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Ideas that change health care

Research paper

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The quality of patient engagement and involvement in primary care

An Inquiry into the Quality of General Practice in England

The quality of patient engagement and involvement in primary care

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Contents

Executive summary

Picker Institute Europe reviewed the quality of patient engagement in primary care, how to measure it, and developments in patient involvement in primary care.

For the purposes of this report we have used the following definitions.

- Patient engagement means engagement in one's own health, care and treatment.

For our review of patient engagement literature, we have focused primarily on the consultation between the general practitioner (GP) and the patient, as this is the most developed aspect of primary care. For this reason we did not focus on engagement in other primary care practitioner–patient relationships

- Patient involvement means involvement in the design, planning and delivery of health services.

Patient engagement

We reviewed studies of patient and GP perceptions of the factors that enable patient engagement, and found that patients and GPs consistently identified very similar themes. From these themes, the following 'domains' of engagement in primary care consultations (that are acceptable to patients and GPs alike) could be identified:

- agreement and understanding of patient and GP responsibilities
- assessing and expressing needs and wants regarding engagement
- confidence in engagement
- consultation length
- understanding of the impact of contextual factors on the consultation (time, resources and so on)
- training and support for engagement
- informational support
- respect
- continuity of care.

We searched the available tools and measures used to assess and monitor patient engagement in general practice consultations. It found many instruments, and classified the common domains of measurement as:

- listening
- involvement in decisions
- information, explanation, questions being answered
- consultation length
- empathy.

On the basis of these two reviews, we are able to propose:

- a set of indicators for measuring the quality of patient experience within these domains
- a list of potential questions capable of monitoring these indicators
- existing sources from which to draw those questions.

Measurement of the quality of patient engagement in primary care in England has not been consistently useful. National surveys for successive regulators from 2002 to 2008 did not provide results at individual practice level, and were therefore not useful for quality improvement. The subsequent General Practice Patient Survey does provide practice-level results, but with questions that could be considered of limited value in terms of the breadth of data that they are able to provide.

Results from the most recent national surveys show that patients report high levels of patient confidence and trust in GPs, and good (probably improving) experience of doctors' communication skills. However, there are significant numbers of patients reporting that they had not been as involved in decisions as they wanted to be.

There is a good availability of measures and indicators for patients' experience of engagement in the consultation, but there are also various issues for consideration by the Inquiry in relation to choosing which measures to recommend.

These include:

- the nature of current and future data collection
- the purpose of measurement and the level at which it is required (individual practitioner, primary care practice, specific practice or comparison across practices)
- preference for research methods ('satisfaction' versus 'experience').

The challenges facing primary care practitioners in improving the quality of patient engagement include:

- training needs – particularly to gain the skills to go beyond basic communications skills; to elicit patients' views, values and preferences; and to assess patients' capacity and willingness to share in decisions
- changing the culture of specific general practices or health centres to focus on engaging patients
- the associated need for an active care-planning approach – especially for people with long-term or recurring conditions
- the length of consultations
- the loss of 'ownership' of the patients' treatment options, through referral to secondary care.

Patient involvement

There are few reliable and robust studies of patient involvement in developing primary care services. In the absence of a solid evidence base, we reviewed recent reports and investigated some of the most interesting current initiatives.

These indicated the following.

- World Class Commissioning and other central guidance on patient and public involvement are not specific to general practice level, and have had little impact.
- LINks are, in the main, struggling to have any impact on patient involvement in general practice.
- Established involvement techniques used at general practice level have often sought patients' feedback on one-off issues, rather than their influential involvement.
- The most widespread initiative to promote involvement appears to be the development and support of patient participation groups (PPGs), which are reported to exist in around 40 per cent of practices. There is an ongoing campaign to establish more.
- Practices tend to support PPGs as long as the role of 'friend' does not become too critical. The majority of PPGs seem to be in a subservient role to the practice, providing additional value to the primary care service.
- If patient involvement in general practice is to be scaled up, the most likely route is through practice-based commissioning (PBC) consortia.
- The Department of Health could be encouraged to issue more specific PBC guidance relating to the involvement of patients and the public.
- PCTs, working within the World Class Commissioning Framework, should be requiring PPI to be demonstrated as part of the business-case criteria for approval of PBC projects.

This report describes three examples of innovative practice. These show that at PBC consortium level it becomes possible to initiate and sustain some more ambitious mechanisms to involve patients in the governance of primary care services and the development of proposals for service change. Some common characteristics in our examples appeared to include:

- a local history of previous commitment to, and development of, effective PPI
- the use of 'networked' patient groups as a ground-level source of participants and consultees – sometimes drawing on PPGs and sometimes establishing new patient networks, using other available channels.
- a willingness of the primary care trust to enable these developments, and to support the growth of PPGs or other local health networks.

Sustaining this type of scaled-up patient involvement requires resources and support – including communications and administrative support – from various local stakeholders, as well as from the GP practices themselves.

Introduction

This report represents the findings of a study exploring patients' engagement in their general practice consultations, and their involvement in the development of general practice services. The study has been undertaken as part of the Inquiry into the quality of general practice in England commissioned by The King's Fund, which has aimed to examine and collect evidence on the quality of care and services provided by general practices in England (King's Fund 2009).

The use of the terms 'patient engagement' and 'patient involvement', and their application both to individual care and to the planning and design of services can potentially be confusing. For the purposes of this report only, and to aid clarity for the reader, we use these terms as follows.

- **Patient engagement** is used to describe patients' engagement in primary care consultations regarding their own health, care and treatment. We have focused primarily on engagement in the consultation between the patient and the general practitioner (GP), as this is the most developed aspect of primary care. We are not able to provide the same level of focus on engagement in other primary care practitioner–patient relationships. This is because the GP–patient consultation is a universal aspect of primary care in terms of the patient's experience, whereas patients' experience of consulting other types of practitioner is likely to vary from patch to patch.
- **Patient involvement** is used in discussions about whether, and how, patients (both as individuals and groups) are involved in the design, planning and delivery of primary care services at the GP-practice or health-centre level.

We explored the measurement of patients' engagement in the general practice consultation by:

- **reviewing qualitative studies** exploring primarily GP perceptions of the key elements of facilitating patients' engagement in the general practice consultation, and patients' perceptions of how their GPs could facilitate their engagement. Where they existed, we also identified and appraised studies exploring the relationships between other primary care professionals and their patients
- **reviewing existing measures of patient engagement** exploring how high-quality general practice care (in relation to patient engagement in the general practice consultation) has been measured in the past. To do this we reviewed existing questionnaires, scales and assessment tools used to assess patient engagement within the general practice consultation. Here, too, we focused primarily on the GP–patient consultation. Surveys such as the GPPS and the regulators' surveys do include questions about 'seeing another health professional', but the variability of this provision militates against comparative assessments.

We compared and contrasted data from both these reviews, to identify domains and indicators of quality of patient engagement that appeared to be important to measure.

Due to the funding available for this project, and its scope, we did not have the capacity and funding to search for the quantitative studies in this area and extract data from those, so we chose to focus our resources on identifying and extracting data from the qualitative literature. This was partly because part of the project aim was to identify concepts that had not been explored in previous quantitative studies, rather than undertaking a meta-analysis of the quantitative data available.

We explored patients' involvement in the development of general practice services by:

- exploring the national drivers of patient involvement in the development of general practice services, and the most likely mechanisms for achieving this involvement
- searching out and describing practical examples of best practice where these existed.

Why patient engagement and involvement matters

The inquiry into the quality of general practice in England commissioned by The King's Fund aims to examine and collect evidence on the quality of care and services provided by general practices in England (King's Fund 2009).

There is a proven association[1] (Coulter and Ellins 2006) between the engagement of patients in their health, care and treatment and the outcomes in relation to:

- patients' recall of information, knowledge and confidence to manage their conditions
- the likelihood of patients reporting that the chosen treatment path was appropriate for them
- patient reports of their experiences, and of their satisfaction with care
- the use of health care resources, where engaged patients are more likely to adhere to chosen courses of treatment, and to participate in monitoring and prevention – for example, by attending screening.

It has also been shown that some interventions to involve patients in sharing the decision over treatment choice result in patients choosing less interventionist (and costly) treatments than their clinicians might otherwise have recommended.

The degree of patient engagement in consultations can be measured through patient experience reports. Patient experience, in turn, is part of the heightened focus on quality stemming from the NHS Next Stage Review (Department of Health 2008c).

Patient engagement is also a strong feature of the professional standards for doctors, enshrined in Good Medical Practice (GMP),(General Medical Council 2006) which gives doctors a duty to work in partnership with their patients.

General Medical Council guidance issued since the last revision of GMP (2006) has further developed and refined the 'partnership' duty. For

1 See also the recently published Invest in Engagement web tool, at: www.investinengagement.info

example, the 2008 guidance on achieving patients' consent emphasises that this should be done in the context of shared decision-making. The 2009 specification of learning outcomes for medical undergraduates (*Tomorrow's Doctors*, GMC 2009) includes new requirements to demonstrate the ability to elicit patients' preferences, and to assess their capacity and willingness to share decisions about their care and treatment.

Training for GPs covers these domains of partnership. For example, the RCGP's consultation observation tool (RCGP 2010b) assesses the skills of students to, among other things:

- encourage the patient's contribution at appropriate points in the consultation
- respond to signals (cues) that lead to a deeper understanding of the problem
- explore the patient's health understanding
- explain the problem or diagnosis in appropriate language
- specifically seek to confirm the patient's understanding of the diagnosis as well as to ascertain whether 'the patient is given the opportunity to be involved in significant management decisions.'

All registered doctors will soon be required to be periodically revalidated and relicensed against the GMP standards. This system will require the use of multi-source feedback for appraisal, which must include an element of patient feedback.

Patients can most legitimately give feedback on the quality of consultation in relation to the skills of the doctor in informing and communicating with them, and in enabling them to be active and to share decisions about their care and treatment (Chisholm *et al* 2006).

With regard to patient involvement – the active participation of citizens, users and carers and their representatives in the development of health services – this is part of the patient and public engagement agenda of the Department of Health and the NHS, and includes, for example:

- a world class commissioning requirement for primary care trusts to 'proactively seek and build continuous and meaningful engagement with the public and patients, to shape services and improve health' (Department of Health 2008)
- a legal duty on NHS organisations to consult patients and the public on significant matters that affect the nature of the services they receive
- membership schemes for foundation trust status
- local involvement networks (LINks)
- rights stated in the NHS Constitution in England for patients to be informed about their condition and about all available treatment options, and to participate in discussions and decisions about their care and treatment.[2]

2 In Scotland, the Scottish government has placed before Parliament the Patient Rights (Scotland) Bill which would legally enshrine patients' rights to receive healthcare that is patient focused, recognises the importance of "providing optimum benefit to the patient's health and wellbeing", encourages the patient to participate

Little of this guidance relates specifically either to the provision of general practice services, or to commissioning by GPs (practice-based commissioning).

However, two current initiatives are in progress that may more closely affect the way that general practices involve their patients in decisions about changes to services. These are:

- new regulations for all providers of health and social care under the Health and Social Care Act 2008, which specify that all providers must monitor and take account of the views of their service users and their carers and families
- the accreditation scheme that has been piloted by the Royal College of GPs, and which encourages the involvement of the patient population in the running of the service.

These initiatives may be linked, since the regulations will be operated and enforced by the Care Quality Commission, which is talking with the RCGP about using the assessment criteria drawn from the accreditation scheme.

Picker Institute Europe: background

In undertaking this work, Picker Institute Europe has drawn on its extensive database of published research literature and previous reviews that it has carried out for the Health Foundation (Coulter and Ellins 2006) and WHO Europe's Health Evidence Network (Coulter *et al* 2008), among others.

We have also built on our knowledge and understanding of how to measure the patient experience elements of primary care quality. Picker Institute Europe carried out the first national survey of patient experience in primary care in England in 1998. Subsequently it developed and coordinated repeat national surveys between 2002 and 2008 (Picker Institute Europe 2009) – mainly for the successive health care regulators – plus, in 2006, one for the Department of Health.

Picker Institute Europe also has a longstanding interest in researching and promoting better engagement of patients in their own care and treatment. In addition to various reviews and published papers, it carried out a three-year research programme on patient-centred medical professionalism, which included investigating patients' and doctors' perceptions of patient engagement and examined the instruments available to measure patient engagement in medical consultations (Chisholm *et al* 2006).

With regard to patient and public involvement generally, Picker Institute Europe is a member of various relevant networks, including the NHS Alliance Steering Group on PPI. It works with primary care trusts to research patient and public needs, views and experiences, and to assist in forming PPI strategies. It has carried out two surveys of PCTs to research their approaches to PPI. It has previously given evidence to the Health Select

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as fully as possible, and provides the information and support necessary to enable patients to participate. As with the NHS Constitution, patients are expected to pursue the achievement of these rights through complaints and feedback, and there is no legal enforcement. Also as with the NHS Constitution, the consequent actions to enable these patient rights are seen as lying with NHS organisations (Boards) rather than specifically with GP practices. See http:––www.scottish.parliament.uk–s3–bills–42-PatientRights–index.htm

Committee inquiry into PPI (2007) and to the Local Government Association's commission on the accountability of local health services (2008).

Picker Institute Europe was a member of the primary and community care advisory group for the NHS Next Stage Review.

From our previous reviews and other work in this area, we can comment on the strength of the evidence base in the areas of patients' engagement in their health care consultation and patients' involvement in developing health services.

At the present time, the evidence base is stronger in the area of patients' engagement in their health care consultations, and weak with regard to patients' involvement in developing health services. For this reason, we have concentrated mainly on patients' engagement in the general practice consultation in this work, although we have done some work exploring patients' involvement in the development of general practice.

Research design

This study focused on two aspects of patients' involvement in their health care. The first is patients' engagement within the general practice consultation (primarily with their GP), and the second is patients' involvement in the development of health services within general practice.

The study consisted of:

- a review of existing qualitative literature in the area of patient engagement within the general practice consultation, primarily with their GP
- a review of existing measures and tools that have explored patients' engagement within the general practice consultation
- identification of existing initiatives that have focused on facilitating patients' involvement in the development of general practice
- three examples of good practice of involving patients in developing health services within general practice.

1 Patient engagement in general practice consultations

This section outlines the aims of this element of the study and the approaches used. Within this element of the study we focused primarily on the GP–patient consultation as the most developed aspect of primary care.

Research objectives and methods

The research objectives were as follows:

- to explore the role and rationale for patient engagement in general practice
- to review published qualitative research exploring:
  - GPs' perceptions of the key elements of facilitating patients' engagement in the general practice consultation
  - patients' perceptions of their GP's approach to facilitating their engagement in the general practice consultation
- to explore and review how high-quality care in relation to patient engagement within the general practice consultation has been measured in the past
- to identify key domains within which it may be important to measure patients' engagement in the general practice consultations.

In terms of methods, we carried out an electronic search of several research literature databases (including PsychInfo, PubMed, ASSIA, EMBASE, CINHAL, the reference lists of all articles included in the review, and prior reviews of similar literature) to identify qualitative studies that explored patients' and GPs' perceptions of the key elements of engaging patients within the general practice consultation. We identified the domains that patients and GPs alike considered important in engaging patients in their care.

We then searched question banks, research literature databases (PubMed, Psychinfo, Science Citation Index and Social Science Citation Index) and Picker Institute Europe research-literature databases to identify existing indicators and measures of patient engagement within the general practice consultation. We identified the key domains of engagement that these tools were measuring.

We then compared the key domains that were considered important (by patients and GPs alike) within the qualitative data to the domains identified within our analysis of existing measures of patient engagement within the general practice consultation.

For a more detailed explanation of the study methods, *see the appendices to this report*.

GP and patient perceptions of key domains

We identified eight papers that focused specifically on patient and GP views of factors that might contribute to patient engagement in primary care.

Study characteristics

Five studies were conducted in the United Kingdom, one in the United States and two in 11 different European countries. Three studies were conducted with studies containing only patients and three with only GPs. Some studies referred to specific populations – for example, patients with chronic illness (Blakeman *et al* 2006; Campbell *et al* 2007), shared decision-making (Edwards *et al* 2001), mental health (Lester *et al* 2006) and older adults (Bastiaens *et al* 2007). Three studies that explored GPs' views on patient engagement did not focus on a specific population.

Five studies employed semi-structured qualitative interviews, and three ran focus groups to explore participants' views. All used thematic analysis to develop and apply a coding frame to each transcript and elicit themes from the data. One study was theory driven, and used Howie's theoretical model for understanding general practice consultations to structure the findings (Blakeman *et al* 2006).

Facilitating factors

We found consistently similar themes across all the studies identified. Factors that could facilitate greater engagement within the general practice consultation were classified into the following areas:

- doctor-patient relationship
- doctor-related factors
- patient-related factors
- contextual factors.

Participants consistently referred to these categories as being either beneficial or detrimental to patient engagement, although study findings were mixed in their appraisal of them. Some studies (Bastiaens *et al* 2007; Talen *et al* 2008) noted positive and negative aspects of these categories. In other cases, a factor that was considered to be facilitative in one study was cited as a barrier to engagement in another.

Although the main focus of the review was to identify and describe factors that contributed to patient engagement, it may be equally beneficial to identify those factors perceived as barriers to patient engagement, in order to improve patient-centred care in the general practice consultation.

Doctor–patient relationship

All studies highlighted that establishing a good doctor–patient relationship was necessary for fostering patient engagement in the consultation (Bastiaens *et al* 2007; Blakeman *et al* 2006; Campbell *et al* 2007; Edwards *et al* 2001; Ford *et al* 2003; Lester *et al* 2006; Talen *et al* 2008; Wetzels *et al* 2004).

They referred to this in various ways, depending on the study context. For example, patients with mental illness referred to the need for GPs to value their lived experience of having a mental illness, and the importance of sharing decision-making through the exploration (Lester *et al* 2006).

In the context of shared decision-making, establishing a good doctor–patient relationship was described as requiring:

- a number of consultations with the same health professional
- mutual respect
- variable engagement in decision-making, depending on the context.

Other papers noted the importance of continuity in care to develop trust and to provide encouragement, reinforcement and advice (Blakeman *et al* 2006; Ford *et al* 2003).

What is more, the doctor and patient were identified as needing to work together in terms of acknowledging a time limit to the consultation and understanding that there is a partnership between the two parties. This was seen to foster respect, trust, tolerance and honesty, and to maintain privacy and confidentiality (Campbell *et al* 2007; Ford *et al* 2003; Talen *et al* 2008). Older adults defined a 'good' relationship as one that was trusting, where the GP knew the patient and tailored their approach to the patient's needs (Bastiaens *et al* 2007). These last two papers (Talen *et al* 2008 and Bastiaens *et al* 2007) cited the opposite approach as examples of these qualities as barriers to patient engagement.

Patient-related factors

Patient-related factors included possible complications that patients might bring to the consultation, such as:

- cognitive impairments, such as those perceived by GPs regarding their patients with mental health issues (Lester *et al* 2006)
- physical impediments, such as deafness in older adults (Bastiaens *et al* 2007)
- holding a negative attitude – in other words, patients not taking responsibility for their own health (Talen *et al* 2008)
- not accepting authority (Wetzels *et al* 2004)
- the perception that those with mental illness would be bad at time-keeping, of poor intellect and possibly violent (Lester *et al* 2006).

A positive way in which patients were perceived to be able to contribute to their care was in being informed and prepared (Wetzels *et al* 2004). This theme was particularly emphasised by Talen *et al* (2008), where they identified that patients could improve patient-centred consultations by:

- having knowledge of their health history, family health, medication and diagnosis
- arriving on time
- describing their illness accurately
- bringing a significant other to the consultation, if appropriate.

GP-related factors

GP-related factors referred to the GP's ability to encourage the consultation to be patient centred (Campbell *et al* 2007; Lester *et al* 2006; Edwards *et al* 2001; Wetzels *et al* 2004). Many qualities were described, including:

- being relaxed, confident, and empathetic
- encouraging shared decision-making
- providing information
- taking time
- empowering the patient.

Communication skills were also frequently mentioned. These were described as involving listening, negotiation, recognising verbal and non-verbal cues, reflective and open questioning, and using eye contact (Ford *et al* 2003).

In some studies, GPs acknowledged their own lack of communication skills (Bastiaens *et al* 2007; Blakeman *et al* 2006; Wetzels *et al* 2004).

Other difficulties were identified insufficient numbers of GPs being available, low accessibility to the GP practice and GPs being too busy (Bastiaens *et al* 2007).

Contextual factors

Contextual factors were frequently identified as barriers to patient engagement, including lack of time in the consultation and lack of resources such as money and personnel (Wetzels *et al* 2004; Blakeman *et al* 2006; Talen *et al* 2008).

Providing a setting conducive to divulging confidential information was also identified as being of importance (Ford *et al* 2003).

Conversely, these factors were identified in one paper as being potential facilitators to patient engagement if they were increased – in other words, if there were more time and resources available (Bastiaens *et al* 2007).

Summary of main points

- Patients and GPs consistently identified overlapping themes in each of the studies, regardless of the health context or location of the research. These are summarised in Table 1.
- Participants felt that patient engagement is multi-factorial, requiring both practitioner and patient to work together to build a relationship.
- Patients and GPs need to develop specific competencies or have certain personal qualities to facilitate involvement.
- Certain barriers were identified at a practical level that could inhibit patient engagement, such as a lack of time.

The studies identified positive and negative aspects of the factors within these categories.

These findings are similar to those published in a previous review, which analysed quantitative and qualitative studies relating to patient priorities

in primary care (Wensing *et al* 1998). For example, that review cited 19 studies asking participants to place in rank order of importance a number of aspects of health care. The five most important qualities were 'humaneness', 'competency', 'patients' involvement in decisions', 'time for care' and 'accessibility' – all of which are also identified in the present review.

Discussion

Although increasing patients' engagement within the general practice consultation is considered to be a good thing, several challenges may exist.

- GPs and their patients may have very specific ideas about their roles within the consultation, and may be concerned about compromising their relationships if these roles change (either through patients seeking to become more involved or through GPs trying to increase patients' level of engagement within the consultation).
- Patients and GPs alike may lack confidence in increasing the level of patient engagement within the consultation. Patients may lack confidence regardless of the GP's best efforts to encourage them to become more engaged. GPs may lack confidence in their skills and experience in facilitating patients' engagement within the consultation.
- Patients may feel that they do not have enough information and support to enable them to become as involved within the consultation to as they would like.
- GPs may feel that engaging patients in the consultation is appropriate and valuable but that they do not have the time, information or resources available to engage patients to the desired level, or that they cannot prioritise this, given the other demands on their time.
- The implicit power dimension within the consultation may also make it difficult for some patients to become engaged within the consultation. Some feel unable to express themselves fully as long as the GP is 'the expert' within the situation.

These issues will need to be taken into account when considering how best to measure patients' engagement within the consultation. For example, for some patients, full engagement in decision-making may be neither desirable nor possible, and any measures of the quality of the consultation would need to take this into account.

Methodological considerations

Patient engagement in care is a widely researched topic. So, finding only eight relevant papers was somewhat unexpected. There were several factors that may have contributed to this.

First, while there are a plethora of papers available on patient engagement in health care, few studies have focused on a primary care setting. Also, research conducted in this area has often focused on patient engagement in specific contexts, such as shared decision-making, older adults, mental health or chronic illness. This means there have been few seminal studies that have been cross-referenced, and researchers have not sought to modify and or replicate findings from other studies.

Table 1: domains of patient engagement

Domain	GPs	Patients
Agreement and understanding of patient and GP responsibilities	Clear ideas and agreement about GP and patient responsibilities within the consultation	Clear ideas and agreement about GP and patient responsibilities within the consultation
Assessing and expressing needs and wants regarding engagement	Ability to assess patients' needs and wants around engagement, and to act accordingly	Ability and confidence to express their needs and wants regarding engagement
Confidence in engagement	Confidence to engage patients	Confidence to become engaged
Consultation length	Time available within the consultation to facilitate engagement	Time available within the consultation to facilitate engagement
Understanding of the impact of contextual factors on the consultation	Recognition of the factors likely to influence patients' engagement within the consultation, such as incentives and clinical factors	Recognition of the other factors likely to influence engagement within the consultation, such as incentives and clinical factors
Training and support for engaging	Need for training to help GPs engage patients who may be difficult to engage, perhaps due to communication difficulties or mental health problems	Support for those who may experience difficulties in becoming engaged
Informational support	Access to information in the appropriate format to inform decisions	Access to information in the appropriate format to inform decisions
Respect	Recognition and respect for one another's skills and experience	Recognition and respect for another's skills and experience
Continuity of care	Continuity of care	Continuity of care

Source: King's Fund (2010)

Additionally, although some patients' conditions are monitored through contact with the GP, many patients visit GPs on a small number of occasions over a protracted period of time, for minor acute conditions. This may have diverted research attention to secondary care, where patients are seen more consistently.

The frequency with which patient engagement has been researched also made it difficult to develop a search strategy that was sensitive yet specific. As with all reviews that retrieve a large number of relevant articles, it may be that certain relevant articles were excluded. However, we did take measures to minimise the chances of this occurring, such as searching the reference lists of all articles selected for inclusion and those of systematic reviews previously undertaken.

Although we retrieved only a small number of relevant articles, we gathered data from more than 12 countries, strengthening the reliability of the findings.

Measuring patient engagement

We identified the following domains of engagement within our review of the factors influencing patients' engagement within the general practice consultation.

Search for measurement tools

We scanned all questionnaires used in the regulators' national surveys of primary care and general practice patients in England[1] and the recent Ipsos Mori national survey of general practice in England (Department of Health and Ipsos Mori 2009a)[2]. We also searched bibliographic databases to identify questionnaires and tools that have explored patient engagement within the general practice consultation.

We focused primarily on surveys carried out in Great Britain and Northern Ireland and in Europe. We did not feel that it was appropriate to include surveys from nations that had a very different primary care system to the United Kingdom.

In total, we identified 15 relevant questionnaires and five relevant studies. Nine studies described the use of questionnaires that had been developed by the researchers as part of their wider studies to explore engagement within the consultation. Eleven studies reported the development of questionnaires that were specifically focused on measuring engagement and enablement within the consultation.

The following questionnaires and tools were identified which explored patients' engagement within the consultation.

Questionnaires

- Local health services survey and question bank 2008 (2009)
- Local health services survey 2003 (2009)
- General Practice Patient Survey (Department of Health and Ipsos Mori 2009a)
- Consultation satisfaction questionnaire (Poulton 1996)
- Consultation and relational empathy measure (Mercer 2004; Mercer 2005)
- OPTION scale for measuring patient involvement (Elwyn *et al* 2003)
- QUOTE instrument (Sixma *et al* 1998, 2000)
- Patient intentions questionnaire (Salmon and Quine 1989)
- Expectations met questionnaire (Williams *et al* 1995)
- Patient enablement instrument (Howie *et al* 1998a, 1999a)

1 National surveys of primary care patients – usually titled 'local health services surveys' – were carried out first by the Commission for Healthcare Improvement (CHI) and later by its successor, the Healthcare Commission (HCC). In 2009 the HCC was succeeded by the Care Quality Commission (CQC). The CQC has no plans to carry out national surveys of primary care patients, given that the Department of Health has commissioned a frequent General Practice Patient Survey. However, the CQC continues to maintain a question bank of primary care patient experience questions. Thus, where we refer to a 'local health services survey (year)' and follow this with '(2009)', this denotes a national survey for the regulator, where the relevant question(s) remain available in the question bank.

2 The General Practice Patient Survey 2008–09, conducted for the Department of Health in England.

- COMRADE scale – patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision-making in consultations (Edwards *et al* 2003)
- General practice assessment survey (Ramsay *et al* 2000)
- Validation of a questionnaire measuring patient satisfaction with GP services (Grogan *et al* 2000)
- Development of a questionnaire to assess patients' satisfaction with consultations in general practice (Baker 1990)
- Medical interview satisfaction scale (Meakin 2002)

Studies

- 'Patients' priorities with respect to general practice care' (Grol *et al* 1999)
- 'Continuity of care in general practice: effect on patient satisfaction' (Hjortdahl and Laerum 1992)
- 'What makes a good GP: do patients and doctors have different views?' (Jung *et al* 1998)
- 'Comparison of patients' preferences and evaluations regarding aspects of general practice care' (Jung *et al* 2000)
- 'Observational study of effect of patient centeredness and positive approach on outcomes of general practice consultations' (Little *et al* 2001)

The domains of engagement used in measurement

From our analysis of the existing tools and measures, the following domains of engagement consistently appear.

Listening

- GP listens carefully to you all of the time regardless of circumstances – for example, if they are very busy
- GP lets you tell your full story
- GP listens to your expectations of your health and care

Involvement in decisions

- Involvement to the degree that you want to be
- GPs helping you to understand when a choice is required, and what the choice options are
- GPs giving you the time to make choices and the opportunity to express your opinions about them
- GP listening to your concerns about the pros and cons of treatment options
- Opportunities provided to review and revisit decisions
- GP acknowledges that the patient has the final choice regarding tests and treatment

Information and explanations given and questions answered

- Opportunities to ask for enough information about your condition and treatment choices
- Understandable information provided about your condition, treatment and referral
- Enough information provided about the condition (causes, progression and likely recovery)
- Enough information provided about treatment and referral (drugs, referral options)
- Enough information provided about the meaning of symptoms
- Confidence in the information provided and in your GP's knowledge about your condition and treatment
- GP checks your preferred information format

Consultation length

- Enough time to discuss your health or medical problem and its treatment
- GP made you feel that you had enough time
- Not feeling rushed or as if you are wasting the GP's time
- Fast service during emergencies

Empathy

- Have confidence and trust in GP
- GP understands what I want from them
- Trusted GP enough to tell them personal things
- Feel that you are treated with dignity and respect
- Felt that you were taken seriously by your GP
- Felt GP was interested in you as a person and not just in your illness or condition
- GP willing to learn about my problems and look at things through my eyes
- GP bothered about how illness affects everyday life, family and personal life
- GP showed care and compassion

Suggested indicators

The indicators in tables 2–6 are recommended for use in surveys. Examples of existing survey questions for each indicator are provided where available. These questions have all been previously tested for use in postal surveys, or in questionnaires administered in the general practice.

Table 2: Indicators for listening and support

Indicators	Questions	Available in
Listening carefully to what you had to say	• Did the doctor listen carefully to what you had to say? Yes, definitely; Yes, to some extent; No	Local health services questionnaire 2005 (2009) Consultation satisfaction questionnaire (Poulton 1996)
Listening carefully to you even if there was not much time available	• Does your GP listen to you no matter how busy he is? All of the time; most of the time; some of the time; never or hardly ever; can't say	National survey of NHS patients 2002 (2009)
Letting you tell your full story	How was the doctor at: • letting you tell your story? • really listening? • The doctor gives me every chance to talk about my problems • The doctor gave me a chance to say what was really on my mind • I really felt understood by my doctor • The doctor did not allow me to say everything that I had wanted about my problems	Consultation and relational empathy measure (Mercer 2004) Patient satisfaction with GP services (Grogan *et al* 2000) Medical interview satisfaction scale (Meakin 2002)
Exploring and listening to your expectations about your care	• The clinician explores the patient's expectations about how the problems are to be managed	OPTION scale (Elwyn *et al* 2003)
Allowing enough time to listen to your problems	• During the consultation, a GP should have enough time to listen, talk and explain to me	(Grol *et al* 1999)
Encouraged to ask questions	• I felt encouraged to ask questions • Understands my emotional needs	(Little *et al* 2001)

Source: King's Fund (2010)

Table 3: Indicators for involvement in decisions

Indicators	Item description	Available in
Involvement to the degree that you want to be	• Were you involved as much as you wanted to be in decisions about your care and treatment? Yes, definitely; Yes, to some extent; No	Local health services questionnaire 2005 (2009)
	• Were you involved as much as you wanted to be in decisions about the best medicine for you? Yes definitely; Yes, to some extent; No	Local health services questionnaire (2009)
	• The clinician asks for the patients' preferred level of involvement in decision-making	OPTION scale (Elwyn *et al* 2003)
	• The doctor gave me a chance to be involved in the decisions during the consultation	
	• My doctor and I agreed about which treatment was best for me	
	• I am satisfied with the way in which the decision was made in the consultation	
	• I am sure that the decision made was the right one for me personally	COMRADE scale (Edwards *et al* 2003)
GP helps you to understand when a choice is required and what your options are	• Were you given a choice about where you were referred (which hospital)? Yes; No, but I would have liked choice; No, but I did not mind; Don't know/Can't remember	Local health services questionnaire (2009)
	• The clinician identifies a problem needing a decision-making process	
	• The clinician states that there is more than one way to deal with an identified problem	
	• The clinician lists options including the choice of 'no action' if feasible	OPTION scale (Elwyn et al 2003)
	• It is clear which choice is best for me	
	• I am aware of the treatment choices that I have	
	• I feel an informed choice has been made	COMRADE scale (Edwards et al 2003)
	• The decision shows what is most important to me	

Indicators	Item description	Available in
GP listens to your concerns about the pros and cons of treatment options	How was the doctor at: • helping you to take control? • making a plan of action with you?	Consultation and relational empathy scale (Mercer 2004)
	• The clinician explains the pros and cons of options to the patient • The clinician explores the patient's concerns about how problems are to be managed • The clinician provides opportunities for the patient to ask questions	OPTION scale (Elwyn *et al* 2003)
GP gives you time to make choices and the opportunity to express your opinions about them	• An opportunity for deferring a decision is provided • Arrangements are made to review the decision (or the deferment)	OPTION scale (Elwyn *et al* 2003)
	• The doctor gave me the chance to express my opinions about the different treatments available	
	• The doctor gave me a chance to decide which treatment I thought was best for me	COMRADE scale (Edwards *et al* 2003)
Opportunities to review and revisit decisions	• I can easily discuss my treatment again with my doctor	COMRADE scale (Edwards *et al* 2003)
GP respects your choices	• A GP should be ready to discuss the investigations, treatment or referral that I want	(Jung *et al* 1998)
GP acknowledges that the patient has the final choice regarding tests and treatment	• GP should acknowledge that the patient has the final choice regarding investigations and treatments	(Grol *et al* 1999)

Source: King's Fund (2010)

Table 4: Indicators for information and explanations given and questions answered

Indicators	Item description	Available in
Opportunities to ask for enough information about your condition and treatment choices	• Were you given enough information about the purpose of the medicine? Yes, enough information; Some, but I would have liked more; I got no information, but I wanted some; I did not want/need any information; Don't know/Can't say	Local health services questionnaire 2005 (2009)
	• Were you given enough information about any side-effects the medicine might have? Yes, enough information; Some, but I would have liked more; I go no information, but I wanted some; I did not want/need any information; Don't know/Can't say	Local health services questionnaire 2005 (2009)
Understandable information provided about your condition, treatment and referral	• Did the doctor explain the reasons for any treatment or action in a way that you could understand? Yes, completely; Yes, to some extent; No; I did not need an explanation; No treatment or action was needed	
	• If you had questions to ask the doctor, did you get answers that you could understand? Yes, definitely; Yes to some extent; No; I did not need to ask any questions; I did not have the opportunity to as questions	Local health services questionnaire 2005 (2009)
	• Did that person explain the reasons for any treatment or action in a way that you could understand? Yes, completely; Yes, to some extent; No; I did not need an explanation; No treatment or action was needed	Local health services questionnaire 2005 (2009)
	• The clinician checks that the patient has understood the information	OPTION scale (Elwyn *et al* 2003)

Indicators	Item description	Available in
Enough information provided about your conditions, treatment and referral	• The doctor told me everything about my treatment/care and explained the reasons for advice given	Consultation and relational empathy measure (Poulton 1996)
	• When you have visited your GP surgery in the last 12 months, how often has your doctor given you enough information about your condition or treatment? All of the time; Most of the time; Some of the time; Never or hardly ever	National survey of NHS patients (2009)
	Health care providers should: • allow me to see my patient notes • give information on combinations of medicines	
	GP should: • tell his findings in follow-up consultations • display information leaflets in their waiting room.	QUOTE instrument (Sixma et al 2000)
	• Telling patients all they want to know about their illness • During the consultation, a GP should have enough time to listen, talk and explain to me • A GP should tell me all I want to know about my illness • A GP should explain the purpose of tests and treatment in detail • A GP and other care providers should not give contradictory information to me • The practice nurses do not take care to explain things carefully • The doctor doesn't tell me enough about the treatment • The doctor fully explains how the illness will affect my future health	(Grol et al 1999)
	• I sometimes feel that I have not been given enough information by the doctor	Patient satisfaction with GP services (Grogan et al 2000)
Confidence in the information provided and in your GP's knowledge	• I understand my illness much better after seeing this doctor	Consultation and relational empathy measure (Poulton 1996)
	• On that occasion, in your opinion did your doctor know enough about your condition or treatment? The doctor knew enough; The doctor knew something but not enough; The doctor knew little or nothing; Can't say	Local health services questionnaire 2005 (2009)
	• As a result of your visit to the doctor today do you feel you are able to understand your illness?	Patient enablement instrument (Howie *et al* 1999b, 1998b)

Indicators	Item description	Available in
GP checks your preferred information format	• The clinician checks the patient's preferred information format	OPTION scale (Elwyn et al 2003)

Source: King's Fund (2010)

Table 5: Indicators for the length of consultation

Indicators	Item description	Available in
Enough time to discuss your health or medical problems and its treatment	• Were you given enough time to discuss your health or medical problem with the doctor? Yes, definitely; Yes, to some extent; No; I did not need to discuss anything	Local health services questionnaire 2005 (2009)
	• Getting enough time during consultations	Grol *et al* (1999)
	• The time I was allowed to spend with the doctor was not enough to deal with everything I wanted	
	• I wish it had been possible to spend a little longer with the doctor	(Baker 1990)
GP made you feel that you had enough time	• How much time did you spend with your doctor?	National survey of NHS patients 2002 (2009)
	• In your opinion was this the right amount of time, too little time, or too much time?	
	• Making you feel you had time during consultations	(Jung *et al* 2000)
Not feeling rushed or like you are wasting the GPs time	• The time I was able to spend with this doctor was not long enough to deal with everything I wanted	
	• The time spent with this doctor was a little too short	Consultation satisfaction questionnaire (Poulton 1996)
	• Sometimes the doctor makes me feel that I am wasting his – her time	
	• I do not feel rushed when I am with the doctor	
	• The doctor gives me every chance to talk about my problems	Patient satisfaction with GP services questionnaire (Grogan *et al* 2000)
Fast service during emergencies	• Quick service in the case of emergencies	(Grol *et al* 1999)

Source: King's Fund (2010)

Table 6: Indicators for interpersonal care, including empathy

Indicators	Item description	Available in
Treated with dignity and respect	• Did the doctor treat you with dignity and respect? Yes, all of the time; Yes, some of the time; No	Local health services questionnaire (2009)
Confidence and trust in GP	• Did you have confidence and trust in the doctor? Yes, definitely; Yes to some extent; No	Local health services questionnaire 2005 (2009)
	• Sometimes the doctor makes me feel I am wasting his/her time	
	• I don't feel confident discussing my problems with the doctor	Patient satisfaction with GP services questionnaire (Grogan *et al* 2000)
GP understands what I want from them	• A GP should understand what I want from him or her	(Grol *et al* 1999)
Trusted GP enough to tell them personal things	• I feel about to tell this doctor about very personal things	
	• I would find it difficult to tell this doctor about some private things	Consultation satisfaction questionnaire (Poulton 1996)
Feel you are taken seriously	• Does your GP take your opinions seriously? All of the time; most of the time; some of the time; never or hardly ever; can't say	National survey of NHS patients 2002 (2009)
Felt GP interested in you as a person and not just in your illness	• I thought this doctor took notice of me as a person	
	• This doctor was interested in me as a person not just my illness	Consultation satisfaction questionnaire (Poulton 1996)
	• The doctor seemed interested in me as a person	Medical interview satisfaction scale (Meakin 2002)
	• A GP should take a personal interest in me as a person and in my life situation	(Grol *et al* 1999)
	• I thought the doctor took notice of me as a person	
	• The doctor was interested in me as a person and not just my illness	
	• There are some things this doctor does not know about me	(Baker 1990)
	• I felt this doctor really knew what I was thinking	
GP willing to learn about my problems and look at things through my eyes	• I felt this doctor really knew what I was thinking	Consultation satisfaction questionnaire (Poulton 1996)
	GP should:	
	• be able to look at things through my eyes	
	be willing to learn about patient's problems	QUOTE instrument (Sixma *et al* 2000)
GP bothered about how illness affects everyday life, family and personal life	• The doctor always asks about how my illness affects everyday life	Patient satisfaction with GP services (Grogan *et al* 2000)
	• Was interested in the effect of the problems on my family or personal life	
	• Was interested in the effect of the problem on everyday activities	(Little *et al* 2001)

Indicators	Item description	Available in
GP showed care and compassion	• How was the doctor at showing care and compassion	Consultation and relational empathy measure (Mercer 2004)
	Support items: • want to receive comfort • want help with emotional problems	(Williams *et al* 1995)
	• The doctor seemed warm and friendly to me	Medical interview satisfaction scale (Meakin 2002)

Source: King's Fund (2010)

Recent, current and future measurement

This section describes the recent, current and future measurement of patient engagement in primary care in England.

Voluntary surveys

Any GP or GP practice may at any time decide to secure patient feedback. Between 2003 and 2008, practices had an incentive to conduct their own surveys using approved instruments, as there were financial rewards within the Quality and Outcomes Framework. As this has been replaced by the General Practice Patient Survey it is likely that the number of practices carrying out additional voluntary surveys will have decreased significantly.

Regulators' surveys

From 2002 to 2008, national surveys of patients using local health services were carried out by the successive health care regulators. These used similar questionnaires and methods to the other surveys in the national programme in England, such as the annual survey of hospital inpatients.

However, the regulators were not responsible for regulating primary care at the practice level, so these surveys were designed to report to primary care trusts about patients' experience of primary care in their local area. The relatively small patient samples, and the fact that results could not be traced back to specific practices for the purpose of quality improvement, limited the value of the results.

However, the aggregated results did give a reliable picture at a national level of patients' experience of primary care across England. These were used, among other things, for reporting on the achievement of Public Service Agreement targets.

The current regulator – the Care Quality Commission – has no plans to continue these surveys.

General Practice Patient Survey

The General Practice Patient Survey (GPPS) was first initiated as a national survey of patients' access to primary care services, and as a means to monitor (at practice level) the achievement of government targets to improve access,

such as the target that every patient should be able to see a GP within 48 hours (Department of Health and Ipsos Mori 2009a).

In 2008, the Department of Health commissioned a three-year programme of the GPPS, to be carried out quarterly.

The GPPS differs from the two types of surveys discussed above, in several ways.

- It is carried out by direct commission from the Department of Health.
- It aims for a massive increase in scale – it is mailed to more than 5 million people, and in 2008/9 more than 2 million responded.
- It returns results for every general practice in England. These results are linked to the QOF incentives for patient experience.

The questionnaire used in the first national survey was not comparable either to the preceding (access-related) GPPS, nor to the regulators' surveys. This interrupted the longitudinal data, so national trends over time cannot easily be identified.

Within the GPPS there is a smaller set of questions relating to the actual consultation with the GP than was included in the regulator's survey. For example, questions relating to the prescription of new medicines were not included, although this is the specific decision most commonly made in primary care (around half of patients responding to the regulator's survey said they had been prescribed a new medicine), and provides a concrete example of the degree to which many patients were informed about, understood and engaged in a specific treatment decision.

Appraisal and revalidation

From 2011 all GPs will need to be relicensed and revalidated at least every five years. Appraisal within this framework must involve an element of patient feedback. For many GPs this will need to take place twice within the five-year period, although the Royal College of General Practitioners also recommends that a GP who has received good reports from patients in the first exercise may not need to carry out the second (RCGP 2010a).

Questionnaires will need to adhere to the General Medical Council's criteria for GP revalidation. At the time of writing, independent research analysts working for the RCGP had assessed three instruments as meeting these criteria and as having been sufficiently tested for reliability. It is likely that other existing questionnaires will be redeveloped specifically to pass these thresholds.

Recent results from national surveys

The last regulator's survey in 2008 reported the following results with regard to GP consultations (where comparisons are to 2005):

> *Patients reported improvements in most aspects of doctors' personal skills. The proportion of people who said that the doctor 'definitely' listened carefully to what they had to say increased from 82% to 83%. A greater proportion of patients felt that they had 'definitely' been given enough time to discuss their problem with the doctor (76% compared*

with 74% in 2005) and 77% received explanations regarding treatment or action in a way that they could completely understand.

However, the survey showed that not all aspects of doctors' communication skills have improved. While in 2005, 77% of respondents said they 'definitely' got answers to their questions that they could understand, this decreased to 75% in 2008.

There was an improvement in the percentage of people who felt that they were involved as much as they wanted to be in decisions about their care and treatment: 70% said this was 'definitely' the case compared with 69% in 2005. The vast majority (93%) felt that they were treated with respect and dignity 'all of the time' and 77% stated that they 'definitely' had confidence and trust in the doctor.

With regard to those patients who were prescribed of new medicines (54 per cent of total respondents), it reported the following results:

There has been a decrease in the percentage of people who said that they had been given enough information regarding the possible side-effects of their medication: 59% said this compared with 61% in 2005. Likewise, a smaller percentage than in 2005 said that they had been given enough information on how to use the medication: 85% in 2008 compared with 86% in 2005.

Furthermore it noted that:

While… a greater proportion of patients report full involvement in decisions about their care and treatment, this is not reflected when it comes to dealing specifically with medication. There has been no increase in the proportion of people who 'definitely' felt involved as much as they wanted to be in decisions about the best medicines for them; this has consistently been around 60% in the last few years. This means that four in ten people are not feeling as involved as they would like to be…

(Healthcare Commission 2009)

Results from the General Practice Patient Survey conducted between January and April 2009 (Department of Health and Ipsos Mori 2009b,) were as follows:

Most say that their doctor is good at the following: gives enough time (90%), asks about symptoms (88%), listens to them (89%), explains tests and treatments (79%), involves them in decisions about their care (73%), treats them with care and concern (85%), and takes their problems seriously (84%).

Variation in patient responses

Using data from the regulator's survey 2008, Picker Institute Europe produced an analysis of variation in the way patients reported their experience of involvement in decisions about care and treatment in primary care ((Picker Institute Europe 2009)). It found that:

Patients who described their ethnic group as white are more likely than patients from other ethnic groups to say that they:

- *were 'yes, definitely' involved as much as they wanted to be in decisions about their care and treatment*

- *were 'yes, definitely' involved as much as they wanted to be in decisions made in primary care about the best medicine for them.*

Table 7 Primary care: patient involvement in decisions

Primary care survey 2008	Were you involved as much as you wanted to be in descisions about your care and treatment?			Were you involved as much as you wanted to be in descisions about the best medicine for you?		
	Yes definitely	Yes, to some extent	No	Yes definitely	Yes, to some extent	No
Self-defined ethnic group	%	%	%	%	%	%
White	72	24	4	61	29	10
Asian or Asian British	54	36	10	54	36	10
Black or Black British	57	33	10	46	31	23

Source: Picker Institute Europe 2009

The analysis also showed that 'older people were more likely than younger people to say that they were 'yes, definitely' involved in decisions about their care and treatment, and in decisions about the best medicine for them'.

Table 8: Primary care: patient involvement in decisions by age and gender, 2008

Primary care survey 2008	Men				Women			
	16–35	36–50	51–65	>65	16–35	36–50	51–65	>65
"'Yes definitely' involved as much as wanted to be"	%	%	%	%	%	%	%	%
"… in decisions about your care and treatment	58	66	73	78	61	69	74	77
"… in decisions about the best medicine for you"	50	53	59	66	56	58	63	64

Source: Picker Institute Europe 2009

There is extensive data from the GPPS that makes available responses to every question, from every practice and health centre, weighted to take account of age, gender, etc(GP Patient Survey 2010)We were unable to locate a secondary analysis of the variation within this data. The full patient data would need to be made available to carry out such an analysis, and in any case the exercise is beyond the scope of this report.

Measurement issues for consideration by the Inquiry

The Inquiry into the Quality of General Practice in England commissioned by The King's Fund wishes to identify the key elements of quality in primary care and the best indicators with which to measure those elements.

With regard to patient engagement in consultations, we have so far shown that there is a widespread consensus among regulatory and professional bodies, shared by patients and GPs, about which are the most important domains. We have further shown that within these domains it is not difficult to identify sets of indicators, and that there is a very good availability of specific questions that can produce these indicators, for use in patient feedback instruments.

So, the task of recommending what and how to measure should be easier in this particular field of primary care quality than in some others.

However, while identifying indicators (and their availability) is not problematic, the choice of indicators within the current regimes of the English NHS is potentially very problematic, and will depend above all on what would be the specific use or purpose to which they would be put. The factors that complicate these choices are set out below.

The extent to which the nature of current or future data collection affects the choice criteria

Since late 2009 there has been only one source of data routinely collected on patient engagement in primary care in England: the GPPS. If immediate availability (and therefore reduced additional cost) is a critical factor, then the consultation questions in the GPPS would be chosen.

However, this set of questions does not incorporate all the key domains of engagement identified in preceding sections. It does not include any specific examples of an action or decision that would test doctors' ability to engage their patients, such as the prescription of a new medicine.

Whether the indicators are to be used in measuring the performance of individual GPs or of their general practice organisations

Most instruments have been developed either for one purpose or the other. For example, the GPPS and the regulator's survey were designed to report at the level of the general practice. This tends to mean that they include organisational questions (relating, for example, to access, appointments procedures, the provision of choices, and so on). Inevitably that limits the range and detail of indicators relating to the consultation itself.

In contrast, where measures are required for use in the assessment of education and training, or for appraisal, it is possible to include greater focus on specific skills and competencies within the engagement domains. Indeed, that content will increasingly be mandated by the requirement to link questions to the specific skills, learning outcomes and attributes required by the GMC.

Whether there is any preference for a particular type of measurement reflected in the framing of questions and response options

Some questionnaire instruments use patient satisfaction questions to produce their indicators. Such questions generally ask patients to rate the GP, on a scale from poor to good, in relation to the various competencies being measured. For example, the GPPS asks patients to rate on a five-point scale how good the doctor was at listening, answering questions and involving the patient in decisions.

The patient satisfaction questionnaire, produced by the RCGP for GP qualification, asks patients to rate the doctor at (for example): 'really listening', 'explaining things clearly' and 'making a plan of action with you', against a seven-point scale ranging from 'poor to fair' to 'outstanding'.

Satisfaction-style questions have been criticised for being subjective and unreliable, and for providing insufficient information to enable the person or organisation receiving the feedback to understand what the rating means and how they could take action to improve it.

Patient experience measures were initially developed in the United States, in an attempt to improve on ratings questions, by asking patients to report factually on whether something actually happened. This is the format used by Picker Institute Europe, and by the Care Quality Commission in national patient surveys. Thus, the primary care survey 2008 asked questions such as 'Did the doctor listen carefully?', 'Did you get answers in language you could understand?', 'Were you as involved in decisions as you wanted to be?', and the response options ask patients for a decisive answer such as 'Yes, definitely', 'Yes, sometimes', or 'No.'

Given Picker Institute Europe's long history of developing and adhering to the patient experience method, as opposed to satisfaction ratings, and our advocacy for the method's greater reliability, our researchers cannot do other than recommend questions in that format.

Conclusions

Our review of studies of patient and GP perceptions of the factors that enable patient engagement found that patients and GPs consistently identified very similar themes to each other. From these themes, we identified the following domains of engagement in primary care consultations, acceptable to patients and GPs alike:

- agreement and understanding of patient and GP responsibilities
- assessing and expressing needs and wants regarding engagement
- confidence in engagement
- consultation length
- understanding of the impact of contextual factors (such as time and resources) on the consultation
- training and support for engagement
- informational support

- respect
- continuity of care.

We searched the tools and measures that were available to assess and monitor patient engagement in general practice consultations. We found many instruments, and classified the common domains of measurement as:

- listening
- involvement in decisions
- information, explanation, questions being answered
- consultation length
- empathy.

On the basis of these two reviews, we are able to suggest, in Tables 2 to 6:

- a set of indicators for measuring the quality of patient experience within these domains
- a list of potential questions capable of monitoring these indicators
- existing sources from which to draw those questions.

There has not been consistently useful measurement of the quality of patient engagement in primary care in England. National surveys for successive regulators from 2002 to 2008 did not provide results at individual practice level, and were therefore not useful for quality improvement. The subsequent GPPS does provide practice-level results, but with questions that could be considered to be limited in value.

Results from the most recent national surveys show that patients report high levels of patient confidence and trust in GPs, and good (probably improving) experience of doctors' communication skills. However, significant numbers of patients are reporting that they had not been as involved in decisions as they wanted to be.

Although there is a good availability of measures and indicators for patients' experience of engagement in the consultation, there are also various issues for consideration by the inquiry in relation to choosing which measures to recommend.

These issues include:

- the nature of current and future data collection
- the purpose of measurement and the level at which it is required (individual practitioner, primary care practice; specific practice or comparison across practices)
- preference for research methods (for example, to report on 'satisfaction' versus 'experience').

2 Patient involvement in development of services

This chapter focuses on the involvement of patients in monitoring and developing services offered within general practice (as opposed to engaging patients in decisions about their own care). As we shall see, some patient participation groups provide additional or enhanced services for their practices, which may be helpful to some individual patients. However, in general we would expect the impact of involvement to be valued in terms of improved quality of the service overall.

We have not found it helpful to define (and therefore limit) exactly what we mean by general practice services when discussing the involvement of patients in their development. We have focused on the traditional family doctor or health centre services, and have not considered the role of non-executive directors on PCT boards.

While it is difficult – not to say dangerous – to make generalisations about what a good general practice service would look like, we can suggest some key factors.

Patients want:

- their health care professionals to have excellent interpersonal skills, as well as demonstrable up-to-date clinical knowledge and the willingness to provide timely and meaningful information
- easy access to their clinicians
- clean, accessible premises
- continuity of care and smooth handovers between health care professionals
- opportunities to take part in their own health care
- a sense that the best possible care will be available when they need it
- to understand that this care will be equitably distributed, and that public money is being used efficiently.

Background

National drivers of patient involvement in the development

From the perspective of national policy-makers, general practice is a subset of the pan-NHS ambition to put 'patient and public engagement' at the centre of services. Most recently, world class commissioning, the NHS Next Stage Review, the resulting NHS Constitution, and the Primary and Community Services Strategy all signal the importance of such involvement (Department of Health 2008d).

The final report of the NHS Next Stage Review committed the 'local NHS' to involve patients, carers, the public and other key partners and to work with them openly and collaboratively (Department of Health 2008c).

There is also a recently revised legal duty (under Section 242 of the consolidated National Health Service Act 2006) on NHS trusts, PCTs and strategic health authorities (SHAs) to make arrangements to involve patients

and the public in an ongoing manner in service planning and operation, and in the development of proposals for changes.

The specific local level of the GP practice or health centre is rarely referred to in these broad policy documents, and is not referred to in the 2006 Act or associated guidance except in relation to practice-based commissioning clusters (Department of Health 2008f).

The following government initiatives have been developed to facilitate patients' involvement within the development of health and social services.

Local involvement networks

Local involvement networks (LINks) aim to identify what people like and dislike about their local services, and to work with service providers and commissioners to help make them better (Department of Health 2008b). At the time of writing LINks are still developing, and the government's stated aim is that they should grow organically at a local level. LINks have a much wider brief than primary care, since they cover the local economy of both health and social care.

World class commissioning

World class commissioning (WCC) is a statement of intent designed to raise ambitions for a new form of commissioning that is hoped to encourage patient engagement and greater involvement within the commissioning process (Department of Health 2007b).

World class commissioning competency 3 requires primary care trusts (PCTs) in England to 'proactively seek and build continuous and meaningful engagement with the public and patients, to shape services and improve health' (Department of Health 2007a,).

The vision and guidance for this competency were being revised at the time of writing. In the world class commissioning assurance framework, published in June 2008 (Department of Health 2008a), the indicators for reaching level 2 (out of 4) for this competency were that:

- the PCT has a strategy in place that actively and continuously engages patients and the public in PCT business
- the PCT actively listens to, understands and responds to the public and patients
- the PCT can demonstrate how local involvement, including regular two-way dialogue with local involvement networks (LINks) or equivalent patient forums, has influenced some aspects of commissioning
- the PCT proactively disseminates information to the public and patients
- the local population somewhat agrees that the local NHS listens to the views of local people and acts in their interest.

Quality and Outcomes Framework

The Quality and Outcomes Framework (QOF) is a system for the performance management and payment of GPs in the NHS in England, Wales, and

Scotland. It was introduced as part of the new GMS contract in April 2004, replacing various other fee arrangements.

The QOF was intended to improve the quality of general practice by rewarding GPs for implementing 'good practice' in their surgeries. Participation in the QOF is voluntary for each partnership. However, for the majority of GPs under the preset contract, the QOF is almost the only area where they are able to make a difference to their income.

In the original 2004 contract, each general practice could accumulate up to 1,050 'QOF points', with a payment for each point gained for each of 146 indicators. The criteria were grouped into four domains: clinical, organisational, patient experience and additional services. These four domains have been retained, while the indicators are revised and developed each year.

The patient experience domain focuses on the measurement of patient experience, including length of appointment and ease of access. These payments are now linked to scores in the GPPS.

As yet, there are no additional QOF points for engaging patients in the day-to-day management of the practices. Some PCTs are running additional incentive schemes – for example, NHS Hammersmith and Fulham's 'QOF plus' initiative includes 11 extra indicators under the patient experience domain. However, even here the inclusion of patients and the public at an organisational level is still not rewarded.

There are local incentives available for practices to set up a patients participation group (PPG). About 40 per cent of practices have a PPG. At the time of writing, the Royal College of General Practitioners, the British Medical Association, the NHS Alliance and the National Association for Patient Participation are running a group initiative focusing on 'growing patient participation'.

Practice-based commissioning

Practice-based commissioning (PBC) is a Department of Health initiative designed to target financial drivers towards primary care and increase clinical involvement in commissioning. All practices receive information on how their patients use health services that can be used for the redesign of services by frontline staff.

PBC is a voluntary undertaking by practices, and governance frameworks are set at a local level. The PCT remains the responsible authority. Department of Health guidance mentions 'stakeholders' rather than patients specifically:

> *PCTs and practices must work with other stakeholders in PBC redesign of services. PBC involves frontline clinicians to commission services that better meet the needs of patients. When designing a new service, PCTs should ensure that relevant partners have been consulted appropriately.*
>
> (Department of Health 2010)

Recent evidence regarding PPI in primary care

In 2007, and again in 2009, Picker Institute Europe surveyed PCTs to gather information about their approaches to PPI within commissioning. In 2009, we reported that:

> *In most PCTs, World Class Commissioning has helped to drive change in organisational culture and boost the status of patient and public engagement – of itself, and–or by complementing pre-existing local drivers.*
>
> *The cultural shift means that PCTs are working towards earlier, more systematic and more strategic engagement; corporate responsibility for engagement as 'everyone's job'; joined-up working with other organisations; and stronger links between engagement and external communications.*
>
> *Executive and managerial responsibility has shifted upward, and engagement has come to be seen as a PCT-wide 'must do'.*
>
> (Picker Institute Europe 2009b)

However, the 2009 survey report also noted that 'PCTs are not yet in a position to demonstrate whether and how patient and public engagement influences commissioners' decisions' (Picker Institute Europe 2009b).

There was a concern expressed that much of the commissioning process looked at user involvement in terms of 'data needs' for commissioning, and still gave more weight to surveys and one-off consultations than to ongoing dialogue. Many of the existing involvement methods seemed to be much more targeted at gathering feedback from users than at creating opportunities to directly shape health services.

Looking for evidence closer to the GP practice, we analysed the data supplied by GP practices in the national GP practice based commissioning survey (Department of Health 2009). Figure 1 shows showing the changes in responses from practices involved in practice-based commissioning waves, from data published by Neil Parkinson.

Since the onset of PBC in 2006, the number of practices that have declared themselves as not engaging with their local population has reduced from 39 per cent to 18 per cent. The association may be coincidental, but it is likely that the advent of PBC has led more practices to engage with their patients. The chart also shows that practices were increasingly involving patient representatives, patient groups and events, and relying less and less on ad hoc methods.

Picker Institute Europe's 2009 survey of PCTs (Picker Institute Europe 2009b) showed that PCTs themselves have been using a widening range of techniques to engage with their populations. Although public meetings, formal consultations and surveys were still heavily relied upon, 40 per cent of PCTs said they were using other methods, giving examples ranging from deliberative events to involving the public in the governance of commissioning.

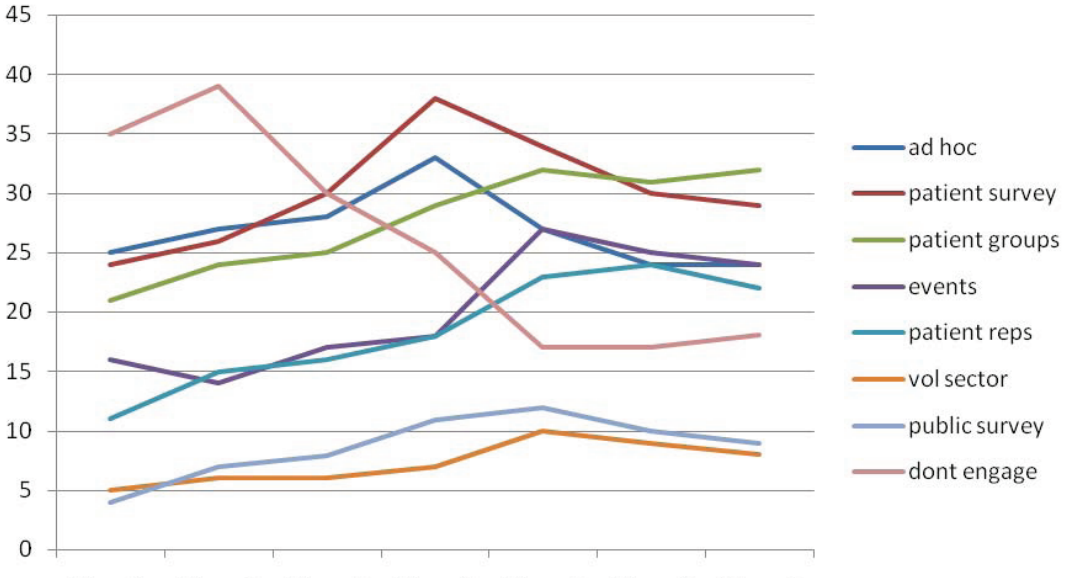
Rapid review of involvement initiatives

Aim and method

We aimed to identify England-based initiatives that focused on involving patients in the development of general practice services.

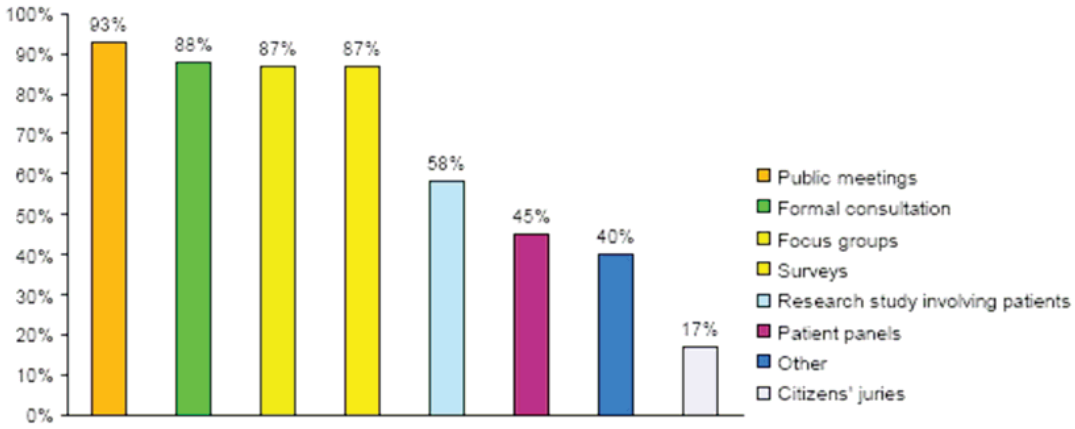
We made contact with a range of interested parties, using a mixture of existing contacts, internet searches (using terms such as 'patient

Figure 1: How, if at all, do you engage with your local population for practice-based commissioning purposes?



Source: Department of Health (2009)

Figure 2: Patient and public engagement methods used in the last 12 months



Source: (Walsh *et al* 2009)

public participation and engagement') and following up leads. We used a snowballing approach with a view to identifying initiatives of note that focused on increasing patients' involvement in the development of general practice services.

Following our internet searches and our existing experiences within the field of patient and public participation, we initially contacted the following organisations:

- Coventry PCT
- Gloucestershire PCT
- Health Services Management Centre
- Liverpool PCT

- Milton Keynes PCT
- National Association for Patient Participation
- National Association of Link Members
- NHS South West
- Norfolk PCT
- Shropshire PCT
- Somerset PCT
- South Staffordshire PCT
- Trafford PCT.

In the monthly e-bulletin of Picker Institute Europe, which has about 4,000 subscribers (individuals and organisations) interested in patient-focused care, we published a request for examples of notable practice in engaging patients in the development of general practices.

Unfortunately the period of fieldwork coincided with the peak holiday season, and we had to take a pragmatic approach when selecting interviewees for the next stage. Extended interviews were undertaken with representatives from:

- the National Association of LINk Members
- the National Association of Patient Participation
- NHS Norfolk
- Nottinghamshire PCT
- Principia PBC
- Shropshire PCT
- staff from two practices in different regions.

Findings from each of these sources are described in the section that follows.

Findings

In this section we use data from our interviewees to describe the issues around implementing the various patient-involvement methods in the development of general practice services. Quotations are anonymised except where extracted from published sources.

LINks

It was hoped that LINks would be major players in involving patients and the public in monitoring and developing general practice services. However, the overall impression is that – with a few notable exceptions – many are struggling to have any sort of relationship with GP practices at all.

Historically, the preceding organisations had little powers over GP surgeries but had:

> *… an active but adversarial engagement with family doctors.*
>
> LINk member

However, the changes in the organisations tasked with monitoring health care have left a sense of dislocation for many people. The majority of LINks are struggling to do their best, with an extraordinarily broad agenda and limited resources. For many, building a relationship with general practices within their sometimes large geographical areas is not at the top of the agenda.

There is some discussion about whether health overview and scrutiny committees have a role to play, but it is probably true to say that involving patients in their deliberations is outside of their brief.

Several of the interviewees we spoke with felt that their LINks were not a factor in their areas:

> *In deference to LINks, we are much closer to the problem.*
>
> Lay member, PBC board

> *We are doing what the LINks were set up to do.*
>
> Patient representative, PBC

Patient participation groups

The majority of patient involvement activity in general practice takes the form of developing patient participation groups (PPGs). Some primary care trusts – for example, Liverpool, Shropshire and Norfolk – are encouraging every practice to consider developing a PPG, and are supporting them with materials and even small budgets to achieve this aim.

Most PPGs operate within GP surgeries and health centres. Unlike LINks, there is no legal requirement for them to exist, so they come into existence almost as an act of goodwill on the part of the practice, drawing on the enthusiasm of patients. For this reason, they are very varied organisations with different priorities that reflect local needs as well as the interests and energies of the people involved. However, as the NHS becomes more overtly patient centred their importance has increased, and they are seen by some as the basic building block of patient and public involvement within primary care.

According to the National Association for Patient Participation (NAPP), around 40 per cent of practices now have some form of group or association of patients. Some have been formed as a result of local public activity, focusing around the practice. Some arose from an interest in consumerism by individual GPs. Yet others, in London and Wales, have their roots in the political beliefs of left-leaning clinicians.

PPGs first emerged in the early 1970s, and by 1979 the National Association for Patient Participation in General Practice (NAPPGP) was formed. Initially, it had 19 affiliated members, but the membership has grown quickly. By 1988, the number reached 80, by 2006 there were 270, and at the time of writing there were more than 400 affiliated organisations.

There is currently a concerted campaign by NAPP, the RCGP and the NHS Alliance, supported by the Department of Health, called Growing Patient Participation, aiming to increase the number of PPGs. The ambitious target is to have a PPG in every practice in the country within one year.

NAPP has researched the reasons why some practices are hesitant to have PPGs. Dr Graham Box, chief executive of NAPP explained:

> *From our research it's pretty clear that practices are worried about the time that would be involved in setting up a group. They're worried about the kinds of patients who might come forward who might make it awkward to run the group. And equally they're legitimately concerned about representing the wider population.*
>
> (Box 2009)

He added that much of the material now available is designed to meet these needs:

> *We're going to be rolling out resources we think will meet the needs we've heard about from the people we've spoken to. The starting point is a step by step guide, so that the setting up of a group is made as easy as possible for practices.*
>
> (Box 2009)

Some PCTs have been supporting the initiation and growth of PPGs with materials, staff time and seed-corn funding. Indeed, the step-by-step guide referred to above credits a Norfolk PCT guide on which it is based.

The Growing Patient Participation initiative includes a national 'Make a difference' fund, to which local organisations can make bids for small grants of under £4000 to develop their work. In some cases the practice cross-funds the PPG, or supports it with administration or by providing space. In many cases, the funding goes the other way: many groups see fundraising for the practice as one of their key roles.

The PPG at one practice in Lincolnshire raises such a volume of money that not only is it providing equipment for the surgery (including clinical apparatus) but has managed to support a half-time post within the practice. This post provides direct support and information for patients, and is seen as an integral part of the practice's work. Patients receive advice about things such as benefits, blue badge schemes and other services available, as well as health advice. It is popular among the patients as well as the clinical staff, who know that they can refer patients to the 'library', where they will receive more time and support than is available in an appointment slot.

The value of a PPG for the practice seems clear from a strategic standpoint. Dr Graham Box explains:

> *They're the way the practice connects to the community. They're the way the practice makes sure that what it's offering is what patients want.*
>
> (Box 2009)

Professor Steve Field, GP and Chairman of the Royal College of GPs, added:

> *This is so important for taking the health service forward at a local and national level. GPs need to be emotionally engaged in this to understand the benefits for them and for the practice, as well as for the patients that they serve.*
>
> (Field 2009)

However, there are some limitations to – and criticisms of – PPGs. One interviewee referred to the relationship between PPGs and their practices as:

… lacking a certain vigour.

NALM member

Some commented that some individuals joined the PPG because it conferred a social status. Others made reference to the fact that the typical PPG was populated almost exclusively by white middle-class retired people, and that the overwhelming impression was of a 'cosy' relationship with the practice.

NAPP prefers PPGs not to be 'doctors' fanclubs'. However, the fact remains that the majority of groups are not in any kind of challenging relationship with their practices.

Other interviewees stressed the need for the PPG and its representatives to be accepted by the practice hierarchy. They talked about needing to be 'on the inside' to influence things. However the 'cosy' relationship can be a limitation for some activists: as one commented, 'If we are not pokey we are nothing'. There seems some acknowledgement of this from the health professional's side:

They [PPGS] are huge supporters. They are almost never adversely critical and almost invariably allies.

Dr Laurence Buckman, GP and Chairman of the BMA's General Practitioner's Committee, podcast

PPGs are not pressure groups, and nor would they ever claim to be. The vast majority exist at the behest of, or certainly with the permission of the practice. Their role is not necessarily to influence the day-to-day running of the practice or to set agendas, but to provide the practice with a ready feedback. They, and the practices, see their role as to augment the health care function rather than to manage their practices:

We provide some of the things that the practice can't pay for.

PPG co-ordinator

We've got two patients that run the herb garden, the organic garden. We've got patients running the integrated library; some meeting and greeting, some organising evening lectures; one ex-school teacher organising an art display in the waiting room from the local primary schools on health and art. So, just about every aspect of health being covered.

Dr Mike Dixon, GP and Chairman of the NHS Alliance, podcast

There is much less evidence of PPGs being used to influence the management and service delivery of practices as a whole, despite the aspirations of some:

I'm against patient groups just fundraising – it's not what they are there for, any more than they are there to be complaints mechanisms. They are there to be critical friends.

PBC lay member

This function [aiding feedback and responsiveness of the practice as whole] is no more complex than running health promotion events or improving communication, but it seems to happen less frequently.

Dr Has Joshi, Vice Chair, Royal College of General Practitioners (RCGP) and Dr Brian Fisher, MBE, former GP and Patient and Public Involvement Lead for the NHS Alliance

We interviewed one practice that had been recommended to us as having a particularly active PPG. The practice happened to be recruiting a new GP partner. There was no intention to include the PPG or its members in any of the recruitment process. Practices are independent entities, and there is no compulsion on them to include patients, service users or other stakeholders in any decision-making – but this seemed an opportunity missed.

Other models

Some practices are investigating the idea of having a citizens' panel model, with a virtual panel of volunteers who are surveyed regularly (by post or email) in order for the practice to gauge reaction to proposals.

Some larger primary care organisations have been organising reference groups of existing stakeholders and patients, usually around issues such as re-building or re-provisioning.

We found several examples of recognisable public meetings or exhibitions run by practices or primary care organisations – usually around single issues, such as developing a new health centre.

There is some interesting involvement work, probably beyond the reach of most practices, that involves taking a community development approach to improving health care services.

Practice-based commissioning clusters – some notable practice

One of the challenges of this review has been the huge diversity of different models of PBC consortia and, inevitably, the very different ways in which each has tried (to some extent) to involve its local population:

When they brought in the idea of PBC, there was a lot of hope that this would give a lot of people the opportunity to get involved in decision-making.

NALM member

This interviewee went on to express their disappointment that this had not materialised. However in our (admittedly limited) review we found a number of engaging initiatives that probably represent some of the most interesting work in the field, some examples of which are cited in the section that follows.

Three examples of notable practice

In this section we consider some examples of notable practice in involving patients in the development of their general practice services. These were not selected because they were 'typical' but because they demonstrate, in some depth, a variety of approaches to patient involvement.

The first example looks at two health centres with patient forums. One forum has gone down a route of formality, with designated officers and control of the agendas and conduct of meetings, while the other has opted for a looser, less formal approach, as a 'friend' of the centre.

The second example looks at a practice-based commissioning structure that is strongly guided by the PCT and is trying to federate existing and new practice representatives into a new and dynamic network.

The final example looks at a different kind of consortium, driven more by the practices themselves, in which patient representatives are integral and essential to the decision-making process, and that is looking to broaden its constituency with an area-wide health forum.

Aims and method

The aims were:

- to develop three case studies of examples of notable practice of patient involvement in the development of general practice services
- to identify lessons for commissioners and service providers wanting to increase patient involvement in the development of their local general practice services.

From the original review of existing patient involvement initiatives within general practice, we approached a number of organisations that had been identified for more intensive follow-up.

These case studies were chosen not because they were typical (in fact, one of them is probably unique), but because their approach differed from the norms of patient and public involvement and offered some learning for other practices or primary care organisations.

The researcher followed up a series of case studies by observing the work in action and interviewing key stakeholders in the initiative, including patients, health professionals, and those involved in organising the initiative. The aim of the case studies was to develop a clear description of the initiative, including the facilitators, and to identify the challenges to running it and to truly involving patients. The three most innovative and useful studies appear below.

Notable practice 1: Successful but different patient participation groups

Whaddon House Surgery's patient forum and Exmoor Medical Centre's patient participation group

The Whaddon House Surgery in Bletchley, Milton Keynes will be moving to brand-new, purpose-built premises during 2010. The Exmoor Medical Centre in Dulverton, Somerset, moved to its new premises on the outskirts of the town in 2008.

Both practices have very active and successful patient participation groups (PPGs). These were brought into existence some years ago, so they have not been part of the current wave of 'growing patient participation'), and both arose from initiatives by the practices themselves. They are both successful in achieving similar aims, but they differ fundamentally in their structures and outlooks. It is worth considering their similarities and their differences.

Whaddon House Surgery's patient forum

Whaddon House Surgery's patient forum was inaugurated in 2006. Discussions had started the year before, when the appointment of a new office manager coincided with the visit of a lay assessor as part of the QOF inspection:

> *Basically, she hauled us over the coals – wonderfully so. It was quite an eye opener when she asked things like 'How do you talk with your patients?'*
>
> Practice manager

Having agreed that some form of patient group was the way forward, the office manager and business manager advertised in the waiting room. At the same time, the GPs were tasked with identifying and inviting possible participants. The practice approached the inaugural meeting with some apprehension:

> *We just collected a load of names, and literally called a meeting.*
>
> Practice manager

Seven patients attended:

> *We all came out on a high thinking 'How fantastic!'*
>
> Practice manager

At the time, the practice was not aware of any guidance on setting up a PPG, which has become more accessible since, so the growth of the group was more organic:

> *We didn't really know what we wanted or what they wanted from us – at that time there were no guides.*
>
> Practice manager

One thread running through their deliberations has been the development of the new premises, which gave them a rewarding issue for discussion. It also had the advantage of sourcing a key individual (the forum eschews formal roles such as secretary, chair and treasurer) who came from a building development background and was able to add to the practice's deliberations around the new premises.

Another key issue in the early days was the consideration of the GPAQ (patient feedback) data:

> *Our members are very challenging… I knew straight away, when somebody asked to see last year's results and [those of] the year before.*
>
> Practice manager

The forum member to whom we spoke does not see his role or the role of the group to be that of holding the practice to account, but sees the relationship to be a partnership:

> *I don't see that our role is to hold the practice to account – I see us as being there to work with the practice to improve the services. That is our aim in life. I guess any service can always be improved.*
>
> PPG member

The thing I am proudest of with the patients' forum is that we have reduced the number of DNAs [did not attends – in other words, missed appointments].

PPG member

This individual gives a large amount of his time to the forum and to related patient representation activities. He has expanded his role to participate in the LINk, and to become a patient representative on the steering group of Health MK, which is the local practice-based commissioning (PBC) cluster. He spends considerable amounts of his time with the local primary care trust (PCT) trying to encourage the development of PPGs in the other practices within the area.

In this respect, he reflects the work being done by the chairman of the Exmoor Medical Centre's patient participation group (*see below*). He, too, spends many evenings trying to persuade practices across Somerset (which has a low proportion of practices with PPGs – perhaps a dozen groups among about 75 practices) of the efficacy and advantages of patient participation groups.

The Dulverton Patient Group

The Exmoor Medical Centre in Dulverton has a patient group with a more formal structure and perhaps a less intimate relationship with its practice than the one described above.

The practice began the process of developing a patient participation group some years ago, and held its inaugural meeting in 2003. It was driven by the senior partner, prompted at least partly by some low scores in patient surveys. The group was initiated largely through GPs and practice staff identifying individuals in their patient population. Most people to whom we spoke approved of this process of 'cherry picking' initial leaders, though opinion was divided as to whether the group should grow naturally or whether further cherry picking of new members with specific skills is appropriate. In some more mature groups, individuals who had initially come forward with complaints had been persuaded to join the PPG.

The chairman of the Dulverton patient group is keen on groups having a formal structure, although he now suggests that the group spent too long in its early days considering issues such as mission statements rather than taking action. Every PPG that we came across was different in structure and approach. If there was a consistent message about the organisation of patient groups, it was this:

This is what works for us. It won't work for everybody – no one size fits all.

PPG member

The Dulverton PPG certainly has a more formal structure than the forum in Milton Keynes:

You have got to have your own chair, you have got to have your own secretary, you have got to have control of the agenda, you have got to write your own minutes. Relying on the surgery to do any of these things is a disaster – you lose control instantly.

PPG chair

There may be some very pragmatic reasons for doing it this way:

> *Practice managers don't want to do it – they don't have the time. They are delighted if it is done elsewhere.*
>
> PPG chair

However, it is probably more about ownership:

> *If the agenda is set by the practice and we are merely invited to say what ideas we would want on that, that's not running a patient group – that's the practice doing what it wants and allowing you in on the end, almost under 'any other business'.*
>
> PPG chair

The Exmoor model involves a more distanced relationship between the practice and group than that of Whaddon House:

> *They see themselves as a sort of OFSTED.*
>
> Practice manager
>
> *Sometimes they are frustrated that they can't be consulted all of the time.*
>
> Practice manager

The group is seen as belonging very much to the patient members, who invite the practice staff and clinicians into their meetings:

> *It is clearly their meeting, and we are invited – I will be there, and a partner, usually the senior partner – but it is theirs.*
>
> Practice manager

The role of the group is to advocate on behalf of patients (as individuals, as well as collectively). This is partly in recognition of the fact that some patients – especially in an extremely rural area where there is no choice of practice – are unwilling to be critical of their clinicians.

At times, the GPs have let it be known that they felt that the PPG was too confrontational in its dealings with them. However, the practice manager is extremely positive about the role and activity of the patient group.

In contrasting style, the forum in Milton Keynes is more relaxed, and has a looser structure. It feels almost like an open meeting:

> *We have discussed it at some length, and we have decided not to go down the chair, treasurer, secretary, fundraiser route. We are a group, and we are achieving what we want to achieve and will carry on like this.*
>
> PPG member

In Milton Keynes, the practice takes responsibility for producing notes. Meetings appear less formal, and the agenda take the form of a list of items for discussion that anybody can contribute to. The two-way flow of information – which seems to be fundamental to a successful patient group – is less rigid, but seems to work for both parties:

> *The forum meets about once a month and there is always lively debate. We don't always get what we want without a struggle to convince the partners that it is what the patients want; but this is quite right as what patients want may not always be practical.*
>
> PPG member (Whaddon House Surgery (2010))

Both groups acknowledge that excellent communications between the group and the practice are essential:

The main function is that the patient group is a communications hub… their real task is to establish good relations with the practice.

… You have to be on the inside track.

PPG chair

These are not unreasonable people… we have to have trust in them, we have to listen to them

Practice manager

There is some sense in which if the communication is good, a great deal of time can be saved, since messages can be distributed and queries answered by patient representatives without reference to the practice. This allows much of the work of the PPG to be done in between meetings. The Dulverton Group is extremely diligent in ensuring that it has representatives from each community, and this efficient two-way communication tool is something that the group and the practice are extremely enthusiastic about:

We just have to update the reps, and it is out there.

Practice manager

Several PPGs to whom we spoke have reflected the National Association for Patient Participation (NAPP) view that one of the key roles of PPGs has been to encourage within patients a sense of understanding of the restrictions within which their practice is operating:

As far as I am concerned, we have broken down all the 'them and us' barriers.

PPG member

I tried to show how we do it – how we organise ourselves.

Practice manager

If they can't do what we want, at least we know the reason, and 99 times out of 100 it is because of our friends in Westminster!

PPG member

Fostering this sense of common cause seems to be a key component of a successful relationship between a practice and its patient group:

A lot of this effort is not directed at the practice but at the PCT

PPG chair

A defining characteristic of successful patient groups seems to be an awareness of the wider health service context within which the practice operates.

Clearly, much activity is focused on the services provided by the practice, but both groups see an important role to be acting in concert with patients, and indeed, with the practice in the wider fields. For example, the Dulverton Group has supported patients to take up issues with the PCT. Meanwhile, many members attended planning committee appeal hearings when

Whaddon House Surgery was attempting to get permission for its new premises.

These two groups offer different models for way of relating to a constituency (their methods for communicating with the wider patient population). Whaddon House relies more on its group membership reflecting their patient population:

We are quite a representative group.

PPG member

However, its members concede that they would find it beneficial to recruit a younger member. (There is always a discussion to be had about whether it is appropriate for PPGs to reflect the majority of general practice users: older people). The group produces a newsletter, which is distributed in the practice, and makes use of a suggestion box within the waiting room. The members do not advertise their contact details, and practice staff direct patients or other interested parties the group from time to time.

The Exmoor Group has a more formalised network of contacts, with identified individuals in most if not all the communities covered by this wide-reaching practice. This provides the patient group with a powerful medium for picking up messages and for distributing them:

It [the patient group] is meant to receive information from the patient population; their views, concerns and aspirations as far as the practice is concerned; and from the practice, the news and changes and so forth back to the patients.

…The patient group should have as broad a base as possible by age, sex, ethnicity and in a rural area like ours particularly by geography

…A group is not representing its own views, it is not there to say what it thinks but what they, the people out there, think

PPG chair

The group communicates internally and externally, largely using email, and there are plans for the group to have a page on the practice's website.

The group has expressed some frustration that, because of the issue of patient confidentiality, it may never know who it is representing. The confidentiality issue can also prove troublesome when an individual's concerns are raised by any patient group members. However, most of the focus of the patient group's concerns is on systems.

Both groups believe firmly that they are not there to be 'talking shops' or 'a forum for moaners'. There is some debate among both groups about the extent to which individual complaints can be taken up (since one patient's bad experience may be indicative of a wider problem), and this is obviously a grey area:

The general view is the most important.

PPG chair

There is also some common ground about the second key role of PPGs – to help provide services with or alongside the practice. Both groups help out with organising events that might be described as 'health improvement initiatives'.

In Exmoor, there have been open meetings about issues of importance, such as the changes in pharmacy regulations, and various initiatives such as well-man and well-woman events. The PPG has also had a large part to play in organising the practice's flu vaccination campaigns each year.

In Milton Keynes, the new premises will allow the patient forum to increase the number and range of its services, including drop-in sessions for disease-specific groups. Obviously, services such as this add to the appeal of any practice, and highlight the practical advantages to practices of supporting PPGs. It is fair to record the view among some activists that some practices would like their patient groups to perform this function without playing a 'critical friend' role. However, most practices claim to welcome the feedback:

> *It is almost like mystery shopping for us it – is a secondary source of feedback.*
>
> Practice manager

> *They provide us with monitoring and a source of feedback as well.*
>
> Practice manager

> *It is what patient groups should be doing – helping GPs understand how they are viewed.*
>
> PPG chair

One area on which these groups agree is that raising funds for the practice should not be a key (if any) part of the group's activities:

> *I do not think that patient participation groups should be involved in fundraising. It is difficult to say 'no', but in principle I do not think patient groups should fundraise.*
>
> PPG chair

This probably sets these groups apart from many PPGs across the country that see their key role as fundraising (even in the current climate, when few people feel that GPs are poorly paid). Fundraising is seen as potentially diverting energies away from the patient group's more fundamental role as critical friend.

Furthermore, both groups are cynical about those groups that might be categorised as 'friends of the surgery' or even 'doctors' fanclubs':

> *We have strong views about 'friends of the surgery'.*
>
> PPG member

> *Like ladies who do the flowers in the church coming together to worship! Do they get involved in decisions-making changes in patient care?*
>
> Practice manager

> *They are not a critical patient group – what is their role?*
>
> PPG chair

Future developments of patient participation groups

As we have seen, a defining feature of many of the successful PPGs is an awareness of the wider health-service context. Several interviewees felt that

while their primary role was, and would remain, to focus on the individual practices, the key decisions for patient care are being taken at a PBC or PCT level:

> *A patient participation group should be part of practice-based commissioning.*
>
> PPG chair

However, there were some concerns that much of the discussion around commissioning is either too obscure or in fact of no interest to most patients:

> *A lot of practice-based commissioning means that patients can't have a valid point of view.*
>
> PPG chair

In addition to playing a role in PBC, many interviewees felt that in order to have more impact in the future they would need to be working more closely together, and maybe even grouping together. In some parts of the country, this co-ordination role is being played by LINks, but these examples are exceptions rather than the rule.

Groups vary enormously in their origins, structures, relative closeness to the practice, and conception of their role. This makes it difficult to make sweeping statements about how effective they are in getting the voice of patients in to the management and delivery of general practice services. An effective group needs to have excellent communication and a mutual respect with the practice.

A good litmus test with regard the extent of patients' influence is to consider whether patients would be involved in recruiting a new GP. We came across one practice where there was full integration with a patients' panel as part of the interview process, versus another where patients' group members had to look on the practice website to discover the name of the new GP.

The challenge may well be to develop patient groups in a way that allows the focus to remain on the local, while looking to form alliances or become the basis for new structures that facilitate meaningful patient involvement in decision-making at a higher level in changing times for the NHS.

Further information is available at: www.exmoormedicalcentre.co.uk and www.whaddonhousesurgery.co.uk

Notable practice 2: North Norfolk Patient Partnership

NHS Norfolk (Norfolk PCT) prides itself on its quality of patient and public involvement. It has a reputation for being one of the leading developers of PPGs, and its guide *How to Set up a PPG* was adapted by the Growing Patient Participation campaign as a model document.

The PCT continues to support and encourage the growth of PPGs within Norfolk. Of its 92 practices, about half now have recognisable PPGs. It has also put considerable efforts into helping these bodies exchange information and build networks. As a result, PPGs are the building blocks of a new way of working at a PBC level.

The development of practice-based consortia within the PCT area has thrown up challenges as to how best to include the voice of patients in the

management and design of general practice services. The area is covered by nine practice-based commissioning consortia, varying in size and structure.

The North Norfolk Health Consortium PBC cluster covers a swathe of the north and east of the county from Wells around to Brundle, taking in Fakenham, Cromer and North Walsham. It comprises 18 practices providing services for about 150,000 patients living in an area similar to (but not co-terminous with) the old North Norfolk district.

The North Norfolk Patient Partnership was formed to give patients at the practices in North Norfolk the chance to get involved with influencing and designing the future of their local health care.

The partnership brings together patient representatives from each general practice in North Norfolk. Some practices recruited their patients from their existing PPG, while those practices that do not have groups already are looking at forming permanent groups.

In September 2008 56 people, including patients and members of practice staff (practice managers and GPs), attended an initial event in September 2008. The agenda focused on PBC and the structures and management of any potential patient reference body. There was a mixture of presentations and discussion groups – a model that has continued.

The members have decided not to meet more than three times a year, although they want communication in between meetings. To this end, they have established a website and a regular newsletter. The group has asked to consider issues such as:

- the Pharmacy White Paper
- a GP-led health centre
- 24-hour ambulatory ECGs
- deep vein thrombosis (DVT) testing
- mental health services in North Norfolk.

The membership enjoys taking part, and the PBC has a readily available pool of people who are engaged in the issues and are willing to contribute. There is a slight concern that some of the participation and activity is driven by health professionals (including GPs), but this may change as the organisation matures.

Notable practice 3: Principia Partners in Health, Nottinghamshire

Rushcliffe, to the south of Nottingham, is becoming recognised as having one of the most patient-centred health care models in the country.

Principia Partners in Health is a practice-based commissioning cluster running as a not-for-profit social enterprise (and registered as a company limited by guarantee) that comprises 16 practices, providing primary health care for about 120,000 patients across the southern part of Nottinghamshire. It was formed in 2006 as Rushcliffe Mutual under the then Rushcliffe PCT, which had a good grounding in patient and public involvement.

Each patient of the constituent practices is automatically a 'beneficiary' of the company, and can seek to become a community (lay) member of the company. Of the 122 members, 61 are GPs, 40 are community clinician

(provider) members and 21 are lay members. Any member has a vote at the annual meeting.

For day-to-day running there is a board of directors, which has 12 members, of whom six are lay members (community directors), three are GPs (general practice directors) and three are community clinicians (provider directors). The chair and vice chair of the board are lay members. This means that there is constitutionally a built-in majority of lay members on the board.

Under this board are two governance groups: a clinical reference group and a patient reference group. Each of these is described below.

Clinical reference group and associated task-and-finish groups

The clinical reference group (CRG) is a multi professional forum to provide clinical leadership to the re-design of care pathways and models of care. The CRG deals with the 'technical' clinical aspects of Principia's operation. It is chaired by a GP and consists of:

- three general practice representatives
- a practice manager
- a board representative
- three provider (community clinician) representatives
- a lay member representative
- two members of Principia's management and admin support.

A lay member of the CRG told us:

> *It was a hard environment to begin with, but over time I have developed good working relationships with the member clinicians that have given me a better insight into some of the difficulties and constraints that they operate under. My presence on the group ensures that the interests of the Principia beneficiaries are taken into account when new initiatives are considered or existing processes are changed.*

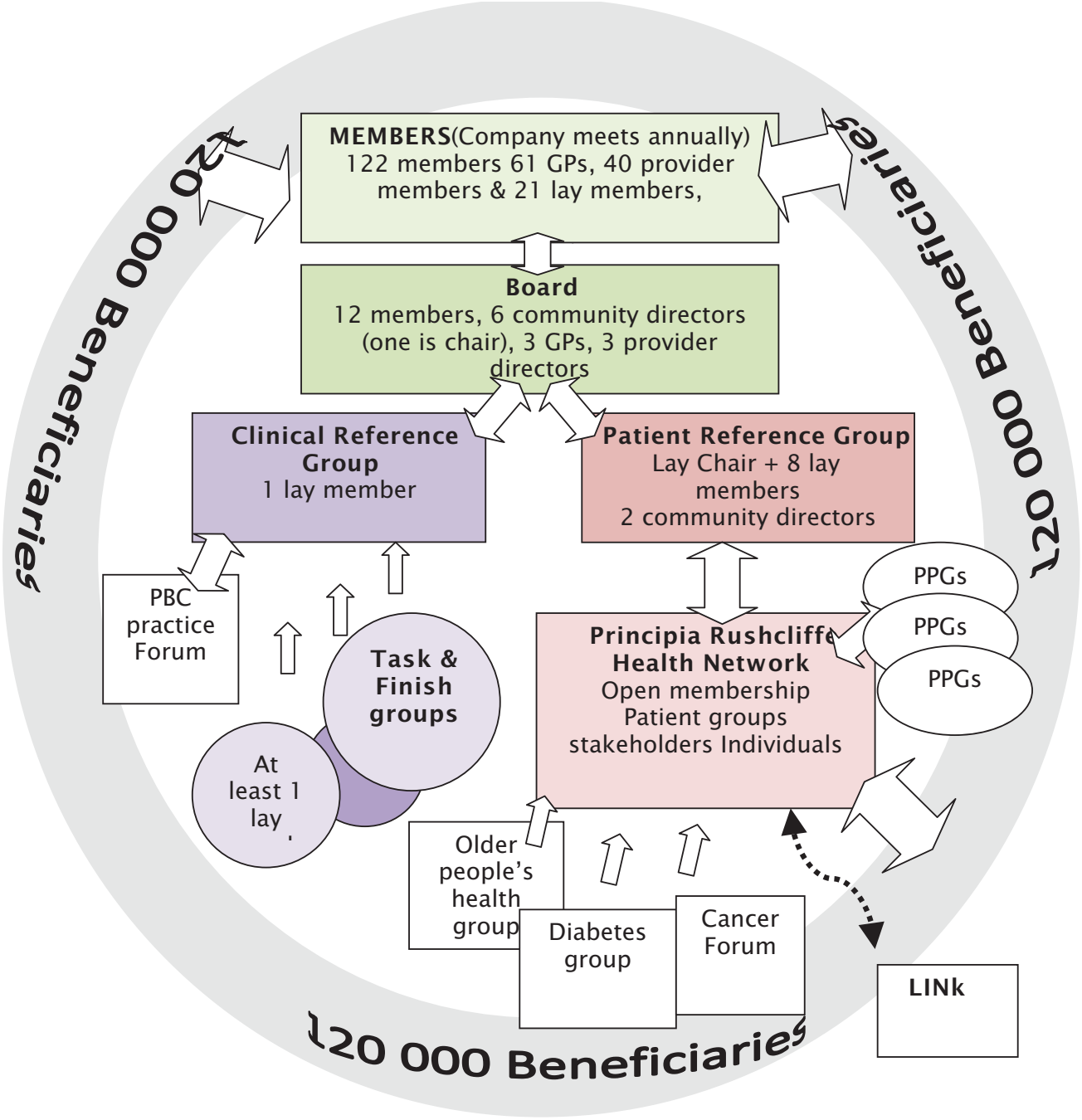
As the workload of the CRG became clear, including reviewing, designing and redesigning services, the group used a model of task-and-finish groups. Again, all of these influential bodies have had a patient membership at their centre. The core of all task-and-finish groups is composed of a GP, a provider, and a beneficiary. The core decides on all the processes, procedures and membership issues that they need to carry out their allotted task:

> *Within this group I ensured that the patient route through the new pathway was simple, clear and purposeful, and that the clinicians' needs and obligations and the patients' expectations were in alignment.*
>
> Lay member of the clinical reference group

As with the board, the role of patient representation is not to provide any kind of a veto for the deliberations of clinicians and professionals:

> *In all cases the lay member is not there to challenge the clinical judgement of the professionals but to ensure that the patient is always at the centre of all activities and systems.*
>
> Lay member of the clinical reference group

Figure 3: Principia's organisation



Source: Our design, based on slides provided by Principia

Patient reference group and associated Principia Rushcliffe Health Network

The patient reference group (PRG) is the focus for all public and patient activity within Principia, co-ordinating the detailed involvement of community members in all aspects of Principia's operations and their presence on the various groups and committees that contribute to these operations.

It also has a major role in ensuring that the views of the Principia community are included in the activities of NHS Nottinghamshire (the county's primary care trust). The PRG has cross-membership with the Principia board and

the CRG, to ensure the development of co-ordinated plans and strategies across all aspects of Principia's work. It has essential links with the Principia Rushcliffe Health Network (*see below*).

The PRG is chaired by a lay member, and consists of:

- the two community directors from the board
- eight further community representatives
- management and administrative support from Principia and the PCT.

From the beginning, any of the patients or beneficiaries have been encouraged (but not compelled) to take an active part in the deliberations of Principia. The organisation has encouraged 'active beneficiaries' to:

- join their local practice participation group
- assist with activities such as publicity, leaflet design and newsletters
- join patient forums
- receive and respond to questionnaires and consultations
- take part in focus groups.

The role of any lay member at each layer of the organisation continues to be to ensure that a patient's needs are taken in to account.

During the first two years of operation there was a great deal of discussion about how eight people can represent a population of 120,000, so the group developed the Principia Rushcliffe Health Network. This was described as:

> *… an open membership group to which anybody, any patient of our 16 practices, can belong.*
>
> Principia staff member

It is managed in partnership with Rushcliffe Council for Voluntary Services, because:

> *They had excellent relationships with a range of voluntary and community organisations, so they act as a trap door through which we (Principia) can access all these organisations.*
>
> Patient reference group chair

The membership of the network is currently being revitalised. Principia has shown commitment to this way of working by recruiting more communications and involvement staff, who will be responsible for updating and maintaining the database of patients who show an interest, inviting them to meetings and continuing to communicate with them on a regular basis.

The original membership was recruited through practices, and with a flyer that was included in a borough council publicity leaflet circulated to every household in the borough. The general open meetings are augmented by specialist groups on issues such as diabetes, older people and cancer care. Any subjects can be tackled apart from individual complaints.

The network provides the board with a standing reference group and a ready source of specialist knowledge, as well as a pool of individuals from which to recruit community directors.

There is no formal link with existing patient participation groups (PPG). Members of the PRG have offered to support practice PPGs, and there have been two training sessions where patients and practice managers have worked together to understand the potential for PPGs. Principia and the PCT are offering support and incentives to encourage those practices that do not have PPGs to form them.

The PCT has hosted networking events for members of PPGs from across the county to come together to learn from each other. Some formal links may be developed in the future. Similarly, Principia is considering the idea of locality groups within the network, in order to make the area slightly more manageable and to match the existing community ward model.

Subjects to be tackled by the network are suggested by the membership, and have included out-of-hours services, PALS and NHS funding.

The work around out of hours persuaded the PRG that there was a shortfall of understanding within the community about how best to use services, and a leaflet was produced and distributed. This sort of feedback persuades Principia and PCT of the value of patient input:

> *It gives us some assurance that what we are commissioning is the right stuff.*
>
> Principia staff member

Patient and public engagement is very much in the bloodstream of the organisation:

> *Now, nobody here would dream of doing anything without involving patient representatives.*
>
> Patient reference group chair

> *The structure will develop forever – not throw the thing in the skip and start again, but the environment changes all the time – it feels like it can be flexible and withstand change.*
>
> Principia staff member

The organisation has gained an impressive profile, both as a social enterprise pathfinder and one of the 16 Department of Health integrated care pilots, and is being looked at as a model by other organisations. However, Principia advises that the model needs to be relevant to local needs, and that it took time to develop:

> *It works with us, but use the ideas – don't try and impose it.*
>
> Patient reference group chair

Further details are available at: www.principia.nhs.uk–index.php

Conclusions

Without a solid evidence base, and with limited time, this rapid review of recent developments was not intended to be comprehensive, and the conclusions offered are tentative. However, the following themes have emerged:

- LINks are, in the main, struggling to have any impact on patient involvement in general practice.

- World class commissioning and other central guidance on patient and public involvement is not specific to practice level, and has had little impact.
- Established involvement techniques used at a practice level have been about seeking feedback rather than influential involvement, often over one-off issues. These techniques probably need developing if they are to involve patients in service delivery and resultant changes.
- The most active element of involvement appears to be the development and support of PPGs.
- PPGs are supported by practices as long as the role of 'friend' does not become too critical. The majority of PPGs seem to be in a subservient role to the practice, providing additional value to the service.
- General practice does not have a culture of listening to its users, but one of the outcomes of the NHS developing choice and competition will be that involvement – really listening to its customers – will become more important.
- If patient involvement in general practice is to be scaled up, the most likely means to achieve that is through practice-based commissioning consortia.
- The Department of Health could be encouraged to issue more specific guidance relating to the involvement of patients and the public.
- At least in theory, PCTs working within the world class commissioning framework should be requiring PPI to be demonstrated as part of the business case criteria for approval of PBC projects.
- At PBC consortium level it is possible to initiate and sustain some innovative and ambitious mechanisms to involve patients in the governance of primary care services and the development of proposals for service change.
- Common characteristics in our examples included:
  - a history of previous commitment to, and development of, effective PPI in the local health economy
  - the use of networked patient groups as a ground-level source of participants and consultees for scaled-up involvement in service development. In some cases this will include PPGs, although Principia demonstrates the alternative approach: recruiting a new health network, using other available channels
  - a willingness of the PCT to enable these developments, and to support the growth of PPGs or other local health networks.
- Sustaining scaled-up involvement requires resources and support from various local stakeholders, as well as the practices themselves. These resources will need to include communications and administrative support.

3 Discussion: the challenges of engagement and involvement in primary care

In response to an earlier version of this document, our peer reviewers suggested that we should reflect on the challenges for primary care practitioners who may seek to engage patients more closely in their care and treatment or to involve patients in the development of services.

This subject goes beyond our original brief, and we believe it is more important to understand those challenges from the perspective of GPs and other primary care staff themselves. Nevertheless, drawing both on the research described above, and on the general experience of Picker Institute Europe, we offer the following notes for discussion.

The challenges of engaging patients in their care

Reviews of professional codes, legislation and regulation in the last four years have brought patient engagement to the fore as a duty and a requirement for all doctors, and all who provide NHS services.

Over the past decade, professional education and training has been revised to highlight the need to work in partnership with patients, and to equip doctors, in particular, with skills and competences so to do. The main focus has been on communication skills training – particularly in relation to careful listening, delivering unwelcome news, and explaining risks and benefits of treatment.

As a working hypothesis, it seems reasonable to assume that these developments are somehow correlated to the general improvements that patients have reported, via the national surveys, in communication within the consultation.

However, it remains the case that significant minorities of patients have a less positive experience of consultations. It is also clear that the improvements in communication have not led directly to a corresponding improvement in the proportion of patients who say they are as involved in decisions about their care and treatment as they want to be.[1] Just under one-third of primary care patients want more involvement, little changed from 2003.

The key challenges are set out below.

Workforce skills

A first possible reason for this disconnect is that patient partnership skills are more likely to be developed in the generation of primary care practitioners trained during the past decade. They are less likely to have senior roles in practice, and the effects of practice and behaviour modelled for them by more experienced or senior practitioners may reduce their enthusiasm for patient partnership or their ability to practice it successfully.

1 A more detailed discussion of these trends, with referenced to the survey data and to variation between age and ethnic groups, is available in Picker Institute Europe's submission to the review of Tomorrow's Doctors: www.pickereurope.org/Filestore/Policy/consultations/Tomorrows_Doctors_Picker_Institute_response_March09.pdf

A second possible reason for the disconnect is that, even where health professionals are trained in, or have a natural facility for, better communication, their skill set may not yet be sufficiently broad. For example, listening carefully to what a patient has the courage to say is not the same as being skilled in eliciting from the patient the values and preferences that may affect whether or not they wish to take up, or adhere to, a treatment choice. Likewise, explaining risks and benefits is valuable, but alongside this needs to go an assessment of the patient's capacity and willingness to take an active share in the decision.

Therefore, the skills of eliciting and understanding the patient's side of the information picture, and of determining the extent to which they wish to, or able to, be 'activated' patients, need to come into focus.

Practice orientation

These discussions also link to another possible factor in the equation – that high-quality patient engagement is most likely to develop where there is a high awareness of its value, and a conscious philosophy or practice mentality that encourages members of a team (such as the health professionals in a primary care practice) to focus on its achievement.

Again, this may be less likely where the senior partners do not bring a patient-partnership approach to the fore. Arguably, it is also less likely to develop where the priorities of the practice or team are focused overwhelmingly elsewhere – for example, on process targets or financial incentives. As discussed in earlier sections, there are currently no identifiable financial incentives or NHS targets that are focused on engaging patients better in their consultations. It remains to be seen whether regulatory incentives, related to CQC registration or medical revalidation, have any measurable effect on practice in this area.

Health literacy

A third challenge for health care professionals is that of patients' health literacy. This refers not just to reading and understanding health information but to the patient's ability to make use of health information and apply it to choices and decisions. This is a known barrier to engagement.

Health literacy is very strongly associated with health inequalities. People with low health literacy tend to:

have poorer health status

- undergo more hospital admissions
- be less likely to adhere to treatment recommendations
- experience more drug and treatment errors
- make less use of preventive services (Institute of Medicine 2004).

In the United Kingdom a study reported that 11 per cent of adults have marginal or inadequate health literacy.

Most strategies to tackle this problem have involved redesigning patient information materials and provision. Evidence (Picker Institute Europe

2010b) shows that this can be effective in increasing patients' knowledge and understanding, where:

- the information is tailored and personalised
- the information is personally delivered by a health professional who can answer questions and add explanations
- patients are supported to make better use of their health service through innovations such as question prompts for consultations, telephone reminders to attend appointments, and various forms of targeted telehealth provision.

The evidence that innovation in service design can better enable patients to make use of services is important, suggesting that the health service needs to adjust to patients' health literacy levels, rather than (for example) blaming patients for missing appointments or failing to adhere to medication.

Patient expectations

A further challenge lies in the expectations that patients themselves bring to the consultation. Although some doctors have a fear of patients becoming ever more demanding 'consumers', most research among patient groups suggests the continuation of a mindset of gratitude and not wanting to be a 'nuisance'. This is especially the case with regard to older people with long-term conditions – the bulk of the primary practice caseload (*see* forthcoming research by Picker Institute Europe for the NHS Service and Delivery Organisation on the beliefs and experiences of this patient segment).

Time factor

Much of this points us back to one of the factors identified in our review, by GPs and patients alike, as working for or against the success of the consultation: the length of the consultation available. To go beyond current average standards of patient engagement implies increasing the length of consultations to allow the health professional time to elicit full information from the patient, assess their willingness and capacity to participate in decisions, explain the clinical aspects and the treatment options in full, and explore with the patient whether they have understood all of this, and how they would like to proceed.

Primary health care professionals are likely to respond that this is unrealistic – and for one-off, minor or acute and non-recurring episodes this may be true.

However, there is a clear danger that unless there is a conscious effort to provide a more extended consultation at some point, people with long-term or recurrent conditions may go through many primary care appointments – plus visits to outpatients, and possibly to A&E and inpatients. Much of this activity could be reduced if primary care professionals worked with these patients in more depth to develop a coherent care and treatment plan that met their needs and accorded with their values, preferences and life circumstances, to begin a more proactive process of enabling and empowering the patient to manage their own condition.

Hence proactive care-planning approaches and high-quality patient engagement are intimately linked.

Fragmented pathways

The issue of incentives, mentioned above, leads to a further challenge. We have seen that better patient engagement can lead to better use of health service resources – for example, by avoiding unnecessary hospital admissions. Primary care practitioners may 'know' that this makes sense, but the system they are currently working in does not encourage joined-up thinking.

In an acute or specialist setting, it is possible to trial patient engagement approaches and to test, in one setting, the impact on service usage. This has been done, for example, at the National Refractory Angina Centre in Liverpool, where referred patients now undergo extensive initial consultations and courses of education before deciding their preferred treatment (Picker Institute Europe 2010a)

In primary care, since the diagnosis, assessment and consultations on specific conditions are very often carried out through referral to an acute or specialist setting, 'ownership' of the patient-professional partnership may in fact be delegated to the specialist physician or nurse.

GPs do not control the decision-making process. Nor do they control the resources required along the chain of referral. As some have commented, GPs are 'spot buyers' of care and treatment.

The challenges of measuring patient engagement

As we have seen, for quality monitoring and improvement purposes, patient engagement is best measured through patients' reports of their experiences. There are well developed instruments for this, designed for various purposes, including:

- national comparative surveys
- the appraisal of candidates for qualification
- the appraisal of practising GPs (and therefore for revalidation)
- performance-management reward structures.

In Section 1 of the report we discussed aspects of measurement. We have also supplied the inquiry with indicator templates with suggested measures.

- In this short section we briefly note some of the challenges of measuring engagement from the perspective of the primary health care practice. **Methodological challenges** for example, securing sufficiently large samples of patients, knowing whether these are representative, and avoiding bias in the responses (for example, where surveys are completed on the premises or with the 'help' of a member of staff)
- **'Purpose challenges** what to use the results for and how to use them
- **'Comparability challenges** surveys conducted by a single practice or health centre do not allow for benchmarking against others, practices resent imposed systems of scoring or comparison – such as those associated with the GPPS
- **Incentivisation challenges** primary health care practitioners tend to distrust systems that tie incentives into patient-experience results,

and to question the methods and thresholds used. Where incentives are tied to loose targets, as was initially the case with the QOF (with reward points being earned simply for carrying out a survey, not for the scored results or the improvement actions taken), there is a risk that measurement will happen for the sake of measurement. However, where incentives are tied to specific scored results (as with the GPPS), practices may rebel against any perceived unfairness – especially where their income is threatened.

Together, these challenges point to the need for a debate within primary health care about how best to use patient experience measurement to raise the quality of care – including the quality of engagement.

Some form of self-owned (and therefore self-regulatory) system might seem most compatible with the 'small business' model of general practice provision, but a genuine commitment to delivering high-quality patient engagement would need to be guaranteed throughout the service – and the comparability question would still remain.

As a last note, we would suggest there may be similarities here with the challenges of patient involvement – that is, that if primary health practitioners want an alternative to centrally imposed targets and measures, this may need to be scaled up through practice-based commissioning. Clearly, where a PBC consortium or cluster is achieving a scale of six-figure patient coverage, and has central administrative resources available, it becomes easier to overcome some of the methodological and comparability challenges.

The challenges of involving patients in service development

The challenges of involving patients and the public in how services are developed and governed are similar within primary care as in other health care settings. No area of health policy and practice has been so plagued by confusion, lack of robust research and the absence of common frameworks of practice, and of monitoring and assessment.

Primary care does have two distinct advantages over other care settings: that it is close to the community, and that practices have a registered population with which to work. In one of our examples of notable practice (that of Principia, in Nottingham), this registered population is treated as the membership of a company. But at the practice or health centre level, relatively small teams with full workloads and limited backroom resources are managing the health needs of a relatively high number of people. This puts a question mark over the possible scale and ambition of involvement initiatives, and their sustainability.

Not surprisingly, in all three of our notable examples achievements in involvement took years to establish themselves and evolve. There are countless other examples of involvement initiatives, started by one or two enthusiastic partners in a practice, that have withered and died within a short space of time.

Sustainability is also difficult to maintain where there is little in the way of policy, guidance or established models for start-up initiatives to make use of. One of our examples, Whaddon House surgery, clearly had a sense of 'making it up as they went along' in the early years. NAPP's resources and

the Growing Patient Participation campaign are designed to overcome some of these deficits, and may help pave the way for more evolved models of the PPG.

However, as our report notes elsewhere, for all the national policy concentration on patient and public engagement and involvement, there are very few initiatives that have been developed from the centre specifically for primary care – whether in policy, legislation or regulation.

Our examination of notable practice examples identified one very important ingredient in scaling up and sustaining activity: the active support and promotion of involvement in primary care by the primary care trust. It is our suspicion – supported to some degree by our surveys of PCTs – that these examples are innovative, and that the majority of PCTs may not be so engaqed.

Picker Institute Europe has produced various forms of guidance and advice relating to patient and public engagement (*see, for example,* Picker Institute Europe 2009, Picker Institute Europe 2008a) These emphasise the need to:

- clearly differentiate between patient engagement in care and patient involvement in service design and development
- be resolutely clear about aims and objectives – spending time up front to refine these
- adopt a single clear objective for each project, where possible. For example, if you are considering starting a forum or participation group, do you want it principally to fundraise, to enhance your service, to collect feedback from a wider population, or to assist in the development or governance of the practice? Don't confuse the various roles or ask it to do too many things
- avoid reinventing the wheel – research all available guidance, and find out what people are already doing, or have already found out, in your area or elsewhere
- choose methods of research among patients, or of organisations of participation, that suit the chosen objectives – and get guidance on that if possible
- ensure that the resources are available to support and sustain the activity
- monitor and review success in meeting the objectives over time.

Picker Institute Europe has also made the argument in various places, including its submission to the NHS Next Stage Review (Picker Institute Europe 2008b that the Department of Health should invest in:

- developing and disseminating a coherent framework for measuring and evaluating the effectiveness of local patient and public involvement work
- commissioning research to identify effective strategies for engaging patients and local people in service design.

4 Discussion and suggestions

The original aim of this report was to provide the inquiry with a review of evidence and practice in relation to patient engagement and involvement in primary care.

During the process of the work we were encouraged – not least by peer-review comments – to develop recommendations for the panel to consider. We still believe that this goes beyond our initial brief, and we feel constrained by the fact that Picker Institute Europe is not a specialist institute for the study of primary care, nor is it part of the general practice professional networks. Our view is that primary care professionals need to take the lead in developing new and innovative approaches to patient engagement and involvement.

We would therefore prefer to characterise what follows as suggestions, rather than recommendations, which may have some value in helping further discussions both within the inquiry and among the professions themselves.

Patient engagement

The key domains of patient engagement outlined in our report are now a matter of consensus at the higher policy levels – that is, at the Department of Health, the Care Quality Commission and the General Medical Council, and within the Royal College of General Practitioners.

What is required now is to close the gaps, where they exist, between policy regulation and mainstream primary care practice.

The Department of Health has driven various strategies that touch on patient engagement (patient choice, information prescriptions, support to self-management education and so on) but has not found the key to unlock a determined drive towards full patient engagement in primary care.

Arguably, this could be due to the following factors:

- that the conduct of consultations and care planning lie within the professional, rather than the policy domain, and are not amenable to the pulling of central policy levers
- that the overwhelming political focus on primary care has been on the question of access, at the expense of considering what happens to patients once they come through the door
- that policy-makers have underestimated the importance and value of shared decision-making.

A comparison to NHS Scotland may be useful. In its new strategy for quality the Scottish government has more strongly identified as one of its three 'quality ambitions' the achievement of 'mutually beneficial partnerships between patients, their families and those delivering health care services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making. (The Scottish Government 2010).

To achieve this ambition, it has identified specific interventions including:

- a self-management strategy

- use of patient experience and patient-reported outcome measures
- defining, supporting and measuring shared decision-making
- implementing the consultation and relational empathy (CARE) measure (*see* University of Glasgow 2010). better resources to improve health literacy.

This person-centred domain of quality is a more comprehensive and more specific package than the patient experience domain in the NHS Next Stage Review formulation in England, and progress its should be watched carefully.

We suggest that primary care professional leaders in England should now be making a concerted approach to the new United Kingdom coalition government to identify a similar comprehensive strategy, putting shared decision-making at its heart, together with the various interventions required to help achieve it, namely:

- health literacy strategy
- self-management strategy
- universal patient access to medical records
- approaches to measuring patient-reported experience and outcomes that serve the purpose of improving the levels and quality of patient engagement.

We note that the coalition's programme for government includes a pledge to 'put patients in charge of making decisions about their care, including control of their health records'. There is as yet no detail, but this is an opening that the professions themselves, allied with patient and service user groups, should now seize.

Our report notes that there is no shortage of potential measures for patients' experience of the key domains of engagement, but the difficult questions are those around the purposes and usage of measurement, and therefore the choice of instruments. A concerted NHS England strategy for engagement would help to clarify these choices and trigger a review of quality measurement strategies.

Our final suggestion is that, given the consensus between patients and GPs (and across the policy and regulatory areas) on the key domains of engagement, any future systems of measurement should attempt to use common questions and indicators. This is the case even where these questions and indicators serve various purposes, and they should always be linked back to the 'patient partnership' duty in *Good Medical Practice* (General Medical Council 2006)..

Patient involvement

The Department of Health should consider producing a clear framework to define good practice in patient involvement, and to help monitor and evaluate patient involvement programmes and interventions. It should do this in partnership with the CQC, which will be able to use this information when assessing registration requirements.

At the top level, this framework should be generic for all health and social care providers. However, we have identified an absence of specific guidance

and resources for primary care, and these should be developed at the secondary level. (We note that there have been some moves in this direction in the Department's recent strategy work on primary care access.)

Primary care professionals and practices who are considering involving their patients in service development or governance currently find it difficult to identify 'what good looks like', including common indicators that would show whether involvement was being achieved.

There is a low base of evidence and practice examples to start with here, and so this is an area that should be prioritised by primary care organisations. We suggest a need for a 'big conversation' generated by the primary care sector itself and involving organisations such as the NHS Alliance, the RCGP and the Clinical Leaders Network. Patient and service-user groups such as the National Voices coalition, Picker Institute Europe and condition-specific charities with active user-representative groups would be willing to play a role in these developments.

Finally, our observations on the potential to scale up involvement through PBC clusters and consortia may seem to have limited usefulness at a time when many commentators are considering PBC to have been unsuccessful. However, the direction of travel of the coalition government points strongly towards further development of, and delegation of commissioning to, the PBC level. Primary care professionals and their organisations should be ready to engage in positive dialogue with the Department of Health on the integration of patient and service-user involvement with any forthcoming new PBC strategies and plans.

Appendix A: The review of qualitative studies of engagement

This appendix describes our review of qualitative studies exploring GPs' and patients' perceptions of patient engagement within general practice consultations.

To explore patients' engagement as partners in their own health care within general practice, we undertook the following pieces of work:

- a review of qualitative literature exploring GPs' and patients' perceptions of the factors facilitating patients' engagement as partners in their health care within general practice
- a review of existing measures of patients' engagement in their health care within general practice.

Aim

To explore what are the key dimensions of facilitating patients' engagement as partners in their health care within general practice, from the perspectives of general practice professionals and patients alike.

Research question

What are the key dimensions of facilitating patients' engagement as partners in their health care within general practice, from the perspectives of general practice professionals and patients alike?

Method

Design

The study is a survey of primary empirical research employing a systematic review method.

Identifying studies for inclusion

The inclusion and exclusion criteria were designed to answer the review question and were defined by the population, study design, interventions and outcomes of the studies that were included in the review. The criteria were piloted. Search terms were entered into the electronic databases and retrieved articles were briefly reviewed to check that they could reliably identify studies of interest. As the extraction process of relevant papers developed, the exclusion criteria were developed and modified to increase the sensitivity of the search.

Studies meeting all of the inclusion and none of the exclusion criteria were included in the review.

Table A1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
An adult population	Studies measuring factors facilitating patient engagement that employed quantitative measures
Studies employing a qualitative methodology	Studies including an observational design including case series, case control, cohort studies, editorials and book chapters
Studies conducted in a primary care setting	
Studies exploring factors facilitating patient involvement	
Studies including a sample containing patients and/or doctor and/or nurses	
Papers written in English	

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Developing the search strategy

AW developed a search strategy to identify qualitative studies identifying factors facilitating patient engagement in primary care. The search strategy was developed with reference to the review aims, CRD (2001) guidelines, keywords of target articles, and discussions with the research team to identify articles from social science and psychological electronic databases and the grey literature. The search strategies included the following terms:

- patient involvement OR patient partnership OR patient communication OR patient centredness OR patient engagement OR patient expectations
- AND
- primary care
- AND
- patients OR doctors OR family practitioners OR nurses (terms defining the population were only included in the PubMed database search).

Data extraction

Articles were identified from: electronic databases (PsychInfo, PubMed, ASSIA, EMBASE and CINHAL), searching reference lists of all articles included in the review and prior reviews of similar literature. References were managed using Endnote computer software to remove duplicate articles and to manage the retrieved references. A data elicitation chart was developed and applied systematically to all articles included in the review. AW read all of the abstracts to see ascertain if they met the inclusion criteria. Full text articles meeting the inclusion criteria were retrieved.

Search results

Psycinfo

Patient involvement OR patient partnership OR patient communication OR patient centredness OR patient engagement OR patient expectations AND primary care =1818.

EMBASE

Patient involvement OR patient partnership OR patient communication OR patient centredness OR patient engagement OR patient expectations AND primary care =303.

CINHAL

Patient involvement OR patient partnership OR patient communication OR patient centredness OR patient engagement OR patient expectations AND primary care =385.

ASSIA

Patient involvement OR patient partnership OR patient expectations OR patient engagement AND primary care =187.

PubMed

Search '1994' [publication date]: '3000' [publication date] AND patient partnership OR patient involvement OR patient communication OR patient centredness OR patient engagement OR patient expectations OR patient priorities AND primary care. Limits: humans, English, all adult: 19+ years = 1011.

Findings

Our search identified eight papers that focused specifically on patient and/or GP views of factors that might contribute to patient involvement in primary care.

Study characteristics

Five studies were conducted in the United Kingdom, one in the United States and two in 11 different European countries. An equal number of studies were conducted with samples containing all patients (n=3) or GPs (n=3 – *see* Table A1). Between 11 and 233 GPs were included in the latter studies and between 16 and 406 patients were included in those studies containing a patient sample (*see* Table A2). Some studies referred to specific populations. For example, studies focused on:

- patients with chronic illness (Campbell *et al* 2007; Blakeman *et al* 2006)
- shared decision-making (Edwards *et al* 2001)
- mental health (Lester *et al* 2006)
- older adults (Bastiaens *et al* 2007).

Three studies interested in GPs views on patient involvement did not focus on a specific population. Five studies employed semi-structured qualitative interviews and three studies employed focus groups to explore participants' views. All used thematic analysis to develop and apply a coding frame to each transcript and eliciting themes from the data. One study was theory driven, and used Howie's theoretical model for understanding general practice consultations to structure the findings (Blakeman *et al* 2006).

Table A2: Type of participants included in studies for the review

Type of participant	Studies
GPs	Blakeman et al (2006)
	Talen et al (2008)
	Wetzels et al (2004)
Patients	Bastiaens et al (2007)
	Campbell et al (2007)
	Edwards et al (2001)
GPs and practice nurses	Lester et al (2006)
GPs, hospital doctors, practice nurses, academics, lay people	Ford et al (2003)

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Table A3: Summary of data extracted from each paper

Author and year	Aim of research	Participants	Data collection and analysis	Factors identified by patients and doctors
Bastiaens *et al* (2007)	Views of people over 70 in involvement in primary care in 11 European countries	406 people between 70 and 96 years of age	Qualitative interview – coding scheme developed and applied to transcripts to elicit themes	1. Patient involvement (meaning) • Doctor–patient interaction • Responsibility of the GP • Responsibility of the patient (informs GP, follows advice) • Contextual factors 2. Barriers • Doctor–patient interaction • Patient-related barriers • Mental status (understanding, forgetfulness) • Low education • Personal characteristics (for example, not feeling equal, not being able to express themselves, anxiety of serious disease or examinations) • Contextual barriers 3. Facilitators • Doctor–patient interaction • Patient-related facilitators • GP-related facilitators • Contextual facilitators
Blakeman et al (2006)	To explore GPs' perspectives on their involvement in the facilitation of chronic disease self-management	16 GPs in 2 primary care trusts	Semi-structured interviews, open coding using Howie's theoretical model of understanding GP consultations to structure the analysis and themes	Central theme to emerge was conflict between different values, and between values and context – although increasing patient involvement and control of health was valued, it was not necessarily prioritised – it clashes with other important values of professional responsibility and accountability, as well as with contextual factors that drive GP behaviour (for example, consultation length)

Author and year	Aim of research	Participants	Data collection and analysis	Factors identified by patients and doctors
Campbell et al (2007)	To identify which aspects of quality are important to patients with common chronic mild-to-moderate mental health problems, and how to involve patients with chronic mental health problems	44–182 questionnaires returned. 16–26 patients from four practices in the North of England took part in interview	Questionnaires and interviews, analysed using thematic analysis	Six key themes in quality deficit: 1. The health care system provides a generic 'one size fits all' service that is incompatible with an individual patient's experience 2. Patients with mild-to-moderate mental health problems often have feelings of powerlessness and of being 'lost' in a system that is more responsive to severe and acute episodes of illness than to chronic morbidity 3. Patients often have unmet needs in relation to the distress of living with mild-to-moderate mental health problems 4. Quality deficits in primary care for people with mild-to-moderate chronic mental health problems 5. GPs are rated highly, and the attributes of a good GP can be identified 6. Engaging with chronic mental health problems in the research–policy process requires generic assessment 7. Quality of mixed methods

Author and year	Aim of research	Participants	Data collection and analysis	Factors identified by patients and doctors
Edwards et al (2001)	To identify the important outcomes of consultations for patients and compare with those reported in the literature	47 participants	6 focus groups 3 general practice based 2 consumer groups 1 group 'patient simulators' Emergent themes identified and discussed with research team	8. Context of discussions in the consultation: 9. a sequence of consultations 10. continuity with same professional 11. respect for individual consumer 12. variable involvement according to context Process of discussions in the consultation: 1. individual contribution to discussions 2. perceived involvement in decisions 3. perceived professional-consumer agreement 4. satisfaction with the way a decision is made 5. and sufficient time to decide 6. certainty that best decision made 7. opportunity to involve others Content of discussions in the consultation: • options and choices specified • information provision • support materials • review arrangements • Health outcomes: • anxiety/reassurance
Ford et al (2003)	To identify the elements and skills required for a successful EBPC Consultation to occur	GPs (n= 11), hospital doctors (n=10), practice nurses (n=5), academics (n=11) and lay people (n=8)	Semi-structured interviews analysed using the constant comparison method	• Doctor–patient relationship: trust, respect, honesty and partnership building • Patient's perspective: related mostly to exploring patients' individual qualities and circumstances • Research evidence–medical information – for example, access to and knowledge of the evidence • Time issues • Decision-making process • Establishing nature of the problem
Author and year	**Aim of research**	**Participants**	**Data collection and analysis**	**Factors identified by patients and doctors**

Lester et al (2006)	To describe types of patient involvement in primary care from primary care health professionals and patients with serious mental illness	45 patients with serious mental illness, 39 GPs, 8 practice nurses	18 focus groups in 6 primary care trusts: six patient, six health professional and six combined focus groups analysed by coding transcripts and developing themes	• the value of lived experience • decision-making in the consultation • the importance of paid work.
Talen et al (2008)	To identify what makes good patient communication	41 GPs	5 focus groups transcripts reviewed for general themes and broad categories	12. Patient knowledge – health and family health history, knowledge of diagnosis and/or condition 13. Patient skills – preparation and articulation 14. Patient attitude – responsibility of own condition, trust, honesty
Wetzels et al (2004)	Aim: to describe GPs views of factors of involvement in 11 European countries	233 GPs in 11 European countries	Semi-structured interviews analysed using a coding frame to build themes	1. Barriers to involvement – GP lack of time, patient feelings of respect and lack of experience in being involved and possible mental and physical impairments 2. Facilitators – more or other resources, better prepared patients and informed patients, GPs using communication skills

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Appendix B: Existing measures of patients engagement

This appendix describes our review of existing measures of patient engagement.

Aim

To explore, identify and critically appraise existing measures of patient engagement in their health care within general practice.

Method

We identified and examined existing measurement tools, questionnaires and scales used to measure patient engagement in their general practice care.

We identified tools by searching the following bibliographic databases: PubMed, CINHAL, Science Citation Index and Social Science Citation Index, and by examining existing surveys of patient experience of general practice and primary care (including those undertaken by the Department of Health, the Healthcare Commission and Ipsos Mori). We also searched the NHS Information Centre, the Question Bank hosted by Surrey University, the Data Archive at Essex University, and the Office for National Statistics Surveys.

When we had identified the existing measures and questions, we examined each measure by:

- identifying the aspects of engagement covered by the measure
- the method and setting of question administration – for example, postal, face to face, home based or at the GP surgery.

We then analysed the extracted measures and scales, to identify the domains that they measured. Finally, we tabulated the measures against the domains of engagement identified.

Development of search strategy

SP developed a search strategy to identify existing measures of patient engagement in their general practice care. The search strategy was developed with reference to the review aims, keywords of target articles and discussions with the research team to identify articles from social science and psychological electronic databases and the grey literature. The search strategy included the following terms:

- quality OR quality of care OR consultation quality OR quality indicators OR quality judgements
- AND
- primary care OR general practice OR family practice
- AND
- patient involvement OR patient expectations OR patient centredness OR patient priorities OR patient satisfaction OR public involvement OR user involvement

- AND
- measures OR scales OR instruments OR process measures OR outcome measures.

Data extraction

Relevant articles were identified from Google scholar and the following bibliographic databases: PsychInfo, PubMed, Science citation index and Social Science Citation Index. References were managed using Reference Manager Software, which enabled duplicate references to be removed. SP read all the abstracts to ascertain if they met the inclusion criteria. Full text articles meeting the inclusion criteria were retrieved.

The key domains that the tools and scales measured were identified and the identified tools and scales tabulated under the key domains.

Table B1: Domains, tools and scales for measuring patient engagement

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'The consultation and relational empathy measure: development and preliminary validation and reliability of an empathy based consultation process measure' (Mercer 2004)	To develop a process measure based on a broad definition of empathy for the evaluation of the quality of consultations in terms of the 'human' aspects of medical care		Provides doctors with direct feedback of their relational empathy as perceived by patients. How was the doctor at … 1. Making you feel at ease 2. Letting you tell your story 3. Really listening 4. Being interested in you as a whole person 5. Fully understanding your concerns 6. Showing care and compassion 7. Being positive 8. Explaining things clearly 9. Helping you to take control 10. Making a plan of action with you
'Identifying predictors of high quality care in English general practice: observational study' (Campbell et al 2001)	To generate a set of face valid indicators for quality of general practice and place them in the public domain for discussion	Wrote to all district primary care lead in England and Wales, asking for details of indicators which they were using or considering using in primary care	Domains of quality identified: 1. Access 2. Organisational performance 3. Preventive care 4. Chronic disease management 5. Prescribing 6. Gatekeeping Very few indicators were focused on the quality of the consultation from the patient's perspective, although the study was undertaken in 1996 Useful indicators representing the patients' perspective were: Adequate patient information should be available in a suitable format for patient self-management of diabetes

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Shared decision making: developing the OPTION scale for measuring patient involvement' (Elwyn et al 2003)	To enable accurate assessments of the levels of involvement in shared decision-making achieved within consultations to provide research data for empirical studies in this area	OPTION scale – item-based instrument completed by raters who assess recordings of consultations. It has been developed to evaluate shared decision-making specifically in the context of general practice. It examines whether problems are well defined, options are formulated, information provided, patient understanding and role preference evaluated and decisions examined from both professional and patient perspectives	Features of quality shared decision-making: 1. Problem definition (and agreement) 2. Explaining that legitimate choices exist in many clinical situations, professional 'equipoise' 3. Portraying options and communicating risk about a wide range of issues – for example, entry to screening programmes 4. Conducting the decision process or its deferment The accomplishment of these competencies form the conceptual basis for the OPTION scale 1. The clinician identifies a problem needing a decision-making process 2. The clinician states that there is more than one way to deal with an identified problem 3. The clinician lists options including the choice of 'no action' if feasible 4. The clinician explains the pros and cons of options to the patient 5. The clinician checks the patient's preferred information format 6. The clinician explores the patient's expectations about how the problems are to be managed 7. The clinician explores the patient's concerns about how problems are to be managed 8. The clinician checks that the patient has understood the information 9. The clinician provides opportunities for the patient to ask questions 10. The clinician asks for the patients' preferred level of involvement in decision-making 11. An opportunity for deferring a decision is provided 12. Arrangements are made to review the decision (or the deferment

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Quality of care from the patients' perspective: from theoretical concept to a new measuring instrument' (Sixma et al 1998)	Sixma developed QUOTE instruments in which quality of care aspects were formulated as importance and performance statements. Importance was assessed without specifying professions or type of organisation. Performance judgements referred to contact with GPs and other health professionals		General indicators – process Health care providers should: 1. Know my problems very well 2. Work efficiently 3. Allow me to decide on which help to get 4. Take me seriously 5. Keep their appointments punctually 6. Allow me to see my patient notes 7. Allow me to choose another professional 8. Give information on combinations of medicines Category-specific indicators 1. GP allows me to tell my story 2. Tells his findings in follow-up consultations 3. Be able to look at things through my eyes 4. Pay attention to the psycho-social aspects of my illness 5. Should be within easy reach 6. Be willing to learn about patients' problems 7. Allow me to manage my own budget for care Regional indicators 1. Listen to me very carefully 2. Display information leaflets in their waiting room 3. Show understanding for contacts with alternative medicine

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Patient expectations: what do primary care patients want from the GP and how far does meeting expectations affect patient satisfaction?' (Williams et al 1995)	Study aimed to report on the types of needs of adult primary care attendees. Second aim was to investigate whether meeting patients' expectations by GPs leads to greater reported satisfaction in primary care patients. Third aim was to see what percentage of patients reported their expectations not being met, and in which areas	Patient intentions questionnaire (PIQ) used to measure patients' expectations. This consists of 42 statements about what they want from the GP during a given visit. The PIQ was used to create the expectations met questionnaire (EMQ), which consists of the same 42 PIQ statements about what they received from the GP during the given visit. The medical interview satisfaction scale (MISS) was selected to measure patient satisfaction with the consultation, since it is one of few consultation-specific measures	Explanation of problem items from PIQ: 1. Is problem related to other parts of life? 2. Want to know why feeling this way 3. Want GP to explain treatment 4. Want to be examined for cause 5. Want GP to understand patients' view 6. Want to know how serious problem is 7. Want to know course of problem 8. Will I have problems in future? 9. Want to know how long until recovery 10. Want to be sure nothing is wrong 11. Want to know what symptoms mean 12. Want GP to talk about problem 13. Want help with medical problem 14. Want GP to explain what is wrong 15. Want GP to understand problem Most frequent expectation was for the GP to understand the problem followed by for the GP to explain what is wrong with them.
			Support items: 1. Want advice on a marital problem 2. Want help with emotional problems 3. Want emotional problems explained 4. Want treatment for nervous condition 5. Want to receive comfort 6. Told about others with the same problem 7. Want to discuss certain life problems 8. Want support with problem 9. Feeling anxious and wanting GP's help 10. Want to know why reacting this way 11. Want to talk about own feelings The most frequently wanted support items were to talk about their own feelings during the consultation

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
			Test and diagnosis items 1. Want to be referred to a specialist 2. Want advice on a drug I am taking 3. Want a previous diagnosis confirmed 4. Want GP to explain test results 5. Want some test results 6. Want to know if problems are real 7. Want to know of any side-effects 8. Want some tests done The majority of patients who wanted the GP to understand their problem and explain what was wrong felt that these expectations, along with many others, were met. However, many of the support items – for example, want to talk about own feelings – were not
'Identifying predictors of high quality care in English general practice: observational study 2001' (Campbell et al 2001)	Study used a range of methods to carry out detailed assessments of quality of care in a stratified random sample of practices Study aimed to assess the extent of variation in quality of care in English general practice and to identify factors associated with high quality care	Authors previously defined the components of quality of care as a combination of access, the effectiveness of clinical care and interpersonal care. Access and interpersonal care was measuring by sending a random sample of 200 adults a copy of the general practice assessment survey	More deprived practices were found to have lower scores for interpersonal care and overall satisfaction No single type of practice has a monopoly on high quality care: small practices provide better access but poorer diabetes care

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Quality at general practice consultations: cross-sectional survey 1999' (Howie et al 1999b)	To measure quality of care at general practice consultations in diverse geographical areas and to determine the principal correlates associated with enablement as an outcome measure	Main outcome measures were: patient enablement, duration of consultation, how well patients know their doctor, and practice list size	Doctors' ability to enable was linked to the duration of their consultation and the percentage of their patients who knew them well, and was inversely related to the size of their practice Patient enablement instrument As a result of your visit to the doctor today, do you feel you are 1. Able to cope with life 2. Able to understand your illness 3. Able to cope with your illness 4. Able to keep yourself healthy 5. Confident about your health 6. Able to help yourself Results • Mean duration of consultation increased when consultations had a high psychological component. High mean duration of consultation was associated with a smaller number of short consultations and a greater number of long and very long consultations • Patients' age over 65 was associated with high enablement and long consultations and consultations for women lasted longer than those for men • The more problems a patient wanted to discuss, the longer the consultation and the greater the enablement. Knowing the doctor well resulted in considerably increased enablement • Enablement was lower in practices of six or more doctors and greatest in single-handed practices • Enablement values for male and female doctors were comparable overall, but female doctors spent more time with their patients than did male doctors – particularly when the patient did not know the doctor well

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'A comparison of a Patient Enablement Instrument against two established satisfaction scales as an outcome measure of primary care consultations' (Howie et al 1998b)	To example the patient enablement instrument (PEI) against two established satisfaction measures, the medical interview satisfaction scale and the consultation satisfaction questionnaire Testing whether enablement and satisfaction are related or separate concepts To test whether enablement and satisfaction are related or separate concepts, and to assess whether the internal consistency of the PEI might be enhanced by inclusion of items from the satisfaction instruments	Questionnaire forms containing the three instruments in a variety of combinations were distributed to 818 patients attending three urban general practices	• Mean scores, expressed as percentages of maximum scores attainable, were 44.1% for the PEI, 76.9% for the CSQ and 77.6% for the MISS • Correlations between PEI scores and scores for the complete CSQ and MISS instruments were 0.48 and 047 • Study shows that enablement is a primary care outcome measure that is related to but different from general satisfaction

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Patients' priorities with respect to general practice care: an international perspective' (Grol et al 1999; Howie et al 1998b)	To identify patients' priorities with respect to general practice care. Priorities defined as aspects of general practice care that patients consider more or less important	Surveys (written questionnaires) were performed in eight countries across Europe. A list of 40 items or aspects of care was developed covering important areas of general practice care. These were divided into five sections: 1. Medical–technical care 2. Doctor–patient relationship 3. Information and support to patients 4. Availability and accessibility 5. Organisation of services Respondents were asked to rate the importance of each separate aspect of general practice care of a five-point scale ranging from 'not important at all' to 'most important' To rank per section the importance of the eight aspects of care in that section by identifying which aspect is to be seen as most important To select the three most important aspects overall out of the five previously identified as the most important ones within the five different sections	Aspects that were valued most in the total sample of patients were: 1. Getting enough time during consultations 2. Quick service in the case of emergencies 3. Confidentiality of information on patients 4. Telling patients all they want to know about their illness 5. Making patients feel free to talk about their problems A relatively low ranking was given to aspects such as: 1. Waiting time before the consultation 2. GPs helping patients to deal with emotional problems related to their health problems 3. GPs accepting it when patients seek alternative treatment Items relevant to involvement: 1. During the consultation, a GP should have enough time to listen, talk and explain to me 2. A GP should tell me all I want to know about my illness 3. A GP should make me feel free to tell him or her my problems 4. A GP should explain the purpose of tests and treatment in detail 5. A GP and other care providers should not give contradictory information to me 6. A GP should understand what I want from him or her 7. A GP should be ready to discuss the tests, treatment or referral that I want 8. A GP should take a personal interest in me as a person and in my life situation 9. A GP should acknowledge that the patient has the final choice regarding tests and treatment

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Continuity of care in general practice: effect on patient satisfaction' (Hjortdahl and Laerum 1992)	To evaluate the influence of continuity of care on patient satisfaction with consultations	Representative sample of 3,918 Norwegian primary care patients asked to evaluate their consultations by completing a questionnaire Patients' overall satisfaction with the consultation was rated on a six-point scale. Continuity of care was recorded as the duration and intensity of the present patient-doctor relationship and as patients' perception of the present doctor being their personal doctor or not	• An overall personal patient-doctor relationship increased the odds of the patient being satisfied with the consultation sevenfold, as compared with consultations were no such relationships existed • The duration of the patient-doctor relationship had a weak but significant association with patient satisfaction, while the intensity of contacts showed no such association • Personal, continuous care is linked with patient satisfaction

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'What makes a good general practitioner: do patients and doctors have different views?' (Jung et al 1998)	To elicit areas of controversy as well as areas of mutual agreement between the opinions of patients and GPs with regard to good general practice care	Questionnaire, distributed to 850 patients and 400 GPs, measured which of 40 aspects of general practice care were given priority. Second questionnaire, distributed to 400 different GPs, measured the GPs perception of the priorities of their patients	The priority rank order of all 40 aspects was highly correlated for patients and GPs (0.72). When comparing the priorities of patients and GPs, 23 out of 40 aspects differed significantly in their rank number Areas that GPs and patients agreed on in relation to involvement 1. A GP should guarantee the confidentiality of information about all his or her patients 2. A GP should make me feel free to tell him or her my problems 3. A GP should guide me in taking my medicines correctly 4. A GP should provide information on services that provide practical or personal support and guidance to my relatives Aspects that were more important to patients than GPs 1. A GP should be ready to discuss the investigations, treatment or referral that I want 2. A GP should acknowledge that the patient has the final choice regarding investigations and treatments 3. A GP should allow a second opinion from a different doctor 4. A GP should accept when I seek alternative treatment 5. A GP should tell me all I want to know about my illness 6. A GP should explain the purpose of investigations and treatment in detail Aspects that were more important to the GP 1. A GP should understand what I want from him or her 2. A GP should take a personal interest in me as a person and in my life situation

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Comparison of patients' preferences and evaluations regarding aspects of general practice care' (Jung et al 2000)	To determine the relationship between patients' preferences and their evaluations of general practice care	Patients visiting five rural practices in the Netherlands were asked to complete a questionnaire measuring their evaluations or their preferences on 44 aspects of general practice care	The longer the period after the consultation, the lower the mean percentage of all 44 aspects of general practice care rated as good, but the higher the mean percentage of all items rated as very important Aspects of general practice care related to involvement 1. The respect shown to you as a person 2. Explaining things to you 3. Involving you in decisions about your medical care 4. Explaining purpose of tests and treatment 5. Opportunities to ask questions about problems 6. Making you feel you had time during consultations 7. Explaining results of tests 8. Interest in your personal situation 9. Make it easy for you to talk about your problems 10. Knowing what other providers did – told you

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Validation of a questionnaire measuring patient satisfaction with general practitioner services' (Grogan et al 2000)	To assess the construct validity and internal reliability of the patient satisfaction questionnaire	1,390 patients from five general practices completed the questionnaire. Responses were checked for construct validity and internal validity	Factor analysis showed that items loaded on the appropriate factors in a five-factor model (doctors, nurses, access, appointments and facilities) Patient satisfaction questionnaire comprises 46 items, participants asked to tick the box from strongly agree to strongly disagree Items related to involvement within the consultation a. The doctor clearly explains why is wrong before giving any treatment b. The practice nurses do not take care to explain things carefully c. The doctor does not tell me enough about the treatment d. The doctor fully explains how the illness will affect my future health e. The doctor is always interested f. The doctor always asks about how my illness affects everyday life g. I sometimes feel that I have not been given enough information by the doctor h. The practice nurse does not always listen carefully when I talk about my problems i. The receptionists explain things clearly to me j. Sometimes the doctor makes me feel I am wasting his/her time k. I don't feel confident discussing my problems with the doctor l. The doctor gives me every chance to talk about my problems m. I do not feel rushed when I am with the doctor

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Development of a questionnaire to assess patients' satisfaction with consultations in general practice' (Baker 1990)	To develop a questionnaire to assess patients' satisfaction with consultations together with initial tests of the questionnaires' reliability and validity	Questionnaire development done in a single general practice. The method of questioning chosen was a five-point Likert scale asking for agreement or disagreement with statements about the doctor and the consultation	Items related to patient involvement a. This doctor told me everything about my treatment b. I thought the doctor took notice of me as a person c. This doctor was interested in me as a person and not just my illness d. There are some things this doctor does not know about me e. I felt this doctor really knew what I was thinking f. I felt able to tell this doctor about very personal things g. The time I was allowed to spend with the doctor was not long enough to deal with everything I wanted h. I wish it had been possible to spend a little longer with the doctor

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'The development of COMRADE – a patient based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations' (Edwards et al 2003)	To develop a new outcome measure for risk communication and treatment decision-making effectiveness To explore the reliability and validity of the measure	Domain and item formulation was based on a systematic literature review and data from semi-structured focus groups with consumers	COMRADE scale measured two factors Satisfaction with communication 1. The doctor made me aware of the different treatments available 2. The doctor gave me the chance to express my opinions about the different treatments available 3. The doctor gave me the chance to ask for as much information as I needed about the different treatment choices 4. The doctor gave me enough information about the treatment choices available 5. The doctor gave enough explanation of the information about treatment choices 6. The information given to me was easy to understand 7. I know the advantages of treatments or not having treatment 8. I know the disadvantages of treatments or not having treatments 9. The doctor gave me a chance to decide which treatment I thought was best for me 10. The doctor gave me a chance to be involved in the decisions during the consultation Confidence in decisions 1. Overall, I am satisfied with the information I was given 2. My doctor and I agreed about which treatment (or no treatment) was best for me 3. I can easily discuss my treatment again with my doctor 4. I am satisfied with the way in which the decision was made in the consultation 5. I am sure that the decision made was the right one for me personally 6. I am satisfied that I am adequately informed about the issues important to the decision 7. It is clear which choice is best for me 8. I am aware of the treatment choices that I have 9. I feel an informed choice has been made 10. The decision shows what is most important to me

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'The General Practice Assessment Survey (GPAS) tests of data quality and measurement properties' (Ramsay et al 2000)	To describe the psychometric properties of the general practice assessment survey and its acceptability to patients in the United Kingdom	200 consecutive patients attending routine consulting sessions at 55 inner London practices were invited to complete the GPAS questionnaire	• GPAS acceptable to patients as evidenced by the low proportions of missing data for all items. Reliability of the instrument was good • GPAS is a useful instrument for assessing several important dimensions of primary care. It is acceptable, reliable and valid Areas that the GPAS measures: access, receptionists, continuity of care, technical care, communication, interpersonal, trust, knowledge, nursing, coordination, referral
'Observational study of effect of patient centeredness and positive approach on outcomes of general practice consultations' (Little et al 2001)	To measure patients' perceptions of patient centredness and the relation of these perceptions to outcomes	865 patients attending 3 general practices given questionnaires measuring patient enablement, satisfaction and burden of symptoms	Factor analysis identified five components 1. Communication and partnership - a sympathetic doctor interested in patients' worries and expectations and who discusses and agrees their problems and treatment 2. Personal relationship – a doctor who knows the patient and their emotional needs 3. Health promotion 4. Positive approach (being definite about the problem and when it would settle) 5. Interest in effect on patients' life Referrals were fewer if patients felt that they had a personal relationship with their doctor If doctors don't provide a positive, patient-centred approach patients will be less satisfied, less enabled and may have greater symptom burden and higher rates of referral

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
			Items related to involvement The doctor: 1. Was interested in my worries about the problem 2. Was interested when I talked about my symptoms 3. Was interested in what I wanted to know 4. I felt encouraged to ask questions 5. Was careful to explain the plan of treatment 6. Was sympathetic 7. Was interested in what I thought the problem was 8. Discussed and agreed together what the problem was 9. Was interested in what I wanted done 10. Was interested in what treatment I wanted 11. Discussed and reached agreement with me on the plan of treatment 12. Knows and understands me well 13. Understands my emotional needs 14. Explained clearly what the problem was 15. Was positive about when the problem would settle 16. Was interested in the effect of the problems on my family or personal life 17. Was interested in the effect of the problem on everyday activities
'Use of the consultation satisfaction questionnaire to examine patients' satisfaction with general practitioners and community nurses: reliability, replicability and discriminant validity' (Poulton 1996)	To examine the feasibility of using a patient satisfaction questionnaire designed for use with GP consultations as an instrument for measuring patient satisfaction with community nurses	1,575 patients in three practices consulting GPs or community nurses were invited to complete a questionnaire	Three dimensions of patient satisfaction were identified: professional care, depth of relationship and perceived time spent with the health professional Study showed that it was possible to use the consultation satisfaction questionnaire for both GPs and community nurses Satisfaction questionnaire statements 1. The doctor listened very carefully to what I had to say 2. The doctor told me everything about my treatment and explained the reasons for the advice given 3. I thought this doctor took notice of me as a person 4. The time I was able to spend with the doctor was not long enough to deal with everything I wanted

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Developing a "consultation quality index" (CQI) for use in general practice' (Howie et al 1999b)	To construct a consultation quality index that reflects the core values of general practice, using as proxies 'consultation length' and how well patients 'know the doctor' as process measures, and patient enablement as an outcome measure	The CQI was constructed from data collected from 23,799 patients consulting 221 doctors in four demographically contrasting areas of the United Kingdom	CQI scores were in the range 4-18, validity was examined by looking at high and low scorers in greater detail and searching for correlates with case mix, patient age, and gender and the deprivation scores of the practices concerned Patient enablement instrument As a result of your visit to the doctor today, do you feel you are: 1. Able to cope with life 2. Able to understand your illness 3. Able to cope with your illness 4. Able to keep yourself healthy 5. Confident about your health 6. Able to help yourself
'The medical interview satisfaction scale (MISS-21) adapted for British general practice' (Meakin 2002)	To examine the validity, reliability and applicability of the MISS-29 in British general practice populations	The first study phase investigated the properties of the MISS-29 in a UK general practice population and resulted in a modified MISS -21 The second investigated the properties of the MISS-21 in a wider UK general practice population	The new 21-item version with the same four subscales of the 29 item MISS was developed which has satisfactory internal reliability Patient asked to indicate their level of agreement on a seven-point Likert scale – very strongly disagree to very strongly agree Items relevant to involvement 1. The doctor seemed interested in me as a person 2. The doctor seemed warm and friendly to me 3. The doctor seemed to take my problems seriously 4. I felt free to talk to this doctor about private matters 5. The doctor gave me a chance to say what was really on my mind 6. I really felt understood by my doctor 7. The doctor did not allow me to say everything that I had wanted about my problems 8. The doctor did not really understand my main reason for coming

Title and Authors	Aims	Data collection and analysis	Questionnaire items or indicators
'Complex health problems in general practice: do we need an instrument for consultation, improvement and patient involvement? Theoretical foundation, development and user evaluation of the Patient Perspective survey' (Laerum 2002)	To develop a novel instrument in terms of a patient administered questionnaire – the patient perspective survey designed to enhance the quality of clinical communication within the consultation	Developed using a comprehensive literature search, discussions and advice with GPs, patients, broad panels of experts and tested in pilot studies	102 item version developed consisting of a main somatic, mental and social domain axis

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