

Research paper

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The quality of GP diagnosis and referral



An Inquiry into the Quality of General Practice in England

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This paper was commissioned by The King's Fund to inform the Inquiry panel.

The views expressed are those of the authors and not of the panel.

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Executive summary

This report forms part of the wider inquiry into the quality of general practice in England commissioned by The King's Fund, and focuses specifically on the quality of diagnosis and referral. The report:

- describes what 'good' looks like for diagnosis and referral within primary care
- describes what is known about the current quality of referral and diagnosis in general practice
- identifies evidence-based means of improving the quality of GP diagnosis and referral
- considers the potential for quality measures of diagnosis and referral within primary care.

The report is based on an extensive literature review of more than 350 published articles examining various aspects of diagnosis and referral. We tested the findings from this review using a validation event attended by GPs and other professionals.

Although there is a substantial volume of research evidence, there are no comprehensive national data sets on which to base assessments of current quality. It is therefore not possible to make a definitive assessment of the current quality of diagnosis and referral in primary care. There is, however, ample evidence to show that there are significant variations in practice, and opportunities for quality improvement in a number of respects.

Diagnosis

The role of the general practitioner in diagnosis is one of problem recognition and decision-making. A crucial aim of the GP in this regard is to marginalise danger by recognising and responding to signs and symptoms of possible serious illness. The objective is not always to reach a definitive conclusion in primary care – the diagnostic process can also act as a gateway to further management of the patient's complaint.

Diagnosis is a complex area of clinical activity that does not often follow a simple linear sequence. The diagnostic process in primary care is made challenging by a number of factors, including:

- the evolutionary and undifferentiated nature of symptoms encountered in primary care
- very low prevalence of certain conditions and the high degree of overlap in symptoms for serious and common conditions
- the difficulty of probability-based reasoning and the weak predictive value of diagnostic tests in primary care
- the high prevalence of medically unexplained symptoms that lack a medically identifiable organic cause.

As a result of these challenges, the diagnostic process in general practice is as often a combination of shortcuts, loops and dead ends as it is a straight line going from presentation to diagnosis.

A high-quality diagnostic process would involve a number of elements:

- gathering sufficient evidence and information
- judging that evidence and information correctly
- minimising delay in further investigation and onward management – particularly if the condition is serious or suspected to be serious
- ensuring efficient use of resources
- providing a good patient experience.

Research evidence suggests that there is variation in the quality of diagnosis, and associated opportunities for quality improvement. For example, recent work done as part of the National Awareness and Early Diagnosis Initiative (NAEDI) for cancer suggests some significant quality issues arising from delays in cancer diagnosis.

A number of factors are likely to be affecting the quality of diagnosis in general practice, including:

- presentation issues (low prevalence of serious conditions, atypical presentations)
- individual practitioner level issues (knowledge, skills, attitudes)
- system issues (access to diagnostics, time taken to receive test results).

There is some evidence that a range of improvement techniques can be successful in promoting the quality of diagnosis. These include:

- education and training
- the provision of decision-support tools
- improving access to testing technologies and providing feedback on over-testing
- interventions focusing on individual and practice level reflection, audit and assessment
- interventions to improve systems and processes of follow-up.

Referral

Referral is a key part of the GP role. It is a process with very direct consequences for patients' experience of care, and an important cost-driver in the health system. Approximately one in 20 GP consultations results in a referral being made to another service. Referrals are made for a number of reasons, including:

- to establish the diagnosis
- for treatment or an operation
- for a specified test or investigation unavailable in primary care

- for advice on management
- for reassurance.

Referral often involves a transfer of clinical responsibility between professionals. It is a complex area where decision-making involves the balancing of several competing concerns and sources of information – not least, the need to respond to patient expectations versus the GP's role as gatekeeper.

High-quality referral involves the following elements:

- necessity – patients are referred as and when necessary, without avoidable delay
- destination – patients are referred to the most appropriate place first time
- process – the referral process itself is conducted well. For example:
 - referral letters contain the necessary information, in an accessible format
 - patients are involved in decision-making around the referral
 - all parties are able to construct a shared understanding of the purpose and expectations of the referral
 - appropriate investigations and tests are performed prior to referral.

Research evidence indicates that there is scope for quality improvement in referral in terms of each of these dimensions. It is difficult to assess the scale of these potential improvements since the research is partial in its coverage and in some cases not current. However, taken as a whole, there is sufficient evidence to suggest that there are shortcomings that could be addressed. Distinct challenges exist within different specialties, and for different types of referral.

Wide variations in referral rates exist, but interpretation of these is highly complex. Referral rates are influenced by multiple factors – for example, population health needs, GPs' attitudes towards risk, and patient pressure.

There is evidence that a number of approaches can be effective in improving quality in referral – for example, educational interventions, referral guidelines, organisational interventions, financial incentives, and the use of measures and metrics. Approaches that encourage peer review among GPs and feedback from consultants appear to be particularly effective.

Measurement of referral rates and benchmarking these against peers can provide a useful tool for GPs, but the interpretation of these measurements is complex. Variations in referral rates should be interpreted with reference to other data, such as population health needs and area deprivation. Overall referral rates cannot be used as a simple proxy for referral quality.

Recommendations

The key recommendations are as follows.

- Variation between different GPs in terms of their diagnostic and referral practices may in some cases reflect inequity in performance, but also represents the complexity of diagnosis and referral and the myriad factors influencing it. While genuine inequity should not be accepted, a naïve pursuit of standardisation could be dangerous, and should not be encouraged.
- There is scope for quality measurement in diagnosis and referral, but most indicators will serve only as 'tin openers' (designed to prompt further investigation) rather than 'dials' (unambiguous markers of performance). Referral rates are an important example of this, and primary care trusts should be strongly discouraged from using overall referral rates as a performance management measure.
- Mechanisms and incentives for improving communication between GPs and specialists should be explored. Good clinical relationships facilitate information exchange, provide learning opportunities and underpin high-quality diagnosis and referral. Good relationships may also make it easier for GPs to seek informal advice, reducing the need for making formal referrals and avoiding duplication of tests.
- A stronger clinical governance framework is needed if we are to better understand and improve the quality of clinical decision-making within general practice, with more collaborative working, retrospective audit and peer review between GPs. The current size and infrastructure of general practice limits the capacity and effectiveness of any peer review or audit process.
- The GP–patient relationship and the quality of the consultation are crucial for high-quality diagnosis and referral. Longer consultation times could be expected to support improved decision-making around diagnosis and referral.
- More research is needed to link diagnostic and referral practices with clinical outcomes. Quality issues around emergency referrals also need further investigation.

1 Introduction

This research project has examined the quality of diagnosis and referral in general practice, with specific reference to enabling patients to make informed choices at the point of referral. We have been able to draw on a substantial volume of literature but little comprehensive, UK-specific research on current quality. What evidence there is points to some significant variation in quality between individual GPs and GP practices. There is a particular dearth of evidence on safety and clinical outcomes.

From the evidence available, this report:

- describes what 'good' looks like for diagnosis and referral within primary care
- describes the current quality of referral and diagnosis in general practice
- identifies proven means of improving the quality of GP diagnosis and referral
- considers the potential for quality measures of diagnosis and referral within primary care.

We consider referral and diagnosis separately, before drawing some overall conclusions.

Context

For the majority of patients in the United Kingdom, general practice is the primary access point to health care, with the GP acting as the gatekeeper to elective specialist and secondary care. In 2008 there were 300 million general practice consultations, of which 62 per cent were undertaken by GPs (Hippisley-Cox and Vinogradova 2009). The proportion of activity undertaken by nurses in general practice has grown markedly in the last 13 years, rising from 21 per cent in 1995 to 34 per cent in 2008, yet the consultation rate with GPs has remained almost constant, rising from 3.0 to 3.4 consultations per patient year in the same period (Hippisley-Cox and Vinogradova 2009). In 2008, GPs made 9.3 million referrals to secondary care (HES 2008), suggesting that around one in twenty GP consultations results in a referral to secondary care. Hospital Episode Statistics (HES) data shows that the number of GP referrals have increased by 14 per cent in the past three years (2005–2008).

The GP's role with respect to emergency care is less clear – especially as GPs are no longer required to provide care out of hours. However, they are still involved in referring 950,000 patients each year as emergency admissions to hospital: 21 per cent of total emergency admissions. The GP therefore plays a central role in ensuring that people receive a timely and accurate diagnosis – either from the GP him or herself, or from an appropriate specialist as a consequence of a GP referral. Figure 1 provides a simplified overview of the elective patient pathways through general practice. (Note that this pathway makes no specific reference to practice nurses and other professionals who work in the general practice setting and who may also play an important role.)

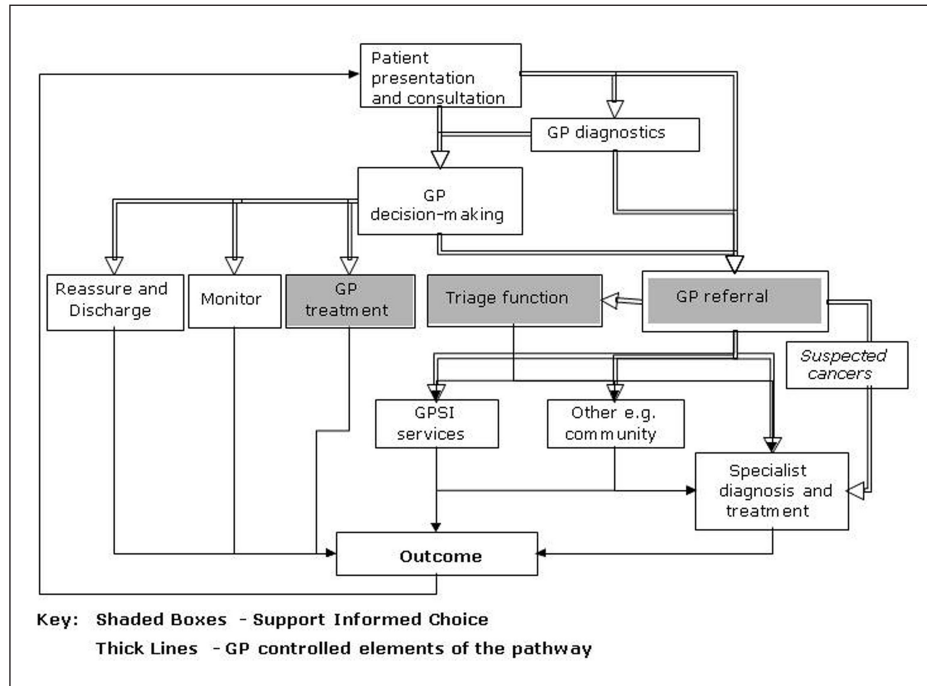
Figure 1: The quality of GP diagnosis and referral

Figure 1 covers both urgent and non-urgent presentations. Specialist diagnosis and treatment may be conducted in a range of settings, including A&E and hospital and community, thus in inpatient and outpatient settings.

While the pathway looks relatively straightforward, the evidence shows that complex and subtle judgements are involved. For example, the GP needs to consider social as well as physical factors, balance organic versus psychological causes, assess evolutionary and undifferentiated symptoms, and often work in the absence of reliable data on family history or even past patient history. As well as a complex decision-making process in assessing the patient (as services become more specialised), there is an increasingly complex array of services and clinical pathways available to the GP to support the future management of the patient.

The past ten years have seen a rapid growth in the number of published clinical guidelines to support referral from primary to secondary care. Some of the early guidance came in the National Service Frameworks (NSFs) published by the Department of Health, mainly in the period 1999–2005. The NSFs set out strategies for improvement for priority clinical areas. In some cases, but not universally, the NSFs set explicit clinical referral criteria and referral–specialist assessment timeframes. The referral guidance within the NSFs has since been largely superseded by the clinical guidelines published in the last five years by the National Institute for Health and Clinical Excellence (NICE).

NICE has now published nearly 100 clinical guidelines, often working collaboratively with the Royal Colleges and other professional representative bodies. The NICE guidelines are evidence based, and set out clear patient referral criteria and timeframes. NICE has also published referral advice (NICE 2001). This provides advice to support prioritisation of common

referrals from primary care to specialist services. It covers 11 conditions¹ selected because 'there is uncertainty about which patients might benefit from specialist services. Such uncertainties could result in variations in the care offered to patients' (NICE 2001, p 3).

The other major development has been the creation of the Map of Medicine. The map is an interactive web-based tool that provides 370 evidence-based care pathways drawing on NICE and other professional guidance. This resource is to be made accessible to all professionals working within the NHS. Meanwhile, the Connecting for Health Pathways of Care programme aims to make use of the Map of Medicine's 'a business as usual' activity. The public are able to access the Map of Medicine pathways online.

The introduction of referral management schemes, which triage GP referrals, have created a further complication for the referral process and the quality of that process. Some argue that referral management schemes can enhance quality by helping to ensure that the referral goes to the appropriate destination, and that it contains all the relevant information. Others believe that the triage function adds unnecessary steps in the patient pathway, and that in some cases it can compromise clinical decision-making and choice because of the financial incentives at play. At a later date, when further research evidence is available, the project will explore a range of issues presented by referral management schemes.

Given current policy commitments, informed choice is a particular issue when a referral is being made. This research project focuses on informed choice as one dimension of referral quality.

Methods

A literature review was conducted to identify published research. Search algorithms were constructed to search three bibliographic databases – PubMed, HMIC and ASSIA – for articles on GP diagnosis or referral (see Appendix C for search terms). The articles identified were screened for relevance. Those accepted for full review were supplemented with other articles identified manually, including a number of articles recommended by experts in the field. The numbers of articles initially identified are presented below in Table 1, along with the number of articles that were accepted for full review.

Table 1: Number of articles included in literature review

| Article type | Diagnosis | Referral |
|---|------------------|-----------------|
| Articles identified by initial bibliographic search | 1,778 | 2,218 |
| Articles reviewed in full | 115 | 257 |

A data extraction framework was developed to allow the content of these articles to be recorded systematically and analysed. The websites of the Royal College of General Practitioners, British Medical Association and Department of Health were also searched for relevant professional guidance and commentary.

1 The 11 conditions are: acne, acute lower back pain, atopic eczema in children, menorrhagia, osteoarthritis of the hip, osteoarthritis of the knee, glue ear in children, psoriasis, recurrent acute sore throat in children, prostatism in men and varicose veins.

Our findings were presented at a validation event attended by 26 participants, mainly comprising general practitioners. A full breakdown of participants is given in Table 2, below. We have incorporated the feedback from this event in the report.

Table 2: Participants attending validation event

| Participant type | Number attending |
|-------------------------|-------------------------|
| General practitioner | 12 |
| Other clinician | 2 |
| NHS manager | 3 |
| Voluntary sector | 3 |
| Patient representative | 3 |
| Academic | 1 |
| Department of Health | 1 |
| Other | 1 |

2 The quality of diagnosis in general practice in England

What is the role of general practice in diagnosis?

Diagnosis in general practice is a complex area of clinical activity without a simple definition. In theory, on seeing a patient presenting with a set of signs and symptoms, a GP may follow a simple, linear sequence from history-taking and examination through to a differential and then final diagnosis. However, the reality of the diagnostic process is often quite different (Elstein 1972). Heneghan *et al* (2009) have tried to summarise this more complex process by setting out the range of diagnostic strategies typically employed in consultations. Their model is summarised in the box below.

Diagnostic strategies in primary care

Stage 1: Initiation of diagnostic hypotheses

- 'Spot' diagnoses (unconscious, almost instantaneous, pattern recognition)
- Self-labelling (patient tells you what they perceive to be the diagnosis)
- Presenting complaint (most often used)
- Pattern-recognition trigger (elements in the history or examination or both).

Stage 2: Refinement of the diagnostic hypotheses

- Restricted rule-out (depends on learning the most common cause of the presenting problem and a shortlist of more serious diagnoses to rule out)
- Step-wise refinement (based on either the anatomical location of the problem or the putative underlying pathological process)
- Probability-based reasoning (specific but probably imperfect use of symptoms, signs, and tests to rule in or rule out a diagnosis)
- Pattern recognition fit (most often used – symptoms and signs are compared with previous patterns or cases and a disease recognised)
- Clinical prediction rule (formal version of pattern recognition fit, based on a widely validated series of similar cases).

Stage 3: Defining the final diagnosis

- Known diagnosis (<50 per cent cases, sufficient level of certainty to start treatment or rule out serious disease)
- Ordering further tests (to rule in or rule out a disease, or if no obvious pattern of disease)
- Test of treatment (response to treatment used to refute or confirm diagnosis)
- Test of time
- No diagnostic label applied (strategies could include re-calling patient for further review, using an exploratory investigation, sharing uncertainty with patient, and referral for second opinion).

Source: Adapted from Heneghan *et al* (2009)

As the box shows, the diagnostic process in general practice is more often a combination of shortcuts, loops and dead ends than a straight line from presentation to diagnosis. GPs may choose to jump to a diagnosis quickly based on experience rather than detailed examination, they may use a range of different methods for refining their diagnostic hypotheses, or they may not reach a precise point where a final diagnosis is actually made. Diagnosis can be dependent on treatment factors, with GPs applying a diagnostic label more as a justification for a decision to prescribe antibiotics than a reason for it (Howie 1972). Diagnosis can also occur without signs or symptoms if the GP chooses to practice opportunistic screening, which has been recommended for a number of conditions such as type 2 diabetes (Evans *et al* 2008) and depression among high-risk groups (Fairfield *et al* 2001).

This complex reality of the role of GPs in diagnosis is a result of the particular challenges faced by diagnosis in primary care (Summerton 2004; Howie 1972; Knottnerus 1991). These challenges include the following.

- **The challenge of assessing evolutionary and undifferentiated symptoms** Where a GP encounters disorders at an early stage and is confronted with vague or poorly differentiated symptoms, a certain diagnosis is difficult. The possibility that somatic complaints could be caused by psychological or social problems adds further to this complexity (Lindsey *et al* 2002).
- **The difficulty of probability-based reasoning and the weak predictive value of diagnostic tests in primary care** Correct assessment of the probability of specific diagnosis is a complex reasoning task made more difficult by the relatively weak predictive value of the tests and information at GPs' disposal (Summerton 2004).
- **Very low prevalence of certain conditions and the high degree of overlap in symptoms for serious and common conditions** For example, in lung cancer, which has a relatively high incidence, a GP with a list size of 2,000 patients and a case mix matching the UK average might see only one or two new lung cancer patients in a year (calculation based on Cancer Research UK 2006), whereas the core symptoms of lung cancer (cough and wheezing) are very common. Similarly, symptoms of acute otitis media overlap with those of the common cold.
- **The high prevalence of multiple co-morbidities** Studies suggest the majority of patients presenting in general practice have multiple problems, including physical, psychological and social (Fortin *et al* 2005).
- **Lack of reliable data on family history or past patient history** Patients may forget things, be unaware of facts (for example, regarding family history), fabricate information, or merge different symptoms into a single event (Barksy 2002).
- **The gatekeeping function of general practice** A GP who is keen not to miss any serious conditions could, for example, refer all patients presenting with unexplained fatigue to an endocrinologist, but the acute sector would become quickly overburdened and patients would be subjected to unnecessary investigations. GPs must therefore base their judgements partly on an awareness of the need to limit access

to specialist services to those most likely in need of them (Knottnerus 1991).

In conclusion, the role of general practice in diagnosis is probably best understood as a combination of problem recognition and decision-making. Or, as the Royal College has described it, rather than making a discrete diagnosis, often 'the GP's task is to formulate a problem list or definition that can open the gateway to further management' (RCGP 2007, para 8.18).

Underpinning this definition is a particular concern with what Marshall Marinker has described as 'marginalising danger' (Marinker 1997). Taking two well-accepted central features of high-quality care – maximising clinical outcomes and patient safety (Institute of Medicine 2001), a crucial role for the GP in problem recognition and decision-making is noticing and acting on signs and symptoms of possible serious illness.

High-quality diagnosis in general practice – what does it look like?

Given the complexity of the role the GP plays in diagnosis, a definition for high-quality diagnosis in general practice must also be complex. In *Good Medical Practice for General Practitioners* (RCGP/GPC 2008), the definition of 'good clinical care' partially covers these issues:

As a GP, you need to be skilful in acquiring information that relates to your patient and his or her presenting problem. Where possible, you should allow enough time so that you can assess problems that may underlie the presenting problem. You should have consulting skills that elicit sufficient clinical information for diagnosis and management... Your consulting style should be responsive to individual patients' needs... You should carry out appropriate physical examinations [so that] you would be able to identify an important problem if one was there.

(RCGP/GPC 2008, p 6)

Continuing with the reframing of diagnosis as a matter of problem recognition and decision-making, high-quality diagnosis means recognising the 'right' problems and making the 'right' decisions. This itself can mean gathering sufficient evidence and information, judging that evidence and information correctly, and then making the correct diagnosis (if that is possible). This is followed by the need to minimise delay in further investigation and onward management – particularly if the condition is serious, or suspected to be serious – ensuring efficient use of resources, and providing a good patient experience. These elements overlap with, and relate to, each other. Each of them is described below:

- **Gathering sufficient evidence and information** Achieving this element of high-quality diagnosis requires knowledge of signs and symptoms and their associated conditions. It also requires skills in history-taking and examination, and in doctor–patient communication. Neighbour (2005), for example, advises GPs to watch and listen in the first 15 seconds of a consultation, looking for internal search moments in patients as well as speech censoring and turbulence, to identify the real reasons for the patient's visit. The participants of our validation event expressed particular concern that some GPs try to limit their patients to raising one worry or symptom in any visit – the so-called 'one consultation, one problem' attitude.

As discussed above, the prevalence of complex, interacting multiple co-morbidities and undifferentiated symptoms in patients presenting in general practice is such that an approach like this risks failing to gather all the relevant clinical information from patients and providing an unsatisfactory experience for patients. Gathering sufficient evidence and information can also require access to diagnostic testing technologies (Evans *et al* 2007), tests of time (Almond and Summerton 2009) or tests of treatment (Glasziou *et al* 2009).

- **Judging the evidence and information correctly** This aspect of diagnosis requires the use of logic and judgement, and therefore requires knowledge of the predictive power of particular symptoms or tests (Doust 2009), skills in clinical diagnostic reasoning (Lilford and Thornton 1992), and skills in iterative diagnosis (Norman *et al* 2009). It can also require the use of guidelines, specialist advice and decision-support tools (Essex and Healy 1994). Importantly, however, it is also a matter of the GP drawing on his or her experience and skills to use mental shortcuts and make reasonable judgements in a short space of time, as recognised by Heneghan *et al* (2009) – sometimes referred to as part of the ‘craft’ of being a GP (Gillies *et al* 2009).
- **Minimising delay in further investigation and onward management** Particularly if a condition could be serious or progressive, minimising the time between presentation and further investigation and, ultimately, treatment and management is an important part of the diagnostic role of the GP. Issues here include the timely and correct ordering of tests, and timely follow-up (Daly and Collins 2007, Jiwa *et al* 2004). However, as discussed above, GPs can rarely be certain that a presentation is indicating serious disease. Indeed, in a US cohort study of 500 patients with common physical symptoms presenting to a family doctor, 70 per cent had improved within two weeks with no clinical intervention, and 60 per cent of the remainder had improved within three months (Kroenke, Jackson 1998).

Roger Neighbour (2005) therefore stresses the importance of ‘safety-netting’, where the GP backs up their working diagnosis and initial investigation or management plan with an explicit attempt to make predictions about and preparations to deal with alternative possible outcomes of the initial approach. This factor relates closely to the aspect of quality identified in our study of referral quality, which we have termed ‘pre-referral management’.

- **Ensuring efficient use of resources** This element of high-quality diagnosis involves seeking to avoid over-diagnosis and associated over-treatment, and to avoid unnecessary tests and investigations, thus limiting access to onward specialist care where it is unlikely to be of clinical or other benefit (Aragones *et al* 2006, Schattner 2008).
- **Providing a good patient experience** Throughout the diagnostic decision-making process, ‘high quality’ must also include ensuring a good patient experience, which includes good doctor–patient communication and involvement in decisions. Since much of the diagnostic process takes place within the consultation, good patient

experience of diagnosis is closely related to good patient experience of the consultation. Studies of doctor–patient communication in consultations recommend specific behaviours and values that GPs should seek to adopt to improve patient experience (Neighbour 1992 and 2005). Communication issues are, of course, particularly acute for patients who do not speak English or who have learning disabilities or low health literacy. Research has also led to the devising of a measure of patient satisfaction in consultations, in terms of patients' self-perceived 'enablement' (Mercer and Howie 2006).

In particular, when communicating diagnostic uncertainty, GPs can risk presenting information unclearly and creating a 'myth of certainty' for the patient about a course of action, even when evidence and uncertainty is discussed in the consultation (Griffiths *et al* 2005). This can have direct adverse clinical consequences if it leads to patients failing to return until their condition becomes unnecessarily worse (CEMACH 2008). Finally, in terms of involvement in decisions, the research on shared decision-making provides advice to GPs on how to involve patients in decision-making of all kinds, if the patient so desires (Elwyn *et al* 1999).

The current quality of diagnosis in general practice

There is no direct national data set or source of up-to-date information on the quality of diagnosis in general practice in England. It could be possible to judge the quality of diagnosis by proxy, by looking at data about the actions taken probably as a result of a diagnosis (referral, prescription, and so on) but these would not be perfect proxies, and are aspects of general practice being covered by other projects within the Inquiry.

Instead, there is both UK and international research evidence covering the following main areas:

- assessments of GPs' cognitive and other clinical abilities related to diagnosis, such as estimating risks and making diagnostic decisions
- retrospective research studies into the diagnosis of particular conditions, often seeking to identify factors leading to delayed or misdiagnosis
- studies of databases of negligence claims against GPs which cite errors in diagnosis
- studies demonstrating the usefulness of particular tests, or sets of signs and symptoms, to support the diagnosis of particular conditions
- evaluations of various types of interventions to improve GPs' diagnostic abilities.

This body of evidence does not provide a definitive assessment of the overall current quality of diagnosis in general practice in England. This is for several reasons. Many of the studies were conducted many years ago, some were conducted outside England, the research questions investigated only partially address the quality of diagnosis and cover only a limited number of conditions, and some of the studies have been independently assessed as being of relatively poor quality (Kostopolou *et al* 2008). In the case of studies

using medico-legal records as a source of evidence, further weaknesses include the time delay inherent in litigation, required confidentiality and the selective collection of information (Esmail *et al* 2004). However, the evidence does suggest that there is variation in the quality of diagnosis. It also points to some of the key factors that drive diagnostic errors, and the associated opportunities that there may be for improvement.

More recent work carried out as part of the National Awareness and Early Diagnosis Initiative (NAEDI) for cancer (see Appendix B) suggests some significant quality issues arising from delays in cancer diagnosis. This has prompted Professor Mike Richards, the National Cancer Director, to state that: 'The area where significant challenges remain is in the stage of diagnosis of cancer in England. Patients in this country are diagnosed later and with more advanced disease than elsewhere in Europe. Addressing this problem could save thousands of lives' (Richards 2009, p 5).

An example of delayed diagnosis was given in a recent analysis of significant event audits of lung cancer diagnoses in the north of England (Mitchell *et al* 2009). The audit found many cases of exemplary practice, but in a small proportion (9 per cent) of the cases reviewed there was also evidence of missed opportunities for earlier diagnosis. This example was cited in the audit as a case of potentially poor practice:

1 week history of cough in a 62 year old smoker treated as a viral infection. The next presentation was 22 weeks later. However, the patient had seven consultations before being referred 63 weeks after first presentation with cough. These consultations included complaints of chest pain (but tender over chest wall and acromioclavicular joint), pains in shoulder and neck, chesty cough, cough and chest pains diagnosed as chest infection, further chest infection, ankle swelling and pleuritic chest pain.

(Mitchell *et al* 2009, pp 24–5)

One part of the strategy to reduce delays in cancer diagnosis is to improve GP access to diagnostic tests, and the government has set a one-week target for access to tests, to be achieved over the next five years (Department of Health 2009c).

Gathering sufficient evidence and information

Several studies have demonstrated the challenge that this task can present the GP, given the nature of the conditions and symptoms often presented in general practice. Delays and errors in diagnosis have been identified as being due to:

- atypical presentations or unusual symptoms (Kostopoulou *et al* 2008; Bjerager *et al* 2006; Esmail *et al* 2004)
- non-specific presentations (Kostopoulou *et al* 2008; Jiwa *et al* 2004)
- the very low prevalence of the condition (Kostopoulou *et al* 2008; Esmail *et al* 2004)
- the presence of co-morbidity and pre-existing disease (Bjerager *et al* 2006; Calder *et al* 2000; Kostopoulou *et al* 2008; Macdonald *et al* 2006)

- perceptual features, meaning the missing of visual or auditory signs of a condition (Kostopoulou *et al* 2008).

One systematic review of research studies into diagnostic error in primary care particularly identified these sorts of issues and attempted to summarise studies into which conditions these sources of error have been identified for, as shown in Table 3, below.

Table 3: Conditions and associated features of difficulty in diagnosis

| Conditions | Features of difficulty | | | | |
|-------------------------------|--------------------------|------------------------------|------------------------|-----------------|------------------------|
| | 1. Atypical presentation | 2. Non-specific presentation | 3. Very low prevalence | 4. Co-morbidity | 5. Perceptual features |
| Breast cancer | X | | | | |
| Testicular cancer | X | | | | |
| Oral cancer | X | | | | |
| Myocardial infarction | X | | | | |
| Meningococcal disease | X | X | | | |
| Dementia and depression | X | | | X | |
| Asthma | | X | | | |
| Childhood cancers | | X | X | | |
| Upper GI cancer | | X | | | |
| Tremor in the elderly | | X | | | |
| Malig spinal cord compression | | X | X | | |
| Iron deficiency anaemia | | X | | | |
| Tongue cancer | X | | X | | |
| Retinoblastoma | X | X | X | | |
| Cancers (various) | | | | X | |
| HIV | | | X | | X |

Source: Adapted from Kostopolou *et al* (2008)

Other studies have identified other related factors that affect doctors' ability to gather sufficient information and evidence, such as GPs' lack of exposure to the condition (Abel *et al* 2008; Bjerager *et al* 2006; Blomgren and Pitkaranta 2003) and limited knowledge of signs and symptoms (Abel *et al* 2008; Bellamy and Smith 2007; Kassirer and Kopelman 1989).

Further studies identify low adherence to guidelines recommending what to look for in certain conditions (Bellamy and Smith 2007; Daly and Collins 2007; Esmail *et al* 2004); poor examination (Weingart *et al* 2009; Singh *et al*

2007); an over-reliance on patient symptoms and information, as opposed to signs and screening (Abel *et al* 2008); not doing a test or investigation (Calder *et al* 2000; Evans *et al* 2007; Singh *et al* 2007; Bouma *et al* 1999; Chapman *et al* 2001); and general uncertainty in diagnostic methods (Blomgren and Pitkaranta 2003).

One study found potential late diagnosis of type 2 diabetes mellitus among the patients that GPs did not know well, and argues that how well GPs know their patients could affect their ability to suspect conditions and gather the necessary evidence (Drivsholm and de Fine 2006).

Many of these issues were also identified in a 2003/4 analysis of 202 randomly selected claims in the Medical Protection Society and Medical Defence Union databases, which found that 50 per cent were accountable to diagnostic delay (Esmail *et al* 2004). Claims in four disease areas (meningitis, ischaemic heart disease, ovarian and cervical cancer and diabetes mellitus) were then analysed in detail. The major themes across the claims were: lack of knowledge and skills, diagnostic difficulties in newborns and children, and an insufficient level of suspicion regarding signs and symptoms of rare but life-threatening diseases.

Clearly, all these factors are closely related to each other – some overlapping, and some perhaps causing others – but each study has used its own taxonomy or categorisation process, which makes precise comparison difficult. Broadly, however, it is clear that a range of studies have identified various factors under our heading of ‘gathering information and evidence’ that can affect quality. Some of these factors are due to the nature of the presentations, and some to the knowledge and skills of the GPs.

Judging the evidence and information correctly

Several studies have assessed GPs’ ability to make accurate risk estimates and diagnostic decisions, some of which demonstrate significant variations in ability (Kassirer and Kopelman 1989; Singh *et al* 2007; Elstein *et al* 2002). Heller *et al* (2004) studied GPs’ and consultants’ ability to make accurate risk estimates of pre-rest probability for ischaemic heart disease in given hypothetical situations, and found that estimates ranged from 5 to 100 per cent probability of the disease being present, and 0 to 86 per cent risk of one-year mortality.

Evink *et al* (2000) sought to directly compare GPs’ diagnostic decisions with that of specialists, and found that family practitioners and paediatricians tended to make the same diagnoses of attention-deficit hyperactivity disorder. In contrast, Chen *et al* (2006) found that dermatologists were better at diagnosing cutaneous pigmented lesions than primary care physicians. Blomgren and Pitkaranta (2003) found that GPs based their diagnoses of acute otitis media on different factors to specialists, and GPs that over-diagnosed in comparison.

Elstein (2002) conducted a review of 30 years of psychological research on clinical diagnostic reasoning, and identified the following sources of error, as shown in the box below.

Sources of error in GPs' clinical diagnostic reasoning

Problem solving

- Failure to generate correct hypothesis
- Misperceiving or misreading the evidence
- Misinterpreting the evidence.

Decision-making: errors in estimate of probability

- Availability (rare cases are more memorable and are overemphasised)
- Representativeness (over-estimating probability by judging how similar a case is to a prototype)
- Probability transformations (when according to prospect theory small probabilities are overweighted and large probabilities are underweighted)
- Support theory/effect of description detail (more detailed case description given higher probability)
- Conservatism in revision of estimation (based on anchor of first probability estimate made, amount of revision normally insufficient)
- Order of presentation of information (later presented info weighted more than earlier presented info)
- Effect of benefits of detection (probably linked to perceived costs of mistakes).

Source: Adapted from Elstein (2002)

Other studies have identified related factors in the judgement of evidence, such as misinterpretation of data from the history and physical examination (Singh *et al* 2007; Elstein *et al* 2002), poor application and interpretation of tests (Macdonald *et al* 2006; Elstein *et al* 2002; Silk 2000; Mitchell *et al* 2009), and an overall failure to suspect the condition given the evidence presented (Bird 2002; Bird 2002; Bird 2005; Gilbert *et al* 2006; Singh *et al* 2007; Mitchell *et al* 2008; Evans *et al* 2007; Dovey *et al* 2002; Silk 2000; Esmail *et al* 2004; Mitchell *et al* 2009). Again, these factors relate to each other and cannot be neatly grouped, due to the different definitions used in the studies. However, here too there is a range of evidence of sources of error in this aspect of the diagnostic process.

However, it is important to emphasise again that the judgement of diagnostic information and evidence can remain a challenge in general practice for even the most knowledgeable and expertly reasoning of GPs, given the nature of the presentations they can face. The issue of medically unexplained symptoms is a case in point (see the box overleaf).

Medically unexplained symptoms

Medically unexplained symptoms are physical symptoms that lack a medically identifiable organic cause. Some studies suggest that one-fifth of initial appointments with GPs concern symptoms of this kind (Burton 2003). Patients with medically unexplained symptoms tend to access primary care services frequently, and are often subject to high levels of diagnostic investigation (Page and Wessely 2003; van der Weijden *et al* 2003). The costs associated with this are estimated to be considerable (Reid and Wessely 2002). Several studies have documented the frustration and powerlessness GPs can feel when dealing with patients who display such symptoms (Lindsey *et al* 2002; Steven *et al* 2001).

In some cases, patients with medically unexplained symptoms will in fact have an underlying psychological cause for their physical symptoms. GPs' first priority is often to rule out an organic illness before exploring possible psychological origin, and it has been suggested that this approach is one of the reasons for low detection rates for mental health problems in primary care (Greer and Halgin 2006). It has also been suggested that this approach can reinforce the patient's view that the cause is physical, which could exacerbate the symptoms – especially if the possibility of something other than an organic cause has not been discussed early on (Page and Wessely 2003; Tora *et al* 2004). It is therefore important to ensure that approaches used in consultation and diagnosis do not in themselves generate or maintain medically unexplained symptoms.

The example of medically unexplained symptoms shown in the box above illustrates the challenges faced by GPs in making diagnoses. It also indicates that high levels of physical examination and testing may not always represent a high-quality diagnostic process, and highlights the importance of exploration of psychological causes.

Minimising delay in further investigation and onward management

Some studies have specifically sought to measure 'diagnostic delay' times for serious conditions such as cancer (Allgar and Neal 2005) and acute myocardial infarction (Bouma *et al* 1999), demonstrating considerable variation in time between presentation and onward investigation or referral, in some cases. The factors causing these delays may well be issues of GPs' knowledge, skills and judgements, as discussed above.

Some laboratory-condition studies have shown that a GP's test-ordering behaviour is directly related to his or her preference for risk (Zaat and van Eijk 1992). However, they also reflect problems with wider system performance. Indeed, several studies do raise problems with GPs' access to investigations and tests. These include a lack of GP access to investigations (Daly and Collins 2007; Fuat *et al* 2003; Evans *et al* 2007), long waiting times for investigations (Bjerager *et al* 2006, Dovey *et al* 2002) and problems with missed test results (Wahls and Cram 2007; Dovey *et al* 2002). In cases where further tests are not immediately sought, many studies have argued that delay was caused by GPs not providing patient follow-up in a timely manner (Bird 2002; Bjerager *et al* 2006; Evans *et al* 2007; Jiwa *et al* 2004; Kantola *et al* 2001; Mitchell *et al* 2009).

Further studies have looked specifically at testing and investigation in general practice, in terms of the quality of subsequent referral. These studies are explored in section 3 of this report.

Some literature addresses the important question of whether diagnostic delay 'matters' in terms of clinical outcomes. To take cancer as an example, this evidence is clear for breast cancer but mixed for other cancers, possibly due to a range of methodological issues and inconsistencies in the studies (Neal 2009).

Ensuring efficient use of resources

Minimising delay and not missing serious diagnoses is clearly important, but over-diagnosis can be a problem too, since it leads to an inefficient use of resources and poor patient experience. For example, some studies have shown that depression can be over-diagnosed in patients who do not have signs of depression but who have antecedents of the disorder or of some form of psychological distress that may suggest future depressive episodes (Aragones *et al* 2006).

Meanwhile, over-testing represents an inefficient use of resources. There is evidence that tests are rising and that many of these are unnecessary, according to guidelines (Schattner 2008). Several studies have looked at how to minimise unnecessary test-ordering by GPs (Verstappen *et al* 2003; Winkens *et al* 1996). For example, one Dutch study tested a practice-based, multifaceted intervention comprising dissemination of guidelines, personalised graphical feedback (which included a comparison of each physician's own data with those of colleagues), and regular small peer-group meetings to discuss quality improvement over a six-month period. It found modest but significant success in reducing over-testing (Verstappen *et al* 2003).

Providing a good patient experience

Little of the literature that explicitly studies the quality of diagnosis has identified patient experience factors, outside of studies of doctor-patient communication more generally. In mental health, some literature discusses the perceptions of some GPs that a diagnostic label would have a negative effect on patient experience, and cite this as a reason for delay in diagnosis. Hansen *et al* (2008) studied how Australian GPs spoke about diagnosing dementia. Some GPs felt that diagnosing too early might be harmful to patients, and that they would pursue formal diagnosis only when they saw it leading to benefits to the patient such as access to services. A qualitative study of primary care professionals in the United Kingdom echoed some of these tensions about early diagnosis of dementia (Illiffe *et al* 2003).

While not specifically concerned with diagnosis, there is a small body of research that has looked at patient engagement within the general practice consultation. This literature, such as the work of John Howie *et al* (1999) on enablement, has identified a range of factors affecting patient engagement, several of which seem particularly pertinent to the quality of diagnosis, such as:

- the patient feeling that the GP listens carefully and allows the patient to tell their full story

- the patient feeling that the GP is empathetic, takes the patient seriously and is willing to learn about the patient's problems
- the patient feels that the consultation is long enough to discuss their problem.

This research has been reviewed by the Picker Institute as part of its research contributing to the Inquiry, and so is not discussed here (see www.kingsfund.org.uk/gpinquiry).

Approaches towards quality improvement

Education, training and decision support

Given the complexity of clinical diagnostic reasoning, there is a case for more education and training of GPs in these logical reasoning skills (Elstein 2002). Indeed, there is a particular case for making such training specific to general practice, since the positive predictive values of many symptoms or tests as taught in hospital training settings will not transfer to primary care accurately. This is because positive predictive value is affected by the population prevalence of the disease, which will be lower in primary care than in secondary care (Knottnerus 1985). This further reinforces the value of diagnostic reasoning training that includes probability-based assessments that are specific to primary care (Summerton 2004).

There is a degree of controversy, however, over how practical decision analysis is. Some have argued that formal medical decision-making analysis is impossible in daily practice because of methodological problems and because complex probability calculations are simply very hard to do (Zaat 1993). Others think that decision theory and other formal methods of using logic should be employed (Lilford and Thornton 1992;).

To make this sort of analysis easier, some recommend the use of clinical prediction rules. These rules quantify the contribution of signs, symptoms and diagnostic test results, and give a probability of a patient having a particular condition. Such rules have been developed and tested for many conditions, such as osteoporosis (Geusens *et al* 2008), adolescent depression (Zuckerbrot and Jensen 2006) and colorectal cancer (Hamilton *et al* 2005), and some large-scale studies have attempted to develop rules for patients presenting with common symptoms giving probability estimates for a range of diagnoses (Okkes *et al* 2002).

While clinical prediction rules are not universally yet of high quality, and few are used in practice at present (Falk, Fahey 2009; Fletcher 2009), the Standards for the Reporting of Diagnostic (STARD) accuracy studies initiative is one attempt to improve them (Bossuyt *et al* 2003). Meanwhile, computer-based clinical decision-support tools that can help with practical application in the clinic (Garg *et al* 2005) are increasingly being developed. One example of such a tool – Isabel – is described in the box on p 23.

The Isabel tool

Isabel is a web-based diagnosis and referral decision-support system designed to help clinicians in all settings, but particularly those in primary care, facing diagnostic uncertainty.

It is a dynamic diagnosis checklist, which, for any combination of signs and symptoms, will present back a list of likely diagnoses to consider. Each diagnosis is linked to knowledge from textbooks, journals and external web resources to help with further consideration. It can also be customised to signpost and deliver local pathways, and can be used on a standalone basis or fully integrated with most electronic medical records.

Isabel has been extensively validated over ten years, and is currently in use in hospitals and practices in the United States, United Kingdom and elsewhere. Early results from ongoing trials in UK primary care show that in 15 per cent of cases the GP felt that they no longer needed to refer their patient or use the consultant advice line after using Isabel, and that in about half of cases they felt that the use of Isabel helped them refer more appropriately.

More information is available at www.isabelhealthcare.com

Many studies of diagnostic error recommend increased education in a particular clinical area (Green *et al* 2005), and there have been many education and training interventions to improve diagnostic accuracy and the interpretation of test results that do demonstrate some efficacy (Chavannes *et al* 2004; LeHew *et al* 2009; Karli *et al* 2007 on headaches, Rosendal *et al* 2003). However, studies that include long-term follow-up of these interventions are lacking.

There is a continuing body of research, across a huge spectrum of conditions, that provides more evidence to inform the development of clinical guidelines for diagnosis in primary care (see, for example, Anderson *et al* 2005; Ankarath *et al* 2002; Ciafaloni *et al* 2009; Dincer *et al* 2008). But keeping up to date with these guidelines and evidence is challenging. Koldjeski *et al* (2005) argue that 'primary care providers should be urged to attend frequent state-of-the-art updates that regard early symptoms as manifestations of ovarian cancer' – obviously, a worthy aim – but a potentially very challenging task.

Getting advice from specialists has also been shown to improve GPs' diagnostic accuracy. Ely *et al* (2000) developed a taxonomy of clinical questions asked by family doctors in Iowa and Oregon, and found that the second and third most common question types asked were 'What is the cause of symptom x?' and 'What test is indicated in situation x?', suggesting these are important information needs for family doctors. We return to the issue of GPs' communication with specialists later in this report.

Access to diagnostic test technologies and feedback on over-testing

Several studies recommend greater use of diagnostic test technologies. For example, guidelines recommend use of spirometry for diagnosis of

chronic obstructive pulmonary disease (COPD) in general practice, but lack of training means it is sometimes used and interpreted incorrectly, and diagnosis of COPD remains imprecise (Bolton *et al* 2005). Others recommend use of a greater range of tests and instruments to aid early diagnosis of Alzheimer's disease (Marin *et al* 2002), greater direct access to echocardiograms to aid the diagnosis of patients with chronic heart failure (Khunti *et al* 2000; Sparrow *et al* 2003), and greater use of medical imaging in the diagnosis of back pain in general practice (Church and Odle 2007).

Greater use of near-patient testing – that is, testing that can be carried out on site without reference to a laboratory, and possibly sufficiently quickly to affect immediate patient management – could be useful, although more evidence is needed of their effectiveness (Delaney *et al* 1999). Some studies have found that GPs do not find this approach very useful, citing pressure on nurses' time as the major limitation (Hilton *et al* 1994).

However, determining the 'right' level of use of diagnostic test technologies in general practice is no simple task. Testing brings with it financial cost as well as potential human costs, such as false reassurance from false-negative result, unnecessary treatment, or further investigation from false positive results – and, for some tests, exposure to radiation, which in itself can be harmful.

In terms of limiting over-testing, a nine-year study of twice-yearly feedback on test ordering found that requests where feedback had included a recommended alternative reduced by 85 per cent, and requests without a suggested alternative reduced by 46 per cent (Winkens *et al* 1996). A related study found that practitioner characteristics such as years of experience and working hours per week in practice were related to test-ordering behaviour (Bugter-Maessen *et al* 1996). Multifaceted feedback strategies to reduce over-testing (where education in guidelines, comparisons with colleagues, personal graphical feedback and group meetings on improvement are used together) have been shown to be particularly effective (Verstappen *et al* 2003).

Individual and practice-level reflection, audit and assessment

Crucial to quality improvement in diagnosis is recognition of the importance of individual practitioner factors. Increased education in use of guidelines and computerised decision support will help some GPs, but there are important personal cognitive and experience factors in diagnostic decision-making that guideline usage would not necessarily affect (Elstein 2002; Heller 2004; Fuat *et al* 2003; Zaat and van Eijk 1992). This means that if quality improvement in diagnosis in general practice is to be effective, it needs to focus adequately on individual reflection and assessment.

At practice level, carrying out significant event reviews and audits into cases of possible missed or delayed diagnosis is a recognised methodology for reflection and learning (RCGP 1995) and is included in the Quality and Outcomes Framework.

System and process improvements

Having said that individual factors are important, for those delay and error factors identified that are due more to system or process error than practitioner error, the answer to improvement necessary lies with system and process change. Wahls and Cram's (2007) study of missed results encountered by primary care physicians in the Veterans Health

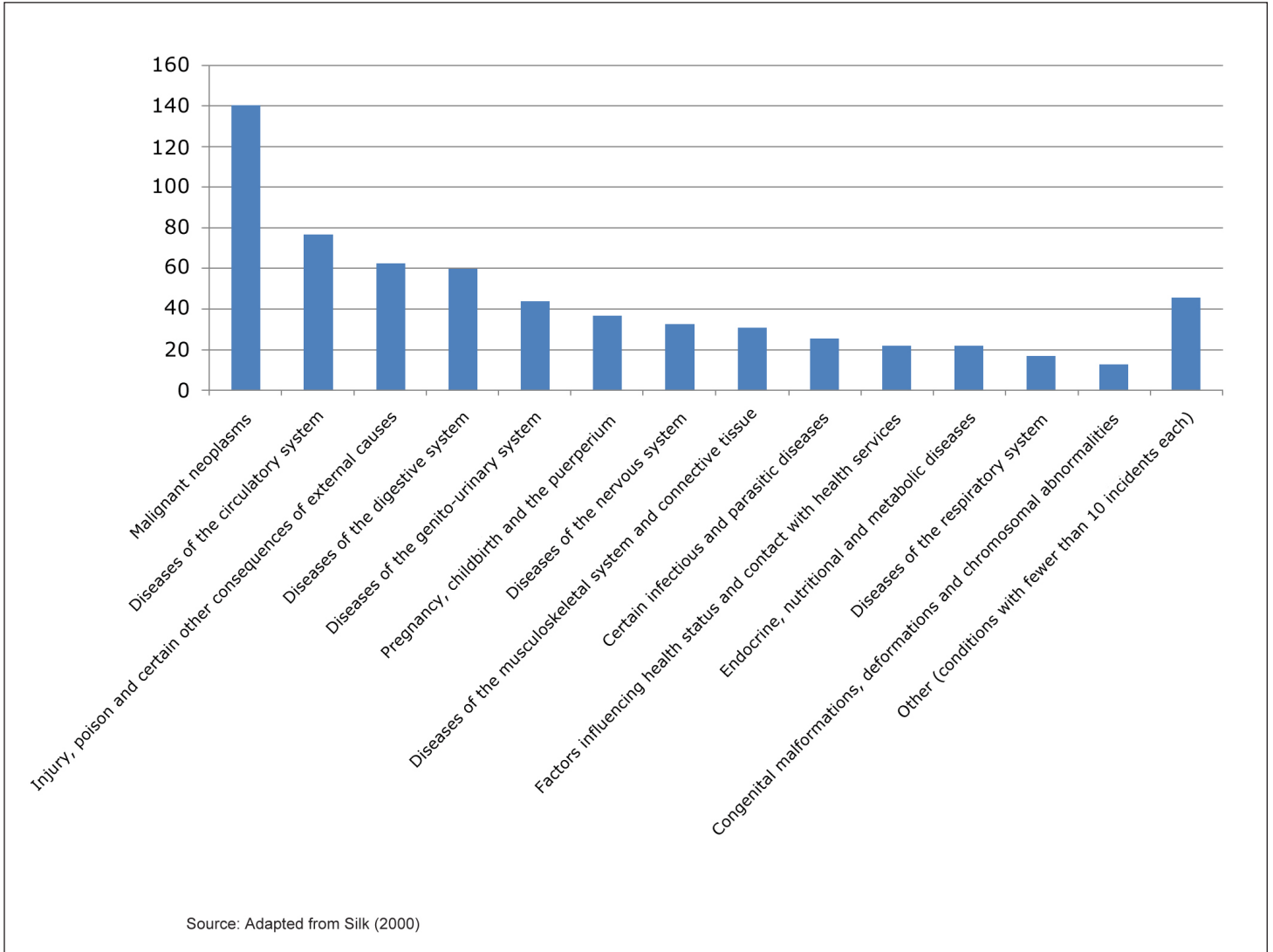
Administration found a significant number of missed results, including imaging studies, clinical laboratory tests, anatomic pathology and other tests, and recommends associated process improvements. Studies of poor follow-up also recommend improvements such as automatic call and re-call systems (Evans *et al* 2007) or follow-up appointments being booked at the time of the consultation (Mitchell *et al* 2009).

Key messages

- The role of the general practitioner in diagnosis is one of problem recognition and decision-making. A crucial aim of the GP in this regard is to marginalise danger, by recognising and responding to signs and symptoms of possible serious illness. Elements of high-quality care in this area include: gathering sufficient evidence and information, judging the evidence and information correctly, minimising delay in further investigation and onward management, ensuring efficient use of resources, and providing a good patient experience.
- Evidence for the current quality of these dimensions of diagnosis in general practice is limited to research studies, the nature of which makes them of little use in judging current quality. However, this evidence does suggest (though does not comprehensively prove) that there are a large range of factors relating to the knowledge, skills and attitudes of GPs – as well as wider system and process issues – that could be affecting the quality of diagnosis in general practice.
- The evidence of diagnosis improvement techniques provides some knowledge about which improvement techniques should be employed, in what circumstances, and with what results. These include education and training; provision of decision-support tools; improving access to testing technologies and providing feedback on over-testing; interventions focusing on individual and practice-level reflection, audit and assessment; and interventions to improve systems and processes.
- It would seem logical to prioritise further research and improvement efforts in those areas where error is particularly significant, but this too is hard to judge. Is lack of education in diagnostic reasoning more important than lack of direct access to certain diagnostic technologies? It is impossible to say. Are some clinical conditions more prone to serious diagnostic error than others?
- More audit and research is needed in England to replicate and extend some of the research conducted elsewhere in the world, or many years ago, and to better understand the quality of diagnosis in general practice at present. One study of 631 claims relating to diagnosis from the Medical Protection Society database (Silk 2000), divided by clinical condition, is set out in Figure 2, p 26. It shows that the greatest number of claims were for cancer, but we cannot with certainty infer from this evidence alone that cancer is the most significant clinical area where diagnosis is weakest. The recent analysis of significant events audits in the diagnosis of lung cancer and cancers in teenagers and young adults did identify a number of ways in which diagnosis could be improved, and some clear cases of poor quality care. However, overall it found that the recognition and referral process

documented was appropriate in the majority of cases (Mitchell *et al* 2009).

Figure 2: Analysis of 631 negligence claims against GPs related to diagnosis by condition



3 The quality of referral in general practice in England

What is a GP referral?

Approximately one in 20 GP consultations results in a referral being made to another service. Broadly speaking, referrals are made when a GP feels unable to manage a patient's care without specialist input. The referral process often involves a transfer of clinical responsibility from the GP to another professional. As the remainder of this report shows, a referral is often not a simple mechanical process but a highly complex interaction that involves multiple stakeholders and that is influenced by a wide range of factors.

It is important to recognise that referrals are not all alike. Research studies put forward several typologies for distinguishing between different types of referrals. For example, Coulter *et al* (1989) described the different reasons a GP may have for making a referral (with percentages, where available, from Bowling and Redfern 2000):

- to establish the diagnosis (52 per cent)
- for treatment or an operation (48 per cent)
- for a specified test/investigation which the GP cannot order (33 per cent)
- for advice on management (32 per cent)
- for a specialist to take over management (not known)
- for reassurance for the GP/second opinion (17 per cent)
- for reassurance for the patient and/or their family (7 per cent)
- for other reasons (11 per cent).

It is also necessary to distinguish between elective referrals and emergency referrals. Emergency referrals are likely to follow a different process to elective referrals, and in some cases may be less mechanistic. The dimensions of a high-quality emergency referral may therefore be different to those of an elective referral (see pp 42–3).

High-quality referral – what does it look like?

There is no commonly agreed definition of 'high-quality referral'. What emerges from our review of the literature is that quality is multi-dimensional. The following questions can be asked (adapted from Blundell *et al* 2010).

- **Necessity** Are patients referred as and when necessary?
- **Timeliness** Is this done without avoidable delay?
- **Destination** Are patients referred to the most appropriate destination first time?
- **Process** Is the process of referral a high-quality one, in the following respects:
 - Do referral letters contain the necessary information in an accessible format?

- Are patients offered a choice of time and location and supported in making this decision?
- Are the GP, patient and specialist able to construct a shared understanding of purpose and expectations of the referral?
- Is pre-referral management adequate?

This section describes each of these dimensions in turn, and discusses their importance.

Necessity

Necessity of referral is clearly an important dimension of quality, since there are patient- and system-level implications both of unnecessary referral of patients who could be managed in primary care, and of non-referral of patients who would benefit from specialist input. It is a dimension that many primary care trusts (PCTs) have focused on – for example, in their efforts to construct referral management systems.

However, referral necessity is a highly complex area. GPs vary in terms of the criteria they use for deciding whether a referral is needed (Chew-Graham *et al* 2008; Cummins *et al* 1981). This variation relates to a number of factors, and much of it may be warranted and appropriate (see pp 40–2). For example, it is generally accepted that a referral that is not clearly necessary on clinical grounds may still be justified in terms of providing reassurance to the GP or patient, and that the necessity of this reassurance will vary from one GP or patient to the next (Blundell *et al* 2010). Some GPs express concern that in certain cases refusal to make a referral can damage the GP–patient relationship (Baker *et al* 2006).

Necessity of referral is also dependent on context. In some cases, a referral may appear unnecessary in the sense that primary care management would be more appropriate, but in practice this depends on capacity and capability within primary care (Jones and Stott 1994). Assessments of necessity also vary between stakeholder groups (Roland *et al* 1991).

Timeliness

Delay in referral has clear implications for patient experience and in some cases for clinical outcome. For example, there is evidence linking late referral to poor outcome for people with renal disease (Levin 2000, Roderick *et al* 2002), psychotic illness (Brunet *et al* 2007) and certain forms of cancer (Richards *et al* 1999).

An important component of timely referral relates to the assessment of urgency. The inclusion of the GP's own assessment of urgency in referral letters can reduce the time between referral and treatment (Patel *et al* 2008). This has become a particularly high-profile issue in the case of the 'two-week rule' for suspected cancer referrals, which has shifted responsibility for assessment of urgency from specialists to GPs. If GPs are not able to make these assessments with sufficient predictive accuracy, the net effect of this shift may be to increase rather than decrease average waiting times for specialist assessment (Martin *et al* 2002).

Timeliness is dependent on several of the other dimensions of quality described here. For example, delays may be encountered if patients are

not referred to the correct destination or if referral letters do not contain adequate information for patients to be triaged appropriately.

Destination

Identifying the most appropriate destination for a referral is an important decision since there are clear implications for patient experience, clinical outcomes and resource use when patients are seen in a setting which is not the most appropriate, or when patients are referred to one service but then need to be diverted to another (Johnson *et al* 2008). In the case of referrals for specific operations or treatments, this decision may be relatively straightforward. The decision may be more complex, however, where the referral is for diagnosis, advice or reassurance – situations where there is inherently a higher degree of uncertainty. It is perhaps as a result of this that more referrals are sent to the inappropriate destination within medical specialties than within surgical specialties (Jenkins 1993).

The 'right destination' for any given referral is dependent on context, varying as a function of what options exist, for example, what community-based alternatives to secondary care are available. GPs' knowledge of these different options will have an effect on performance against this dimension of quality.

The decision of where to refer a patient is becoming more complex with increasing sub-specialisation in secondary care. Within this context, the question of destination is becoming ever more important as a dimension of quality.

Referral process

This dimension of quality includes issues relating to referral letters, shared expectations, patient choice, and pre-referral management.

Referral letters

As the principal means of communication between the referring GP and the specialist, the content of referral letters is a crucial dimension of quality. Without adequate referral letters specialists are less able to make decisions regarding risk assessment, triaging or resource allocation (Graydon *et al* 2008; Bodek *et al* 2006).

The necessary content of a good quality referral letter varies by referral type. Nonetheless there is a reasonably high degree of consensus about what details should usually be included (Newton *et al* 1991). Common elements described in the literature include the following:

- reason for referral and expected outcome a clear statement of the purpose and expectations of the referral (Grol *et al* 2003; Jenkins 1993; Tattersall *et al* 2002; Newton *et al* 1991; Bodek *et al* 2006; Srirangalingam *et al* 2006)
- diagnosis (Bodek *et al* 2006; White *et al* 2003; Speed and Crisp 2005)
- clinical signs and symptoms (Patel *et al* 2008; Srirangalingam *et al* 2006)

- examination or test results (Gran *et al* 2000; Molloy and O'Hare 2003; Tattersall *et al* 2002; Newton *et al* 1991; Speed and Crisp 2005; Kada *et al* 2007; Srirangalingam *et al* 2006)
- medical history including important co-morbidities (Jenkins 1993; McNeill 2008; Tattersall *et al* 2002; Newton *et al* 1991; Mead *et al* 1999; White, Marriott 2004; Srirangalingam *et al* 2006)
- current and past medication (McNeill 2008; Tattersall *et al* 2002; Tuomisto *et al* 2007; Newton *et al* 1991; White, Marriott 2004; Srirangalingam *et al* 2006)
- relevant psychosocial details (Jenkins 1993; McNeill 2008; Tattersall *et al* 2002; Mead *et al* 1999; White, Marriott 2004)
- GP's assessment of urgency (Patel *et al* 2008; White and Marriott 2004)
- known allergies (Tattersall *et al* 2002, Newton *et al* 1991, Mead *et al* 1999)
- patient's understanding of referral or of what information has been given to the patient already (White *et al* 2003; White and Marriott 2004).

The importance of each of these will depend on the particularities of each referral. For example, including details on social history may be more relevant for a frail elderly patient suffering a fall than for a young patient admitted after a heart attack (Mead *et al* 1999).

For mental health referrals, it is important to include relevant details on physical health, especially where these may interact with mental health or where the patient originally presented with somatic symptoms (Culshaw *et al* 2008). In the case of surgical referrals it is particularly important to include information that will allow the surgeon to assess risk. For emergency admissions to acute care, referral letters must contain enough information to allow admitting doctors to manage patients safely before other sources of information are available (Mead *et al* 1999).

Shared expectations

In high-quality referrals, patients should be aware of the reason for their referral, and specialists should understand the expectations of the referral held by the GP and patient (Grace and Armstrong 1986). For example, all parties should share an understanding of whether the primary reason for the referral is for advice, diagnosis, treatment, investigation or reassurance. This requires adequate communication between the GP and patient during the consultation, and clarity of purpose in referral letters. Differences in understanding may limit the value of referral and damage GP-patient relationships (Grace and Armstrong 1986).

One study found that patients who were involved in, and informed about, the referral process were more satisfied with their GP consultation (Greenhow *et al* 1998). The importance of this involvement and understanding seems to relate to a patient's sense of progress during the referral process. A patient who does not know what to expect of a referral is more likely to experience feelings of powerlessness and of being 'in limbo' (Preston *et al* 1999). This sense of making progress through the system appears to be a key aspect of the patient experience of referral.

A shared understanding between the GP and specialist is equally important. There is some evidence suggesting that referral letters that are assessed as being inappropriate are less likely to contain an explicit reason for referral. The association is not necessarily causal, but may indicate that GPs who fail to think through the exact reasons for referral are more likely to make inappropriate referrals (Jenkins 1993).

The construction of shared expectations requires that GPs have a good understanding of what specialist services are able to provide, and of what is likely to happen to the patient after the referral (Chew-Graham *et al* 2007; Watson *et al* 2001).

Patient choice

The majority of patients say they want a choice over where they receive hospital treatment (Appleby and Phillips 2009). The Department of Health requires GPs to offer all patients referred for elective care the choice to be treated at any clinically appropriate NHS or registered independent-sector provider (Department of Health 2007b).²

The GP has a key role to play in eliciting a patient's preferences, directing them to information to aid their decision and helping them to interpret that information and select a provider that fits with its preferences (Rosen *et al* 2005). GPs can use their experience and knowledge of local hospitals, as well as published performance indicators, to advise patients. Some patients will need extra support, and may want time to reflect on the information they have been given and to make a decision after their GP consultation (Health Link 2004). Without extra support for groups who find it difficult to choose, some fear that offering patients a choice will exacerbate health inequalities as less educated patients, or those who find it difficult to understand English, may miss an opportunity to choose a higher-quality provider (Appleby *et al* 2003).

In addition to offering patients a choice of provider, a high-quality referral should include an opportunity for the patient to choose the time and date of their appointment. An electronic appointment booking system called Choose and Book has been installed in GP offices to facilitate this, and should make appointments more convenient for patients and reduce the number of missed hospital appointments (Department of Health 2004).

There is some debate as to whether GPs have time to provide the support needed to help patients choose, and GPs show some resistance to offering choice (National Audit Office 2006; Rosen *et al* 2007) and to using the Choose and Book system (National Audit Office 2005). However, one study found that the modal number of referrals eligible for choice made by a GP each week was two (Taylor *et al* 2004). The extra time required to support these patients is therefore likely to be small.

² The following referrals are exempt: urgent referrals for suspected cancer or to rapid access chest pain clinics, maternity referrals, mental health referrals, and some very specialist referrals such as specialist paediatric work, where few provider options are available. In areas where referral management or clinical assessment centres operate, GPs refer patients to the centre, which then assesses them and offers a choice if elective referral is deemed appropriate.

Pre-referral management

High-quality referral depends not only on the referral itself, but on what happens in primary care before the referral. Specialists stress the importance of 'working up' the patient in primary care, performing relevant tests, examinations and risk assessments prior to referral (Chew-Graham *et al* 2007; Bowling and Redfern 2000), although there is some disagreement on how thorough GPs' assessments should be (Chew-Graham *et al* 2007).

It is important that, as well as performing necessary tests and investigations, GPs are able to interpret the information gathered correctly. There is some evidence to suggest that poor information gathering, or misinterpretation of the information gathered, is a common cause of inappropriate referral (Jenkins 1993).

However, there is a limit to the extent to which investigations and tests can be usefully performed in primary care. Specialists are not always able to use GPs' test findings, for a variety of reasons, and sometimes need to repeat what has already been done. In some situations it may be more useful for GPs to concentrate on tasks such as accurate history-taking rather than performing investigations that would be better done in secondary care (Springall *et al* 1988).

Conclusions

Quality in referral is multi-dimensional. As we have seen, the research literature identifies at least seven dimensions: necessity, timeliness, destination, and process, including the content of referral letters, patient choice, construction of shared understandings between stakeholders, and pre-referral management. Much attention has been given to reducing 'unnecessary' referrals to specialist care, but the literature suggests that the process of identifying those referrals is highly complex. Focusing on other dimensions of quality is of at least equal importance.

The quality of current GP referral

The available research evidence is not adequate to support a comprehensive assessment of the current quality of GP referral. However, it does indicate some areas where improvements could possibly be made. This section describes the evidence relating to quality in each of the dimensions described in the previous section. It also discusses the variation that exists between GPs in the United Kingdom in terms of their referral rates and asks what, if anything, can be deduced from this. It concludes by exploring the important distinction between emergency and elective referrals.

Necessity

Qualitative studies suggest that necessity, as defined in a narrow clinical sense, is not the sole determinant of a GP's decision to refer. Nandy *et al* (2001) found that referrals could be divided into proactive 'referrals to', where the GP has defined expectations of the outcome of the referral, and 'referrals away', which are primarily a response to feelings of frustration, time limitations or a sense that GP management has failed. In a similar vein, Clemence and Seamark (2003) distinguished between three kinds of referrals to physiotherapy:

- **appropriate referrals** in which the focus is wholly on patient benefit
- **load-sharing referrals** in which the intention is to share responsibility with other professionals as part of a planned management strategy that is hoped to be of some benefit to the patient
- **dumping referrals** in which the primary aim is to relieve pressure on the GP, with little expectation of patient benefit.

In some cases, GPs make a referral because they perceive a need to 'do something' but cannot afford to spend any more time on the consultation (Bowling *et al* 2006). Similarly, limitations on capacity and capability may mean that for some patients who could theoretically be managed in primary care, a referral may be necessary in practice (Jones and Stott 1994). This illustrates that the necessity of referral needs to be considered in relation to local context.

Quantitative studies suggest that, in some specialties at least, it may be legitimate to question the necessity of a proportion of the referrals made (see Table 3). However, such findings should be treated with caution. This is because it is not always possible to balance such figures against the (often unknown) number of patients who may need a referral but fail to receive one. If there is any trade-off between the sensitivity and specificity of the referral decision, it may be difficult to decrease unnecessary referrals without increasing the number of patients who would benefit from a referral but are not offered one.

Also, it should be noted that different stakeholders do not always agree on assessments of necessity. In a study of musculoskeletal referrals, 43 per cent of referrals rated as 'probably' or 'definitely unnecessary' by the GP were rated as 'definitely appropriate' by the consultant (Roland *et al* 1991). Perhaps unsurprisingly, evidence suggests that patients almost always see their referral as necessary (Bowling and Redfern 2000).

Table 3: Summary of evidence on necessity of GP referrals

| Study | Speciality | Key findings on quality |
|-----------------------------|---------------------|---|
| Jones and Stott (1994) | All referrals | 35% of 168 referrals could have been managed in primary care |
| Roland <i>et al</i> (1991) | Musculoskeletal | 23% of referrals to orthopaedics assessed by specialists as being unnecessary and more appropriate for primary care management. GPs considered 11% of referrals unnecessary |
| Patel <i>et al</i> (2000) | Cancer | 28% of urgent referrals and 37% of non-urgent referrals assessed as unnecessary |
| Bowling and Redfern (2000) | General outpatients | 95% of patients rated their referral as necessary |
| Forrest <i>et al</i> (2003) | Children | GPs refer young children more readily than older children with equivalent need, suggesting lower confidence levels and referral thresholds for younger children |

Timeliness

There is evidence of late GP referral for several kinds of cancer (for example, Khattak *et al* 2006; Clark *et al* 2005), although in the majority of cases GPs refer within recommended timeframes. An important component of cancer referral relates to the assessment of urgency. The ‘two-week wait’ system for suspected cancer referrals introduced in the United Kingdom gives GPs the responsibility for making an initial assessment of urgency, and there is a growing evidence base questioning GPs’ ability to do this accurately (for example, Khawaja and Allan 2001; Potter *et al* 2007). Cancer referrals are explored in detail in the separate case study report presented in Appendix B.

Late referral also appears to be a particular issue for nephrology. Many patients start kidney dialysis late, resulting in a poorer prognosis (Roderick 2002).

It is important to distinguish between delays in referral and other sources of delay outside of the GP’s control. A study comparing the relative contribution of different sources of delay in treatment of psychosis found that only a small part of the overall delay can be attributed to delayed GP referral, compared to delayed help-seeking behaviour or delay within specialist services (Brunet *et al* 2007).

Table 4: Summary of evidence on timeliness of GP referrals

| Study | Speciality | Key findings on quality |
|------------------------------|---------------------------|---|
| Roderick <i>et al</i> (2002) | Nephrology | 38% of 250 patients were referred late, and 45% of these late referrals were assessed as avoidable. Of direct referrals from GPs, 16% were late, and in 36% of these were avoidable |
| Levin (2000) | | 20–50% patients starting dialysis are late referrals |
| Brunet <i>et al</i> (2007) | Mental health (psychosis) | 9% of overall delay can be attributed to delayed GP referral, compared to delayed help-seeking behaviour or delay within specialist services |
| Clark and Thomas (2005) | Cancer | 8%–14% of GP referrals to soft-tissue sarcoma unit deemed too late |
| Khattak <i>et al</i> (2006) | | 38% of patients with colorectal cancer not referred in 6 weeks |
| Potter <i>et al</i> (2007) | | Specificity of two-week wait referrals has declined each year from 1999 to 2005. 90% of two-week wait patients have benign disease |
| Khawaja <i>et al</i> (2001) | | 50% of two-week wait referrals assessed by specialists as either inappropriate or non-urgent |
| Bestall <i>et al</i> (2004) | Palliative care | Often too late at crisis point when hospice admission impossible |

Destination

Evidence suggests that, within particular areas, there is scope for improvement on this dimension of quality. Getting the right destination appears to be more challenging in the case of medical specialties rather than surgical specialties (Jenkins 1993), and can be a particular issue for musculoskeletal referrals, with a lack of clarity over whether patients are best sent to orthopaedics, rheumatology, physiotherapy or elsewhere (Speed and Crisp 2005).

Several studies look at the proportion of referrals to secondary care that could have been seen in community settings. The evidence suggests particular opportunities for diversion in the case of dermatology and musculoskeletal referrals.

Table 5: Summary of evidence on destination of GP referrals

| Study | Speciality | Key findings on quality |
|---|----------------------|--|
| Jenkins (1993) | General outpatients | 7% of referrals to medical specialties and 2% of referrals to surgical specialties assessed as having been referred to the wrong speciality |
| Clews (2006) Salisbury <i>et al</i> (2005) | Dermatology | Around 50% of referrals could have been treated in community settings 49% of referrals could have been treated by a GPSI |
| Speed and Crisp (2005) Clews (2006) | | 27% of referrals to orthopaedics were more appropriate for rheumatology Around 50% of referrals could have been treated in community settings |
| Gilbert <i>et al</i> (2005) | Respiratory medicine | 23–58% of referrals could have been treated by a GP with special interests (GPSI) |
| Coulston <i>et al</i> (2008) | Hernia | 84% referred to general surgeon or as an open referral – only 14% referred to hernia specialist |

Referral processes

Referral letters

The quality of referral letters is a heavily researched area. There is strong evidence suggesting that quality could be improved for at least a substantial minority of letters. In one survey, 38 per cent of specialists in outpatient departments reported that referral letters contain inadequate information ‘fairly often’ or ‘very often’ (Bowling and Redfern 2000). In a study examining emergency referrals, 17 per cent of referral letters were assessed as containing ‘inadequate’ information by the admitting doctor (Mead *et al* 1999). Meanwhile, several studies have found that a proportion of referral letters do not contain sufficient detail to allow specialists to make reliable decisions about prioritisation and triage (Webb and Khanna 2006; Patel *et al* 2008) or to decide on the most appropriate destination for the referral (Speed and Crisp 2005).

The adequacy of the content of a referral letter varies from one referral to the next, but a general consensus is that it is often useful to include information on a number of factors, as listed in the previous section. For each of these, Table 5

shows the percentage of GP letters that fail to include adequate information, as reported in the research literature. This indicates weaknesses in several areas.

Nearly all letters contain some description of the reason the patient is being referred. However, this description is often limited. For example, in a study of cardiovascular referrals, while an indication of the reason for referral was given in 98 per cent of cases, in 48 per cent this was limited to a list of symptoms. In 79 per cent there was no indication of the GP's expectations of the referral (Bodek *et al* 2006). Another study found that 36 per cent of letters contain a medical history but no other details (Elwyn *et al* 1999).

The studies cited in Table 5 suggest that in around half of all referral letters the GP does not offer a clinical diagnosis. Diagnosis is not possible for 100 per cent of patients, but GPs may be able to include their hypotheses and tentative diagnosis. Other information for which there is evidence of poor reporting includes the results of examinations and investigations, the GP's own assessment of urgency, and relevant psychological and social details. Details on what information has been given to the patient regarding the referral are rarely included.

While there is usually some description of symptoms, the severity of these symptoms is sometimes inadequately recorded (Burbach and Harding 1997).

For mental health referrals, a particular issue appears to be the inclusion of relevant details about physical health problems. One study reported that 71 per cent of letters do not mention physical health (Burbach and Harding 1997). Another found that only 5 per cent gave information of physical examinations or investigations, despite the fact that 40 per cent of these patients originally presented with somatic symptoms (Culshaw *et al* 2008).

The finding that 'some GPs do not believe the consultant reads the letter of referral' (Jiwa and Burr 2002, p 342) suggests that perceptions around professional roles and the function of referral letters may limit the information that some GPs include. These perceptions inform internalised standards of case presentation (Dowie 1983).

Table 5: Summary of evidence on quality of referral letters

| Content item | Study | Specialty | % of letters with missing, incorrect or unsatisfactory information |
|-----------------------------|---------------------------|-----------------------|--|
| Reason for referral | Jenkins (1993) | General outpatients | 8 |
| | Bodek <i>et al</i> (2006) | Cardiology | 2 |
| | White <i>et al</i> (2003) | All specialties | 0 |
| | Taylor and Markar (2002) | Learning disabilities | 9 |
| GP expectations of referral | Bodek <i>et al</i> (2006) | Cardiology | 79 |
| | Jenkins (1993) | General outpatients | 12 |

| | | | |
|-----------------------------|------------------------------|-----------------------|--------------------------|
| Diagnosis | Bodek <i>et al</i> (2006) | Cardiology | 68 |
| | White <i>et al</i> (2003) | All specialties | 50 |
| | Mitchell <i>et al</i> (2008) | Emergency care | 13 |
| | Speed and Crisp (2005) | Musculoskeletal | 63 |
| | Mead <i>et al</i> (1999) | Emergency care | 25 |
| | White <i>et al</i> (2003) | All specialties | 50 |
| | Burbach and Harding (1997) | Mental health | 41 |
| | Taylor and Markar (2002) | Learning disabilities | 17 |
| Signs and symptoms | Patel <i>et al</i> (2008) | Vascular | 90 |
| | Burbach and Harding (1997) | Mental health | 53 |
| | Taylor and Markar (2002) | Learning disabilities | 24 |
| Examination results | Molloy and O'Hare (2003) | Medical outpatients | 72 |
| | Speed and Crisp (2005) | Musculoskeletal | 68 |
| | Mead <i>et al</i> (1999) | Emergency care | 42 |
| | White <i>et al</i> (2003) | All specialties | 46 |
| Investigation results | Molloy and O'Hare (2003) | Medical outpatients | 32 |
| | Speed and Crisp (2005) | Musculoskeletal | 58 |
| | Taylor and Markar (2002) | Learning disabilities | 71 |
| Details on prior management | Speed and Crisp (2005) | Musculoskeletal | 41 |
| Medical history | Jenkins (1993) | General outpatients | 28 |
| | McNeill (2008) | Stroke | 9 |
| | Mead <i>et al</i> (1999) | Emergency care | 20 (recent) 31 (past) |
| | Elwyn <i>et al</i> (1999) | Prostatism | 50 |

| | | | |
|-------------------------------|----------------------------|-----------------------|----|
| Current/past medication | McNeill (2008) | Stroke | 12 |
| | Jenkins (1993) | General outpatients | 26 |
| | Mead <i>et al</i> (1999) | Emergency care | 28 |
| | Burbach and Harding (1997) | Mental health | 66 |
| | Elwyn <i>et al</i> (1999) | Prostatism | 63 |
| | Taylor and Markar (2002) | Learning disabilities | 31 |
| Relevant psychosocial details | Jenkins (1993) | General outpatients | 21 |
| | McNeill (2008) | Stroke | 63 |
| | Mead <i>et al</i> (1999) | Emergency care | 74 |
| Known allergies | Jenkins (1993) | General outpatients | 12 |
| | Mead <i>et al</i> (1999) | Emergency care | 84 |
| Assessment of urgency | Patel <i>et al</i> (2008) | Vascular | 66 |
| | Coxon <i>et al</i> (2003) | Cancer | 87 |
| | Burbach and Harding (1997) | Mental health | 81 |
| Information given to patient | White <i>et al</i> (2003) | All specialties | 98 |

Shared expectations of referral

Evidence suggests that GPs, consultants and patients often do not share a common understanding of whether a referral is primarily for diagnosis, investigation, treatment or reassurance. Grace and Armstrong (1986) found that in two-thirds of cases there is disagreement on this. For example, of those patients referred by the GP for a specific investigation, 52 per cent were understood by the consultant to be referrals for diagnosis, while another 19 per cent were thought to be referrals for treatment.

Qualitative evidence suggests there is particular scope for mismatch between patients' expectations and those of their GP in the case of referrals for chronic health problems, stigmatising conditions and problems thought to be of psychological or social origin (Preston *et al* 1999). Mental health referrals have also been identified as an area where there can be differences of understanding between GP and specialist (Broomfield *et al* 2001).

In one study, 16 per cent of outpatients were unclear about why they had been referred (Molloy and O'Hare 2003). A lack of understanding about what to expect can produce feelings of anxiety and may negatively affect the experience of care (Preston *et al* 1999). Given the finding reported above (see p 35) that referral letters sometimes fail to include full details about the reason for referral and associated expectations, lack of clarity on the part of the patient represents a further communication failure, with potential consequences for quality of care.

GP perceptions may present a barrier to achieving this dimension of quality. There is evidence that some GPs feel it is 'unnecessary, if not presumptuous to tell the consultant what they want from a referral', and that some specialists 'are not interested in the reason for referrals' (Grace and

Armstrong 1986, p 146). Consistent with this, evidence from the Netherlands found that specific requests in letters from GPs rarely receive an explicit answer in specialists' reply letters (Grol *et al* 2003).

Table 6: Summary of evidence on shared understanding of purpose

| Study | Speciality | Key findings on quality |
|--------------------------------|-------------------------------------|--|
| Grace and Armstrong (1986) | 11 medical and surgical specialties | In 67% of cases, there was no shared understanding of reason for referral between GP, patient and consultant |
| Molloy and O'Hare (2003) | Medical outpatients | 16% patients did not understand reason for referral |
| Broomfield <i>et al</i> (2001) | Mental health | Referring GP and recipient psychologist disagreed on 'reasons for care' in 40% of cases. One-third of anxiety referrals and half of depression referrals were treated differently than envisaged by GP |
| Watson <i>et al</i> (2001) | Cancer genetics | Common misconceptions among GPs – 31% thought that patient would have genetic testing. In reality, this is rarely performed |

Patient choice

There is little evidence as to whether GPs support patients to choose a hospital that fits with their preferences. A Department of Health-funded research project examining this question has recently been published by The King's Fund (Dixon *et al*). The main source of information currently available is the Department of Health's bi-monthly monitoring survey (Department of Health 2009a), which shows that many patients were not offered a choice, did not discuss options with their GP, and did not attend the hospital they wanted. The main results of interest are outlined in Table 7 below.

Table 7: Summary of evidence on patient choice

| Study | Area | Key findings on quality |
|------------------------------|---|--|
| Department of Health (2009a) | Offering choice | 47% of patients re-called being offered a choice of provider. Variation by PCT ranged from 27% in Newcastle PCT to 80% in Solihull PCT |
| Green <i>et al</i> (2008) | | 41% of patients in one hospital's outpatient department re-called being offered a choice |
| Department of Health (2009) | Awareness of choice | 50% of patients aware that they had a choice of hospital before visiting their GP |
| Department of Health (2009a) | Patients attending the hospital they wanted | 89% of patients who were offered choice went to the hospital they wanted, compared to 46% of those who were not offered choice |
| Hansard (2009–10) | Choose and Book usage | 53% of GP referrals made through Choose and Book |
| Department of Health (2009a) | GP support | 41% of patients discussed which hospital they should go to with their GP |

Pre-referral management

Several studies suggest that for a proportion of patients it would be beneficial if GPs performed more thorough investigations or examinations before making the decision to refer, or started preliminary treatment in primary care. There may also be shortcomings in the interpretation of the information gathered (Jenkins 1993).

Table 8: Summary of evidence on pre-referral management

| Study | Speciality | Key findings on quality |
|--|---------------------|---|
| Bowling and Redfern (2000) Jenkins (1993) | General outpatients | In 22% of referrals, specialists reported that the GP could have done more before referral. 42% of specialists said that GPs do not perform adequate pre-referral investigation or treatment Referral letters for referrals assessed as inappropriate all showed evidence of misinterpretation of clinical symptoms/signs or investigation results |
| Molloy and O'Hare (2003) | Medical outpatients | Inadequate pre-referral investigations performed in 55% of cases. Where performed, results were not enclosed in 32%. In 61% of cases treatment could have been started before referral, but in 36% of these cases this was not done |
| Bodek <i>et al</i> (2006) | Cardiology | 56% of patients received neither basic investigation or treatment before referral |

Variation in referral rates

When examining the quality of referral practices, a common approach has been to measure variation in referral rates. Some studies have reported up to tenfold variation between the rates at which GPs refer to a particular specialty within a single area (Ashworth *et al* 2002; Creed *et al* 1990). Some of this can be accounted for by random variation (Moore and Roland 1989; Noone *et al* 1989) or by differing levels of morbidity between different groups of patients (O'Sullivan *et al* 2005). It is therefore likely that the extent of 'real' variation in referral behaviour is less than tenfold (O'Sullivan *et al* 2005). However, neither chance nor differing morbidity levels can account for all of the variation observed, and a large number of studies have explored associations between non-clinical factors and referral rates.

Table 3.8 lists a range of factors that have found to be associated with referral rate. A systematic review found that for some of these, the evidence base is conflicting (O'Donnell 2000). For example, some studies have found an association between GP age or experience and referral rate, while others have not. The review also noted that none of these factors alone exerts a strong influence on the decision to refer, and no study has been able to account for all variation in referral rates. Taken together, patient characteristics (such as age, sex and social class) and practice characteristics (such as size and distance from the nearest hospital) may explain up to 50 per cent of the observed variation (O'Donnell 2000).

There is good evidence that patient pressure and preferences can play some part in the decision to make a referral (Bowling *et al* 2006; Gardener, Chapple 1999; Roland *et al* 1991). The role played by patient pressure seems to be stronger when the GP does not perceive a clear medical need (Little *et al* 2004) and for some specialties more than others – particularly psychiatry, rheumatology, dermatology and orthopaedics (Armstrong *et al* 1991).

There is also good evidence that referral is influenced substantially by GPs’ cognitive or psychological characteristics (Baker *et al* 2006; Calnan *et al* 2007; Forrest *et al* 2006; Franks *et al* 2000b; Grimble *et al* 2003; Herrington *et al* 2003; Ingram *et al* 2009; de Marco 1993; Dowie 1983) – for example, their:

- willingness to tolerate risk and uncertainty
- fear of accusations of malpractice
- sensitivity towards patient demands
- attitudes towards hospital admission
- beliefs about the benefits of referral to particular services.

This suggests that referral decisions are informed not only by clinical considerations but by the personal referral thresholds constructed by each GP on the basis of their values, skills and experiences (Newton *et al* 1991). In the case of mental health referrals, these types of characteristics have been found to have more of an impact on referral rates than more stable characteristics such as the GP’s age, gender or ethnicity (Kravitz *et al* 2006; Ashworth *et al* 2002).

Table 9: Factors associated with referral rate

| GP or practice factors | Patient factors | Structural factors |
|---|-----------------------------|---|
| GP beliefs or expectations about benefits of referral | Severity of symptoms | Distance to specialist service |
| GP age or experience | Desire for referral | Area deprivation |
| GP gender | Age | Availability or accessibility of specialist care |
| Degree of training in relevant specialty | Gender | Availability of specialist care |
| GP–patient relationship, congruence between GP’s and patient’s attitudes | Social class | Availability of community alternatives to specialist care |
| GP relationship with specialist | Diagnosis | Time available for consultation |
| Practice size | Co-morbidities | |
| Fund-holding history | Help-seeking behaviour | |
| Services available in practice | Perception of the problem | |
| GP psychological characteristics – for example, ability to tolerate uncertainty, concern that non-referral might damage patient relationships | Attitudes towards treatment | |

Sources: Armstrong *et al* (1988); Armstrong *et al* (1991); Ashworth *et al* (2002);

Baker *et al* (2006); Balduf and Farrell (2008); Bowling *et al* (2006); Calnan *et al* (2007); Campbell *et al* (2003); Carlsen *et al* (2008); Chen (2001); Cowen and Zodet (1999); Forrest *et al* (2006); Forrest *et al* (2003); Franks *et al* (2000a); Gardener and Chapple (1999); Grimble *et al* (2003); Herrington *et al* (2003); Hugo *et al* (2000); Hull *et al* (2002); Ingram *et al* (2009); Kravitz *et al* (2006); Little *et al* (2004); de Marco (1993); Newton *et al* (1991); O'Donnell 2000; O'Neill and Kuder (2005), Suter *et al* (2006); Trude and Stoddard (2003)

There are important questions concerning the relation between variation in referral rates and referral quality. It is clear from the research literature that referral rates do not provide a straightforward measure of referral quality (Anthony 2003; Fertig *et al* 1993; Knottnerus *et al* 1990; Reynolds 1991). Inappropriate referral may account for only a small amount of variation in referral rates. In one study, removing inappropriate referrals reduced a 2.5-fold variation to a 2.1-fold variation (Fertig *et al* 1993). A study in the Netherlands found that the same distribution of referral quality existed among high-referring GPs as among normal referrers (Knottnerus *et al* 1990).

Interpreting information on referral rates is complicated further by the high number of factors influencing a GP's likelihood of making a referral. For example, a low referrer may be missing patients who would benefit from referral, or may simply have a greater range of services and professionals available in house, thus preventing the need for referral.

There is also a question about the extent to which the variation 'matters' in the sense of having an impact on outcomes, costs or patient satisfaction. A study in the United States found that despite wide variations in referral rates from primary care, there was no relationship between referral rate and patient outcomes or costs after adjusting for case mix. This suggests that low referrers and high referrers are able to generate equivalent outcomes – perhaps because differences in referral behaviour are balanced against differences in other aspects of clinical behaviour. However, higher referral rates were associated with higher patient satisfaction (Franks *et al* 2000a). In the United Kingdom, in patients with breast or colorectal cancer, referral rate has been found to be unrelated to outcome (Hippisley-Cox *et al* 1997).

While accepting these caveats and complications around using variation as a quality indicator, there remains some scope for targeted use of variation as an indicator for particular problems. For example, a practice with high prevalence of coronary heart disease but very low referral rates to coronary artery bypass surgery (relative to local peers) may be a legitimate cause for concern requiring further investigation. Such measurement should not be ruled out *per se*, but must be carried out carefully, with variations in referral rate being analysed in relation to population health needs, area deprivation and other relevant variables. Measurement and comparison of referral rates could be an appropriate starting point for practice-based audit or peer review, but is not well suited for external use or performance management. In other words, it should be used as a 'tin opener' rather than a 'dial' (Carter *et al* 1992).

Emergency versus elective referrals

It is important to draw a distinction between emergency and elective referrals. 37 per cent of hospital admissions in England are unplanned (Ingram *et al* 2009), and 40–70 per cent of these are referred from GPs (Dempsey, Bekker 2002). Despite this, most of the research literature on

GP referral concentrates on elective referrals, with little exploration of how decision-making processes may be different for emergency referrals.

Decisions regarding referrals are often highly consequential but are pressurised by time and involve complex trade-offs between the priorities of the different stakeholders involved (GP, patient, relatives and specialists). This is particularly so in the case of emergency referrals – a fact that may encourage the use of heuristics or ‘short-cuts’ in decision-making, which increase the potential for inappropriate referral (Dempsey, Bekker 2002, Dowie 1983).

Many emergency cases are referred from out-of-hours services. The 2005 GP contract gave GPs the option of transferring responsibility for their registered patients outside of office hours to dedicated providers. It is particularly likely that decision-making processes are different in the case of referrals from these services, since GPs working within them have to make their decisions with little prior knowledge of the patient, no medical notes and less access to a second opinion. They also receive little or no feedback on the consequences of their decisions, compared to those regarding daytime referrals (Calnan *et al* 2007).

GPs in one out-of-hours collective exhibited a wide variation in referral rates, with the highest referrer sending 22 per cent of 1,656 patients to hospital, and the lowest sending 2 per cent of 1,755 patients: a five-fold difference between the upper and lower quartile (Rossdale *et al* 2007). Subsequent research suggests that cognitive factors may be key in explaining this variation – specifically, levels of professional confidence, tolerance of risk and uncertainty, and attitudes to hospital and community-based alternatives (Calnan *et al* 2007; Ingram *et al* 2009). This seems plausible given the context in which these decisions are made.

Given the importance of emergency referrals, both for individual patients and as a significant cost driver in the health care system, the number of research studies examining quality issues in this area is disappointingly low. Further work in this area should be a priority.

Referrals to community services

There is evidence to suggest that GPs experience particular challenges in making referrals to community services such as district nursing, occupational therapy, chiropody or physiotherapy. In the case of district nursing, a review by the Audit Commission conducted in 1999 suggested that 10 per cent of referrals were inappropriate (Audit Commission 1999). More recent studies confirm that this remains a problem (Cook 2006; Thomas *et al* 2006).

There appears to be a lack of clarity among some GPs around the role of professionals such as district nurses (Thomas *et al* 2006) and physiotherapists (Clemence, Seamark 2003) and the services they can provide. The problem may lie partly in the frequency with which job roles and titles in this area change (Cook 2006). Meanwhile, community services tend to be shaped by the referrals they receive, rather than by strict referral criteria (Audit Commission 1999), and this lack of clear referral criteria is likely to contribute to high levels of inappropriate referral (Thomas *et al* 2006).

Given the key role of community services in responding to the increasing burden of long-term conditions, it is important that GPs are able to refer patients to them appropriately.

Conclusions

There is evidence of scope for improvement in all seven dimensions of quality. Particular sets of challenges exist for different types of referral. For example, in the case of musculoskeletal referrals, destination seems to be a key challenge – with a lack of clarity around whether referrals should be made to orthopaedics, rheumatology, physiotherapy or elsewhere. For mental health, there is evidence of inconsistencies between the expectations of referral held by GPs and specialists, and of a lack of detail on physical symptoms and co-morbid medical conditions in referral letters.

However, this evidence needs to be treated with caution, due to several caveats. Assessment of referral quality needs to be sensitive to local contexts and to the fact that referrals are highly heterogeneous. For example, a referral deemed unnecessary in one area may be considered appropriate in another. What is more, different stakeholder groups do not always agree on assessments of quality. Some of the disagreement on the appropriate content of referral letters, or on what should be done in primary care before referral, reflects divergent conceptions of different professional roles (crucially, the role of the GP versus the role of the specialist). It may be difficult to improve referral quality without addressing these cultural aspects.

Nevertheless, there are clear cases of poor quality in referral, and the subtleties in definition should not undermine attempts to measure and improve this area of practice. The King's Fund has recently carried out research on referral management schemes. As part of this, we have interviewed GPs and consultants and asked their opinion on what constitutes high and poor quality referral. The following quotation exemplifies the risks that flow from poor quality referral as a result of poor quality patient examination:

Probably the lowest quality referral I ever saw was in Southampton. We had a soft-tissue clinic there and a GP wrote 'Please will you see this patient with shoulder pain?'. So it got triaged to the back of the queue and I saw her some six months after this letter had been written in the shoulder clinic, and the lady said 'Well, it's the lump I'm worried about,' and I said 'Lump – what lump?' And she took her shirt off and she had an egg-shaped lump about the size of an ostrich egg, if you like – an absolutely massive lump on the back of her scapula.

It turned out to be TB that was tracking out through her scapula, and the GP had actually clearly not examined the patient, let alone thought about whether the soft-tissue shoulder clinic was the most appropriate place to send her. So that illustrates the dangers of not having looked properly – not having thought about the implications of what you do.

(Consultant rheumatologist, interviewed September 2009)

The literature on variation in referral rates highlights the importance of cognitive and psychological characteristics that influence a GP's decision to refer, and of factors such as patient pressure and preferences. It is clear that referral decisions involve more than a simple computation of objective clinical facts, and that factors such as a GP's attitudes towards risk and personal perceptions of the options available will influence decision-making.

An important conclusion to draw is that while there is a need to examine referral quality in terms of the various dimensions described here, and while there may be merit in measuring and comparing referral rates, a degree

of sophistication is required in interpreting such measurements and taking action on the basis of them. The following section sets out what forms that such action may take, and the evidence base relating to this.

Approaches towards quality improvement in referral

This section assesses approaches that have been taken to improve referral quality in terms of the seven dimensions discussed earlier (see p 32). The improvement approaches can be broadly divided into the use of guidelines, education, organisational restructuring and financial incentives. The focus is primarily on those approaches that have proved effective in improving quality.

A list of interventions that have improved GP referrals in each of the quality dimensions previously identified is provided in Appendix A.

Referral guidelines

Referral guidelines are tools designed to assist GPs in making their referral decision. Systematic reviews have shown that referral guidelines are effective in changing referral behaviours if combined with feedback from peers and/or specialists (Akbari *et al* 2008; Faulkner *et al* 2003). Providing guidelines in combination with such feedback and/or other aids – for example, desktop summaries, structured referral sheets, pro formas or standardised letters and risk-factor checklists – increases the effectiveness of guidelines in changing referral thresholds, timeliness, letter content, and pre-referral management (Bennett *et al* 2001; Griffiths *et al* 2006; Kerry *et al* 2000; McRobbie *et al* 2008; Wright *et al* 2006; Jiwa *et al* 2006; Kourkouta *et al* 2006; Navarro *et al* 2002; Lucassen *et al* 2001; Junghans *et al* 2007; McRobbie *et al* 2008; Wright *et al* 2006; Wright *et al* 2006).

In comparison, passive dissemination of guidelines is not effective for quality improvement (Akbari *et al* 2008; Idiculla *et al* 2000; Wright *et al* 2006). Any benefit is seen in the short term, if at all (Hill *et al* 2000). A mental health study concluded that the content of referral letters will only be improved through a closer integration of GPs and specialists in terms of working styles, models of care and treatment settings, rather than through an approach that emphasises adherence to referral protocols alone (White *et al* 2004).

Educational interventions

A common theme in the research literature is the need for improved feedback loops in the referral process. GPs often welcome feedback from consultants on the necessity of referrals, referral letter content or expectations of pre-referral management, and this feedback provides an effective educational tool to improve referral quality (Gagliardi 2002; Elwyn *et al* 2007; Junghans *et al* 2007; Wright and Williams 1996). Increasing such communication and feedback may also provide opportunities for specialists to benefit from advice from generalists. However, there is some evidence of unease among consultants that providing feedback would increase their workload (Gagliardi 2002).

An alternative to incorporating feedback as an integral part of the referral system is to organise ad hoc training opportunities for GPs – for example, through educational workshops, led by specialists, covering where to direct

different referrals, what to include in referral letters and so on. There is some research indicating that such approaches can be effective, although the evidence is mixed (Akbari *et al* 2008).

Recent evidence from the Torfaen Referral Evaluation Project in Wales reinforces the power of peer review and consultant feedback in improving referral quality. An intervention involving weekly practice-level referral review meetings and six-weekly cluster meetings, including consultant feedback, was found to achieve the following after one year (Evans 2009):

- 30 per cent reduction in hospital referrals, with patients being directed to community-based alternatives instead
- reduced variation in referral rates
- improved awareness and use of referral guidelines
- improved referral letter content
- improved pre-referral work up – for example, more use of magnetic resonance imaging scans (MRIs).

The intervention was also reported to be highly popular with general practitioners.

A systematic review highlighted that there are only a few studies that investigate how patient education has affected referrals, although two such studies identified that a malignant melanoma campaign increased specific referral rates (Faulkner *et al* 2003).

Organisational interventions

There has been a drive by PCTs throughout the United Kingdom to intervene in the referral process in order to manage demand and improve the quality of referrals. The establishment of referral management centres, through which some or all referrals pass, has been one method adopted by some PCTs. The primary purpose of the centres, and the approach taken, has varied from one PCT to the next. Some have had the explicit intention of improving the quality of referral, some to redirecting referrals to alternative out-of-hospital services, and some to act as a further gatekeeper and to deflect referrals for low priority procedures. A number were initiated to support the uptake of choice, but since the advent of the national Choose and Book programme have ceased to perform this role. Some centres use GPs or other extended role practitioners to review referrals, while others have been staffed purely by non-clinical staff.

There is much debate about the effectiveness and cost-effectiveness of such interventions, but little evidence so far, (Davies *et al* 2006). An evaluation of the effectiveness of referral management centres will be published by The King's Fund in mid-2010.

Changes to the structure and content of primary care have also been used in the attempt to improve referrals. A systematic review found evidence that requiring a practice-based second opinion can reduce unnecessary referrals, and that attaching a physiotherapist to the GP practice can increase the proportion of musculoskeletal referrals sent to the most appropriate destination (Akbari *et al* 2008). Another study found that in-house triaging by clinicians can improve the timeliness of referrals (Gormley *et al*

2003). Integrating musculoskeletal care, establishing community-based musculoskeletal clinics and using a specialist referral management system were all effective ways of improving the accuracy of referral destination (Rymaszewski *et al* 2005; Maddison *et al* 2004).

Financial incentives

In addition to guidelines, education and restructuring, financial incentives have been shown to alter behaviour and improve quality. One study demonstrated that the incorporation of referral standards into GP contracts is an effective method of improving referral letters (Wright *et al* 2006), while a PCT-led referral management system, driven by financial incentives, was effective in re-routing 50 per cent of referrals to GPs with special interests (GPSIs) (Clews 2006). However, a direct enhanced service payment to GPs in 2006/7 to encourage use of the Choose and Book system has led to only 50 per cent of appointments being booked through the system (Connecting for Health 2009). This indicates that where deeper cultural and technical barriers exist, financial incentives may not be sufficient to change behaviour.

Measures and metrics

GPs often welcome information that allows them to compare their referral practices with their peers. However, there needs to be careful consideration of what is measured and how the information collected is used. For example, measurement and benchmarking of referral rates may increase GPs' knowledge about how their referral patterns compare to those of their peers, but this has been found to have little direct effect on referral behaviour (Akbari *et al* 2008). This is not surprising given the myriad factors that influence referral rates highlighted above (see pp 40–2). Potential measures and metrics for referral and diagnosis are discussed in the combined conclusion to this reports.

Cost-effectiveness of improvement approaches

While there is evidence that improvement approaches exist that can increase the quality of GP referrals in all seven dimensions, the cost implications of the innovations needs to be analysed. For example, re-directing patients to GPSIs for dermatology appointments has been found to produce considerable additional cost (Salisbury *et al* 2005). So, the cost-effectiveness of improvement approaches needs to be examined. While some studies do measure innovation costs, there are difficulties in defining and measuring cost-effectiveness (Faulkner *et al* 2003). For example, a decrease in referrals may be cost-effective in the short term but not in the long term, because a lower referral rate could potentially lead to higher long-term costs for certain conditions. Furthermore, some studies calculate cost up to the point of referral without taking into account a potential shift in the future cost burden.

Conclusions

A range of interventions and approaches have been found effective in improving the quality of GP referrals in some studies. However, the evidence base relating to many interventions is conflicting, with similar approaches having different outcomes in different contexts. This highlights the

importance of local factors in designing quality improvement strategies. It is also commonly found that interventions work better in combination than on their own.

Key messages

- Referral is a key part of the GP role. It is a process with very direct consequences for patients' experience of care, and an important cost-driver in the health system. The evidence reviewed here presents many opportunities for improving the quality of GP referral but few quick solutions.
- Referrals are highly heterogeneous. The process of making a referral, and the implications of it, vary according to the purpose of the referral (for example, for diagnosis, for a particular treatment or for reassurance), whether it is an emergency or elective referral, and according to other characteristics, such as the specialty being referred to.
- Referral involves the balancing of several competing concerns and sources of information – not least, the need to respond to patient expectations versus the GP's role as gatekeeper.
- High-quality referral is multi-dimensional. Improving the quality of referral will require attention to be paid to:
 - the necessity of referrals
 - the timeliness of those referrals
 - the referral destination
 - the quality of referral processes, including the content of referral letters, patient choice, the construction of shared understandings of the referral between stakeholders, including patients, and pre-referral management.
- Patients' experience of referral is strongly influenced by their sense of making progress through the system. Involving patients in decision-making and informing them about the referral process increases patient satisfaction, and can help limit feelings of powerlessness and being left 'in limbo'. Factors that may facilitate this kind of patient-centred consultation style are discussed in the report on patient engagement and involvement compiled for The King's Fund GP Inquiry (see www.kingsfund.org.uk/gpinquiry).
- It is important to avoid a preoccupation with eliminating unnecessary referrals if this is detrimental to other aspects of quality. A narrow focus on necessity may not deliver the same results as a more comprehensive approach, even in terms of efficiency of resource use. For example, ensuring that patients are referred to the most appropriate destination, and that referral letters contain adequate content, may also improve efficiency.
- High-quality referral is highly context dependent, so it will not look the same in all geographical areas. A referral that may be unnecessary in one context may be quite appropriate in another – for example, in an area with a different configuration of health services.

- It is not possible to give a comprehensive assessment of the quality of GP referral based on the material examined, but it is possible to say that in all of the dimensions of quality explored, there is evidence of scope for improvement. Distinct challenges exist within different specialties, and for different types of referral.
- There is evidence that a number of approaches can be effective in improving quality in referral – for example, educational interventions, referral guidelines, organisational interventions, financial incentives, and the use of measures and metrics. Approaches that encourage peer review among GPs and feedback from consultants appear to be particularly effective.
- Evidence on the cost-effectiveness of different improvement approaches is lacking.
- In addition to using quality improvement approaches based on a mechanistic or ‘information-processing’ model of referral (for example, referral guidelines), it is important that approaches are also adopted that draw on a ‘relational’ model (see p 50). For example, mechanisms and incentives for improved communication between GPs and specialists should be explored. The importance of the GP–patient relationship in facilitating high-quality referral should also be remembered.
- Measuring referral rates and benchmarking these against peers can be useful for GPs, but the interpretation of these measurements is complex. Variations in referral rates should be interpreted with reference to other data, such as population health needs and area deprivation. Overall referral rates cannot be used as a simple proxy for referral quality, and primary care trusts should be strongly discouraged from using them as a performance management tool.
- Variation among GPs in terms of their referral activity may in some cases reflect inequity, but also represents the complexity of referral and the myriad factors influencing it. While genuine inequity should not be accepted, a naïve pursuit of standardisation could be dangerous, and should not be encouraged.

4 Discussion and conclusions

This section summarises our key findings. It sets out the approaches to improvement that we have identified, discusses the potential for the development of measures of the quality of diagnosis and referral in general practice, and draws some final conclusions.

Key findings

High-quality diagnosis and referral is core to the provision of 'good clinical care' by GPs.

The guidance document *Good Medical Practice for General Practitioners* says 'Providing competent assessment and treatment is at the heart of good medicine' (RCGP/GPC 2008, p 6), and argues that good clinical care must include:

- a. adequately assessing the patient's conditions, taking account of the history (including the symptoms and psychological and social factors), the patient's views, and where necessary examining the patient
- b. providing or arranging advice, investigations and treatments where necessary
- c. referring a patient to another practitioner, when this is in the patient's best interests.

(RCGP/GPC 2008, p 5)

Our research has shown that both diagnosis and referral are complex and demanding areas of clinical activity within primary care. A range of factors create particular difficulties, including:

- assessing evolutionary and undifferentiated symptoms
- the weak predictive value of diagnostic tests in primary care
- the low prevalence of certain conditions, and the high degree of overlap between symptoms for common and serious conditions
- a lack of reliable data on family and patient history
- the need to manage the competing demands of being a primary care provider and acting as gatekeeper to secondary care.

In addition to the immediate challenges of clinical problem recognition and decision-making, GPs operate in a complex service environment. The trend towards clinical sub-specialisation and more differentiated hospital and community-service provision makes the referral process increasingly difficult. While clinical guidelines offer clear signposts to optimum care, the fact that there is a growing number of these can mitigate against their utility.

Our research has revealed a wide body of literature on the quality of GP diagnosis and referral, but much of it is partial, out of date, or context specific. It is therefore difficult to make a comprehensive and conclusive assessment about the quality of diagnosis and referral. There are particular deficits in the areas of clinical outcomes, patient safety and patient experience. However, the evidence that is available points to significant variation in clinical practice across the many dimensions of diagnostic and referral quality.

Recommendations for approaches to improvement

Table 10 below summarises the improvement approaches we have identified and their applicability to the different dimensions of high quality diagnosis and referral.

Table 10: Improvement approaches

| Improvement approaches | Quality dimensions | |
|--|--------------------|-----------|
| | Diagnosis | Referral |
| | 1 2 3 4 5 | 1 2 3 4 5 |
| Guidelines | ✓ ✓ ✓ ✓ | ✓ ✓ ✓ ✓ |
| Education and training | ✓ ✓ ✓ ✓ ✓ | ✓ ✓ |
| Decision-support tools | ✓ ✓ ✓ ✓ | ✓ ✓ |
| Increased direct access to tests | ✓ ✓ ✓ ✓ | |
| Improved processes for call or re-call and test feedback | ✓ ✓ | |
| Financial incentives | | ✓ ✓ |
| Feedback or advice from specialists | ✓ ✓ ✓ | ✓ ✓ ✓ ✓ ✓ |
| Integrated delivery models | | ✓ ✓ |
| Structured referral forms | | ✓ ✓ |
| Referral management centres | | ✓ ✓ ✓ |

Key

✓ indicates that there is evidence that a quality improvement approach can work in this area.

Diagnosis quality dimensions

- Gathering sufficient evidence and information
- Judging the evidence and information correctly
- Minimising delay in further investigation and onward management
- Ensuring efficient use of resources
- Patient experience

Referral quality dimensions

- Necessity
- Timeliness
- Destination
- Referral letter content
- Shared understandings
- Pre-referral management

There are two alternative perspectives to clinical decision-making that emerge from the literature. The first sees it as an information-processing task that involves evaluating probabilities and applying rule-based systems. The second sees referral and, to a lesser extent, diagnosis as a social or relational issue – a question of negotiation and compromise between different stakeholders (GP, patient and specialist).

These two perspectives are not mutually exclusive – indeed, there is merit in both. However, they do tend to lead towards different approaches to quality improvement – the first lending itself to the use of referral guidelines and decision-support tools while the second leads to solutions focusing on

relationships, communication and an attention to patient preferences.

Consistent with the social/relational model, GPs argue that good relationships between GPs and specialists facilitate information exchange, including feedback from specialists to GPs, providing a learning opportunity that may lead to improved quality diagnosis and referral in future. Good personal relationships are also believed to make it easier for GPs to seek informal advice, reducing the need for making formal referrals, and to allow a smooth division of labour, reducing duplication of tests (Anthony 2003).

In this context, it is important to note that many GPs feel that a number of factors in today's NHS make it harder for GPs and specialists to forge close relationships. Key among these is the fact that the Choose and Book systems mean that GPs are often unable to refer to a named clinician. This has frustrated some, who feel it undermines the relationships they have built with particular hospital consultants.

Many quality-improvement approaches are based on a mechanistic understanding of referral and diagnosis, the aim being to improve the way information is processed – for example, through the use of referral guidelines or decision-support tools. Such interventions can be effective, but our research suggests that there is a danger of the relational aspect of referral/diagnosis being neglected. For example, it is important that attention be paid to relationships between GPs and specialists and to finding ways of improving them.

Potential quality measures

Developing quality measures for diagnosis and referral presents a range of difficulties. First, the complexity and uncertainty inherent in this area of clinical decision-making makes it difficult to identify valid measures. Most indicators will serve only as 'tin openers', designed to prompt further investigation, rather than 'dials', or unambiguous markers of performance (Carter *et al* 1992).

In addition, the nature of the activity means it can only partially be captured by routine data. In the case of diagnosis, the QOF does capture a certain amount of information that can provide a limited marker of quality for several major disease areas, and through its organisational measures captures the quality of record-keeping in order to support good clinical decision-making. For referral, there is little routine information available on quality, although HES data does allow benchmarking of referral rates. We are also conscious of the potential bureaucratic and information burden generated by any additional routine data collection in a clinical area that accounts for 90 per cent of the routine NHS activity. These limits of routine data underline the need for investment in continuing professional development, audit and benchmarking.

Finally, while it is clear that there is evidence of variation in the quality of diagnosis and referral, it is not clear how judgements could be made about what degree of variation should be deemed 'acceptable' and therefore at what level any measures of quality ought to be set. Clearly not every GP can be a world-leading diagnostician spotting every obscure condition from the vaguest of symptoms and making perfectly judged referral decisions every time. However, what level of variation in quality should be deemed acceptable is a crucial clinical and societal question to answer.

Diagnosis

In general, the diagnostic process does not lend itself to easy quality measurement, since so many of the determining factors of quality are internal to the consultation and reasoning processes of the GP. As has already been mentioned, the quality of diagnosis can be inferred through measures of any activity that has followed diagnostic decisions (treatment, referral etc), but these proxies measures would not adequately indicate what factors caused diagnostic error and so are of limited use for quality improvement in diagnosis specifically. The QOF requires GPs to undertake appropriate diagnostic tests to support accurate diagnosis for the majority of major disease areas and these measures do provide an insight into one of the dimensions of clinical decision-making.

Overall, more retrospective audit and significant event audit could prove useful to begin to assess the scale of potentially significant problems with the quality of diagnosis. Such approaches are currently being taken in the cancer services, and are common in the research literature on other conditions. Conducting significant event reviews already forms part of the Quality and Outcomes Framework.

The activity around the first two dimensions of the quality of diagnosis (gathering sufficient evidence and information, and judging the evidence and information correctly) takes place largely within a consultation. It would therefore seem necessary to measure and assess doctors' skills and behaviours in consultations as part of their continuing professional training and assessment. Practice audits could assess the use of guidelines and decision-support tools, and local assessments could study availability of in-house diagnostic technologies and direct access to external diagnostic services.

Measuring the third dimension of quality (timeliness in further investigation and onward management) is possible using retrospective case audit.

On the fourth dimension (ensuring efficient use of resources), measures for 'appropriate' testing or investigation rates would be difficult to develop accurately, although at a practice or individual level interventions have shown that providing feedback on comparative information on testing rates can reduce over-testing.

Finally, looking at the quality of patient experience of diagnosis, extensions to the GP patient survey and/or the inclusion of specific experience measures in the QOF could begin to gather information on patient experience at least of the consultation overall, if not specifically of the diagnostic process.

Referral

In terms of the necessity, timeliness and destination of referral, the most straight-forward quality measure would be compliance with best practice guidelines. However, our research has highlighted the need to exercise caution in interpreting this kind of data. Judgements around necessity and destination are often context dependent, and assessment can vary from one stakeholder to the next. Measures of timeliness need to distinguish between delay over which the GP has some control versus delay that is driven by other factors. For some surgical specialties, such as orthopaedics, an alternative, would be to use conversion rates in secondary care as a measure of referral necessity and appropriateness of referral destination. Similar caveats around interpretation would apply.

Many research studies have explored whether referral rates can be used as a proxy measure for referral quality. Their findings would caution against this, as there is no clear correlation between quality and rate. However, GPs report that benchmarking referral rates against peers can be illuminating and useful. It may also be helpful to triangulate referral rates with other key indicators, such as disease-incidence or disease-outcome measures.

Referral processes may be more easily subject to quality measurement. For example, the quality of referral letters could be measured in terms of inclusion of key details (see pp 27–32). This could be used to provide GPs with a useful overview of how their referral letters compare to those of their peers. However, to use the data collected as a measure of quality would require the list to be adapted for different types of referral.

Data would need to be triangulated from GPs, consultants and patients in order to measure the extent to which understandings of the referral purpose are shared between the three groups. Patient-reported data could also be used to measure satisfaction with the provision of choice at the point of referral. However, collection of such data may pose an unacceptable administrative burden.

Conclusion

There is significant variation in clinical practice across the many dimensions of GP diagnostic and referral quality. In some clinical areas the consequences of this for patient care are likely to be profound. In cancer, for example, studies suggest that 5,000 or more lives could be saved each year in England if our diagnosis rates matched the best in Europe (Richards 2009). More audit and research is needed to understand the quality of diagnosis and referral in general practice, and to identify the areas that should be priorities for action.

However, if from the available evidence we can conclude that diagnosis and referral are areas of clinical practice fraught with potential errors and complex cognitive and judgement challenges, one possibility could be to consider ways to better support GPs to spend a greater proportion of their time on these activities. However, what they could spend less time on, in return, would need to be identified by other projects within the Inquiry.

The other key conclusion is that if we are serious about the need to better understand and improve the quality of clinical decision-making within general practice, then a stronger clinical governance framework is needed. The current size and infrastructure of general practice limits the capacity and effectiveness of any peer review or audit process. This stronger framework would be facilitated by GPs working together more collaboratively.

Appendix A: Effective interventions

The following table lists interventions that have been found to provide effective ways of improving the quality of referrals, in terms of the quality dimensions identified in this report.

Table A1: Summary of evidence on effective interventions

| Dimension of quality | Intervention | Studies |
|-----------------------------|--|---|
| Destination | Feedback from peers or specialists | Gagliardi (2002), Wright and Wilkinson (1996) |
| | Specialist outreach schemes | Faulkner <i>et al</i> (2003) |
| | Integration of care | Rymaszewski <i>et al</i> (2005), Maddison <i>et al</i> (2004) |
| | Community-based clinics | Rymaszewski <i>et al</i> (2005), Maddison <i>et al</i> (2004), Salisbury <i>et al</i> (2005) |
| | Specialist referral management | Rymaszewski <i>et al</i> (2005), Maddison <i>et al</i> (2004) |
| Threshold | Feedback from peers or specialists | Kerry <i>et al</i> 2000), Elwyn G (2007), Gagliardi (2002), Wright and Wilkinson (1996) |
| | Guidelines | Kerry <i>et al</i> (2000), Lucassen A <i>et al</i> (2001) Griffiths <i>et al</i> (2006), Junghans <i>et al</i> (2007) |
| | Training | McRobbie <i>et al</i> (2008), Griffiths <i>et al</i> (2006) |
| | Financial regulation | Faulkner <i>et al</i> (2003), Clews (2006) |
| Timelines | Guidelines | Wright <i>et al</i> (2006) |
| | Referral templates | Wright <i>et al</i> (2006) |
| | Desktop summaries | Wright <i>et al</i> (2006) |
| | Educational workshops | Wright <i>et al</i> (2006) |
| | Incorporating standards into contracts | Wright <i>et al</i> (2006) |
| | Individual discussions with GPs | Mondry <i>et al</i> (2004) |
| | Nurse-led referral management (emergency admissions) | Lees (2003) |

| | | |
|--------------------------------|--|---|
| Content | Feedback from peers or specialists | Gagliardi (2002), Jiwa <i>et al</i> (2004) |
| | Desktop guideline summaries | Wright <i>et al</i> (2006), White <i>et al</i> (2004) |
| | Performance feedback (referring to protocol) | White <i>et al</i> (2004) |
| | Structured referral sheets | Akbari <i>et al</i> (2008) |
| | Pro formas | Koukouta <i>et al</i> (2006), Jiwa <i>et al</i> (2006) |
| | Guidelines | Koukouta <i>et al</i> (2006), Tuomisto LE <i>et al</i> (2007) |
| | Nurse-led referral management (emergency admissions) | Lees (2003) |
| | Standard letters | Navarro <i>et al</i> (2002) |
| Shared | Feedback from peers or specialists | Faulkner <i>et al</i> (2003) Gagliardi (2002) |
| | Patient education | |
| Pre-referral management | Feedback from peers or specialists | Gagliardi (2002) |

Appendix B: Case study

The quality of cancer diagnosis and referral in general practice

The role of general practice in cancer diagnosis and referral, and what 'high-quality care' mean in this context

After a patient presents to their GP with symptoms that could be relevant to a possible cancer diagnosis, the GP has to decide whether to refer the patient urgently to a specialist, to refer the patient non-urgently, or not to refer the patient at all – at least for the time being. Patients chosen for urgent specialist assessment would fall under the government's 'fast-track' standards for cancer, set out in the box below. To help GPs choose between these alternatives, the Department of Health issued cancer referral guidelines in 1999, which were subsequently updated by NICE in 2004/5.

Government 'fast-track' standards for cancer diagnosis and referral relevant to general practice (correct prior to the 2010 general election)

Two-week standard

From urgent GP referral with suspected cancer to first hospital assessment

From GP referral with breast problems to first hospital assessment.

62-day standard

From urgent GP referral with suspected cancer to first treatment

Hospital specialists have the right to ensure that patients who were not referred urgently by their GP, but who have symptoms or signs indicating a high suspicion of cancer, are also managed on the 62-day pathway.

The defining feature of 'high-quality' general practice in this context is therefore to make the 'right' decision with each patient, in a timely manner. Since cancer is a progressive and sometimes life-threatening condition, the overarching quality concern evident in the academic, policy and patient-group literature is with minimising the delay in cancer being diagnosed. For the purpose of brevity, and given the overwhelming focus on delay in the literature, this case study focuses on avoiding delay as the central feature of quality.

Nevertheless, it is important to mention that there are further features of high-quality general practice care in this context, such as avoiding over-referral to specialists and ensuring good doctor–patient communication. There is also an important and growing literature attempting to study the relationship between delay and clinical outcomes in cancer. To date, this provides a mixed picture of the degree to which minimising delay in cancer diagnosis improves survival, but we await a forthcoming worldwide systematic review of the literature due in 2010 with interest (see Neal 2009).

What we know about delay in cancer diagnosis and referral in general practice

A limited number of sources of evidence are available on quality of cancer diagnosis and referral in general practice. These can be grouped as:

- performance against the fast-track standards
- research measuring length of primary-care delay
- research identifying primary-care delay factors.

Each of these is described below.

Performance against the FT standards

A number of research studies, usually of particular hospitals or specialties, have examined how GPs have responded to the FT regime (Hanna *et al* 2005; Smith *et al* 2006; Rai, Kelly 2006; Thorne *et al* 2006; Trickett *et al* 2004; Lyons *et al* 2004; Hobson *et al* 2008; Cox *et al* 2008; Singh, Warnakulasureiya 2006). All find that the yield of cancer cases on the fast track is low – typically about 10 per cent. However, some higher rates have been observed (Singhal *et al* 2008).

Some of the studies reported here were carried out soon after the guidelines were issued. It might be expected that GPs would adhere more closely to the guidelines over time, but there is limited evidence that this has happened (Imkampe *et al* 2005).

But there is also evidence that selection has declined in effectiveness. Potter *et al* (2007) found in relation to breast cancer that the number of cancers detected among those referred under the two-week rule fell though the total number of referrals had risen. Similarly, Rai and Kelly (2006), reviewing a number of studies, and Allgar *et al* (2006) found a rising volume of referrals accompanied by a lower cancer-detection rate.

A study of referral rates in 49 practices (John *et al* 2007) found that more than half had not used the fast track for colorectal cancer. One in five were not aware of the fast track or of colorectal guidelines.

Overall, this limited evidence suggests that the referral guidelines and the creation of the fast track have not fully had the desired effect. There is limited support for the view that performance has improved over time, and some evidence pointing the other way.

Research measuring length of primary-care delay

Some of the evidence available suggests that for most patients, primary-care delay is short. Evidence from Denmark of the relative contribution of practitioner delay in primary care to overall delay in symptomatic cancer diagnosis) was small in comparison to patient delay (the time between the onset of symptoms and the patient presenting to the GP) (Olesen *et al* 2009).

In a retrospective study of colorectal cancer patients, carried out in 2002, Barrett *et al* (2005) found that the maximum mean delay – 14 days – was found in patients having a positive faecal occult blood test. Khattak *et al* (2005) in a similar group of patients found a median delay of 28 days for 'elective' patients and 14 days for 'emergency'.

However, another study of colorectal patients (Stapley *et al* 2006), carried out at a similar time, found much longer delays – up to 133 days (median) for patients presenting with abdominal pain or mild anaemia, with shorter delays for other symptoms but still longer than those recorded above. A study of oral cancer patients found a median delay of one week, but the range was from 0 weeks to 38 weeks.

These data do not allow an accurate picture to emerge for the country as a whole. However, what evidence is available suggests that even where median delays are modest, some patients experience very long delays before they are referred.

Research identifying primary care delay factors

A range of studies into delay in primary care have identified a range of delay factors, most recently presented in a report of two worldwide systematic reviews (Macleod *et al* 2009). Many of these factors are interrelated but are loosely grouped below under some indicative headings. These studies include GP surveys, patient surveys, practice case studies and audits, cohort studies and reviews.

- **Patient demographic factors** Factors such as age, gender, socioeconomic status, education and ethnicity have been found to have different relationships with delay for different cancers (Macleod *et al* 2009)
- **Presentation complexity** Confounding effect of existing disease and co-morbidity (Macdonald *et al* 2006; Bjerager *et al* 2006), atypical presentations (Mitchell *et al* 2009) and patients presenting multiple problems in short general-practice consultations (Jiwa *et al* 2004)
- **Multiple presentation** Failure to link previous presentations together – either through failure to review recent presentations, or lack of continuity of care within practice (Mitchell *et al* 2009)
- **Knowledge** Lack of physician exposure to the malignancy and lack of knowledge of associated signs and symptoms, failure to follow referral guidelines (Abel *et al* 2008; Bird 2002b, Daly and Collins 2005; Mitchell *et al* 2009)
- **Examination** Inadequate examination (Mitchell *et al* 2008; Weingart *et al* 2009), reliance on patient symptoms to prompt referral as opposed to signs and screening (Abel *et al* 2008)
- **Misdiagnosis** Failure to consider cancer in the differential diagnosis, diagnosis other than cancer given, and treatment for non-cancer causes (Macdonald *et al* 2006; Mitchell *et al* 2008; Evans *et al* 2007; Mitchell *et al* 2009)
- **Investigation** Inaccurate investigations, poor application and interpretation of tests, long waiting times for investigations, lack of direct GP access to investigations, non-investigation of symptoms (Mitchell *et al* 2008; Macdonald *et al* 2006; Bjerager *et al* 2006; Daly and Collins 2005; Evans *et al* 2007; Barrett *et al* 2006; Trickett *et al* 2004; Mitchell *et al* 2009)

- **Follow-up** Failure to follow up the patient in a timely manner or lack of an explicit follow-up appointment (Bird 2002b; Bjerager *et al* 2006; Evans *et al* 2007; Mitchell *et al* 2009)
- **Referral guidelines** Failure to follow referral guidelines (Webb and Khanna 2006; Flashman *et al* 2004; Duvvi *et al* 2006; Chohan *et al* 2005; Mitchell *et al* 2008) or inaccuracy of the guidelines themselves (Allgar *et al* 2006; Kattak *et al* 2005; Mckie *et al* 2006; Eccersley *et al* 2003)
- **Co-ordination with secondary care** Poor communication with hospital services (Daly and Collins 2005; Mitchell *et al* 2009).

Ongoing research

This is a particularly busy time in research into cancer diagnosis and referral in England. Following the publication of the NHS Cancer Reform Strategy (Department of Health 2007a) a range of projects have been established to investigate symptomatic cancer diagnosis further, under the auspices of the National Awareness and Early Diagnosis Initiative (NAEDI) for cancer. Three of these projects are summarised in Table A3, below.

Table B2: Examples of NAEDI projects

| Project area | Summary |
|--|---|
| National audit of cancer diagnosis in primary care | The RCGP and the National Cancer Action Team have established a national audit of cancer diagnosis in primary care, now being used in 18 cancer networks. It will build a national picture of the diagnosis of 5,000–10,000 cancer cases for further research, and will also be useful locally as a reflective and learning tool for primary care health professionals. |
| Significant event audits (SEA) of cancer diagnoses in primary care | Through the North of England Cancer Network, SEA reports from 92 practices for lung and teenage and young adult cancer have been analysed. The report of this analysis was published in August 2009 (Mitchell <i>et al</i> 2009). |
| The Diagnosis of Symptomatic Cancer (DISCOVERY) project | A new NIHR-funded research programme under Dr Willie Hamilton at the University of Bristol will undertake a range of linked projects investigating both patients’ and GPs’ perspectives on cancer diagnosis, and looking at systemic questions such as current referral patterns and what levels of risk need rapid investigation. |

Source: Department of Health (2009b)

Conclusions

The fundamental issue in improving the quality of the role played by general practice in the diagnosis and referral of symptomatic cancer is to focus on GP’s ability to select patients accurately for urgent referral. The evidence suggests that can be extremely difficult to do. Despite the guidelines having been in use for a decade, there has not been an improvement in the proportion of fast-track patients found to have cancer.

A number of options have been proposed to improve identification and

minimise delays in symptomatic cancer diagnosis in primary care. These include:

- lowering the thresholds for referral or abandoning patient selection for referral at GP level (as has happened already for patients with breast symptoms)
- improving the capacity of GPs to make accurate diagnoses, through easier access to diagnostic tests and decision aids
- updating and improving the cancer referral guidelines with more recent research, including studies of the predictive power of different combinations of symptoms
- providing feedback to GPs from secondary care and the performance of their peers, using locally agreed guidelines
- further education of GPs on use of guidelines.

All of these have the potential to improve the quality of symptomatic cancer diagnosis in primary care, but the merits of each have yet to be fully evaluated. The work of NAEDI will yield important further information in the near future.

Appendix C: Search terms used in literature review

Articles had to contain one term from column A, and one from column B.

| A | B | |
|----------------------|--|--|
| | Diagnosis | Referral |
| GP | (diagnosis AND quality) | (referral AND quality) |
| Primary care | (diagnosis AND 'patient experience') | (referral AND 'patient experience') |
| General practice | quality / accuracy of diagnosis | quality / appropriateness / timeliness / suitability / necessity of referral |
| General practitioner | inaccurate / false / incorrect / wrong / missed / late diagnosis | referral quality / appropriateness / timeliness / suitability |
| | delay in diagnosis | inappropriate / late / unsuitable / unnecessary referral |
| | quality / accurate / right / correct / good / timely diagnosis | delay in referral |
| | diagnostic quality / accuracy / errors / mistakes / delay | quality / appropriate / timely referral |
| | diagnosis quality | variation in referral rate |
| | diagnostic errors* | |
| | early diagnosis* | |
| | computer-assisted diagnosis* | |

*MeSH terms

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