1 Understanding the process of patient participation

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Commentary

A number of trends, pressures and policy shifts are promoting greater patient involvement in health care delivery through consultations, treatments and continuing care. However, while the literature on different methods of involvement is growing fast, little attention has been given so far to the role which patients themselves wish to play, or to the conceptual meanings behind involvement or participation.

This introductory chapter sets the scene for the book by delineating areas of research relating to patient participation in health care consultations. It outlines some findings from previous research, models for practice that reflect aspects of patient participation, and some interventions designed to promote it.

Against the background of this existing work, this chapter introduces the potential of qualitative methods and empirical research, the orientation of this book, for understanding what patient participation means, how it works, how it may be practised, and how it may be measured.

The fact is that food varies, and that is what makes it so interesting. Today’s piece of cod may be slightly thicker, has larger or finer flakes or thicker skin, than yesterday’s. One brand of butter may be different from another. Olive oil changes with every bottle; that is part of its joy. So how can anyone be so pedantic as to give exact timings? Each egg, each steak, each potato is different and will behave in a different way in the pan. That is what cooking is about, and that is why it is essential to understand what you are doing rather than just mindlessly following a recipe.

(From Appetite by Nigel Slater 2000: 34)
Introduction

In recent years, patient participation (and patient involvement and partnership) have gained increasing prominence in health care. Patient participation has been prioritized in policy initiatives, has provided the impetus for research programmes, and has found expression in recommendations for professional practice.

Debates about participation reflect a growing unease with the paternalistic philosophy that has traditionally dominated the view of health care consultation, and within which patients were assumed to play minimal and passive roles. Recent decades have seen a ground shift towards initiatives which encourage health care service users to view themselves as active participants in consultations, with individual rather than homogenized needs, and which encourage health care professionals to provide a service which seeks to achieve this. Calls for increased participation from patients and the public are evident in government policy. For example, in the UK, the Inquiry into the tragedy at the Bristol Royal Infirmary (2001) concluded by advocating greater participation by patients and the public. A series of UK health policy documents (Department of Health 2000; 2001; Scottish Executive Health Department 2000; 2003; National Assembly for Wales 2001) prioritize the ‘patients’ voice’ and patients’ active roles in their health care. To quote two examples: ‘In the twentieth century NHS patients were assumed to be passive recipients of care. In the twenty-first century NHS patients will be active partners in care’ (Department of Health 2001: 23); and ‘The patients’ voice is recognised as being centrally important in the drive for service improvement. [Patients] want to be cared for by professionals who understand their needs and concerns’ (National Assembly for Wales 2001: 34). Statements such as these are paralleled in health policy on an international scale.

There are also NHS initiatives to encourage patient and public involvement in health care planning and delivery. One is the Expert Patients Programme (Department of Health 2001) which recognizes that people with chronic diseases are often experts in their own conditions. Another is the involvement of patients and patient groups in communication training for health care professionals, for example, the Patients Accelerating Change initiative, and the use of simulated patients in consultation skills teaching (Spencer and Dales 2006).

From an academic viewpoint, many researchers have investigated patient participation, or similar phenomena such as patient enablement, involvement or partnership, in the past few decades. They have done so for two main reasons. Some promote patient participation in its own right. In the words of Guadagnoli and Ward (1998: 337), ‘patient participation in decision making is justified on humane grounds alone and is in line with a patient’s right
to self-determination’. Others advocate patient participation on the grounds that it will lead to benefits such as improved patient satisfaction, co-operation with health professionals, better management of disease, increased trust and enhanced patient–professional relationships. For example, Coulter (2002) argues that involving patients in treatment and management decisions improves the appropriateness, safety and outcome of care, while at the same time reducing the number of complaints and risk of litigation.

How are these ideals and standards to be realized in practice? A number of obstacles stand in the way of their achievement. One is that, in practice, achieving patients’ involvement in their care presents difficulties. Health professionals are increasingly encouraged to deliver patient-centred care, to communicate with their patients and to promote patient participation in consultations but the evidence suggests that patient-centred care and shared decision-making are not widely practised, that many health professionals lack the requisite skills and guidance, and that the contexts in which health care is delivered (including socio-economic influences, work pressures and resource limitations) bring their own constraints. The majority of patient complaints to disciplinary bodies relate to the breakdown of communication between patients and doctors (BMA Board of Medical Education 2004). The literature on shared decision-making has shown that practitioners do not involve patients to any great extent (Stevenson et al. 2000; Elwyn et al. 2005; Ford et al. 2006). Low rates of competency in involving patients in decisions have been detected in formal assessments of doctors’ consultation skills (Campion et al. 2002). Similarly, in nursing, despite its long-standing association with the ideals of patient participation and individualized care, there has been little evidence of their application in practice (Cahill 1996; Hartrick 1997).

These difficulties in achieving patient participation are compounded by the increasing diversity in areas of health care, and the increasing variability in patients’ expectations. Patients have greater access to information about diagnosis, treatment and care, and are becoming more actively involved, for example, by bringing their choices about treatment to consultations (Richards 1998; Department of Health 2001). At the same time, there continue to be limits to, and uniqueness in, individuals’ experiences of health care, for while some patients expect greater understanding and involvement, others want little (for example, Sutherland et al. 1989; Street 1991; Little et al. 2001; Barratt 2005).

Such developments present real communication challenges for health professionals and patients. They demand high levels of sensitivity and flexibility on the part of the health professional in managing the consultation, establishing shared understanding, and accommodating patient and biomedical perspectives. The onus on health professionals to adapt their communication approach to meet individual patients’ needs is reiterated in many professional,
policy and research documents (for example, Charles et al. 1999; Department of Health 2001; Elwyn et al. 2001; General Medical Council 2001; Stewart 2001; Fallowfield et al. 2002; Coulter and Magee 2003; Hasman et al. 2006).

A related and perhaps more fundamental source of difficulties concerns the fact that, despite the many studies of patient participation, there is little consensus about what participation means. While it may be relatively easy to prescribe or advocate participation (whether in a research project, in a policy document, or in a clinic), it is less easy to understand how it works, or how to make it happen. Practising and facilitating participation between people require skill, understanding, and competence: something more (to borrow Nigel Slater’s words above) than ‘mindlessly following a recipe’.

In approaching the study and practice of patient participation, this book views communication in the health care consultation as a central influence. The consultation is a principal arena in which patient participation is enacted, may be encouraged and also restricted. Through the consultation, activities such as information exchange, decision-making about treatment, symptom description, and so on, are played out; and how they are played out depends in a large part on communication.

This book sets out to explore the meaning and the practice of patient participation – what participation means, how it works and how it may be promoted. By taking the consultation as the focal point of investigation, this book recognizes the central part played by communication. This is not to deny the importance of the wider context (see Entwistle and Watt 2006), aspects of which are invariably referenced and mirrored in any single patient–health professional encounter. Rather, it is argued here, processes of interaction in the consultation can provide the site of study for that wider context. In each chapter in this book, the consultation is the common reference point for those who contributed (as citizen, health professional or patient) and for the views they expressed. This book is about communication, but it is also about using communication as a way of understanding various influences on the process of participation, many of which extend outside an individual health care encounter.

In pursuit of an understanding of what patient participation means, the next section provides a review of recent developments in health care research and practice that have prioritized patient participation and sought to define it. Building on this background, the third section proposes a more inclusive view of, and approach to the study of, patient participation. The contributions of this book are then outlined. In the concluding section, readers are invited to take different routes through the book, depending on their particular interests and motivations in the study and practice of patient participation.
Previous research on patient participation in health care consultations

Patient participation is not a new concept. It needs to be understood within the context of long-standing debates about the doctor–patient relationship (Balint 1957), the development of an approach to the consultation that integrates the biomedical and health professional agenda with the patients’ concerns and expectations (McWhinney 1972); a tradition of observational research that pays attention to what actually happens in consultations (Davis 1978; Strong 1979); and Tuckett et al.’s (1985) groundbreaking work demonstrating that patients and doctors do not share or exchange ideas to a great degree.

The past decade has witnessed a wealth of research literature and associated interventions for professional practice which make explicit reference to patient participation. The review presented here is necessarily selective, and the divisions it makes are somewhat artificial; the fields presented separately here overlap in practice and share some similar concerns. For other reviews and useful summaries of research relating to patient participation, see Chapter 3 in this volume; Cahill (1996); Robinson (2003); Farrell (2004); and Heritage and Maynard (2006).

In order to introduce the particular strengths of this book, this review of previous research is organized according to the various approaches that have been taken to studying patient participation. Quantitative studies have tended to focus on measuring concepts such as information exchange, shared decision-making, patient enablement, verbal dominance and communication control. They have also developed conceptual models and interventions to promote forms of patient participation and their observed effects. Qualitative studies have tended to focus on professional responsibility and behaviour, and on details of observed and recorded communication in consultations, as well as on the structure of the consultation and its phases.

Quantitative approaches

A number of coding systems have been developed to study patients’ participation and associated topics such as shared decision-making in consultations. Some of these systems have their origins in the social psychological Interaction Process Analysis (IPA) system developed in the 1950s (Bales 1951). Others have developed as a consequence of attempts to measure the distribution and determinants of quality of care (Howie et al. 2004). These approaches have provided useful information on, for example, the extent to which patients talk in the consultation, and factors influencing the interpersonal effectiveness of the health professional, such as length of consultation or continuity of care.
Roter’s Interactional Analysis Scale (RIAS) is one of the most influential of these coding systems (Roter and Larson 2002). Roter (2000) used the term relationship-centred care to connote the optimal form of patient–physician relationship. She characterized this as medically functional, informative, facilitative, responsive and participatory. In describing participatory relationships, she claimed that physicians have an obligation to help patients assume an authentic and responsible role in the medical dialogue and in decision-making. In order to measure relationship-centred care, she devised two quantitative indicators: verbal dominance and communication control. These indicators were used to analyse a large corpus of primary care consultations which Roter described as either biomedical or participatory. The biomedical exchanges accounted for two-thirds of the consultations. The participatory consultations were those in which the physicians were less verbally dominant and patients had more communication control. In these consultations, there was more talk in the psychosocial domain, with the exception of consumerist consultations during which physicians provided patients with much biomedical information.

Models of the consultation

Models of patient-centred consultations and shared decision-making reflect a similar orientation towards physician behaviour, and are widely employed in the teaching and training of health professionals. The patient-centred process, long advocated by Stewart et al. (1995), has six interactive components. These are: (1) exploring both the disease and the illness experience; (2) understanding the whole person; (3) finding common ground; (4) incorporating prevention and health promotion; (5) enhancing the patient–doctor relationship; and (6) being realistic. The Calgary–Cambridge guide to the medical consultation, which is widely used in doctors’ training, identifies tasks under five headings: (1) initiating the session; (2) gathering information; (3) physical examination; (4) explanation and planning; and (5) closing the session (Kurtz et al. 1998). Similarly, Elwyn et al. (2003a) set out nine professional competences for shared decision-making. These are: (1) problem definition; (2) portrayal of equipoise; (3) portrayal of options; (4) checking the patient’s understanding; (5) exploring the patient’s ideas, concerns and expectations; (6) establishing the patient’s role preference; (7) decision-making; (8) deferment if necessary; and (9) making arrangements to review the decision if appropriate.

Interventions

Researchers have also developed and evaluated interventions to increase patient participation in health care consultations. These interventions have been targeted at different aspects of participation, and have been evaluated
using a range of outcome measures (for a recent review, see Haywood et al. 2006).

Middleton et al. (2006), for example, took a dual approach, targeting both patient and professional behaviours. They ran workshops for general practitioners to increase their awareness of patients’ agendas. They then provided the patients of these doctors with agenda forms for the patients to complete in the waiting room before their consultations. Patients were encouraged to write down their concerns and show them to their doctor. The results of this randomized controlled trial showed a small increase in the number of problems identified and a commensurate increase in consultation length. The patients were more satisfied with the consultations, but there was no change in the number of ‘by the way’ presentations of extra problems, arising after the doctor considered the consultation to be finished.

Another much-cited study (Greenfield et al. 1985) used an intervention in which patients were helped to read their medical records before the consultation, and were trained to ask questions and negotiate medical decisions. Assistants coached patients to write down any questions that they found potentially embarrassing. Results showed that patients who received the intervention were more satisfied afterwards and reported fewer physical limitations than the control group. However, despite the overt encouragement, patients did not ask significantly more questions but instead found indirect methods for obtaining more information from their physicians.

Mercer and Howie (2006) employed a measure of consultation quality (CQI-2), using questionnaire techniques, to explore the interpersonal effectiveness of general practitioners. This measure was devised to capture elements of consultation ‘outcome’ (patient enablement), ‘process’ (continuity of care), and ‘structure’ (consultation length), which were recorded for each participating patient’s consultation. Patients were also asked about their confidence in their GP, whether they felt able to discuss problems with their GP, whether they would recommend their doctor to others, and about their overall satisfaction with the consultation. Doctors completed the same empathy measure, and were also asked to rate their general performance and their view of the importance of empathy in consultations. The results revealed, among other findings, positive correlations between doctors’ CQI-2 scores and their view of ideal consultation length; that doctors who felt patients didn’t value the job they did had lower CQI-2 scores; and highly significant correlations between CQI-2 scores and mean patient scores for confidence in the doctor, whether they would recommend the doctor to others, and their overall satisfaction. This application of the CQI-2 measure suggests some significant links between empathy, enablement, consultation length, and a doctor’s interpersonal effectiveness.

These studies and others have shown that it is possible to increase patient
participation from a low base level, although at present it remains unclear how transferable these interventions are to routine clinical practice.

The problem with these quantitative coding systems, questionnaires, and models of the consultation is that they do not tell us how the coded actions relate to one another, for example, how the patients’ information-seeking actions are interpreted by the health professionals, and whether or not such actions on the part of the patient receive a response; or how the length of a consultation might influence the way in which topics are talked about and whether and how an individual patient’s priorities and concerns are characterized and addressed. They have not examined the interaction, the specific ways in which the talk of one participant influences that of the other, nor considered the context in which the interaction takes place. Thus, they do not provide insights into how the actual interaction enables the development of rapport, for example, or into the details of how a health professional behaviour, such as interpersonal effectiveness, is actually enacted and practised through communication in the consultation. Their findings, however, do point to the normative structure of medical consultations, and suggest that a more nuanced approach to understanding patient participation is necessary.

Qualitative approaches

Another area of work on patient participation concerns qualitative analyses of communication between patients and health professionals. One of the strengths of much of this research is that it has not specifically set out to study patient participation, and therefore reveals particular facets of it. A range of studies seek to show how the interrelationship between the patient’s concerns and the biomedical agenda is a dynamic, constantly at play in the consultation. They demonstrate the co-presence of patient and doctor perspectives, the different competencies that the patient and the doctor each bring, and the interactive consulting processes through which the agenda is constructed.

In its recognition of different voices in the consultation, Mishler’s (1984) work has been particularly influential. Mishler distinguished two ‘voices’ – the voice of the lifeworld that represents the natural attitude of everyday life and the voice of medicine that represents the technical-scientific assumptions of medicine. In his analyses, Mishler began by noting the dominant voice of medicine. He provided examples of how patients’ meanings conveyed in the voice of the lifeworld tended to be treated by doctors as non-medically relevant.

Mishler’s work was motivated by a concern to isolate features of discourse that, in a medical encounter, might ‘retrieve the possibilities of a more humane medical interview’ (1984: 139); and he identified qualities of interaction that have since been substantiated in the work of others. These
qualities, he observed, differ according to whether the doctor integrates the two voices, or proceeds in the voice of medicine alone, and ignores the voice of the lifeworld.

A related theme concerns the patient’s and doctor’s discrepant competencies. While doctors are communicatively competent in both voices, most patients are communicatively competent only in the voice of the lifeworld. To the patient, the doctor’s questions come one after another with no apparent connection between them, and do not enable the patient to maintain the flow of his/her story. The doctor must translate the patient’s lifeworld statements into medical terms, and medical statements of problems into patients’ terms.

Mishler’s work pointed to two significant dimensions of consultations. One concerned the two voices, their characteristics, and where and how each was used. The other concerned the different competencies of the patient and the doctor. These dimensions are reflected in the work of Barry et al. (2001).

Barry et al. applied Mishler’s conceptualization of the two voices to their analyses of data which included interviews with patients and doctors, and a measure of consultation outcomes, as well as recordings of the consultations themselves.

The four patterns of communication that Barry et al. (2001) identified reveal a more complex interrelation between the two voices than Mishler (1984) previously showed. ‘Strictly Medicine’ described those encounters in which both doctor and patient used the voice of medicine exclusively. This pattern was found in consultations for acute problems, and it appeared that these consultations were most effective. However, in some cases the pattern resulted in major misunderstandings on diagnosis and prescription. In ‘Lifeworld Blocked’ consultations, glimpses of the lifeworld revealed the patients’ concerns, but these were not taken up by the doctor and were blocked by the voice of medicine. In ‘Lifeworld Ignored’, only the patients used the voice of the lifeworld, while the doctors conducted the whole of their communication in the voice of medicine. In the final group, the Mutual Lifeworld, both doctors and patients predominantly used the voice of the lifeworld. The authors describe (Barry et al. 2001: 496): ‘a much more relaxed feel to these consultations, with more evidence of responsiveness on the part of the doctors in recognising and respecting the patient’s unique situation’.

They accounted for this in part through the psychological nature of the patients’ presenting problems, the sources of which belonged more in the lifeworld. The greatest dissonance was found in consultations about chronic physical problems. To the patients, these conditions were a lifeworld issue, though the doctors seemed to regard them as a physical issue requiring the voice of medicine (Barry et al. 2001: 504).

These two studies (Mishler 1984; Barry et al. 2001) demonstrate ways in which the consultation agenda is defined interactionally. Through the interaction, patients’ concerns and biomedical perspectives are shaped and are
accorded their respective place. These studies illuminate the patient’s part in the process; and they show that there are choices or alternatives open to both patient and professional in the interaction, in particular, ways in which the doctor’s reasoning processes, and the sources of coherence which underlie the consultation management, can be made more transparent for the patients.

In these respects, the studies supply insight into what is at stake in constructing the consultation agenda, what gains recognition and import, and the problems in understanding that arise between the patient and the health professional. But their descriptions of the communication – e.g. ‘open’ and ‘closed’ questions (Mishler 1984), the ‘relaxed feel’ and ‘doctors’ responsiveness’ in Mutual Lifeworld consultations (Barry et al. 2001) – leave a great deal unsaid.

To uncover the intricacies of the sequential organization and delivery of communication, and to determine the specific consequences for patients’ participation, research in the field of conversation analysis can be helpful. While conversation analysis is not the only way of analysing interaction in consultations, it does provide a detailed and well-established method of understanding social interaction and the processes through which participation is realized. In this book, we have employed conversation analysis as our main approach to describing and understanding forms of patient participation in consultations. We have done so as a means of drawing on data that allows us to observe what actually happens, and to investigate what patient participation actually means and what it looks like in practice. Thus, we are using conversation analysis, along with other methods, to illuminate observable forms of patient participation; and we do not wish to imply that conversation analysis is the only method.

In conversation analysis (hereafter CA), the consultation is viewed as realized by health professionals and patients in and through the interaction that takes place between them. The participants present and acknowledge concerns, ask and answer questions, give and accept or reject treatment proposals. Consequent turns of talk by the participants form sequences of action, which in turn build up into phases of activities that can be seen to comprise the main ‘task’ of the consultation, and, on the societal level, the purpose of the institution. In doctor–patient consultations, the main task and its purpose are to attend to, and find treatment for, the patient’s health-related problems; while in hospital admission interviews carried out by nurses, it might be to record general information about the patient, in relation to their medical history and their activities of daily living. In CA research, the consultation is regarded as consisting of phases of activities that have been located in empirical research based on video or audio recordings of actual consultations. The phases observed in doctor–patient consultations are the opening of the consultation, the problem presentation, verbal examination (including history-taking), physical examination, discussions of treatment,
and closing (see also Byrne and Long 1976). Depending on the nature of the consultation (whether it is a first consultation or a follow-up, an acute and visible concern or a chronic one) as well as on other contingencies that may occur in consultations, some phases may be left out or they may occur in various orders, and/or overlapping each other.

Particular features of the opening lines of the consultation have been shown to shape the expression of the patient’s concerns (Coupland et al. 1992; Ruusuvuori 2000; Gafaranga and Britten 2003; Heritage and Robinson 2006a; Robinson 2006). For example, Ruusuvuori (2000) analysed the opening phase of primary care consultations to consider how control is managed in interaction. She identified the patient’s use of a narrative format to regulate the space for describing the ‘reason for visit’, and observed that the patient could take ‘temporary control’ through an extended turn, part of which involved justifying the reason for visiting. The doctor, in response, tended to negotiate the move away from the patient’s presenting concern in such a way as to also acknowledge its import. To give another example, Robinson (2006) depicts the different designs of doctors’ questions for eliciting patients’ concerns, with each design reflecting an orientation to a particular type of problem – new, follow-up, and routine re-check. Patients, in response, demonstrate their understanding of the shaping role these questions play in characterizing their problems; and they may resist answering if the question does not reflect the nature of their presenting problem.

While the problem presentation is described as the prime opportunity for a patient to voice concerns (Heritage and Robinson 2006a), the history-taking phase which follows it has repeatedly been shown to be a relatively restricted environment for patient-initiated actions (Stivers and Heritage 2001: 165; and see Heath 1992; Robinson 2003; Gill and Maynard 2006). Boyd and Heritage (2006) and Stivers and Heritage (2001) observe a variety of resources by means of which, in the course of history-taking, patients can resist question agendas and expand beyond them. Gill and Maynard’s (2006) study of patients’ explanations for their illnesses highlights the dilemmas faced by patients and doctors in offering and receiving explanations. Patients try to offer explanations in a relevant sequential environment (the history-taking) while not disrupting this information-gathering phase, and doctors can then find themselves in the position of receiving and acknowledging patients’ explanations prior to having gathered all the data necessary for analysis.

Moving on from history-taking to the other aspect of information-gathering, the physical examination phase, Heritage and Stivers (1999) show how the on-line commentary that physicians provide can serve both to provide reassurance for the patient, and to justify and forecast an upcoming diagnostic evaluation. This on-line commentary is demonstrated, in many cases, to shape patients’ expectations towards a certain outcome – a no-problem evaluation.
In terms of diagnosis and treatment decisions, Heritage and Maynard’s (2006) review of the conversation analysis literature notes less opportunity to participate in diagnosis than in the treatment phase. In the diagnostic phase of the consultation, Peräkylä (1997; 2002) identifies two alternative formats by which doctors deliver diagnoses, one which allows patients to participate in the diagnosis (perhaps by enhancing or resisting it), and another which does not. In discussions about treatment, Stivers (2002) demonstrates how the particulars of the turn design format employed by doctors can engender patients’ participation in treatment decisions.

With regard to the closing phase of the consultation, West’s (2006) analyses of primary care consultations show that although doctors conduct consultations under certain time pressures, the manner in which they bring them to a close serves to maintain their attentiveness to their patients’ interests and thus works to ensure continuity of care and to maintain the doctor–patient relationship.

The conversation analysis studies described above show how patients’ concerns are expressed in numerous ways at different points in consultations. This research displays the sensitivities and dilemmas faced by both doctors and patients in their communication of the consultation agenda, and it demonstrates the particular capacity of conversation analysis to handle the intricacies of communication in consultations, as a route to understanding patient participation.

However, the CA research, referenced above, also houses certain biases that may stand in the way of achieving some balanced consideration of exactly what patients and health professionals contribute to the construction and management of the consultation agenda. For the most part, these biases result from the predominant focus of this research on areas such as primary care and doctors’ consultations, and on activities such as diagnosis and treatment discussion. Conversation analysts have themselves recognized these preoccupations, and have begun to investigate patient-initiated actions, occasions where patients initiate radical departures from the medical agenda, and patients’ hidden agendas and points of view (for example, Drew 2001; Gill and Maynard 2006). However, as CA studies concentrate on analysing the process of interaction, they cannot adequately deal with other equally relevant dimensions of the process of patient participation, such as what is left unsaid in the consultation. For those other dimensions, other forms of data, such as patient questionnaires, semi-structured interviews and focus groups are more useful.

Summary

Broadly speaking, the research reviewed in this section can be separated into two strands. One strand has tended to focus on information exchange, shared
decision-making, and professional behaviour, and has examined statistical links between their measures and outcome measures such as compliance with medication, professional behaviour, or features of the consultation. It has developed typologies, for example, of the doctor–patient relationship, of shared decision-making, which are often theoretical conceptualizations. The other strand has examined the details of interaction in consultations, and the structures of communication with regard to the consultation’s phases. Taken together, these studies outline what might be considered to be essential features of, or prerequisites for, participation.

The studies reported above make important contributions to understanding patient participation but they also display certain limitations. These studies have tended to stand alone, and to take particular stances towards participation. They begin with a particular ideal or conception of participation; emphasize either content, or process; recommend a wholesale, global application of patient participation; exhibit a preoccupation with measuring patient participation and those professional behaviours which may be considered to promote or restrict it; limit their investigation to doctor–patient interaction (as opposed to the consultations of other health professionals such as nurses); and focus, almost exclusively, on primary care.

In sum, these studies can only show us a partial view of patient participation. In this book, we aim to open up a wider view on the subject, by facilitating dialogue between different qualitative approaches to the study of patient participation, by concentrating on what actually happens in real interactions between patients and health professionals, and by studying the process of patient participation.

**Building a more comprehensive view of patient participation**

This book aims to add to previous analyses and conceptualizations by approaching the question ‘what is patient participation?’ as a problem to be posed, both in research and in practice.

This book, like those studies reviewed above, assumes that patient participation is desirable and achievable. But it also proposes that, until we understand what patient participation means, and how it works in different contexts, we should be wary of beginning to promote it. Rather than viewing patient participation as a concept or practice to be sold and adopted wholesale, our aim is to develop a more nuanced understanding of its forms and variations; one founded on empirical data and on the expressed views and observable practices of both patients and health professionals. Understanding participation means becoming attuned to variations between individuals, recognizing and accommodating individual sensitivities and different levels
of responsiveness at different moments. Thus, this book models a cautious, context-sensitive and questioning approach to the concept and practice of patient participation. In our view, an openness to what patient participation means, and an acknowledgement of its context-sensitivity and changing forms, are necessary to ensure quality in health care.

This book takes a wide view of patient participation. It aims to describe the various forms that patient participation takes, bringing on board its everyday meanings, and not just the significant errors and policy statements, and the questions of professional performance and imposed standards, as presented in the review above. In relation to interventions in health professional practice, this book takes the view that rather than adopting interventions that focus on professional behaviour and responsibility, or giving advice to health professionals about appropriate responses, a more constructive approach is to sensitize health professionals to the complexities and variations of forms of patient participation, according to different contexts. In order to document this diversity, the studies are descriptive in orientation, and focus on the interactional processes that may foster participation, or perhaps restrict it.

The questions this book raises include the following (and see the Educational Supplement, p. 197). What is patient participation, and how can it be studied? Is patient participation assumed to be a good thing? Or is it being questioned? How may patient participation be described? How may it be measured? In what respects may patient participation be recommended and advocated? How can we facilitate it? Can it be effectively taught?

There are certain questions this book does not deal with. These include questions concerning the development of appropriate measures of participation, and the effects of patient participation on health care outcomes. Rather, this book focuses on what participation is, using a range of qualitative approaches, in order to be able to specify it more clearly. Until this is done, it is not possible to devise quantitative measures for participation, or to assess the effects of participation on health care outcomes. In a sense, then, we are going back to the drawing board, and hope that our work will be useful to those wishing to develop measures of participation or to examine the links to outcomes.

The contributions of this book

The book is divided into three parts, and includes educational supplements and an appendix with CA transcription. The introductory Part I (Chapters 1 and 2) outlines the policy background, the conceptual framework, and the research methodologies employed. Continuing the line of argument presented in this chapter, Chapter 2 (‘Methods for studying patient participation’, Bugge and Jones) invites experimentation with combinations of methods, researcher
interpretations, and health professional and patient perspectives, as a means of achieving greater understanding and insight into the concept of patient participation.

In Part II (Chapters 3 to 8), the empirical part concerned with how participation is enacted in practice and in everyday situations, patient participation is explored by reference to a range of types of data, collected in different health care settings. It opens with two chapters (Chapters 3 and 4) which explore health care users’ views of participation. Chapter 3 (‘The meaning of patient involvement and participation in health care consultations: A taxonomy’, Thompson), examines empirical evidence from a qualitative study of the views and preferences of citizens, patients, and members of voluntary/community groups. The extent to which involvement was desired and sought depended on a variety of factors (e.g. type of illness, personal characteristics and patients’ relationships with professionals). Participation was seen to occur when there was reciprocity with professionals through dialogue and shared decision-making. Chapter 4 (‘What is a good consultation and what is a bad one?’ Stevenson) presents patients’ views of ‘good’ and ‘bad’ consultations, elicited through interviews immediately following from consultations in general practice. The range of patients’ responses reflected several influences on their perceptions of involvement: the personalities of health care providers, the way in which consultations are organized, notions of rights and responsibilities, and issues relating to the structural organization of health care.

Chapters 5, 6, 7 and 8 make up the remainder of the empirical section. These chapters focus primarily on recordings of consultations and analyses of interaction. Each one illuminates aspects of structures of communication in consultations, and demonstrates ways in which features of these structures, and their variations, promote or restrict patients’ participation. Chapter 5 (‘A feeling of equality’, Chatwin et al.) explores qualities of communication with reference to a consultation taking place in an NHS homoeopathic hospital. Through detailed consideration of one instance of a consultation opening, accompanied by extracts from a themed discussion and interviews with health professionals, this chapter discusses environmental influences on consultations, and specifies features of the interaction that appear to promote mutual respect and rapport between the patient and the doctor. Chapter 6 (‘Patient participation in formulating and opening sequences’, Gafaranga and Britten) takes two communication practices in general practice consultations, openings and formulations, that have been studied elsewhere, and re-examines these practices to consider what each one illuminates about the meaning of patient participation, and how it may be promoted. Chapter 7 (‘What is patient participation?’, Peräkylä et al.) explores patient participation in three different health care settings in Finland (general practice, homoeopathy and psychoanalysis). This chapter provides a comparative description of patients’ comments on practitioners’ expert statements, and highlights some distinctive
features of patient participation in relation to each of these settings and types of activity. Chapter 8 (‘Nursing assessments and other tasks’, Jones and Collins) describes the constraints on and opportunities for the raising of patients’ concerns, as found in interactions between patients and nurses in three different nursing contexts.

Part III (Chapters 9 and 10) draws together the main findings from the collection of studies to present a conceptual and methodological framework for understanding patient participation, and to develop ideas concerning how it may be recommended, fostered and measured. These chapters build on the multi-faceted definition of participation developed through Chapters 1 to 8, to reflect its context-sensitive properties and its interactive and dynamic forms. Chapter 9 (‘Components of participation’, Peräkylä and Ruusuvuori) considers the methodological dimensions of research on patient participation, and what these reflect about the practice of participation. Chapter 10 (‘An integrative approach to patient participation in consultations’, Thompson et al.) summarizes the main arguments and findings from this book into a conceptual overview. This overview integrates the various contributions and takes these through from micro-level studies to the macro-level. Its aim is to explore the potential for mapping these contributions into a holistic framework which will enable those working in patient participation to locate their particular area of research, practice, or experience within it.

The final part of the book is a series of educational supplements, linked to the chapters. Each supplement offers additional data examples, discussion questions, analytic exercises, and prompts for teaching and research, in relation to the themes of each chapter.

**Contexts for participation**

The context for this book is processes of communication in health care consultations. We have deliberately chosen to examine a range of settings and different types of health care practitioner. This range provides more than a broad basis for our conclusions; it also invites comparison and exchange of communication practices, across different health care contexts. We consider consultations in primary and secondary care, including homoeopathy, general practice, head and neck cancer outpatient clinics, diabetes in primary care, family planning and psychoanalysis. The practitioners are doctors, nurses, homoeopaths and psychoanalysts, and the chapters include material from the United Kingdom and from Finland. The rationale for studying other types of consultation, in addition to orthodox medical consultations, is that these permit a broader analysis of what patient participation is, and of what it might be, given the very different contexts of practice and world-views of their practitioners. Thus, the study of homoeopathic or psychoanalytic consultations gives us different lenses through which to examine medical consultations.
The chapters represent a diversity of experiences across different patient populations, with a rich variety of empirical data gleaned from consultations, interviews, and discussion groups with a range of health service users, patients and professionals. The reader can use the book to make their own comparisons, for example, of the difference between people’s stated preferences for involvement and actual consultations (Chapters 4, 5 and 6); between forms of patient participation in conventional medical consultations and forms of patient participation in homoeopathy and psychoanalysis (Chapters 5 and 7); or between nurses’ and doctors’ communication (Chapters 2 and 8). Our conceptual overview (presented in Chapters 9 and 10) is derived from these diverse sources, ranging from analyses of actual consultations to the views of those not currently in need of health care.

Methods for studying patient participation

As well as examining a range of contexts, this book also uses a range of qualitative methods, as each method on its own can only provide a partial picture. Chapter 2 shows how a combination of methods can provide a more rounded view. As the focus of the book is on the consultation, several chapters are based on recordings of actual consultations, for which we have principally employed conversation analysis (Chapters 2, 5, 6, 7 and 8). We have also used qualitative interviews, focus groups and themed discussions, non-participant observation and retrospective think aloud techniques (and this range is also echoed in the educational supplements). This range of methods means that our analysis is not confined either to what people say they do (in interviews or focus groups, for example) or to what they can be observed to be doing (in recordings of consultations), but embraces both.

The picture of patient participation presented in this book

In policy documents and in the research literature, the concept of participation is often presented as if it were ubiquitous, as if to suggest that it has a single and commonly understood meaning. This is not the case. As shown in Chapter 3, it is closely related to the concepts of ‘involvement’, ‘collaboration’ and even ‘partnership’. Chapter 3 explores the meanings of the words ‘participation’ and ‘involvement’ to citizens and patients, and the ways in which these meanings might differ from those held by professionals and researchers. For some, silence may represent an obvious form of non-participation, while in Chapter 2 we show how a patient’s silence may influence the subsequent course of a consultation. Patient participation may be defined in one way when studying consultations, and in another way when talking to patients afterwards. It may mean one thing to a healthy citizen in a focus group, and another to a patient in a head and neck cancer outpatient
clinic, and something else again to a nurse, GP, homoeopath or surgeon. Thus, in this book, we aim to examine the concept of patient participation from a wide range of perspectives. We include the views of citizens, as well as patients; professional, lay and academic perspectives; those in secondary and primary care; in health care policy in nursing and in medicine; in Finland and in the UK. In Chapter 9, we identify five key components of patient participation, each with its specific site of empirical manifestation and each with its own specific research method(s). These components may be used as a conceptual model to inform future research. In the last chapter, we link these components to levels of patient participation and examine the contexts of participation.

How to use this book

The structure of the book is designed to help its readers use it in different ways. An editorial commentary opens each chapter in the book, to introduce themes and highlight the direction being taken. By reading the series of commentaries alone, the reader can gain an overview of the whole book. Each chapter concludes with a summary of recommendations. Linked to each chapter is an educational supplement, with ideas and applications for communication skills teaching and for reflecting on clinical practice. The chapters and supplements can be read in different orders, and the reader can start and stop in different places; read only selected parts, or the book as a whole. The Appendix presents the notation for the Conversation Analysis transcripts used in the book.

The book is intended to progress the reader’s understanding and knowledge by one or more of the following routes:

- providing the reader with different ways of characterizing patient participation;
- enabling the reader to see and understand differences between patient and professional perspectives;
- encouraging interdisciplinary thinking and debate;
- enlightening understanding about the process of patient participation.

The book is also intended to inspire the reader, in a number of activities, for example:

- identify a theme for a course assignment;
- create a new taught course, using the educational supplements;
- try out new communication techniques in health care practice;
- review current health care policy;
• review organizational features of health care consultations, clinics, or interdisciplinary team management;
• develop strategies for advising and supporting user groups;
• compile a leaflet based on patients’ stories;
• set up a piece of research;
• try a new research method.

The data extracts in themselves can be compared with other examples from students’ own research and/or areas of professional practice. The information contained in each chapter can be employed to pose and answer questions with applications in research and in professional practice, such as: ‘How can we as professionals make the openings to encounters with patients more therapeutic?’, or ‘What are the various ways in which patients wish to be involved in consultations, compared to how they actually are involved?’

Different ways of reading the book reflect different ways of being involved and of participating. We hope that you will find it an enjoyable and stimulating experience.

**Recommendations: summary**

• Patient participation should always be considered in context: it may mean different things when seen from different perspectives.
• In promoting patient participation either in policy or in practices of health care, we should remain open to its context-sensitivity and changing forms.
• In order to understand the process of patient participation, and thus how to influence and develop measures of participation and its effects on health care outcomes, it is necessary to pay close attention to what actually happens in interactions between patients and health professionals.