crafting and advocating this policy borrow the term ‘co-creation’ to describe the mental and cultural paradigm shift they hope to achieve, as patients partner with professionals and health services to co-create their own health (Cayton 2006). Meanwhile, the Internet represents a significant source of health information, advice, and support for patients, who use it in ways that both complement and conflict with the care they receive through the formal health service. NHS Direct is particularly interesting in the context of professional/lay relations as perhaps the most explicit attempt by policy-makers to place health professionals in a supportive rather than directive role. Those from lower SES groups were less likely to have used the service (Knowles, Munro et al. 2006), which will disappoint those observers who had expressed the hope that the phone-based service would be favoured by those with less ready access to the Internet.

**Informal Carers and Health Professionals:**

Policy-makers hope to rely on informal carers to an increasing degree in the future, but many of their needs are presently unmet, and there are many things health professionals could do to better support them in caring for their shared patient. Informal carers face considerable strain in their role, and many suffer adverse health consequences as a result (Vanderwerker, Laff et al. 2005). Research shows informal carers to strongly value ready access to the professional caring for their loved one (Grande, Farquhar et al. 2004). Informal carers do not appear to draw major distinctions between medical and non-medical issues related to their informal care role, and have reported a desire for their primary care practice to be a one-stop-shop for all information and support related to this role (Hare, Rogers et al. 2006), including help finding financial resources, and ordering equipment and services (Kirk and Glendinning 2002). Finally, informal carers are likely to identify more needs of the patient than either the patient or the professional, leading scholars to the conclusion that professionals could thus help both patient and carer by creating more opportunities for carers to partner with them and discuss their concerns regarding the patient (Sharpe, Butow et al. 2005).

### 2.3 Options for Action

For better or worse, encounters with health professionals remain at the heart of the public’s perception of what constitutes illness prevention and treatment. Though tools and technologies for self-diagnosis, advice and information will continue to increase over the next generation, it is difficult to conceive of a health service without practitioners. While the formal training those professionals receive teaches them to evaluate evidence to solve difficult problems, it teaches them less about how to present that information. Information sharing is a skill that can be taught, as can emotional care and sensitivity to a patient’s preference for information and decisional control.

Continuity is in the eyes of the patient (Haggerty, Reid et al. 2003), and efforts should therefore continue toward a seamless care service. It is associated with numerous desirable outcomes, and is particularly valued by the chronically, mentally, and seriously ill, all of whose numbers are increasing. It doesn’t seem impossible that the chronically ill, whose regular consultations may be scheduled in advance, should experience any less of this type of continuity. Team continuity is a lesser replacement for interpersonal continuity, but may also complement it, as may informational continuity.
Patients’ desire for involvement in their care can change even within the period of the consultation, and health professionals must learn to solicit and be sensitive to these changing preferences if patient participation is to gain traction at the consultation level. The test of how much policy-makers value patient participation (which is linked to higher satisfaction, adherence, and self-efficacy) may be in how willing they are to fund it. While the critical question at first appears to be who makes the decision about treatment, evidence shows that patients seem to value the process more than they care about whether the decision was truly their own (Edwards and Elwyn 2006), and consultations could be redesigned to reflect this. Reviewing audio transcripts of their own consultations appears effective in changing physician behaviour (Towle, Godolphin et al. 2006).

In order to maximise our use of both evidence-based medicine and patient involvement in decision-making, relevant evidence-based information needs to be put in the hands of the patient, so that they may consider it alongside their knowledge of themselves and their preferences. This is a difficult task to complete within a ten minute consultation (Edwards, Elwyn et al. 2005). Sharing information and reaching consensus takes time, and may demand longer consultations could be lengthened. A series of short consultations may prove even more effective, allowing consultation with family members and other information sources like decision aids (Elwyn, O’Connor et al. 2006) as well as time for questions or concerns to develop. Relatively few medical decisions in our age of chronic illness must be made immediately. Also, where shared decision-making has been tacked on to the existing consultation model it has largely failed (Towle, Godolphin et al. 2006), as the original consultation’s purpose was to transmit information from patient to doctor, not the other way around, as the new model would be designed to do. The relatively new field of conversation analysis may help with this, as it has been able to pick up startling differences in outcomes like patient feelings of efficacy and participation with the substitution of a few mere words or sentences (Heritage and Maynard 2006).
3. Annotated bibliography

3.1. The patient/professional relationship in the context of patient-centred care:

What is meant by patient-centred care? In theory at least, the old paternalistic model of a well-intentioned, all-knowing doctor or nurse and a passive, obedient patient is being displaced by a new partnership model, that of the professional and the patient as co-collaborators, both experts in their respective specialties. This shift can be characterised as one from ‘doctor-centred’ to ‘patient-centred’ care. Some note, however, an asymmetry between doctors’ and patients’ understandings of their relationship and sense of its significance. Others argue that doctors often have little sense of their role in their patients’ larger “illness narrative” and could stand to gain from understanding it better. Some observe that for much of the public, interactions with a medical practitioner represent not a relationship but a series of transactional encounters, more in common with exchanges with cab drivers (Potter and McInlay 2005).

- (Gillespie, Florin et al. 2004) interviewed health care leaders in the UK regarding their understanding of patient-centred care, and found that different professional groups had developed different understandings of the concept, from ones rooted in the individual doctor-patient encounter to ones more focused on patients as citizens influencing policy and strategy.
- (Haidet, Kroll et al. 2006) interviewed 16 primary care patients in the US and analysed their “illness narratives.” In these stories they observed five general “illness-management strategies” based on style of partnership (or lack of partnership) with their health professional. Arranged from least productive to most, these strategies were passivity/fatalism, unguided searching (for information without a professional’s guidance), adherence to the doctor’s instructions, self-motivated change (choosing an option without much influence from a professional), and negotiated empowerment. The authors theorise that doctors may be able to better influence their patients’ choice of these strategies, and movement from one strategy to another, by understanding the four key components of a patient’s illness narrative: 1) how important is the illness in the patient’s life, 2) how much the patient believes the “plotline” of the illness can improve, 3) how much the patient engages in “illness-related activity” and 4) the patient’s perception of their doctor’s role in managing their illness.
- (Heritage and Maynard 2006) summarise the main sociological and medical approaches to the doctor-patient relationship that have appeared in recent history, from Parsons and Balint, through the first large descriptive studies of the early seventies, and on to the burgeoning literature of today. The authors think a more recent development, conversation analysis, is very promising, as it has been able to yield consistent results that illustrate relatively small differences in ways of communicating that show a surprisingly large change in a patient’s response (improved self-efficacy, willingness to state preferences, etc).
- (Lings, Evans et al. 2003) studied doctor-patient relationships in the US primary care setting in order to understand the possible changes in the UK driven by the priorities of improving access and availability. What they found from their focus groups was an asymmetry of perceptions between doctors and patients, which suggested to them a problem with the “meeting between...
experts” model, as well as the significance for both parties of “liking” and trust.

- **(Morgan 2003)** summarises much of the research and thinking behind the current trend toward “patient-centred care”, which he defines as un-paternalistic and designed to elicit more participation from the patient in the conversation leading to decisions about diagnosis and treatment, characterised by “open” rather than “closed” questions, and built on a relationship of “mutuality.” Larger societal factors are driving this trend, such as patients’ increased medical knowledge through the media and the internet, social values increasingly oriented toward individual autonomy and responsibility and a consumerist ideology, and the increasing prevalence of chronic illness which requires long-term self management. Morgan argues that the chief factor in determining the doctor-patient relationship is the doctor and that, further, most doctors are either patient-centred or not but rarely somewhere in the middle.

- **(Oliver 2001)** interviewed 16 British chronic obstructive pulmonary disease (COPD) patients, and found a close correlation between their perceived relationship with their GP and their expectations of health care support and reported ability to control their symptoms, though causal relationships are more difficult to ascertain. For better or worse, they perceived their GPs to have immense power over their lives, and the majority sought a more active role in their disease management.

- **(Potter and McKinlay 2005)** suggest that environmental changes in the American health care system—its corporatisation and undermining of both physician and patient authority—have changed the doctor-patient relationship. It is not patient encounters or outcomes which are the main contributors to doctors’ stress levels, but regulation and insurance companies. Whereas in the middle of the century patients’ relationships with their doctors, though paternalistic, could at least be characterised as enjoying both lateral (multi-faceted) and longitudinal (long-term) depth, today’s patients enjoy neither, their encounters with doctors having more in common with encounters with shoe salesmen or other service providers. In taking this environmental view, the authors take some of the responsibility for improving relationships off doctors’ shoulders and argue for systemic change.

- **(Roberts 2004)** argues for the value of the doctor-patient relationship. She points to evidence showing that empathy, continuity, trust, and a doctor’s relational skills are particularly important to the elderly and the chronically ill. They encourage people to take their medication more whilst overall fewer prescriptions are written, and points to other evidence suggesting that beyond its therapeutic effect, patient-centred care ‘provides the conditions for understanding and the avoidance of misunderstanding’.

- **(Wiles and Higgins 1996)** reason that since patients regularly report disappointment not with their clinicians’ technical knowledge or skills but with their relationships with them and the degree to which they provide information and patients’ ability to ask questions, changes in this direction may appear first in a more consumer-driven doctor-patient relationship, i.e. in private care. They therefore surveyed 649 private patients and conducted follow-up interviews with a representative sample of 60. They found that the private patients were overwhelmingly satisfied with their care relative to that they received through the NHS. In addition to enjoying shorter waiting lists, better
access, and longer consultations, the most interesting finding was the positive feeling private patients had about their relationships with their doctors, some even characterising them as friendships. The authors argue that though many of these patients were assertive types, and they were paying for their relationship with their doctor as well as the care they received, they remained dependent on the doctor for care, which diluted the consumerist nature of the relationship. Moreover, patients seemed to prefer this. For their part, one may assume that doctors, preferring to steer clear of a consumerist relationship, do what they can to direct their relationships toward this kind of model. The article was published 10 years ago, and based on data collected in 1991, but was unable to find anything published more recently.

**How much value does patient-centred care have for patients?** There is little doubt expressed that patients would rather experience a warm, empathetic medical encounter than a cold, transactional one. But how significant is this preference, and what sorts of sacrifices would patients make to maintain it? Some researchers and practitioners have argued that the experience of a satisfying medical encounter itself may be therapeutic, beyond any information, advice, or treatment that follows from it.

- **(Buszewicz, Pistrang et al. 2006)** find that patients are generally positive about the mental health treatment they receive from their GPs, who provide the bulk of care for psychological problems. In particular, GPs who projected an attitude of warmth and empathy were highly valued in these contexts, as was interpersonal continuity. Patients appreciated their relatively easy access to a ‘safe space.’

- **(Dixon, Sweeney et al. 1999)** discuss the placebo effect created by GPs’ attentions, arguing that since it has been demonstrated that the doctor’s attitude can affect health outcomes, and that patients often seek a warmer relationship with their clinician, GPs can kill two birds with one stone by maximising their ‘ancient healer’ effect and becoming a bridge between impersonal medical science and their patients’ real lives.

- In a much-cited article, **(Little, Everitt et al. 2001)** studied 865 patients in the UK and found that patient satisfaction and symptom relief were most positively associated with patients’ perceptions of quality of their communication and partnership with their doctor, as well as a ‘positive approach’, in which the doctor acts in a confident and sure way, keeping any uncertainties to herself.

- In reference to out-of-hours paediatric care, **(Scott, Watson et al. 2003)** found that parents in Aberdeen and Glasgow reported that they would value a doctor who listened to them over access and convenience.

- **(Woolhead, Tadd et al. 2006)** Focus groups of elderly patients reported that appropriate forms of address, listening, giving choices, including them, respecting their privacy, and making them feel valued were very important to their feelings of dignity and self-worth. Focus groups of health and social care staff meanwhile, while acknowledging the importance of good communication practices, admitted that they often failed to implement them because of lack of time, staff, resource scarcity, regulation and bureaucracy.

**Nurses and GPs in creating/maintaining patient centred-care:** Nurse practitioners (NPs) appear better able to meet patients’ expectations of a warm, empathetic medical
encounter, both because of their professional culture and training and their longer consultation times that allows for more listening, discussion, and informal interactions.

- (Seale, Anderson et al. 2006) report that NPs have been found to receive higher satisfaction scores from patients than GPs and to deliver comparable clinical quality. Analyses of audio transcripts of 18 NPs and GPs in consultation with patients revealed that NPs spent a higher proportion of their time with the patient discussing various treatments, their use, and their side effects, and demonstrated greater concern for the acceptability of various treatments to the patient. Also, whereas GPs in their short time with the patient focused on gathering information related to diagnosing and treating the immediate presenting complaint, nurses practiced a more holistic approach. It is the content of the encounter as well as its longer duration that makes NPs preferable to patients over GPs.

- (Williams and Jones 2006) interviewed ten patients who had consulted with NPs in the UK and found high satisfaction for the care they received. They appreciated the ease of access to NPs. Whereas GPs in the practice they studied spent 4-6 minutes per consultation, NPs spent 10-15 minutes, and patients felt that this extra time made for conversations with richer detail and context. There was also evidence that the extra time enabled the discussion to take on a warmer tone. The authors suggest that the different character of NP and GP consultations may be due less to length of consultation than to different professional styles.

- (McGarry 2003) interviewed ten community (or ‘district’) nurses in the Midlands about their work and role. Because these nurses spent most of their time with patients in those patients’ homes, as a “guest”, they perceived patients to have more control over the encounter. The nurses also described spending a great deal of time negotiating care plans, as otherwise they feared that the plans would not be adhered to. For this reason, as well as for the reason of wanting to ensure that they were invited back, they viewed the development of personal relationships as very important, which they said was made easier by seeing the patient in their home context. The nurses reported that friendships sometimes developed between them and their patients, which sustained them but could also contribute to burnout, as well as what they described as too much dependency of the patient on them. They were clearly worried about becoming too attached to some patients and about maintaining professional boundaries and distance. They would thus occasionally rotate patients to other colleagues if they felt professional distance was in danger of being compromised.

Patient centred care and professional authority: collusion with illness? Not everyone is happy about the ascendancy of patient-centred care. Some argue that in focusing too much on maintaining good patient relations, professionals may become reluctant to challenge patients’ strategies for managing their health and illnesses.

- (Butler, Rollnick et al. 1998) suggest that GPs continue to prescribe antibiotics for obvious viral ailments despite the known risks—converting to the problem of drug-resistant viruses, strengthening patients’ expectations about the results of future GP visits, and missing an opportunity to educate patients about their health—because doctors are too eager to maintain good relations with their patients.
• (Chew-Graham, May et al. 2004) take a ‘tough love’ approach in their reaction against the notion that maintaining a positive GP-patient relationship should be the primary aim of the consultation. They argue that there is a particular type of demanding or needy patient—chronically unhealthy yet unwilling to modify behaviour—is incapable of challenging and with whom this approach colludes. Under a paternalistic model, doctors had the authority and power to challenge these patients to get better, and now they are just a drain on resources and morale because doctors are unable to do anything but smile, nod, and privately disagree with their patients’ preferred course of action.

• (Hare, Gaur et al. 2006), on the other hand, seek to disprove the hypothesis that GPs prescribe more because it shortens consultation time. They study 2739 doctor self-reported consultation duration times, and find that time spent in consultations with children complaining of respiratory symptoms that resulted in a prescription was not significantly less than those where no medication was prescribed.

• (Kumar, Little et al. 2003) interviewed 40 GPs and found that the GPs believed that maintaining a good relationship had little to do with their prescribing habits. Instead, they responded that they are more likely to prescribe for sicker patients and lower SES patients because of fear of complications, as well as in pressured clinical contexts.

3.2 Continuity of care

How much do patients value interpersonal continuity? Interpersonal continuity between health professionals and patients is under threat. There is debate about how much patients now value it and might mourn its disappearance in the future.

• (Coulter 2005) argues that “the really important changes need to occur at the level of individual interactions between patients and health professionals.” Patients want access, continuity, and the ability to choose their level of involvement in their health decisions (including help with self-care.) She argues that though younger and healthier people seem to privilege access over continuity, that does not mean that they favour doing away with the GP list system altogether.

• (Guthrie 2002) studied 25,994 visits to 53 general practices in four different regions of the UK in 1998 to find out how often patients saw their regular doctor. He found that overall 61.6% saw their regular doctor, though this varied dramatically between practices. At the largest 40% of practices patients had only one-fifth the odds of seeing their regular doctor compared to patients in the smallest 20%. The dominant explanation for why young people care less about continuity is that older people are used to it from the past and thus expect it (a ‘cohort effect’). He cautions against this assumption about future preferences, however, arguing that older people suffer from many more chronic and complex conditions than younger people do, and that this affects their preferences for continuity (a ‘lifecycle effect’). Evidence showing that men’s preferences are no different than women’s by middle age may further support the case that a preference for interpersonal continuity is a lifecycle rather than cohort effect, and that we may be mistaken to think that interpersonal continuity will not be important to
patients of the future. He also suggests a couple of changes that could be made to large practices to make continuity more available to those who want it, while preserving access: operate personal lists for those with chronic illness (because these appointments are far more predictable), subdivide larger practices to maximise the advantages of both, or settle for small team continuity (which some view as having its own advantages).

- **(Kearley, Freeman et al. 2001)**, in surveys and interviews of patients and GPs in Oxfordshire, find that both GPs and patients highly valued their personal relationship. When more serious psychological and family issues were present, 77-88% of patients valued a personal relationship over a convenient appointment.

- **(Love, Mainous et al. 2000)** surveyed asthmatic Medicaid recipients in Kentucky and found that interpersonal continuity of care was much more important to their overall feeling about their medical encounters than it was for those without a chronic illness. They warn that a shift away from interpersonal continuity may therefore affect chronic illness sufferers disproportionately.

- **(Sweeney and Gray 1995)** ask who the people are who do not receive continuity of care in the UK. 110 patients without continuous care were studied against a continuity group: they were less likely to be old and more likely to be poor (and live in council housing), more likely to have violence in the home, marital problems, and problems with their children, more likely to suffer from several general symptoms, and suffer various other disadvantages. Interestingly, a third of this group’s consultations were recorded as ‘difficult’ (that was only true of 3% of the continuity group), and they were more likely to both skip GP appointments and attend the A & E.

**Outcomes associated with interpersonal continuity in care:** Interpersonal continuity is linked with better clinical outcomes.

- **(Cabana and Jee 2004)** performed a large literature review to determine whether interpersonal continuity of care was related to better clinical outcomes. Of the 18 studies they examined, in none of these did continuity of care produce worse outcomes and in many continuity was associated with more uptake of preventative care, fewer A & E visits, fewer hospitalisations, and higher patient satisfaction, suggesting that the claim of a link between interpersonal continuity and quality of outcomes is valid, particularly with regard to chronic conditions.

- **(Freeman, Horder et al. 2002)** review much of the recent literature on changes to General Practice, especially with regard to consultation length, and argue that although in 1998 87% of the public reported satisfaction with the length of their most recent consultation, patients who receive longer consultations are even more satisfied. In addition, these patients have better outcomes, fewer consultations, are prescribed fewer drugs and receive more lifestyle advice. The authors also note that while booking times have stayed the same, actual lengths of consultations in general practices have gone up. They add that there is evidence that continuity builds trust and may improve outcomes, and that continuity is disappearing. They advocate for longer consultation times, more attention to allowing patients to consult with their preferred GP rather than one of their colleagues in the practice, as is often the case. Less duplication, more trust (and thus faith in "wait-and-see"
recommendations), less prescribing, and fewer GP visits per capita overall would compensate for the greater expenditure.

- **(Gray, Evans et al. 2003)** strongly believe that a policy move away from interpersonal continuity of care is a bad idea. They review the literature on continuity and based on this make five conclusions (3 strong and 2 tentative). They strongly conclude that patients with continuity a) are more likely to practice preventative care, b) more likely to adhere to their treatment plan and take their medication correctly, and c) be more satisfied with their care. More tentatively, they conclude d) that for patients living with chronic diseases the quality of their care goes up (though advice on disease management may become less strict), and also e) that patients like continuity of care: this is less strong because men and the young value it less. These findings are consistent across various systems and countries. They also suggest that there is no reason to assume that larger practices cannot continue to provide interpersonal continuity of care.

- **(Saultz and Lochner 2005)** also find evidence that interpersonal continuity yields better outcomes. In a review of 40 studies, they find 51 examples of outcomes improved by continuity and only 2 that were worsened by it. They also observe that 20 studies observed an inverse relationship between cost and continuity. They thus conclude that interpersonal continuity is cheaper and higher quality than the alternatives.

**Can interpersonal continuity be replaced?** Some wonder whether other kinds of continuity, like continuity of information and continuity among a team of professionals, can replace interpersonal continuity.

- **(Alazri, D Neal et al. 2006)** studied patients in focus groups with type 2 diabetes in Leeds who were in clinics with various degrees and types of continuity. They distinguish between relational (or longitudinal) continuity, cross-boundary (or team) continuity, and continuity of information. They aimed to assess the benefits of each type, as experienced by chronically ill patients. Patients identified various benefits, drawbacks and risks of each, the most interesting being the higher risk of misdiagnosis with an individual doctor than a team. Preferences depended on personal factors (like relationships with doctors).

- **(Dowrick 1997)** notes that as general practices get larger and include more specialists and the use of teams, the emphasis for GPs is shifting from maintaining a positive and trusting relationship to conducting effective “consultation techniques”.

- **(Freeman, Olesen et al. 2003)** point out that the recent GP contract reassigns patients to practices rather than doctors, and that this policy decision will surely accelerate what has been a general trend away from interpersonal continuity of care. They are unhappy with this trend, and argue that (in addition to social forces) it has been partly due to unspecific definitions of continuity that are broad enough (including continuity of information, for example) to reassure us that we are not really losing continuity at all. To confuse definitions of continuity is to confuse kinds and skills of care: if we lose interpersonal continuity but gain informational continuity (through electronic clinical records etc), we are not where we started; those are two separate aspects of medicine. Finally, they point out that the central reason to defend interpersonal continuity is that it imparts
‘the ability to make and value a multidimensional diagnosis, based on the biopsychosocial model within the patient’s context’, and that this diagnosis is not only more accurate, but more applicable as well.

- **(Haggerty, Reid et al. 2003)** derive an obvious but important point from a large literature search for definitions of continuity of care: continuity is in the eyes of the cared for. While continuity may be experienced through repeated consultations with the same individual, with members of a team with similar and developing knowledge of the patient, or through consistent advice about management, the critical element is that the care must be experienced by the patient as “connected and coherent.”

- In interviews with 24 GPs, **(Ridd, Shaw et al. 2006)** find that the vast majority of them regarded interpersonal continuity as important, particularly for patients with complex or psychological problems. Continuity is increasingly being provided by teams associated with a practice rather than a single point of contact, and it is unclear whether the benefits of continuity are replicable in a team framework.

- **(Tarrant, Windridge et al. 2003)** interviewed 40 patients, 13 GPs, 10 nurses, and 6 administrative staff in practices around Leicestershire in order to solicit opinions on whether interpersonal continuity is a necessary component of individualised care. Many patients felt that interpersonal continuity was not critical to personalised care, particularly if there was continuity among a team of caregivers, though interpersonal care was nevertheless highly valued. The subjects reported that interpersonal continuity was not nearly as important with relatively straightforward or very acute problems. Interestingly, other members of the practice, such as the receptionists, were pointed out as having an important effect on whether the care one received at the practice felt ‘personal’ or not.

### 3.3 Patient participation in care

**Models of patient involvement: how is ‘shared decision-making’ defined?** Much of the discussion in medical sociology centres around describing the ideal model that shared decision-making (SDM) between professionals and patients should take.

- **(Charles, Gafni et al. 1997)** lay out a basic theory of SDM, focusing their attentions on situations involving life-threatening illnesses for which there is no one clear clinical path because of scientific uncertainty or multiple significant options from which the patient and professional must choose. As they use the concept, SDM involves four major components: the doctor and patient are both involved in reaching the decision, both parties share necessary information, the parties work toward consensus, and an agreement is reached. They juxtapose SDM against both a paternalistic, doctor-led and decided approach on the one extreme and a patient-led “informed decision-making” model (where the doctor’s job is merely to pass along information), arguing that their approach lies somewhere in the middle and thus involves and satisfies both parties. They also observe that carers may offer additional support to the doctor in conveying information and eliciting the involvement of the patient (or may simply pursue their own preferences on behalf of the patient). Health professionals should be sensitive to both possibilities.
• (Charles, Gafni et al. 1999) add doctor flexibility to the model of SDM put forward in their 1997 article. They advise doctors to pay close attention to the decision-making style preferences of their patients over time, even within a single consultation, as a patient who initially indicated an interest in following whatever advice the doctor indicated may develop an opinion with further experience and information, or even wish to go back and reconsider decisions made earlier by the doctor.

• (Gafni, Charles et al. 1998) compare two important models of the doctor-patient relationship: one where the patient draws as much knowledge from the doctor’s expertise as she can before making a decision (the “informed treatment decision-making” model), the other where the doctor learns as much about the preferences, social context etc from the patient before making a the best decision for that patient (the “physician as perfect agent” model). They argue for the first model, on the grounds that it is easier for the doctor to transfer relevant knowledge to the patient than vice versa because we have better “technologies” for that sort of information transfer, and because the patient’s situation and preferences are more unstable.

• (Makoul and Clayman 2006) reviewed 418 articles about SDM in medicine, and found no common definition of the concept. They therefore attempt to establish a definition by consolidating all of the research done so far and borrowing from the most common features of many different models. Their resulting definition includes both “essential” characteristics that must be present, as well as “ideal” elements that are not critical but improve the experience of the patient or professional. Essential elements: both parties define/explain the problem, present options, discuss the pros and cons of each, as well as the values, preferences, and abilities of the patient, and perhaps the recommendations of the doctor, clarify each others’ understanding, and explicitly make a decision, rather than keeping one’s intentions when one walks out of the room to oneself. The authors argue that the basic process can still occur if the essential elements are present during the consultation, even if the patient or the doctor (by request) is taking more control over the final decision.

• (Wirtz, Cribb et al. 2006) criticise models of patient involvement in decision-making developed so far for their neglect of two issues at the heart of decision-making: which decisions it is most important that patients be involved in, and how specifically they should be involved. They argue that the issue of professional ethics is far more important than acknowledged by these models, and that the lack of attention paid to this issue may explain their neglect of the first two issues.

**Who wants more involvement and how much?** Much demographic research has been carried out on which segments of the population (subdivided by class, gender, ethnicity, age, and so on) would like more involvement in the decisions concerning their care, and who would prefer to leave the locus of decision-making control in the hands of the professional. Similar work has examined the role that advancement of illness, length of experience with the health care system, and diagnosis play in this preference. SDM is linked to better outcomes, higher satisfaction, and more perceived self-efficacy, leading to the question of how to increase the number of patients who want more involvement, rather than simply how to accommodate those that already do. Desire for increased involvement has also risen over time.
• **(Bentley 2003)** found that the consumerist ethos had made little impact in elderly residents of a UK village, who continued to favour the traditional rather than partnership model of professional-patient relations. The author fears that new health services, which may favour assertive patient behaviour, may leave his subjects at a further disadvantage.

• Surveying 210 UK adults with asthma, **(Caress, Beaver et al. 2005)** found that when presented with five points on a continuum running from completely preferring that the doctor make decisions to preferring to make decisions oneself, and then to describe one’s actual consultation experience, only 33.5% attained their preferred role, and 55% wished for more involvement. Further, the more active one wished to be, the greater the likelihood that one had been disadvantaged with the actual level of one’s involvement.

• **(Cohen and Britten 2003)** find that men recently diagnosed with prostate cancer were generally happy to let their doctor take the lead in their care, though over time they wished to be more included in decision-making, and sometimes to revisit decisions made earlier by the doctor. Barriers to involvement were a fear of showing disrespect as well as fear of making a wrong decision. (See also **Charles, Gafni et al. 1999**.)

• **(Edwards and Elwyn 2006)** ask why SDM has not been instituted in practice on a mass scale despite the positive research findings and policy support of the past decade. They hypothesise that interviews with patients of GPs committed to shared decision-making might shed light on the obstacles to greater implementation. Half their sample reported that they had made the final decision themselves, while half reported the decision-making had been shared, but significantly neither of these groups exhibited more satisfaction than the other, resulting in the authors’ conclusion that they were involved to the extent that they wished to be. Patient dissatisfaction resulted from misalignment between the GP and the patient as to how much decisional responsibility the patient should have. From their study they conclude that involvement in the decision appeared to deliver more satisfaction to patients than the act of decision-making itself. The important thing from a patient satisfaction perspective, they argue, is that the GP seek to understand how much decision-making involvement the patient wants and align her behaviour appropriately, rather than fretting about how much or little decisional responsibility they cede to their patient. In short, the process of decision-making is more important to the patient than who actually makes the decision.

• **(Fischer, Visser et al. 2006)** asked similar questions of Dutch prostate cancer patients. Most of these patients felt that they had participated in the treatment decisions (though only 18% reported that they had made the decision on their own, while 60% reported that the decision had been made collaboratively). Both sicker and older patients were less likely to report being involved. Unsurprisingly, younger patients reported the least overall satisfaction when they felt they were uninvolved. The authors note that better informed patients are more likely to prefer involvement.

• In an editorial, **(Griffiths 2005)** argues for more SDM in asthma management. For reasons specific to this condition, involving patients in the consultation and decision-making is critical to success. He is wary of self-care measures which potentially decrease patient/professional interaction, instead pointing to successful, collaborative consultations as the key ingredient in improving and maintaining patients’ self management of their condition. He argues in
particular that patient-centred care may be the best opportunity we have to affect the poorer outcomes for asthma sufferers among minority ethnic groups (even absent language barriers). Finally, he notes that the demand for participation is increasing: a 1984 US study found that almost half (47%) of asthma patients preferred a purely passive role, while the number preferring a purely passive role was only 14% in 2004 (Caress, Beaver et al. 2005), albeit in a separate UK study.

- (Longo, Cohen et al. 2006) trained GPs in 20 South Wales practices in SDM techniques, and then studied 548 patients’ perceptions of treatment with the trained GPs. While they found that the training provided to the doctors had an impact on patients’ perception of their involvement in decision-making, they also found that shared treatment decisions were valued less than other attributes of the consultation, such as whether they felt that their doctor was a good listener. They add, however, that their data suggests that patients may value shared decision-making more after trying it the first time.

- In interviews with 60 lay Australians about their understandings of the medical encounter, (Lupton 1997) found that patients acted as both consumers of health care and as passive patients, that they wanted both, and that passivity, dependence and sympathy are all aspects of health care product we seek to consume. Her larger project is to dismiss the notion of the rational, reflective, autonomous self as little grounded in the realities of real people and their complex relationships with what they want and what they should do.

- (Say, Murtagh et al. 2006) summarises 33 qualitative and quantitative studies (including many based outside the UK) studying patients’ preferences for involvement in the decisions about their care. They find that younger patients prefer a more active role in decision-making (17 out of 22 studies), as do women (5 out of 8), and people with higher education (16 out of 20), while poor people of lower social class were found to prefer a more passive role (5 out of 6 studies). Regarding changes in the preferences of patients as they progress through an illness (or develop a new medical condition) the studies appear divided, with some showing that as patients become more ill they become more passive, while others show that as they gain experience with their illness and the health care system, they desire a more active role. Patients preferred a more active role in decisions about modifying behaviours, and the most serious decisions, like heart surgery, as well as very minor ones, like colds. They preferred to cede most of the decision-making to the doctor with physical problems in between these two extremes. Finally, they warn that not all patients who seek more information would prefer more decision-making responsibility.

- Health economists (Vick and Scott 1998) surveyed 101 patients of a general practice in Aberdeen and found that although patients preferred more information to less, only women and the most highly qualified respondents preferred to choose the treatment themselves. Their survey was different from other satisfaction surveys, in that it forced patients to consider opportunity costs and prioritise their preferences. They also found that patients attached greatest importance to ‘being able to talk to the doctor’ and found that of the choices presented to the sample ‘who chooses your treatment’ was least important to patients. There were a few other nuggets in their results as well: of the 16 patients who had changed their GP, only 6 had done so for “consumerist” reasons. Also, they found no support for the claim that better
educated patients seek more health information; rather they found that (relatively) healthier patients sought more information than those in poor health. The authors note, however, that the sample is small.

**How much patient involvement is there at present?** Patient involvement has been embraced by many important stakeholders in health care. However, it is rarely employed in practice to an extent that satisfies patients.

- **(Lester, Tritter et al. 2003)** found that among 45 schizophrenic patients receiving care through the Northern Birmingham Mental Health Trust, there was a very significant gap between the reality and the rhetoric of user involvement in these patients’ consultations. The authors argue that greater satisfaction with their primary health care could be achieved if the gap could be narrowed between GPs views of schizophrenia as an incurable life sentence and the importance to patients of hope for recovery.

- In a study observing nurse-patient interactions, **(Millard, Hallett et al. 2006)** find that being cared for in one’s own home does not necessarily mean one will have a greater role in one’s own care, that some nurses are able to engage their patients with their care to a much greater extent than others and through many various methods, and that some patients do not wish to be involved in their care.

- **(Seale, Chaplin et al. 2006)** report that after interviewing 21 psychiatrists in the UK about their care for their psychiatric patients, “a self-perception of patient-centredness may not preclude psychiatrist from fulfilling a social control function.” On many levels, psychiatrists felt that aspects of patient-centredness would be inappropriate for their patients, such as explaining the side-effects of medication when that could potentially run the risk of putting the patient off their medication.

**Patient involvement in decision-making and trust in health professionals:** Researchers have discovered a complex relationship between patients’ trust in their health professional, the level of emotional support offered by that professional, and patients’ desire for increased decisional control:

- **(Kraetschmer, Sharpe et al. 2004)** find that trust in one’s doctor is inversely correlated with one’s preference for participation in decision-making. In this Canadians study, patients who distrusted doctors preferred a more autonomous role in the relationship, and vice versa. Those who preferred a shared decision-making style were somewhere in the middle. The authors conclude that doctors who want to engage in SDM with their patients may need to foster a more trusting relationship. See also Lowton and Ballard 2006.

- **(Maly, Umezawa et al. 2004)** find that among breast cancer patients over 55 years old in Los Angeles County, whether surgeons had solicited patients’ treatment preferences was a powerful predictor of patients’ self-reported participation in decision-making and feelings of self-efficacy, controlling for demographic and SES characteristics. Intriguingly, greater perceived emotional support from surgeons was negatively associated with patients’ self-reported participation in decision-making, and both the patient’s age and the amount of information the physician gave had no relation to patient participation. (See also Jackson, Putnam et al. 2004).
• (Van den Brink-Muinen and Rijken 2006), in a Dutch study, ask whether chronically ill people's trust in health care professionals and institutions affects their use of complementary and alternative medicine (CAM). Using a survey, they find that chronically ill people trust CAM practitioners less than regular health care professionals. They also find, however, that the chronically ill (particularly the young and well-educated among them) have less trust in future health care than present health care, that lack of trust is a significant predictor of CAM use, and that CAM use may likely increase. Given this, the authors advise that CAM should be regulated more strictly.

Worries about ‘fake’ involvement: An important piece of the theoretical underpinning of shared decision-making is that while control over the decision need not necessarily be split 50-50, both parties must agree on the chosen option. This is called concordance, and there is a risk that decisions may appear more concordant than they really are.

• (Goodyear-Smith and Buetow 2001) note that while we hope we are moving away from an “adult-child” doctor-patient relationship toward an “adult-adult” relationship, reasonable adults often disagree. In these cases paternalism can creep in again as the doctor exerts her power, but that tendency can be limited by encouraging all parties to explicitly acknowledge power issues present in the encounter.

• (Stevenson and Scambler 2005) define concordance as the idea that both patient and practitioner should work toward a treatment option upon which they both can agree. They like the idea, but worry that it is being promoted by a variety of societal forces (consumerism, fall in status of medical professionals, wider public education) just as other societal forces are acting to make the idea impossible to achieve. They worry that for these reasons, we may end up in the future with something that looks like concordance but is hollowed out by the hidden inequalities in the professional-patient relationships it supposedly describes.

Parents, children and health professionals: Shared decision-making takes on a different appearance when those in the consultation with the health professional are children and their parents.

• (Gabe, Olumide et al. 2004) apply the SDM model developed by Charles, Gafni et al to paediatric care, where the patient arguably has fewer decisional rights and the parent has more (as well as more responsibility). They imagine scenarios where a doctor and parent may collude to pursue an option the child objects to, or alternatively the professional may be able to create space for the child to make a decision out of the shadow of the parent. They also observe that legal and ethical issues are more apt to appear in pediatrics: do and should children have similar rights to adults? What sort of responsibilities do parents have over their children?

• (Young, Moffett et al. 2006) found that most decisions in the care of children with cerebral palsy were made unilaterally, although often not by the health care professional. In interviews with children, parents, and practitioners in an inner city area of northern England, each group claimed responsibility for various types of decisions. While practitioners claimed a large role in decisions about resource allocation, and therefore about the effectiveness of interventions, parents laid the greatest claim to decisions about interventions,
followed by children, who were mostly restricted to negotiating about how the interventions were implemented.

The barriers to patient involvement: What are the barriers to greater patient involvement, and what measures can remove them?

- **(Bugge, Entwistle et al. 2006)** find that in interviews that both doctors and patients omit information significant to decision-making during consultations, sometimes impairing the decision-making process. This is unsurprising given typical consultation times, however the authors worry that decisions are made too quickly and with too little information.

- **(Coulter 1999)**, in an important and much-cited editorial, is cautiously optimistic about policymakers’ turn from paternalism to consumerism to partnership, but warns that implementation could be a far more complex story. The new NHS may not be as cheap as the policymakers hope: patients may not always choose the most conservative, cheapest option, and informing and supporting patients through a decision-making process is likely to be resource intensive.

- **(Edwards, Elwyn et al. 2005)** trained 20 GPs in South Wales in SDM skills, had them practice for six months, and then interviewed them at the end of the six-month period. The GPs described a positive result in their patient consultations when they used the techniques they had gained, but did not appear to have used them in the majority of their consultations, citing time and patients’ preference for a low level of involvement. The authors conclude that proponents of SDM need to resolve the time issue, as well as further research the question of how to increase patients’ preference for involvement and clear expression of that preference.

- **(Elwyn, O'Connor et al. 2006)** review the boom in decision-making aids available to practitioners: from 15 in 1999 to over 500 in 2006. While there is evidence that use of decision aids improves patients’ expectations and knowledge, as well as satisfaction, they also vary considerably in quality and bias. Decision aids remain a promising method of efficiently and effectively conveying information and choices to patients in the short time available in a typical consultation.

- **(McQueen 2000)** argues that with recent developments aimed at encouraging better informed patients and a more active role in decision-making, nurses represent the ideal vehicle, given their culture, training, and ability to form trusting relationships, to meet patients’ needs for increased information, skill, confidence and support. She argues, however, that nurses’ greatest and most unique quality, their ability to empathise and support patients, is ‘hidden work’ that is undervalued. This emotional work involves skill and hard work, with a high therapeutic payoff for the patient, which if more highly valued could be better taught.

- **(Towle, Godolphin et al. 2006)** find that communication patterns between doctors and patients are ingrained and resistant to change. They found that six doctors trained in SDM and enthusiastic about the model did not fully implement the practice (though they believed that they had, assuming that being ‘nice’ to patients, for example, equated treating them like partners). The researchers found that analysing audio transcripts of consultations was the most effective way to convey to doctors the concept of SDM.
• (Ward and Innes 2003) recommend that patients collaborate with doctors in assessing the completeness and accuracy of their medical records, for two reasons: inaccuracy of existing records, and the benefits of this process for the doctor-patient relationship. GPs corrected errors in more than half of printouts of electronic records pointed out by patients from an economically deprived area of the UK. The authors conclude that enormous infrastructure investments that improve access to this information do not do anything to improve the quality of the information recorded.

3.4 Expert patients

*Expert patients as co-creators of health:* Patients who are fully engaged with their health and care are a central plank of present health policy. Some who are crafting and advocating this policy borrow the term ‘co-creation’ to describe the mental and cultural paradigm shift they hope to achieve, as patients partner with professionals and health services to co-create their own health.

• (Cayton 2006) employs the metaphor of the ‘flat-pack patient’ to describe an increasing number of patients who actively want to be co-creators of their own health and health services, rather than being forced into the role by an economizing health service. While ‘flat-pack’ furniture, from which he borrows the term, is attractive to customers because it is less expensive, many also derive pleasure from the experience of putting it together at home. He argues that health services must continue to change in ways that support communities and individuals to better look after themselves. According to Cayton, part of what makes the Expert Patient Programme effective is that its classes teach people how to change their behaviour and relate to health professionals, as well as support a more active patient role, rather than simply giving them detailed information about their illness.

**Do doctors or nurses engage with expert patients better?**

• (Lowton and Ballard 2006) interviewed 31 young cystic fibrosis (CF) patients in southeast England and found that they had been influenced and emboldened by the ‘Expert Patient Programme’ to behave more like consumers. These patients’ perceptions of a satisfactory doctor-patient relationship were influenced by three factors: the GPs understanding of how people live with CF, the doctor’s ability to prescribe certain specialist medications, and sensitivity to costs potentially incurred by the patient. Trusting relationships were also viewed as desirable.

• (Wilson, Kendall et al. 2006) surveyed over 200 English patients, carers, and health professionals on the ‘expert-patient’/health professional encounter. While doctors and physiotherapists were very comfortable with active, knowledgeable patients, the majority of nurses were not (with the significant exception of nurse specialists). They felt that expert patients took more time, that they challenged nurses’ own expertise and authority, and that they were a litigation risk. Nurses were also more sceptical of expert-patients’ ability to self-manage their care and complained of lack of trust in them as nurses. Patients valued nurses most highly for their empathy and relational skills, yet when asked nurses did not seem to value these skills in themselves. The authors point to the relative success of nurse clinicians in their encounters with expert-
patients as evidence that nurses can gain the ability to partner with expert patients managing chronic disease.

**The Internet:** The Internet represents a significant source of health information, advice, and support for patients, who use it in ways that both complement and conflict with the care they receive through the formal health service.

- **(Broom 2005)** studied the use of online support groups among Australian men with prostate cancer, and found that the virtual medium possibly allowed for more intimacy, and thus possibly stronger support, among men than a face-to-face encounter, though many deemed the information less trustworthy. Broom also reports that some doctors viewed online support groups as a threat to their control over the decision-making process.

- **(Hardey 1999)** predicted that the internet would transform the professional-patient encounter, and its transformative power would come from the democratising effect of increasing access to information. Users, not experts, will decide what information is most relevant.

- **(Marco, Barba et al. 2006)** describes a popular Spanish-language internet service (most participants were in Spain but a third were from Latin America) where patients can anonymously submit queries to an infectious disease specialist about HIV/AIDS and hepatitis. 80% of queries were from men, 79% concerned HIV transmission, and 37% of queries were made on Mondays and Tuesdays (presumably concerning risky weekend behaviour). The authors state that the demand for this type of service comes from its anonymity, free access, and immediate feedback.

**The case of NHS Direct: who uses it, why, and is it empowering?** NHS Direct was established as a professionally staffed phone hotline to provide 24 hour access to information and advice as well as redirect patients away from A & Es and general practices. It is particularly interesting in the context of professional/lay relations as perhaps the most explicit attempt by policy-makers to place health professionals in a supportive rather than directive role.

- **(Greatbatch, Hanlon et al. 2005)** reports that the complex computer system designed for use by triage nurses at NHS Direct, which was supposed to standardise advice given to patients, is not always used in the way it was intended. Nurses often trusted their own expertise and tailored their advice to the individual circumstances, context, concerns, and symptoms of the caller. This is partly because human professional experts are more flexible, complex, and subtle than expert machines.

- **(Knowles, Munro et al. 2006)** sent a survey to a large sample with access to NHS Direct to determine who used it. 25% of respondents had used the service at least once. Those from lower SES groups were less likely to have used the service, which will disappoint those observers who had expressed the hope that the phone-based service would be favoured by those with less ready access to the Internet (see Coulter 2005, for example).

- **(May, Finch et al. 2005)** describe the different routes of IT innovation that have been attempted in the NHS. Those that offer advice (NHS Direct) or information (the Internet) have caught on more rapidly than those that aim to provide actual care and measurement remotely. They argue that this is because efforts to modernise patients are much better suited to the overall direction of British health care policy than modernising systems, given trends in
resource allocation and the popularity of the self-care model. Thus, the telecare efforts that may gain the most traction are those that act as surveillance systems, evaluating patients’ ongoing ability to manage their own care.

- *(May, Gask et al. 2000)* studied the use of telepsychiatry (psychiatric consultation by video-phone) by two general practices in England. GPs appeared more worried than patients about the potentially weakening impact of this practice on their relationships with patients, but patients appeared pleased by the ease with which they could speak with a psychiatrist about their anxiety and depression issues. Everyone agreed that the video-phone altered behaviour and communication from that of a live face-to-face encounter, with less use of body language, for example. While this was not necessarily good or bad in itself, it required training and practice from all the participants.

- *(O’Cathain, Goode et al. 2005)* interviewed 33 NHS Direct staff and 60 NHS Direct service users, and analysed 120 calls, to consider the claim that the service empowers patients. While the rhetoric around the service includes claims that it empowers patients by giving them the tools to care for themselves, they wonder whether rather than enabling patient control, it instead offers another level of gate-keeping and authorisation. They report that patients relied particularly on NHS Direct when unsure which course of action to take for themselves or a loved one, not wanting to appear as time-wasters by going to the GP or A&E for an ‘unnecessary’ reason, and thus sought authorisation via the service. In other words, they called not simply to collect information before reaching a decision themselves, but to share responsibility for the decision or even to cede decision-making authority to a professional. On the other hand, patients appreciated NHS Direct because they did not have to work as hard to get information or treatment options as they perceived they would from the wider NHS, which they said forced many into an uncomfortably assertive role. The authors observe that NHS Direct offers not just information but concern and sympathy, which patients may in many contexts value over empowerment. Finally, they caution against viewing decreased use of wider services as evidence of empowerment: from the patient’s point of view, being able to see their GP more often may indicate more empowerment, not less.

### 3.5 The challenge of evidence-based medicine (EBM): Biomedicine strikes back?

**Individualised care and evidence-based medicine**: There is a tension between the trend toward standardised, evidence-based medicine (EBM) premised on the assumption that there is a single best treatment option and the countervailing trend toward patient-centred, individualised care. There is evidence that trusting relationships between health professionals and patients may increase compliance with EBM, though some doctors also fear losing their patients trust if they push EBM-favoured tests or treatment options too hard.

- *(Freeman and Sweeney 2001)* conclude, after interviewing a number of GPs in the UK, that GPs ‘regard clinical evidence as a square peg to fit in the round hole of a patient’s life’. Most interestingly, they describe GPs’ fears that changing medication too often (e.g. every time a new study appeared) would lead their patients to lose confidence in their care.
(Jackson, Putnam et al. 2004) relied on qualitative data previously collected in Canada from interviews with doctors of cardiac patients to explore the relationship between trust and the discrepancy between doctors' knowledge of evidence-based medicine and their implementation of EBM treatments. The doctors described a patient's trust as playing a key role in whether the patient took up the doctor's recommendations, sometimes more so for EBM options rather than older options with which the patient might be more familiar.

(Summerskill and Pope 2002) worry about the downsides to individualised care in treating coronary heart disease (CHD). They find that the doctor-patient relationship may be the primary barrier to the implementation of proven quality care. Doctors reported that they did not advocate a particular treatment if they felt that the patient would not comply with the intervention or because of personal circumstances, and spoke of not wanting to further upset their patients. There is perhaps another kind of well-meaning paternalism operating here. The authors suggest that perhaps it is too much to ask doctors to balance their relationships with their patients with evidence-based practices recommended from on high, and that doctors should refer CHD patients to nurse-led protocols rather than doing it themselves.

Patient involvement and evidence-based medicine: Just as the trend toward EBM seems to conflict with the motivation to create and maintain a positive patient/professional relationship, there also exists a tension between belief in the scientifically-derived ‘best’ option, and the belief that patients, if they wish, should have at least some control over which option is picked.

(Ford, Schofield et al. 2003) discuss the viability of implementing ‘evidence-based patient choice’, a model that seeks to bring together the important parallel movements of evidence-based medicine, which arises from the biomedical tradition, and patient involvement, which arises from the patient-centred, psychosocial tradition. Theoretically, an approach that unites the two trends in the consultation will maximise both the health professional's and the patient’s knowledge of the medical problem, its context, and options for care. Main components of the model are transfer of evidence-based information to patients, through health professionals and other information sources, and the discernment by the doctor of how much information an individual patient wants or needs. In interviews with 45 lay people, nurse practitioners, doctors, and academics in the UK, the authors found that though these people displayed a clear understanding and support for the main themes of the model, they viewed it as a presently unachievable ideal. Nearly all voiced scepticism that patients could receive all of the information they needed to make an educated, confident choice about their care within the consultation time constraints presented by the NHS. Perhaps because time seems such an obvious factor in the success of this model, the authors suggest, little research has been done into how best to apply the model in practice.

(Montori, Gafni et al. 2006) enumerate the drawbacks of clinical guidelines (EBM, quality audits, etc) which encourage physicians to choose the ‘best’ treatment over the objections of their patients—in this case, diabetes patients. The doctor may succeed in choosing a treatment option that the patient can only unenthusiastically follow, or even passively resist. That in turn will yield an unsatisfactory doctor-patient encounter, a disengaged patient, and possible non-compliance. They conclude that the value of the ‘best practice’ treatment
may not outweigh the value of encouraging and respecting patient participation.

- (Penston 2007) argues that the pressures on practitioners to push their patients toward guideline-favoured treatment options (financial rewards for meeting targets, pressure to comply with guidelines, time constraints) are greater than the pressure on practitioners to arrive at a treatment decision by way of shared decision-making, and that all of this adds up to a situation where it is not in practitioners’ interests to present their patients with complete, unbiased choices. In studies, meanwhile, patients are often unmoved by the presentation of marginally small benefits associated guideline-preferred options. As patients often come to different conclusions, given full information, professionals cannot assume that they would choose the guideline-based and therefore take the shortcut to not fully inform them.

- (Rhodes, Langdon et al. 2006) present findings that argue against nurses’ use of computerised checklists in consultation with diabetes patients. They found that this use of ‘biomedical audit’ enforced a rigid agenda and suppressed the patient’s agenda, and thus works against a patient-centred approach. (See also Morgan 2003, who argues that if patients have access to the screen computers may play a positive role in the consultation).

3.6 Informal carers and professional carers

What informal carers want from health professionals: Policy-makers hope to rely on carers to an increasing degree, but many of their needs are presently unmet, and there are many things health professions could do to better support them in caring for their shared patient.

- (Grande, Farquhar et al. 2004) studied carers of 48 dying cancer patients and 12 non-cancer patients providing palliative home care in Cambridgeshire to determine what additional support they sought from their family members’ health professionals. Above all else the carers valued accessibility of the GP and nurse who cared for their relative. The authors point out that in the hospital, this is not as much of an issue, but when the patient is at home, the bereaved and anxious carer is home alone with a very sick person. They go on to point out that though this accessibility is resource-intensive, it leverages vastly more resources in the form of better supported carers.

- (Hare, Rogers et al. 2006) conducted focus groups in the UK with long term survivors of stroke and their carers. The subjects revealed that they viewed primary care as their first point of contact on any and all issues relating to stroke care, even non-medical ones. The implication is that because these patients and their carers did not draw distinctions between medical and non-medical issues, and wanted their primary care practice to be a one-stop-shop for information, health professionals ought to think about how they could make more information accessible to these people via GPs’ offices.

- (Kirk and Glendinning 2002) interviewed parents of children with serious health conditions in the UK that required sophisticated technology and skill for their maintenance to find out more about what support was provided to those parents and what support they needed most. They also interviewed the professionals caring for those children. In total they interviewed 23 mothers and 10 fathers of 24 children, as well as 38 care professionals, including social
workers, doctors, and nurses. While a few of these professionals reported feeling threatened by these expert parents, most accepted that the parents were in a primary caring role, and brought much expertise to the table, whereas the professionals were in a more supporting role. Whether professionals communicated their recognition of parents’ expertise to them was very important to the parents. Also of importance to parents was the professionals’ ability to help with practical tasks not related to their direct care work: things like ordering the right equipment and services, and finding financial resources. Parents were on the whole happy to perform the direct care work themselves. Finally, parents needed much reassurance from professionals, as well as ready and accessible sources of information (and reassurance about the quality of those sources). The authors note in conclusion that parents’ expertise will certainly not render that of professionals obsolete, as among other things parents seem to depend on the reassurance and advice of professionals in order to maintain such a sophisticated and stressful role.

- **(Vanderwerker, Laff et al. 2005)** find that a large proportion of carers for advanced cancer patients suffer from psychiatric disorders. While some sought treatment on their own, carers were more likely to use mental health services if their relatives health professions discussed the topic with them.

- **(Waldrop 2006)** explored the relationship between formal and informal caregivers in interviews with 64 families caring for dying relatives. He found that what the families valued most from professionals was kindness and compassion, clear and straightforward communication, information, guidance, and respect for self-determination.

**Partnerships between informal and formal carers:** Health professionals could do much more to partner with carers in their mutual care for the patient.

- **(Guberman, Nicholas et al. 2003)** describe successful workshops developed in the UK, Sweden and Canada that make health professionals more sensitive to the role of carers. The authors argue that professionals must explicitly and directly elicit the engagement of carers in the health care of their loved ones. It is critical that professionals view carers as partners in the care of the patient, both for the patients’ sake and for that of the carers.

- **(Merrell, Kinsella et al. 2006)** interviewed 20 Bangladeshi carers in Wales in order to investigate the question of Bangladeshi carers’ awareness and utilisation of formal support services. They find that most had little idea that there were formal social and health services available to them in their caring role. However, all were in regular contact with their family members’ doctors, and reported that GPs and hospital doctors were their main source of information. The majority spoke little or no English, and so were disadvantaged with respect to seeking and receiving information. None reported having their caring needs assessed (a legal requirement). The carers were also sceptical that their cultural preferences would be met or understood by providers of services.

- **(Pickard and Glendinning 2002)** observe that policy has paid increased attention to partnerships between community nurses and carers, with the National Strategy for Carers stating as one of its principle goals that carers ‘may become real partners in the provision of care to the person they are looking after’. Patients are much sicker at the point when they are discharged.
from the hospital than they used to be, and this has increased carers’ burden. Despite policy objectives, little change has been achieved on the ground, and most still feel excluded from, rather than included in, healthcare decisions about the person they care for. In order to encourage the development of real teamwork between formal and informal carers, Pickard suggests that primary care trusts establish carer protocols and frameworks explicitly geared toward cooperation between the parties.

- (Sharpe, Butow et al. 2005) studied 57 advanced cancer patients, 45 of their carers, and 40 of the patients’ health professionals. They found that carers identify more needs of the patient than either the patient or the professional, and that patients’ unmet needs were an important factor in carers’ own deteriorating health. Professionals could thus help both patient and carer by creating more opportunities for carers to discuss concerns regarding the patient.

4. Conclusion and Recommendations

There are two distinct and important medical traditions influencing the lay-professional relationship today: biomedicine and psychosocial medicine (see figure 1). Evidence-based medicine and professional authority come out of the first, while patient-centred care and patient involvement in decision-making have their roots in the second. Biomedicine is more doctor-centred and based on the application of scientifically measurable evidence. Psychosocial medicine is holistic and inclusive of more kinds of evidence. While the goal of psychosocial medicine is to provide individualised care based on the unique circumstances and preferences of the patient, biomedicine aims to know and to apply the best odds, based on trials of various possible treatment options.

Practitioners are not always motivated primarily by the first movement, or patients by the second: biomedicine and psychosocial medicine do not represent a top-down approach or a bottom-up approach, respectively. Rather, practitioners, policy-makers and patients share goals with their roots in both movements simultaneously. Many health professionals, including both nurses and doctors, may recommend an option different than that preferred by evidence-based medicine, privileging the preferences of the patient (explicit or perceived) or relying on their own professional experience as practitioners. While one pair of researchers recommend that nurses in a practice unburden GPs from the complication of recommending a possibly anxiety-raising CHD protocol to patients with whom they may have a long-term relationship or who are presenting with another condition (Summerskill and Pope 2002), another research group found that nurses deviate regularly from the NHS Direct protocols in conversations with patients with whom they share no relationship (Greatbatch, Hanlon et al. 2005). The directive to treat the patient rather than the illness has existed for a long while among health professionals in the UK, particularly those in general practice, but gains salience and complexity in the context of the tension between evidence-based medicine and individualised care.

The question of who provides the care is also influenced by these distinct movements. The biomedical model of care privileges care work which is standardised, auditable, and utilises a shared professional education and language, while the psychosocial model is more inclusive of informal types of care, such as that performed by carers or oneself. Professionals are accountable for both processes and outcomes, while the quality of
care provided by self-carers and informal carers is widely varying, hardly auditable, unaccountable, and un-standardised.

The two approaches to medicine also privilege different definitions of continuity of care. Interpersonal, longitudinal continuity is more psychosocially motivated, with its reliance on relationships rather than encounters, and personal knowledge of an individual’s preferences, personality, circumstances, and history. From a biomedical perspective, on the other hand, the most important type of continuity is informational, relying less on the trusting and relational accumulation of knowledge than on the paper (or digital) transfer of specific knowledge from health professional to health professional. A closely related debate to this one is that between those who advocate the greater use of generalists rather than of specialists, who may know less about the patient but more about the condition.

Evidence-based medicine, expanded patient involvement, informational as well as interpersonal continuity, and professional care as well as self-care have all been shown to improve clinical outcomes on their own, and it shouldn’t be inferred that they are mutually exclusive of one another. Indeed, most patients who opt to take a greater role in their care would want to know the most information and the latest odds before coming to a decision, and most would be upset with their regular doctor if they couldn’t retain from consultation to consultation the information they had previously given them.

It would also be a mistake to believe that the individual goals rooted in both traditions rise and fall as blocks: that biomedicine is gaining ground against psychosocial medicine, or the other way around. In both theory and practice, evidence-based medicine and patient-centred care have made considerable strides forward in the last generation, and both are strongly present in many consultations, though neither as present as its proponents desire. Informational continuity is on the rise, while respect for self-care and informal caring is also trending upward. Professional authority has decreased in the last 30 years, while respect for science over individual experience has grown among practitioners and policy-makers, and possibly among patients (though that was not within the scope of this review). It is partly because the basic model of the medical consultation is biomedical, and habits die hard, that despite enthusiasm from academics, policy-makers, and many practitioners far fewer patients are as involved in their care as they wish to be. Shared decision-making’s relative lack of success in infiltrating and transforming the consultation is surely also for lack of time and resources.

Though it does not fit neatly into the binary presented above, another observation worth mentioning is the possible tension between skill and willingness to provide emotional care, and willingness or effectiveness at soliciting greater patient involvement. Though data is limited, an inverse relationship has been observed between the emotional support U.S. breast cancer patients reported receiving from their doctors and their self-reported participation in decision-making (Maly, Umezawa et al 2004). Meanwhile, while nurses/NPs are reportedly better able/trained to provide more holistic care (Coulter 2005; Seale, Anderson et al 2006, Williams and Jones 2006), nurses also appear more nervous engaging with expert patients than do GPs. Nurses with further training do not appear to share this apprehension, implying that there is something in the training regimen of various health professions that factors into this anxiety (Wilson, Kendall et al 2006). It may on the other hand be a consequence of the self-selection of those who pursue further education. These findings are further complicated when viewed alongside those of Summerskill and Pope (2002), to whom doctors reported that they sometimes
did not advise their patients of new and important health information if they felt that they
would further upset them. These findings together present us with an interesting set of
new questions: Was it that the patients who were more in need of emotional support
than participation got what they wanted? Are doctors to whom emotionally supporting
patients comes more easily less gifted at or somehow more weary of patient
participation? Or are patients who require more emotional support simply more difficult
to give information to and solicit participation from? If it is true that nurses are better
trained to provide emotional support, does that same training make shared decision-
making and dealing with expert patients more difficult? What implications might this
have for both recruitment and training for each group? Conclusions can hardly be drawn
from present data, but the questions raised are worth exploring in more detail.

It goes without saying that most practitioners desire goals rooted in both movements –
they want to include their patients' preferences and histories alongside the most
scientific evidence on their illness, and they want to allow their patients as much choice
as possible whilst ensuring that their patients clearly understand the odds and
implications of their choice. For a number of reasons, including individual habit,
institutional inertia, limited resources and sometimes conflicting policy goals, their efforts
to implement goals from each side have proven problematic. Further, policy-makers and
academics have struggled to surmount the tensions often in play when attempting to
simultaneously implement goals from different perspectives.

While academics, practitioners, patients and policy-makers advocate goals from both
psychosocial medicine and biomedicine, efforts to implement goals from each side have
proved problematic (Ford, Schofield and Hope 2003), as some of the goals, and the
processes associated with each, get in the way of each other. Recommendations for
implementing each goal are given here, as well as recommendations that might better
surmount the tensions between goals rooted in different perspectives.

- In order to advance the goal of patient-centred care, the evidence appears to
  suggest that the NP role should continue to be expanded and deployed, and their
  training and consultation length allows them to pass more information to patients
  as well as better solicit their preferences. A good bedside manner appears to
  produce measurable clinic outcomes, as does a show of confidence in diagnosis
  and treatment, and health professionals should be taught to do both. At the same
time, the evidence patients bring to the consultation should be respected and
  placed alongside scientific evidence when coming to a decision about care.

- Continuity is in the eyes of the patient, and efforts should therefore continue
toward a seamless service. Interpersonal continuity is associated with better
  outcomes, more satisfied patients, and possible cost savings over the long term
  (though this link must be explored further). Maintaining it should be a high
  priority. This is particularly true for those who value it the most: the chronically,
  mentally, and seriously ill, and examples of practices that are able to maximise
  patient choice of interpersonal continuity or easy access should be encouraged
  and closely studied. It doesn’t seem impossible that the chronically ill, whose
  regular consultations may be scheduled in advance, should experience any less
  of this type of continuity. Team continuity is a lesser replacement for
  interpersonal continuity, but may also complement it, as may informational
  continuity. This means retaining staff, including support staff and receptionists, so
  that a patient knows more practice members than their GP or NP, and making
  sure that all relevant parties have easy access to the same patient information.
Involving patients in the review and correction of their own data may also be satisfying to patients as well as important in improving the quality and accuracy of patient records.

- Patients’ desire for involvement in their care can change even within the period of the consultation, and health professionals must learn to solicit and be sensitive to these changing preferences. The test of how much policy-makers value patient participation (which is linked to higher satisfaction, adherence, and self-efficacy) may be in how willing they are to fund it. Greater use of NPs may help with this, especially in light of the new GP contract. Efforts to increase it have thus far been largely successful, owing largely to a consultation too short for the sort of exchange and consensus-building envisaged by academics and sought by many more patients than experience it. While the critical question at first appears to be who makes the decision about treatment, evidence shows that patients seem to value the process more than they care about whether the decision was truly their own, and consultations should be redesigned to reflect this. Reviewing audio transcripts of their own consultations appears effective in changing physician behavior.

- While some nurses appear to be made anxious by expert patients, this apprehension disappears with further education, so interacting with expert patients may a skill that can be taught and rehearsed. While NHS Direct Online was established for those of higher SES, and NHS Direct phone service would seem to have no obvious SES related barriers, the comparatively low-tech service, though popular, has not been used as widely by lower SES people as had been hoped (they instead continue to disproportionately visit their GP). We need to figure out why this is, or similar advances toward increasing capacity for self-care may continue to only hit the relatively well off.

- Fuller implementation of evidence-based clinical decisions would result from RCTs targeted at more demographic groups, co-morbidities, or other specific factors, rather than the population at large, thus meeting practitioners concerns about their patient’s individual characteristics. Evidence-based medicine could also be targeted directly at patients and the public, much as recent efforts inviting patients and visitors to ask their practitioners whether they have washed their hands have been.

- Informal carers have much additional evidence to add to the efforts of the practitioner caring for their loved one, and vice versa. While carers need more information about services available to them, practitioners who partner with carers appear to lessen the burden on the carer, as well as improve their care for the patient. Carers also seek a one-stop-shop for more of the services they need perform their role, and to some the most obvious place for this to be located is the general practice.

A strategy to simultaneously advance these several goals, despite their occasionally contravening processes, is not impossible, but it would require coordination and resources. It is not that evidence-based medicine and shared decision-making are at odds with one another, but that they compete for the finite resources of time, focus, and training. At the centre of a strategy to pursue these several goals are a redesigned and lengthened consultation, educated patients and carers, and professionals trained to maximise both the input of patients and carers and the information they receive.
In order to maximise our use of both evidence-based medicine and patient involvement in decision-making, relevant evidence-based information needs to be put in the hands of the patient, so that they may consider it alongside their knowledge of themselves and their habits. This is, of course, incredibly hard to do in a ten minute consultation. Sharing information and reaching consensus takes time. Lengthening the consultation to twenty or even thirty minutes may be what is required to achieve this goal. A short, rapid series of consultations may prove even more effective, allowing consultation with family members and other information sources (including those like decision aids given by the professional), as well as time for questions or concerns to develop. Relatively few medical decisions in our age of chronic illness must be made immediately. It is important to remember that not all consultations need be lengthened. Also, where shared decision-making has been tacked on to the existing consultation model it has largely failed, as the original consultation’s purpose was to transmit information from patient to doctor, not the other way around, as the new model would be designed to do. The relatively new field of conversation analysis may help with this, as it has been able to pick up startling differences in outcomes like patient feelings of efficacy and participation with the substitution of a few mere words or sentences.

For the investment of resources in lengthened and possibly additional consultation times to be worthwhile, patients and their carers need to be trained to maximise their capacity to absorb and use that information. Because we are all patients at one time or another, the suggestion shouldn’t seem absurd that teaching people how to participate in medical decisions should begin in school, rather than in the midst of a medical crisis. Whereas the Expert Patient Programme seeks to teach people with a shared chronic health condition more about their specific illness and strategies for best managing it, a parallel programme could be established to teach the tools for evaluating evidence and interacting with health professionals. There is a burgeoning literature of this sort within sight of any grocery queue – the government could produce its own high quality or demographically targeted versions.

For better or worse, encounters with health professionals remain at the heart of the public’s perception of what constitutes illness prevention and treatment. Though tools and technologies for self-diagnosis, advice and information will continue to increase over the next generation, it is difficult to conceive of a health service without practitioners. While the formal training those professionals receive teaches them to evaluate evidence to solve difficult problems, it teaches them less about how to present that information. Information sharing is a skill that can be taught, as can emotional care and the sensitivity to a patient’s preference for information and decisional control.
Figure 1: Differences in Approaches of the Biomedical vs. Psychosocial Models of Medicine.

<table>
<thead>
<tr>
<th>Biomedical model</th>
<th>Psychosocial model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evidence-based medicine -Single best solution determined by RCTs, scientific method, etc</td>
<td>Individualised care -Multiple best solutions based on patient’s preferences, circumstances</td>
</tr>
<tr>
<td>Professional authority -doctor as decider in treatment of medical condition, provider of information</td>
<td>Shared decision-making, patient as equal partner, or patient as consumer -perhaps Expert Patient Programme -professional in supporter role to patient, who holds ultimate responsibility for treating illness</td>
</tr>
<tr>
<td>Informational continuity, access</td>
<td>Interpersonal continuity</td>
</tr>
<tr>
<td>Specialisation</td>
<td>General practice</td>
</tr>
<tr>
<td>Treat disease</td>
<td>Treat patient</td>
</tr>
<tr>
<td>Professional carers provide the bulk of care, in a way that is auditable, accountable, and standardised</td>
<td>Informal carers provide much of the care, despite variability in quality, oversight, training</td>
</tr>
</tbody>
</table>
5. References


Tarrant, C., K. Windridge, et al. (2003). ""He treats you as a person not just like a number" - How important is personal care in general practice?" British Medical Journal 326(7402): 1310-1312A.


