DEVELOPING PAEDIATRIC QUALITY INDICATORS FOR UK GENERAL PRACTICE

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Abstract

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The overall aim of this thesis is to define a candidate set of quality indicators that are evidence-based, feasible to implement, and have the potential to improve the quality of care provided for children in UK general practice.

The indicators were developed using a three-stage process. First, the areas and aspects of care of highest priority for quality indicator development were identified. This was achieved by seeking the views of primary care clinicians and by undertaking a formal analysis of unplanned hospital admissions for ambulatory care sensitive conditions. Then, the evidence-base to underpin indicator development was identified through an overview of Cochrane systematic reviews of interventions relevant to the primary care of children. A search of SIGN and NICE national guidelines was also conducted to inform the evidence-base. Lastly, an expert panel determined the formulation and selection of indicators by applying the RAND appropriateness methodology.

This process created a final set of 26 quality indicators in six priority areas: early recognition of potentially serious illness (n=7); child protection and safeguarding (n=4); mental health (n=4); health promotion (n=1); routinely managed conditions (n=6); and general practice management (n=4). The main strength of these indicators is that they reflect a strong professional consensus on their validity and feasibility. The main weakness is that the indicators are underpinned by evidence mainly derived from expert opinion rather than formal research; the requirement for professional consensus means that they do not challenge existing models of care delivery.

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Chapter 1: Introduction

"It is quality rather than quantity that matters."

- Seneca (4 BC-AD 65), *Epistles*

I have two passions: paediatrics and quality improvement. During medical school, these interests prompted my involvement in numerous initiatives ranging from health advocacy and leadership training to medical education and paediatric research. While these initiatives offered a broad range of career directions, during a medical elective in Uganda I realised that one career in particular would enable me to pursue my desire to work with children and make a significant difference in medical practice: paediatric primary care.

My long-term goal is to become an academic clinician-scientist at a Canadian university. I intend to focus on paediatric primary care research and implement this research into health policy and clinical practice. For years I considered pursuing additional academic training to provide me with the skills to achieve these goals. After further consultation with senior Faculty members at the Department of Paediatrics, I realised that neither the University of Alberta, nor any other Canadian institution strongly researches childhood epidemiology and primary care paediatrics.

I searched internationally for universities and programmes where I could pursue these goals. The UK stood out because of the similar structure of the health care system to the one in Canada (i.e. publically funded). The vital role that general practice plays in the National Health Service (NHS) coupled with a long history of high quality primary care research meant that the United Kingdom was the ideal place to pursue

my research. In particular, the Department of Primary Care Health Sciences at the University of Oxford had a strong track record of research focusing on ways to improve the health care of children.

In April 2008 I expressed my interest to the Head of Department. I wanted to determine whether I could pursue a topic of research that would be relevant and applicable to the Canadian health care system. We identified several potential research projects, and in November 2008 I was awarded a Rhodes Scholarship which enabled me to enroll at Oxford as a doctoral student.

Through my initial reading, I became familiar with the new UK pay-for-performance system that was introduced in general practice in 2004, the Quality and Outcomes Framework (QOF). This framework rewarded good clinical practice by linking general practitioners' pay to markers of high quality care. Initial research suggested the framework was effective since it elevated the standard of care and reduced variation in clinical practice. In Alberta, physicians are primarily remunerated on a fee-for-service basis with little focus on evaluating the quality of care or the unexplained variation in the care provided by different clinicians. I felt this could be a relevant area in which to undertake research with a long-term aim of improving the evaluation of health care delivery for children in Canada.

After arriving in Oxford in October 2009, I met with both my supervisors (Prof Mant and Dr Harnden) who pointed out three things:

- There is a recognised deficiency in child health outcome markers in primary care. For example, children under 18 comprise approximately 20% of a general practice population yet less than 3% of the QOF markers apply to them.

- Many of the existing clinical quality markers actively exclude children. For example, the diabetes and epilepsy quality markers only apply to adults.

- The confidential enquiry into child deaths highlighted a number of areas in which the primary care of children could be improved: recognition of serious illness; chronic disease management; children with disability; palliative care; and mental health of teenagers. The Child Death report called for consideration of quality markers for children to be included within the QOF.

I therefore spent the first few months reading the existing literature about these issues, seeking to define the precise research question my doctoral thesis should address. Chapter 2 provides a summary of this literature review. Chapter 3 specifies the key questions I chose to address in the thesis and the research I undertook to answer them.

Chapter 2: Developing quality indicators for children in primary care – literature review

"We should, instead, do homage to our past by building upon it."

- Avedis Donabedian, 1919-2000 (1)

2.1 Aim

When I began work on this thesis, the UK Quality and Outcomes Framework had recently been implemented. The QOF largely excluded any assessment of care quality for children despite the fact that child health care is an important and substantial part of the UK general practice workload. I therefore hoped to develop a DPhil project that would fill this gap by undertaking research to develop evidence-based indicators which could be used for children and might be taken up by QOF.

This chapter presents the literature review I undertook to explore the wider historical and international context of quality indicator development, with a particular focus on indicators of the quality of care provided for children. I did not want to re-invent the wheel, and was therefore keen to understand how (and which) quality indicators had been developed and applied successfully.

In order to develop a defensible research methodology for my thesis, I needed to read about the methods used by other researchers to: 1) identify the priority areas in which quality indicators should be developed; 2) ensure quality indicators developed are evidence-based; and 3) select a set of quality indicators which could be implemented in practice.

2.2 Methods

To identify the relevant literature, I began by conducting an electronic search in PubMed using the following keywords (free text and MeSH headings): ‘quality indicator’; ‘quality marker’; ‘outcome indicator’; ‘clinical indicator’; ‘quality and outcomes framework’; ‘QOF’; ‘pay-for-performance’; ‘quality of health care’; ‘quality of care’; ‘quality assessment’; ‘outcome assessment’; ‘quality comparisons’; ‘quality improvement’; ‘performance indicator’; and ‘performance measurement’.

In addition, to try and identify articles relevant to the primary care setting, I applied several free text and MeSH headings related to primary care such as ‘family practice’; ‘family physician’; ‘general practitioner’; ‘general practice’; ‘family doctor’; ‘primary health care’; ‘community health services’; ‘primary care’; ‘ambulatory care facilities’; ‘community health centres’; and several combinations of the above terms. I defined primary care as referring to care delivery outside the hospital setting, including the emergency department which is frequently used for primary care in systems with reduced access to primary care (e.g. United States).

Many articles in this area were difficult to capture. I thus followed up this initial search by scanning references and snowballing to find relevant articles. I also looked at the websites of agencies responsible for developing quality indicators such as NICE and the Agency for Healthcare Research and Quality, and followed up suggestions made by my supervisors and other experts in the field I encountered. To keep the preliminary review broad, I considered children up to the age of 21. Many paediatricians in the United States continue to treat patients up to this age. The original search was completed in October 2009 and updated in February 2010.

Initial attempts to complete a systematic review proved difficult given the heterogeneous use of terms to define primary care and quality indicators (i.e. whether inclusion should refer only to studies that are explicitly defined as a quality indicator or whether they describe interventions which could be developed into a quality indicator). A systematic review would have likely been feasible if a specific condition was selected but I sought to keep the review, and subsequent thesis, focused on overall care of children in UK general practice. After several months of extensive searching and meetings with an information specialist, the decision was made to complete a narrative review and conduct a systematic overview focused on the evidence-based to support potential quality indicator (described in Chapter 7).

2.3 What are quality indicators?

2.3.1 Historical perspective

In laboratory experiments, it was often necessary to monitor the acidity or alkalinity of solutions during chemical reactions. Prior to technological developments that precisely measured hydrogen ion concentrations with pH meters, natural compounds were added which changed colour in certain pH ranges (but did not interfere with the reaction). For example, phenolphthalein was colourless in acidic solutions but bright pink when it turned alkaline. Therefore, phenolphthalein was used as an indicator, not because the colour change itself was important but because it easily and reliably detected pH change.

The wish to do something about the poor microbiological quality of milk, which often led to outbreaks of disease, prompted similar public health indicators. These measures

could not be (and were not required to be) comprehensive. Nor did they need to be a direct measure of the pathogenic element. For example, in 1884 Spiegelhalter measured the average water content in milk, not because water itself was important but because it was simple to measure, and irregularities in water content could predict disease (i.e. high water content implied the milk had been diluted with unsanitary substances).(2)

2.3.2 Quality indicators for health care

The concept of a '*quality indicator*' (QI) was first applied in the context of health care in the middle of the 20th century. The Institute of Medicine (IOM) defines quality as the "degree to which health care services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge."(3) Many definitions of quality have been used in the literature, such as by Campbell and colleagues (4), but defining it is beyond the scope of this thesis. The IOM definition of quality is described as it highlights that the responsibility of health care providers is to both individuals *and* populations, and the ultimate aim is to improve health outcomes. The '*desired outcomes*' can be defined by patients (e.g. satisfaction with care) or by health care providers (e.g. mortality) but both are bound by current professional knowledge which is constantly changing.

Over 60 years ago, the US Subcommittee on Medical Care recommended monitoring care delivery standards, describing "methods by which these [quality] standards can be approached."(5) These methods in essence described a number of quality indicators thought to be "valuable in controlling abuses and promoting quality of care."(5) In 1957, Swaroop and Uemura, working with the WHO, developed a single

comprehensive indicator, a "yardstick by which broad inter-country comparisons may be made" on health and demographic conditions.(6)

In 1966, Donabedian synthesised the means by which indicators could be applied to quality in health care by defining three domains: *structures* (the settings in which care took place), *processes* (the care delivered to the patient), and *outcomes* (the ultimate consequence of care).(7) While this framework was conceptually helpful, it was neither new (Codway first described outcomes or '*end results*' in 1916 (8)) nor unique to health care. In car manufacturing, for example, the same concepts applied. Structures or *inputs* referred to the resources consumed (e.g. iron, tyres, electricity), processes represented *productivity* or *efficiency* (e.g. number of cars produced per day) and outcomes referred to the *results* (e.g. safety performance).

2.3.3 Should QIs monitor process or outcome?

The literature on quality indicators reveals a tension between monitoring the desired outcome directly and monitoring the process (or structure) of care leading to the outcome. For most monitoring instruments, there is a trade-off between ease of measurement and validity. To take a clinical example, it is easier but less precise to measure the temperature of a febrile child in the axilla rather than rectally.

Indicators, irrespective of the area, need to be able to detect changes in what they are trying to measure (i.e. they need to be *sensitive to change*). Indicators also need to be valid, and their validity is contingent on how closely they are linked to the outcome of interest. Good indicators have a close *proximity* to the outcome of interest: changes in the indicator are closely linked to changes in outcome. For example, prescribing

inhaled corticosteroids to children with asthma is considered to be a valid process indicator because there is evidence that increased prescribing reduces accident & emergency (A&E) visits and hospital admissions.(9)

While outcome indicators are the most valid measures of quality (if they are measuring directly the outcome of high quality care), they are often insensitive to changes in care delivery. In children, outcomes such as death or serious disability are rare and the underlying causes multi-factorial, often related to factors which are not directly related to the quality of care provided (e.g. parental smoking and others socio-economic issues). These contextual factors are magnified by the fact that children rely on their parents/caregivers to access services (e.g. transport) and provide appropriate care (e.g. take medication). For example, a US study conducted by Flores *et al.* found parents' "failure to pay greater attention to medication-related issues as the single most common reason for children's avoidable hospitalisations."(10) For these reasons, process (and structure) indicators are often chosen in preference to outcome indicators. For example, rather than monitoring unplanned hospital admission as an indicator of the quality of care of children with asthma, prescribing is often chosen instead as a preferable quality indicator: it measures directly the behaviour of the responsible clinician; it is easy to measure and sensitive to change; it is known to impact the outcome; and less account has to be taken of contextual factors in its interpretation. There is also evidence that prescribing is an effective indicator in influencing care quality: indicators introduced to manage children with asthma increased the percentage of patients receiving appropriate medication prescriptions and self-care plans from 4% to 88% over three years.(11)

2.3.4 Distinguishing between QIs and quality standards

In the application of quality indicators it is important to draw a distinction between the indicators and the quality standard adopted for the indicator. An *indicator* specifies what is high quality care while the *standard* sets a quantified *target* for the delivery of such care. For example, vaccination coverage may be adopted as a quality indicator. The quality standard or target for this indicator is usually the minimum proportion of children who should have been vaccinated who have been vaccinated.

Confusingly, the terms are often used synonymously (e.g. NICE quality standards are actually *indicators* which detail specific *targets* which practices should achieve (12)). It is important to distinguish between indicators and standards, since demanding 100% adherence to a requirement to deliver care in a certain way may not be appropriate. Not only may it be an unrealistic aspiration, but sometimes good care also requires responsiveness to the individual child, taking into account the wishes and personal circumstances of the child and parent. For example, setting a *standard* for immunisation of 100% coverage is unrealistic and likely to lead to inappropriate coercion. The decision to set standards is usually made *after* indicators are developed and is often decided locally.

2.3.5 Does professional acceptability matter?

The processes that have been used to develop quality indicators for paediatric care are reviewed in the next section, but several researchers have suggested that acceptability to stakeholders is a key characteristic of any quality indicator for health care.(13) To take the UK as an example, in 1995 Majeed and Voss recommended that GPs should "be involved at all stages in the development and implementation of performance

indicators" (14) and in 2007 Roland reiterated that "future developments of the QOF should focus on areas where there is clear professional consensus that care needs to be improved."(15)

The justification seems to be that clinician involvement is essential to develop effective quality indicators. In other words, if indicators are not supported by clinicians, or clash with professional values, implementation of a quality indicator may adversely affect physician behaviour rather than motivate them to improve their care quality. There is some evidence to support this hypothesis. In the UK, Spooner *et al.* found quality improvement initiatives were more successful when clinicians agreed and supported the financial incentives.(16) McDonald *et al.* similarly found that early QOF indicators were supported because they aligned with what GPs and nurses perceived to be good medical care.(17) In contrast, a later study by McDonald and Roland described how a lack of support for incentivised indicators in primary care has a negative influence on behaviour.(18)

Evidence from psychological research helped explain these observations: a large meta-analysis by Deci *et al.* found that providing rewards for an activity which was perceived to have no value undermined *intrinsic motivation*.(19) But Self-Determination Theory postulates that extrinsically motivated behaviour (e.g. motivated by tangible rewards or punishment) can become autonomous through the process of '*internalisation'*.(20) Internalisation outlined how, when an individual took in the values, beliefs or attitudes of the regulatory structure, their behaviour was no longer driven by external factors but by values or personal goals. Therefore, behaviour driven by '*internalised extrinsic motivation*' was driven autonomously and

shared many characteristics of intrinsic motivation; the activity itself was not interesting but important for one's personal values and goals (i.e. to deliver high quality care). By acquiring clinicians' views before quality indicator development, it should be possible to carefully structure indicators to align with clinicians' goals and lead to autonomously motivated clinicians.

However, the interests of clinicians and their patients are not synonymous. The over-investigation and treatment evident of patients in many health economies (because clinician income is based on activity rather than outcome) is a good example. While recognising that successful implementation of quality indicators in the health care sector may depend on clinician involvement, it is also important to acknowledge that this involvement will increase the moral hazard of prioritising indicators that reflect the financial interests of clinicians rather than the health needs of their patients.

2.3.6 Quality indicators for children

It is clear from the literature that there are particular challenges with developing quality indicators for children. The care of children involves three rather than two people: the child, the parent/carer and the health care professional. Young children in particular often cannot provide the most relevant information easily (for example, on their personal experience of care) and the reliability and validity of third-party information has been questioned.(21) Similarly, basing quality indicators on medical records is made more difficult because adolescents often have confidentiality concerns about what is recorded (particularly in relation to sexual or other personal history) if they think their parents might have access to the record.(22)

The high incidence of episodes of care for acute conditions (23) and low prevalence of chronic illness in children is clearly also an issue for quality indicator development. The focus on chronic disease in the UK QOF indicators for adults has the effect of improving overall care because these chronic conditions (e.g. hypertension, diabetes and coronary heart disease) are common, with many adults having more than one of these conditions.(24, 25) In contrast, most children are healthy and interact with the health care system only for preventive services and minor self-limiting illnesses.(26) Therefore, to address the overall quality of care for children, quality indicators have to address acute episodes of care which, as the literature suggests, is not easy. Equally, the low prevalence of children with chronic medical conditions (e.g. epilepsy) (27) indicates that focusing on these conditions may have little overall impact on care quality. Additionally, the resource cost of implementing quality indicators may be high.

2.4 How have the areas of care for QI development been selected?

Historically, the motivation to develop quality indicators has usually arisen from a perceived problem with health care quality. In some cases, the concern has been relatively specific (e.g. about care of a certain condition or the impact of a change in health policy) while in other cases the concerns have been raised about overall care quality of paediatric care in a health system. However, in both cases, an implicit or explicit choice has had to be made about which specific *aspects of care* should be selected for quality indicator development. This section reviews the different approaches that have been taken to make this choice. I focused on describing indicator

sets that were: a) developed using a rigorous and transparent methodology; b) evaluated in a clinical setting; and c) applicable to children in UK general practice.

2.4.1 Areas selected to address perceived poor care quality

Several indicator sets have focused on single conditions where there has been a specific concern about care quality. For example, Nordly *et al.* (28) developed quality indicators and measured them in 1335 Danish children with diabetes in an effort to address the concerns raised by previous Danish studies that had reported poor quality of care for children with diabetes. Interestingly, although the process indicators suggested satisfactory care, the outcome indicators flagged poor care. Similarly, concerns about the inability to evaluate care quality for infants who were small at birth (less than 1500 grams) drove Wang *et al.* (29) to develop 70 indicators. Two indicators were evaluated in a retrospective study of 2182 children with very low birth weights: 23% (241/1052) received suggested eye examination and 20% (48/241) received eligible hearing rehabilitation.(30)

Other indicator initiatives have been driven by concerns about care quality after policy changes. In response to concerns about potential sub-standard health care following a reorganisation of Dutch out-of-hours primary care, Giesen *et al.* (31) developed indicators for 'internal quality improvement'. The 24 indicators, developed directly from 29 national guidelines, focused on prescribing and referring as elements of care that were easy to measure. Ten indicators focused on acute paediatric infections such as pneumonia, otitis media, sinusitis, conjunctivitis, and urinary tract infections. Only approximately one in five patient contacts (7344/36 254) were relevant to the indicators developed. These indicators resulted in the Dutch College of

General Practitioners developing additional guidelines specifically for out-of-hours care.

In 2006 the AHRQ developed Paediatric Quality Indicators which used hospital data to identify problems "amenable to prevention by changes at the system or provider level."(32) While most of these were focused on inpatient care, five were relevant to primary care, described as 'area-level indicators', including asthma, diabetes, gastroenteritis, urinary tract infection, and perforated appendix.(33) Similarly, the OECD Healthcare Quality Indicator Project (HCQI) developed indicators for the broader health care systems in different countries.(34) Primary care, including the broader domains of prevention and health promotion, was flagged for additional marker work (35) which led to indicators focused on hospital admissions for '*ambulatory care sensitive conditions*' (ACSCs).(36) ACSCs were described by Billings *et al.* as conditions where timely and effective primary care reduced the chance of hospital admission.(37)

In the US, ACSCs are primarily an indicator of primary care access rather than quality (given the absence of a universal health care system) but Caminal *et al.* validated a set of ACSCs for European GPs to evaluate primary care effectiveness.(38) Many of these admissions, however, are insensitive to the quality of primary care. For example, Flores *et al.* identified children admitted to hospital for an ACSC and interviewed the children's parents, the hospital clinician and the primary care physician: only 13 to 46% of admissions were classified as '*avoidable*.'(10) Therefore, while high quality primary care can reduce the severity by which children present to hospital (e.g. good asthma chronic disease management and timely

immunisations), the ultimate decision to admit a child to hospital is made in secondary care and is influenced by numerous factors further discussed in Chapter 5.

2.4.2 Aspects of care selected in order to measure overall primary care quality

The United States has been developing indicators to assess the overall quality of primary care provision for several decades.(39) Many early initiatives focused broadly on the conditions most commonly treated in primary care. In the early 1990s, the National Committee for Quality Assurance introduced the Health Plan Employers Data and Information Set (HEDIS).(40) HEDIS was used to generate '*report cards*' for over 90% of managed care plans on outpatient care. Many indicators focused on immunisations to prevent common infections (17 of 75 current measures were child specific, see Table 2.1 (40)). These '*report cards'* identified inequalities in care coverage: for example, vaccination rates of children enrolled in private or commercial insurance plans were higher than children in Medicaid (i.e. state-run plans).(41) Plans monitoring the HEDIS indicators showed that from 2003-2007 the childhood immunisation rates increased whether children had state (59% to 72%) or commercial plans (70% to 81%).(42)

Several decades of work culminated in the RAND Quality of Care Assessment Tools (QA Tools) (43) for children and adolescents in 2000 (and four other sets). The 453 indicators were selected to monitor care quality for common ambulatory care conditions (representing 55% of visits) and the main causes of child mortality and functional disability (Table 2.1).(43) These tools provided a '*global'* indicator of quality with '*composite'* measures which sought to minimise gaming.(44) The RAND QA Tools were developed using a conceptual framework based on type of care (e.g.

acute), function (e.g. diagnosis), and modality (e.g. history). Mangione-Smith *et al.* (44) applied 175 of the indicators to 1536 randomly selected US children from a broad geographic area using data from 1996 to 2000. The composite care quality was 47% (8% lower than adults (45)) and varied according to type of care: preventive (41%), chronic (53%), and acute (68%). Adherence also varied considerably based on the condition; it was low (33%) for the management of acute diarrhoea but high for allergic rhinitis and URTI (85% and 92% respectively).

In 2001 in the UK, the National Primary Care Research and Development Centre and the Nuffield Trust, working with RAND and informed by the QA Tools, adopted a similar approach by developing 229 indicators for British primary care (covered 60% of visits).(46) The child-relevant conditions with indicators are outlined in Table 2.1. The comprehensiveness of indicators for each condition varied with the strength of evidence and professional consensus for its management. Kirk *et al.* (47) assessed the feasibility of applying these indicators in 16 practices (100 patients per practice) in 2000-01. The proportion of records containing the relevant data to allow the indicators to be assessed for two child specific conditions was 6-50% for acute childhood diarrhoea (32% overall) and 44-97% for otitis media (87% overall).

The Dutch College of General Practitioners took a different approach when it developed 139 indicators (17 paediatric specific; Table 2.1) from 61 guidelines to quantify whether care was in "agreement with clinical guidelines."(48) These indicators were designed to measure structures (n=10), processes (n=124), and outcomes (n=5); process indicators were further categorised into 'diagnostics', 'referrals to primary and secondary care', 'prevention', and 'health education'. These

indicators failed to measure important domains such as patients' views of the care provided (deficits also observed in RAND QA Tools and NPCRDC indicator sets).(48)

Table 2.1: Summary of conditions in select primary care quality indicator sets described in section 2.4.2

Condition	RAND QA Tools (43) US	Marshall *et al.* (46) UK	Westert *et al.* (48) Netherlands	NCQA HEDIS[1] (40) US
Acute conditions				
Acne	X	X	X	-
Allergic rhinitis	X	X	X	-
Atopic dermatitis	X	-	O	-
Conjunctivitis	-	-	O	-
Diarrhoeal disease	X	X	X	-
Enuresis	-	-	X	-
Febrile illness	X	-	X	-
Headache	X	O	-	-
Lower respiratory tract infection	X	-	-	-
Musculoskeletal injuries	-	-	X	-
Otitis media (acute, externa, effusion)	X	X	X	-
Skin infections	-	-	O	-
Stomach pain	-	-	O	-
Tuberculosis	X	-	-	-
Upper respiratory tract infections	X	X	X	X
Urinary tract infections	X	X	O	-
Vaginitis / Sexually transmitted diseases	X	-	X	-
Chronic conditions				
Asthma	X	X	X	-
Attention deficit hyperactivity disorder	X	-	-	X
Depression	X	-	O	-
Diabetes	X	O	-	X
Preventative care				
Adolescent preventive services	X	-	-	-
Immunisations	X	X	O	X
Well child care	X	-	-	X
Other domains				
Access	-	-	-	X
A&E visits	-	-	-	X
Patient experience	-	-	-	X

Notes: X, child-specific indicators explicitly defined. O, likely relevant to children although not explicitly defined. [1] National Committee for Quality Assurance (NCQA) Health Plan Employers Data and Information Set (HEDIS).

2.4.3 Areas prioritised to allow international comparison of quality

Specific aspects of care have also been selected for indicator development in order to allow comparison of different national primary care systems. In response to European unification, Engels *et al.* (49) developed indicators for general practice management to facilitate national comparison and identify where care needed improvement: nearly all (57/62) of the indicators were measurable.(50) The markers were similar to QOF organisational indicators (51) and focused on infrastructure, staff, information, finance, and safety. The successful initiative likely reflected the inclusion of primary care experts from various European regions.

Rigby *et al.* (52) described a European-wide programme which developed child health measures, referred to as the 'Child Health Indicators of Life and Development Project.' There were 38 markers that covered four broad domains: 'demographic and socio-economic'; 'child health status', 'well-being; health determinants, risk, and protective factors'; and 'child health systems and policy'.(52) These indicators were used by the World Health Organisation to measure the care quality of children in Europe.(53)

2.4.4 Methods used to prioritise areas for QI development

The indicator sets developed by large organisations or by governments frequently used a prioritisation process to select particular aspects of care. For example, before topics were prioritised, factors such as morbidity, prevalence, and cost were considered by the NICE QOF Indicator Programme.(54) Consequently, there was a trade-off between these competing factors, and these decisions were not always objective or transparent. Even the advisory committee, which selected topics for

marker development, conveyed a "need for a clearer criteria and better understanding of the scoring system" on which topics were prioritised.(55) Formal consensus techniques (56) such as the Nominal Group Technique (NGT) were used infrequently. This consensus methodology uses a highly structured format to prioritise responses from an expert group.(57) The NGT was particularly useful in areas prone to subjective judgements (58) and performed better than informal group methods.(56)

In Canada, Guttmann *et al.* (59) used the NGT to prioritise topics for quality marker development in paediatric emergency care. A 9-member panel was provided data about the common conditions seen in the emergency department. They were then asked to prioritise the most important clinical areas based on several factors such as diversity of clinical conditions and strength of evidence. The panel members were mixed (included clinicians from a range of settings and administrators) because the measures were intended for public reporting. Generally, multi-specialty groups were recommended over single-speciality groups (60) but the effect of group membership on NGT results was inconclusive. Others have suggested diversity of panel membership usually improved performance as long as participants did not express extreme views and provoke conflict.(56) The 68 clinical indicators developed by Guttmann encompassed a broad range of conditions including mental health, infections, injuries, and chronic conditions, but only 19 could be measured in the A&E setting.(59)

2.4.5 Aspects of care which have not been prioritised for QI development

Despite these attempts to develop indicator sets that reflect overall quality of care, and the adoption of formal methods for prioritisation, there are some very obvious gaps.

Quality indicators have not been developed for areas of care that appear to be problematic. For example, the 'World Mental Health Survey Initiative' found life-long mental disorders were frequently identified by adolescence (61) but only a small number of indicators have focused on mental health conditions (e.g. adolescent depression). There are consequently significant gaps in the management and treatment of other disorders (e.g. self-harm and anxiety).

Similarly, few quality indicators have focused on identification and management of developmental or behavioural disability (e.g. autism and language delays) despite one in six US children having one or more of these conditions.(42) The indicator gap also extends to common conditions (such as atopic eczema, nocturnal enuresis, constipation, and injuries) and there are few indicators focused on preventing life-long conditions that start in childhood. For example, 8 out of 10 obese adults were obese teenagers (62) yet indicators focused on BMI screening, nutrition counselling and physical activity are scarce.

It is, however, difficult to tell from a retrospective analysis whether these obvious gaps reflect an initial failure to identify these aspects of care as priorities or a subsequent failure to develop quality indicators in the priority areas identified.

2.5 Methodology used to develop quality indicators for children in selected priority areas

2.5.1 Developing evidence-based indicators

The most rigorous approach taken has been to develop only those indicators that are supported by strong evidence (i.e. RCTs showing that the structures or processes measured by the indicator affect morbidity or mortality).(13) The limitations (and potential benefits) of this approach in UK general practice have been outlined by others.(63) A major limitation is that even where there is trial evidence demonstrating the effectiveness of an intervention, there is inadequate evidence to guide its use in paediatric practice. Starfield has argued that this problem arises because the focus of most research is on "internal elegance rather than external relevance."(64) Others have also expressed significant concerns about publication bias (which leads to over-stated benefits and under-stated harms) (65) and inadequate description of the interventions (which makes it difficult to generalise results and decide *how* the intervention could be implemented in clinical practice).(66)

This generic limitation in the value of evidence is exacerbated by the specific lack of evidence to support paediatric clinical practice (which is often generated from adult populations (67)). Rudolf and colleagues found that less than half of the activities of UK community paediatricians are estimated to be supported by evidence of effectiveness from high quality studies.(68) No evidence underpins counselling/advice interventions (13% of activity) while 53% of prescriptions (4% of activity) are supported by evidence, although most of these studies rely on off-label or unlicensed medications which have not been empirically tested.(69) Similarly, Scholle *et al.* found that less than half (8/17) of the US Preventative Services Task

Force recommendations on child health have sufficient information to make a recommendation for or against the service.(42) Many paediatric studies are low quality, with either cross-sectional designs or small sample sizes (usually single centred).(70) Despite the increased generation of research (71), adult RCTs were increasing ten times faster than paediatric RCTs.(72) Klassen *et al.* also pointed out the serious methodological limitations in paediatric clinical trials.(73)

In order to fill this evidence-gap, those developing quality indicators have had to rely on expert opinion. For example, 72% of the RAND QA Tools indicators were supported by expert opinion or descriptive studies while only 18% were supported by evidence from rigorous studies.(22) A similar need to augment evidence from clinical trials with expert opinion is evident from quality indicator development in other countries. Marshall *et al.* (46) commissioned a group of over 20 expert GPs to complete systematic reviews on the top 20 most common conditions, and then asked each GP to interpret the evidence and suggest a list of indicators relevant to clinical practice. Similarly, in the Netherlands recommendations were identified from evidence-based national guidelines using the iterated consensus rating procedure (13) to develop indicators for Dutch primary care.(48) But these guideline-derived recommendations were seldom expressed in a form that directly translated into a statement about care quality that formed the basis of a quality indicator. An expert panel converted these into precisely defined indicators.(74) Formal consensus methods to incorporate expert opinion have been shown to produce judgements that are more consistent with the evidence when the expert panels are provided with literature reviews.(60) Rating systems have also been developed which can make more explicit the relative contribution of expert opinion and formal evidence. For

example, in developing national guidelines, UK NICE uses the GRADE rating system (Grading of Recommendations Assessment, Development and Evaluation).(75)

To avoid re-inventing the wheel, previously published indicators (such as those from the AHRQ National Quality Measures Clearinghouse (76)) have been integrated into consensus development methods (such as Guttmann *et al.* (59)). This supports the transferability of indicators between countries, but only *after* an intermediate process has been implemented.(77, 78) This enables the indicators to be placed in the context of a different health care system, taking into consideration variation in clinical practice.

2.5.2 Selecting a sub-set of quality indicators

While careful and precise wording is a necessary condition for any quality indicators, it appears not to be sufficient. For example, Campbell found that formal consensus methodology was required to identify a sub-set of indicators which could be implemented in clinical practice and were perceived as valid amongst potential end users.(13) The two key consensus methodologies described in the literature are the Delphi Technique and the RAND/UCLA Appropriateness Method (the RAND method).(13, 56)

The Delphi method uses two or more rounds of postal surveys to generate consensus.(79) After each round, the results are collected and fed back to the group either statistically (i.e. summary of individual and group scores) or qualitatively (i.e. summary of comments).(80) Additional surveys are administered until a consensus is generated. A panel can be composed of large numbers of people (e.g. up to several

thousand) over a wide geographic area and is relatively inexpensive. A panel has thus been used for a wide range of topics described by Hutchings.(60) However, the lack of a face-to-face meeting, while it minimises potential group intimidation, is reported to restrict debate and discussion of different viewpoints. This method has been used to develop indicators for general practice management in Europe (49) and to identify a set of markers for Canadian family practice (81) but it has not been widely used to develop quality indicators for children in primary care.

The most widely-used and rigorous methodology described in the literature is the RAND method (also known as the modified Delphi consensus process).(82) It is described by Naylor as the "only meticulously tested and systematic method for leavening limited evidence with expert opinion and inference."(83) While the RAND method was developed several decades ago (84) to evaluate the appropriateness of diagnostic and therapeutic care (such as coronary angiography (85)), it has been used extensively to develop paediatric indicators in Canada (59), the US (29, 43) and the UK.(46) NICE uses the RAND method to develop indicators for consideration of use in the UK QOF.(54)

The standard RAND method involves an expert panel (of about 9 members) completing two rounds of rating. The first round is a postal rating in which panellists read the relevant literature and then rate indicators on a set of '*a priori*' defined statements (i.e. *validity* and *feasibility*) anonymously, using a 9-point scale. Subsequently, the panel meet face-to-face to discuss each indicator in turn, clarifying points of uncertainty and modifying wording of the indicators. The panellists then anonymously re-rate the indicators. The final list of indicators is based on a cut-off score and level of panel agreement.(82) Despite its widespread use, the RAND

method is not without limitations (86) but its reproducibility is increased when a higher cut-off score is used for the median value (e.g. 8 out of 9).(13) Frequently, a more rigorous cut-off score is used for validity.(46)

The results of consensus methods are substantially affected by panel composition.(60) The recommended composition of the expert panel depends on the research objectives and the stakeholders it purports to represent (87), but the output is more likely to be accepted when generated by a group perceived to be credible.(56) In North America, the panels tend to be composed of a mix of specialists and generalists nominated by professional organisations. In the UK, where quality indicators have mainly been developed for use in general practice, panel membership is often restricted to general practitioners. Marshall selected panel members who were Fellows by Assessment of the RCGP on the grounds they would be familiar with critical appraisal and "grounded in the reality of 'real' (though high quality) general practice."(46) Similarly, the NICE QOF Indicator Programme appointed a mix of GPs (i.e. those who work on the frontline, and those with a special interest in areas under consideration).(54)

2.6 Summarising the literature review findings

The concept of an '*indicator*' emerged from the need for a tool that predicted an outcome of interest validly but could be more easily and reliably measured. Indicators have been employed to monitor the quality of health care delivery since the middle of the last century. Traditionally, they have been categorised as measuring either

structure, process, or outcome, although the same three necessary characteristics apply – *ease of measurement, reliability* and *validity.*

While outcome indicators might be seen as self-evidently the best measure of care quality, evidence shows that they are often insensitive to changes in care delivery. Process indicators have been more commonly used for monitoring paediatric care quality because the adverse outcomes of interest are often rare and influenced by multiple factors, such as parent behaviour, which are beyond the influence of clinicians.

The process of indicator development is usually done in two stages: 1) agreement on the clinical areas in which care quality needs to be monitored; and 2) development of a set of quality indicators to measure care quality in these areas. Previous initiatives have either focused broadly on the common conditions treated in primary care (reflecting the overall care workload) or, more narrowly, on specific conditions (usually areas of perceived poor care). One way used to identify areas of poor care quality in primary care has been to identify high-rates of hospital admissions for '*ambulatory care sensitive conditions*.'

Some initiatives (e.g. NICE) have used a structured process to identify priority areas for quality indicator development, but the decisions taken are not transparent and it is not clear if they would be reproducible. A few indicator sets have been derived using a more formal consensus methodology such as the Nominal Group Technique, and this appears to be particularly useful when there is little to guide the choice of area except expert opinion.

Expert opinion has played an important role in developing quality indicators in defined priority areas, even when the explicit aim was to derive indicators that were 'evidence-based'. Expert opinion has been important for two reasons: 1) lack of trial evidence on the effect of the health care interventions used in everyday practice; and 2) the inadequacy of the existent evidence for defining the conditions under which the proven intervention is most appropriately applied. The consequent evidence-gap has often been filled by using national guidelines (usually based on a synthesis of formal evidence and expert opinion) to underpin quality indicator development.

In health care, quality indicators are used as a mechanism to improve the quality of care delivered. In this context, the *acceptability* of the indicators to health care professionals seems to be particularly important. Evidence suggests that indicators that are not supported by or clashed with professional values adversely affect physician behaviour, undermining intrinsic motivation and leading to unintended negative consequences. It is therefore now common practice to involve clinicians closely in the development of quality indicators to ensure that the indicators are perceived to be valid and feasible to measure in clinical practice. Formal consensus methodology is routinely applied to achieve this end. In particular, the RAND Appropriateness Method has been widely used, including by NICE, to develop quality indicators for children.

In the next chapter, I identify the aims and objectives of this thesis and outline the specific focus of the studies undertaken.

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Chapter 3: Aims, objectives and structure of thesis

3.1 Aims and objectives

The aim of this thesis is to fill the knowledge gaps identified in Chapter 2 by defining a candidate set of quality indicators that are evidence-based, feasible to implement, and have the potential to improve the quality of care provided for children in UK general practice. The specific objectives are:

1. To define clinical areas in which indicators of the quality of primary care provided to children should be developed.

2. To develop evidence-based quality indicators for these clinical areas.

3. To select a sub-set of quality indicators that would have professional support and could feasibly be implemented in UK general practice.

3.2 Studies to address these objectives

Objective 1: To define clinical areas in which indicators of the quality of primary care provided to children should be developed.

To seek local general practitioners' views on the development of quality indicators for children in primary care (Chapter 4). A semi-structured qualitative interview study with 20 UK general practitioners in the Thames Valley region in Oxfordshire was undertaken to explore their overall views about quality indicators and the difficulties likely to be encountered. This study also sought to identify specific aspects

of the clinical care of children that GPs perceived as markers of quality to determine which areas could be aligned with GPs' professional values.

To identify problems in the quality of primary care delivered to children in England by exploring hospital admissions for ambulatory care sensitive conditions (Chapter 5). A cross-sectional study was undertaken using national Hospital Episodes Statistics (HES) data from 1998 to 2010 in England to identify which ambulatory care sensitive conditions (i.e. conditions for which hospitalisation reflects a failure of management in the community) in children were associated with high rates of emergency admissions to hospital, or substantial local variation. Time-trends were used to identify temporal associations with organisational changes that could have influenced the trajectory in rates of admission.

To identify the clinical areas of child primary care for which national experts thought quality markers should be developed (Chapter 6). The Nominal Group Technique was used with a nationally convened panel of general practitioners (with specific expertise in child health and with representation from England, Scotland, Wales, and Northern Ireland) to generate professional consensus on the clinical areas of child primary care for which it was most important to develop quality markers.

Objective 2: To develop evidence-based quality indicators for these clinical areas.

To identify the evidence-base for the effectiveness of clinical interventions delivered to children in primary care (Chapter 7). A systematic overview of Cochrane

systematic reviews was undertaken to identify clinical interventions delivered to children in primary care for which there is strong evidence of effectiveness.

To identify the clinical interventions recommended in national guidelines relevant to primary care (Chapter 7). All published UK national guidelines (NICE and SIGN) relevant to children in the clinical areas identified in the Nominal Group Technique were identified and the recommendations on care provision extracted. Quality indicators to measure the implementation of these recommendations were then generated by a local expert panel of academic general practitioners using an iterated consensus rating procedure informed by the evidence-base identified in the Cochrane Library.

Objective 3: **To select a sub-set of quality indicators that would have professional support and could feasibly be implemented in UK general practice.**

To select a sub-set of quality indicators which UK general practitioners perceive as valid and feasible to measure (Chapter 8). A modified RAND Appropriateness Method was used to generate professional consensus on which quality indicators were perceived as valid and feasible for use as part of the UK general practice Quality Outcomes Framework. The technical issues raised by the expert panel were collated and used to draft technical specifications for the final quality indicator set to guide indicator operationalisation and pilot testing.

Chapter 4: General practitioners' views on quality markers for children in UK primary care

4.1 Introduction

Primary health care for children in the UK is delivered mainly in general practice surgeries by doctors trained as general practitioners and nurses working as either practice nurses or health visitors. While general practices are now contracted to deliver care only during standard working hours, some general practitioners continue to provide acute out-of-hours clinical care under contract to other provider organisations.

Most general practitioners are either principals or partners, contracted by the NHS directly to deliver primary care services to a registered population on a self-employed basis or employed by principals on a salaried basis. The principals therefore play an important administrative as well as clinical role, employing the other members of the primary care teams (including the nurses and ancillary staff as well as the salaried doctors) and organising the delivery of care in each practice. This administrative role includes taking responsibility for ensuring compliance with defined quality indicator standards set out by the Quality Outcomes Framework.

This chapter presents the results of a qualitative study conducted to explore the views of general practitioners, (mainly general practice principals), on the development of quality indicators for the care of children. Their opinions were sought on the value, feasibility and potential content of quality indicators which could be incorporated into the Quality Outcomes Framework, thereby providing a financial incentive for improving the quality of primary care for children.

Seeking professional views as part of the process of developing the quality indicators against which they will be assessed is regarded as good practice for two reasons: 1) professionals have expert knowledge about the determinants of care quality; and 2) professionals are less likely to oppose quality indicators if they feel some ownership of them.(1) However, under the NHS pay-for-performance system introduced in 2004, about 30% of the amount paid to general practitioner principals under their NHS contracts depends on meeting the standards defined by the Quality Outcome Framework. Experts therefore have a potential financial interest in suggesting quality indicators which can be easily met.

4.2 Aims and objectives

The overall aim of the research reported in this chapter was to determine general practitioners' views on the development of quality indicators for children in primary care. The specific objectives were:

1. To identify a range of GPs' views on quality measurement in primary care, specifically focused on quality measurement in children (to determine whether GPs support or oppose the concept of child specific indicators).

2. To explore a range GPs' views on the difficulties likely to be encountered when developing quality markers for children (which could be taken into consideration when designing child indicators).

3. To determine GPs' views on whether admission to hospital for commonly managed conditions in primary care is a valid quality indicator of primary care provision (to determine whether the previously described "*ambulatory care sensitive conditions*" could be used in the UK).

4. To identify specific aspects of clinical care and childhood conditions to focus indicator development in UK general practice (to determine which areas markers could be designed that are aligned with GPs' internal motivation and professional values).

4.3 Methods

4.3.1 Study design

Face-to-face semi-structured interviews with GPs were conducted to explore their views on the use of indicators to assess the quality of primary health care provided for children and to guide future indicator development. Semi-structured interviews were selected (instead of open-ended or structured interviews) because they permitted the exploration of new themes while allowing the interviewer to pursue pre-specified questions as recommended by Murphy *et al*. (2). The Oxfordshire Research Ethics Committee A (10/H0604/42) reviewed the protocol and granted ethical approval. Results from this chapter have been published in *BMC Family Practice*.(3) This study was funded as part of the NIHR National School for Primary Care Research grant awarded to the Department of Primary Care Health Sciences, University of Oxford.

4.3.2 Participants and sample strategy

GPs were sampled from a single geographic area in the Thames Valley region of England which at the time included five Primary Care Trusts (PCTs). The five PCTs – East Berkshire, West Berkshire, Buckinghamshire, Milton Keynes, and Oxfordshire – served a combined population of over 2.2 million patients (of whom 450 000 were children aged 15 or younger).(4) Over 1500 GPs were registered as providing primary care services. The region includes a range of rural and urban environments with substantial ethnic minority populations in some localities.

Purposive sampling, as recommended by Coyne (5), was used to identify a maximum variation sample of GPs based on their personal characteristics (i.e. age, gender, professional experience, and full time/part time) and their practice population (i.e. list size, deprivation levels, and ethnic minority groups). Maximum variation sampling was selected to identify a broad range of GPs' views and perspectives on quality measurement. The sampling strategy was not informed by an '*a priori*' theoretical framework developed prior to the study, nor did emerging theories during the data analysis inform the sampling strategy; however the background literature informed the development of the interview schedule described in section 4.3.5. Deviant or negative viewpoints that emerged within cases were explored and discussed but were not actively sought by purposive sampling criteria other than those stated above.

It was anticipated that between 12 and 40 participants would need to be recruited to achieve data saturation (Guest *et al.* (6) found 12 interviews was the minimum number before it could be concluded that no new themes were likely to emerge). It was agreed in advance that data saturation would be considered achieved when three

consecutive interviews failed to contribute new themes or ideas; this was suggested by Francis *et al*. (7). Throughout the interviews, I continually reflected on the emerging themes to monitor for data saturation in discussion with Dr Jenny Hislop (Senior Qualitative Researcher, Health Experiences Research Group, University of Oxford). We agreed that data saturation had been reached after 17 interviews and validated this opinion by conducting a further three interviews which produced no additional codes or emergent themes.

4.3.3 Recruitment procedure

The Thames Valley Primary Care Agency was contacted and provided an updated list of all 1564 GPs with information on their gender, registration date, practice size, and PCT. Information on the index of multiple deprivation was identified from practice postal codes. Invitation letters (and information packages which outlined the study design) were sent by post. Physicians interested in participating were required to contact me by phone or email. The research ethics committee did not permit the GPs to be contacted directly, nor to send a reminder letter.

Table 4.1 shows the staged process by which the sample was selected and invitation letters were sent. Of 1564 GPs, 165 were contacted; 23 responded and 20 (12% response rate) were interviewed. Of the three GPs who responded but were not interviewed, two failed to respond after initial contact for an interview date and the third made contact after data saturation had been reached. The low response rate was likely due to the inability to send a follow-up letter (which was not permitted by the Research Ethics Committee), the time required to organise and complete the face-to-face interview, a lack of interest in the topic area either pertaining to child health or

quality indicators, and a preoccupation with the major NHS organisational reforms that were happening contemporaneously.

Table 4.1: Number of general practitioners contacted and interviewed

Round	Date	Invited	Responded	Interviewed	Percent
1	02/10/2010	10	4	3	30%
2	13/01/2011	50	3	3	6%
3	26/01/2011	14	5	4	29%
4	09/02/2011	25	2	2	8%
5	16/02/2011	24	4	4	17%
6	16/03/2011	42	5	4	10%
Total	-	*165*	*23*	*20*	*12%*

My qualitative supervisor suggested that I should begin interviewing and refine recruitment based on the GPs interviewed. Therefore, initially GPs were randomly selected based on the purposive sampling strategy outlined above; some were also suggested by my supervisor (most Oxford based). If a GP did not respond a replacement was sought with similar characteristics. After the initial low response rate, I met with the student teaching coordinator in the Department to identify GPs who would be more likely to respond that fulfilled the maximum variation sample characteristics sought; these suggestions were used for the 4th and 5th stages. As I had limited funding, the sampling strategy emphasised practices that could be easily reached by public transportation.

Young GPs, female GPs and GPs serving deprived areas proved the most difficult to recruit. The final stage of recruitment targeted participants with the necessary characteristics particularly GPs practicing in deprived areas. These GPs were recommended by GPs already involved in the study and were therefore more likely to agree to participate. Information about the GPs invited and interviewed is described in Table 4.2.

Table 4.2: Information about GPs invited (n=165) and interviewed (n=20)

Information about participants		Number of general practitioners	
Characteristic	***Description***	***Invited (%)***	***Interviewed (%)***
Registration date[1]	<5	28 (17%)	4 (20%)
	5 to 14	66 (40%)	8 (40%)
	15 to 24	55 (33%)	5 (25%)
	≥25	16 (10%)	3 (15%)
Sex	Male	88 (53%)	12 (60%)
	Female	77 (47%)	8 (40%)
Location	Buckinghamshire	27 (16%)	3 (15%)
	East Berkshire	36 (22%)	3 (15%)
	West Berkshire	15 (9%)	0 (0%)
	Milton Keynes	21 (13%)	1 (5%)
	Oxfordshire	66 (40%)	13 (65%)
Deprivation	Low (least deprived)	52 (32%)	5 (25%)
	Low-moderate	22 (13%)	3 (15%)
	Moderate	37 (22%)	6 (30%)
	Moderate-high	45 (27%)	5 (25%)
	High (most deprived)	9 (6%)	1 (5%)

[1] GP registration date was used for recruitment; number of years GPs were qualified is reported in Table 4.3.

Interviews were held at the GP's practice, residence, or the Department of Primary Care Health Care Sciences in Oxford according to the preference of the interviewee. Informed consent was obtained at the time of the interview. Information was sought about the GP's age, year of qualification and working pattern as well as the characteristics of the practice at which they worked. General practitioners were reimbursed £70 for participating in the study. They were also informed that participation in the study would count towards Continuing Professional Development learning credits.

4.3.4 Participants recruited

The characteristics of the GPs interviewed and their practices are summarised in Table 4.3. They were aged between 32 and 62 years, and most (12/20) had been qualified for over 15 years. All but one were members of the Royal College of

General Practitioners. Twelve were male and 16 worked full-time. Most saw between 30 and 49 patients per day. Five saw over 50 patients per day.

Table 4.3: Characteristics of interview participants and practices (n=20)

Information about participants			**Information about practices**		
Characteristic	***Description***	***No.***	***Characteristic***	***Description***	***No.***
Age	Mean	47	No. of GPs	1 to 2	2
	Range	32 to 62		3 to 5	9
	<40 years	4		6 to 8	6
	40 to 49 years	8		≥9	3
	50 to 59 years	7	No. of nurses	1 to 2	8
	≥60 years	1		3 to 4	7
Years qualified	<5	3		5 to 6	5
	5 to 14	5	No. of patients	<5000	5
	15 to 24	5		5000 to 9999	5
	≥25	7		10 000 to 14 999	7
MRCGP	Yes	19		≥15 000	3
Principals	Yes	14	Teaching practice	Yes	11
Ethnicity	Asian	4	Training practice	Yes	12
	Caucasian	15	Deprivation	Low (least deprived)	5
	Chinese	1		Low-moderate	3
Sex	Male	12		Moderate	6
	Female	8		Moderate-high	5
Location	Buckinghamshire	3		High (most deprived)	1
	East Berkshire	3	Ethnic minority	<10%	8
	Milton Keynes	1		10 to 19%	4
	Oxfordshire	13		20 to 29%	3
Workload	Part-time	4		≥30%	5
	Full-time	16	Setting	Mixed	2
Patients per day	<30	4		Rural	1
	30 to 49	11		Semi-rural/urban	5
	≥50	5		Suburban	2
				Urban	10

Notes: Information based on general practitioners response (not verified independently).

GPs worked in practices located in diverse settings, including urban (inner city/town centre), suburban and rural. Practice sizes ranged from 1000 to 19 000, most between 5000 and 14 999. Over half the 20 practices were involved in undergraduate teaching or postgraduate training (11 were teaching and 12 were training). Five practices served populations with moderate to high levels of health deprivation, many of whom were from ethnic minorities.

4.3.5 Interview schedule

I conducted all interviews after completing training courses in the conduct and analysis of qualitative research: the 5-day module on Qualitative Research Methods as part of the MSc in Evidence-Based Health Care and two 2-day courses on conducting and analysing qualitative interviews run by the Health Experiences Research Group, University of Oxford. In developing the interview schedule, an initial draft was discussed in detail with an academic GP with experience of interviewing (Dr Peter Rose). This led to several changes including language modification to improve clarity (e.g. replacing 'paediatric' with 'children') and altering the order of questions to improve their logical sequence. Two pilot interviews were then completed with GPs in the department to confirm that the revised interview schedule worked well in practice and to hone my skills as an interviewer.

The interviews were conducted between October 2010 and June 2011 and lasted between 30 and 60 minutes. They were audio-recorded and transcribed in full by a professional transcriptionist for analysis. Each transcript was then reviewed in detail and checked against the recording for errors. Participants were invited to review their verbatim transcript prior to the data analysis to check for errors such as text corrections and typographical errors.

The first part of the interview commenced with an open-ended question and encouraged the respondents to produce an account in their own words, focusing on the issues that were important to them. Following this open-ended question, a semi-structured interview schedule (Appendix A.1) was used to explore key topics in greater depth based on the following domains of enquiry:

- Role of practitioners in the care of children
- General practitioners' viewpoint on child health
- Perceptions of quality of care provided to children in UK general practice
- Use of quality markers in general practice
- Quality markers for children in primary care
- Implications of quality markers on the care of children
- Childhood conditions to focus quality marker development

Towards the end of the interview schedule, participants were asked to suggest specific quality markers which were then explored further. Suggested markers were then incorporated into the interview schedule to discuss with successive participants. Consistent with thematic approach described by Pope *et al.* (8), the constant comparison method was used to look for anticipated and emergent themes as the analysis progressed. The schedule was revised as data collection generated new issues and areas to be explored in further interviews.

Data were kept secure in a password-protected spread sheet in Microsoft Excel 2007. A unique ID number was generated for each participant which linked their paper documentation (e.g. invitation letter, consent form) to an electronic spread sheet. I had sole access to the participants' personal data.

4.3.6 Data analysis

Grounded Theory, originally developed by Glaser and Straus in 1960s, describes a method of qualitative analysis where theories emerge inductively which are refined with additional data collection and analyses; no pre-existing theories are verified.(9)

Rather than pursue a traditional Grounded Theory approach, I selected a thematic approach to analysis based on modified Grounded Theory, as referenced by Charmaz.(10) This decision, made in consultation with my qualitative supervisor, was appropriate as the literature review described in Chapter 2 informed the analysis.

Each transcript was read and re-read, as recommended by Ziebland and McPherson (11), to familiarise the research team with GPs' views. The data analysis began after the first interview was transcribed and proceeded simultaneously with the data collection as recommended by Pope and colleagues.(8) Dr Jenny Hislop (my supervisor for this part of my thesis) and I each coded the first two transcripts independently to produce a coding structure. The coding structure was reviewed and any points clarified by consensus. Next, I read through the interview transcripts repeatedly and coded them for analysis using the constant comparative method, looking for anticipated and emergent themes. Dr Jenny Hislop checked and revised the coded text. Negative cases were also sought and discussed as recommended by Mays and Pope.(12) Thematic analysis of the data was facilitated by QSR International's NVivo 9 computer software.

Initial themes and concepts were informed by the existing literature on quality indicators as well as by careful reading of the transcripts. Individual statements in the transcripts were then categorised and tagged according to these concepts to facilitate sorting the data by themes. The "OSOP" or "one sheet of paper" analysis technique described by Ziebland and McPherson (11) (which involves the researcher going through the data iteratively and noting the key issues that emerge on a single sheet of paper, labelled with the participants' ID) was used in this sorting process. I did not

pursue respondent validation since I had evidence of poor recruitment therefore felt it was unlikely to be successful.

To illustrate the key themes identified in the analysis, quotations are labelled with the GPs interview number (e.g. GP9). This code is separate from the unique identifier that each GP was assigned in the study.

4.4 Results

4.4.1 Quality measurement in children

Most general practitioners supported the development of quality markers for children in primary care. They viewed markers as "benchmarks" or "standards" that evaluated care, identified outliers, and reduced inequalities. As one GP observed, markers function to "systematically document the state of health of the child" (GP7).

> *'...because we've got no markers of it, or nobody has actually looked at it, how would we know? We think we're doing best practice but we have no idea.' (GP5)*

> *'I suppose by knowing your rates for a whole hosts of conditions…knowing what good quality care could produce, what was regarded as good quality care by whoever set the benchmark as it were, you could see how well or how badly you were doing.'(GP6)*

Participants stated numerous reasons for developing quality markers: the rising prevalence of health conditions and the associated long-term implications; the fact that children should have received the same high quality care and attention as adults in the QOF; the variation in management of acute and chronic conditions; and to formalise and ensure consistency of care across the UK.

'It's nice to think quality things happen, but they don't always just happen do they? They often need encouragement to happen.' (GP13)

However, not all physicians responded positively to indicators and deviant opinions were voiced. For example, one GP believed that quality measurement was "political rhetoric" that led to "homogenised mediocrity" (GP8) rather than excellence. A few questioned whether a quality marker framework was required for children or whether it should "just happen out of good practice" (GP3).

GPs suggested various ways to measure quality in children including audits, clinical templates, questionnaires, health service use (or overuse), prescription rates and significant event analysis. A dichotomy of proposed measurement tools emerged between fairly simple markers which reflected standardised clinical care for all patients (e.g. urine dipstick for all suspected urinary tract infections) and more complex markers that would vary with local facilities (e.g. community pathway for management of croup).

Other suggested ways to measure quality were condition-specific templates for consultations that would ensure all aspects of care were provided consistently and were documented in the medical record (e.g. vital signs). However, there was a reluctance by the GPs to collect additional data unless it served an explicit purpose or had clear evidence of benefit. Several GPs were frustrated by data-collecting tasks that lacked clear explanation or supporting evidence and felt it "would be a waste of resources to try and push something with no evidence" (GP1).

> *'I mean one could be having a register of kids with a BMI of over a certain number. Could be what proportion of your children have their height and weight measured in the last year? [pause] But I would be reluctant to suggest that a register or some recording of data should be promoted without their being clear evidence of benefit resulting from collecting the data, because there is nothing that pisses GPs off more than being told you need to collect this data. It's no real benefit, nobody knows if there's any benefit from collecting the data but you still need to collect it.' (GP1)*

On the contrary, another GP felt that for "epidemiology and data collection there's no better place than to actually do it in general practice" (GP17) highlighting the perceived distinction between collecting evidence for a proven purpose and data collection for its own sake. Communicating a clearly defined rationale and purpose behind potential paediatric quality markers is probably important even when indicators are linked to financial incentives. The importance of communication and careful recording in the medical record was reinforced several times as the "health disasters you hear about are all about failures of communication and failures of documentation" (GP4).

> *'I think we could coordinate care between health services; GP and secondary care services, a lot better. I think we are a long way apart from each other and increasingly getting further rather than closer.' (GP9)*

One GP provided an example of a structured approach to missed appointments:

> *'They are sent three appointments, if then on the third appointment they don't turn up then it would be flagged up to all of us that actually this person hasn't, that the immunisations are not up-to-date, and so for someone to have a conversation with them about it. The nurse, if she gets an opportunity would ring them and if she felt that was appropriate, she'd ring them to see you know, that, it's how far you take it with them to get an impression of whether they'd made a conscious decision.' (GP16)*

GPs explained how they wanted markers which captured the complexity of child health and measured the most important elements in the care of children. Yet these

markers related to the importance of the patient consultation – the unique interaction between the child, the parent or carer, and the clinician – and participants did not want these "soft markers" to become "mechanistic" and thus lose their meaning.

4.4.2 Powerlessness and lack of control

Most GPs preferred quality markers which related to outcomes over processes and structures, as "what are important are the outcomes" (GP1) yet they raised numerous concerns about their perceived lack of control over the outcome.

> *'If you look at outcomes for example, neonatal and infant mortality, sudden infant death rates, these are relatively hard outcomes which are measurable. The numbers of children who are hospitalised for a specified condition like asthma for example that is a proxy for measuring the true health status. You look at process outcomes like how many children are taken to care, but those kinds of outcomes are very much influenced by factors other than the child's health or care status.' (GP7)*

Outcomes such as childhood mortality are rare in general practice and influenced by a multitude of factors. The GPs felt these circumstances limited the applicability of such outcomes as a quality indicator. Several participants described a feeling of powerlessness when poor outcomes had occurred, and they believed GPs' impact on outcomes varied from minor to major depending on the condition. For example, GPs played an important role in caring for children with asthma but their role in the management of obesity was minor, if not negligible. Many factors that influence children's health were perceived to be out of the GPs' control, such as the priorities politicians placed on health values.

> *'For instance child obesity, oh God that's a heck of a hand grenade. Who's fault is it? The advertisers, parents and the school dinner ladies? So no one's going near that. Similar as there is no really joined up approach to obesity because everyone basically knows it's an overall problem but no one knows how to do anything about it, and really the government has been somewhat insignificant [to use] political will to control what kind of food you can sell, what kind of advertising you could have and so forth… there are community and social issues around it.' (GP2)*

Participants felt that schools, transportation, government, physicians, and society as a whole had collectively abstained from addressing the obesity epidemic: there was no cohesive approach to the problem. Other influences on the health of children were the severity of illness, the role of parents and carers, the availability of regional health care facilities and secondary care services, and societal factors. Most of these were felt to be difficult to capture in a quality measurement tool.

GPs also expressed frustration with the deleterious actions of NHS managers and other health care professionals. For example, the re-structuring of out-of-hours care services after the 2004 general practice contract prompted several concerns.

> *'...education that you don't need an antibiotic for everything. Because one thing that really pees me off is you look after them, you look after them, 'no you don't need this, you don't need that, you don't'... and then they go to the out-of-hours, and the out-of-hours say here's amoxicillin. And that just drives us mad. Because it just completely undermines what you've done up to that point. Yes, snotty nose, snotty nose, snotty nose, antibiotic in the out-of-hours. There's no need for an antibiotic.' (GP14)*

Clinicians who work in these out-of-hours settings were often perceived to be unfamiliar with the local population and the services available, and largely reliant on telephone triage over face-to-face clinical assessment. GPs also felt that the use of out-of-hours clinicians resulted in a lack of continuity in care with patients. Relationships established with families were undermined and eroded by contradictory advice. Some participants felt that these seemingly minor and innocuous actions in

other health care settings had important implications for the care of children. However, other clinicians commented on the exceptional service provided by out-of-hours care in their PCT which highlighted the variability in the Thames Valley region.

The theme of powerlessness and lack of control emerged repeatedly when A&E visits and hospital admissions in children were discussed. Commonly cited factors by GPs included caregivers' anxiety and coping strategies, and a lack of health care facilities to observe sick children.

> *'Whether somebody is admitted with asthma or sent home, obviously in some ways depends on how bad the asthma is, but it is much more likely to depend on how anxious the parents are and the parents' level of coping strategies whether that's innate or maintained by other people. I don't think it's got much to do with the quality of the general practice.' (GP8)*
> *'But it does rely on good education of populations about where to go first because sometimes it's a cultural or a lack of knowledge about how health care systems work. And so sometimes you see, especially you know, people who just may be, we've got quite a high immigrant population who just literally, just immigrated and who may not realise about how to register with a GP and therefore their only access to health care is kind of via A&E.' (GP15)*

The key domains of powerlessness that emerged in the interviews, particularly those relating to unplanned hospital admissions, were categorised into three groups outlined in Figure 4.1: patient, health care system, and societal.

Figure 4.1: Summary of the sources of powerlessness perceived by GPs as preventing them from influencing childhood hospital admissions

Patient ▪ Patient morbidity ▪ Health service use behaviour ▪ Parents' request second opinion ▪ Caregivers' failure to give medication ▪ Chaotic lifestyle of caregiver ▪ Parents' coping strategy ▪ Severity of illness
Health care system ▪ Lack of facilities to observe sick children ▪ Lack of senior doctors in emergency department ▪ Varying quality of out-of-hours care physicians ▪ Inadequate health care facilities ▪ Varying admission thresholds at hospital
Societal ▪ Education of population ▪ Outbreaks of illnesses ▪ Bank holidays / vacation dates ▪ Conflicting health messages ▪ Deprivation and poverty ▪ Cultural factors

GPs wanted to minimise unplanned hospital admissions but were concerned that admissions would be blamed on them, especially when they felt powerless to prevent them. A broad consensus emerged among the GPs that it was unreasonable to set quality markers relating to issues such as A&E visits or hospital admissions over which they had very little influence; rather they were "good markers of how GP services are working" (GP20). Nevertheless physicians expressed a "need to know" if a hospitalisation occurred to ensure appropriate care was provided.

> *'I think if anything really badly went wrong with a child. I think I need to feel that each time I see a child, because we know that within half an hour a clinical situation can change, and I need to know, because I'm the type of person that if the children became seriously ill half an hour within seeing me, I need to know that I used my best clinical judgement at that time.' (GP5)*

Participants valued analysing each hospital admission for preventable factors to identify when hospital admissions may have been avoided and to implement steps to avoid similar cases in the future.

> *'You can look at individual admissions and pick out things that could have been done before the admission and in other cases the fact that a child's been admitted with asthma does not mean there's been poor care at all. You could see that every stage in the British Thoracic Society Guideline has been followed to the nth with a brilliant care plan, everything's been measured and admission for that child wasn't a failure of care, it was timely and appropriate for that child.' (GP11)*

Several GPs discussed the complexity of primary care, particularly in areas of high social deprivation and with large immigrant populations. Participants stated that there may be unintended consequences if markers are linked to payment yet failed to capture the clinical context and the challenges of general practice. GP15, who practices in an urban centre in an area of high deprivation, explained further:

> *'We normally [have] over a hundred a day calls from people saying it's an emergency, saying they have to be seen that day. So if I see a child, I have to make a judgement, within often a five minute consultation because we run five minute consultations, as to whether they are safe to go home with no treatment, safe to go with treatment, or whether they need observation. And if they need observation then I have to admit them, because I haven't got the scope to bring them back later in the day to see because we just haven't got any staffing or any facilities to do that. If we had more staff, then you could probably do that, and they could be avoidable admissions but if you then use that as a marker, especially linked to payment then the funding for the deprived practices goes down further.' (GP15)*

One participant cited Julian Tudor-Hart's Inverse Care Law to describe the potential unintended consequences, the principle that "the availability of good medical care tends to vary inversely with the need for it in the population served."(13) The possibility of incorporating additional features into quality measurement (e.g. parents' noncompliance with therapy or clinicians' poor adherence to practice guidelines)

raised the practical issue of how these features could be measured without creating time consuming activities: “how do you code for admission because the doctor had not followed guidelines?” (GP11). Many GPs were opposed to activities that would increase paperwork or result in data collection without clear reasons.

4.4.3 Possible adverse effects on children

GPs described the differences between adults and children. These differences were primarily related to communication, autonomy, confidentiality and patient consent as further evidence for feeling powerless.

> *‘There are major issues of consent in children because clearly legally the consent for underage children is eighteen and certainly for children under the age of, under the age of Gillick competence shall we say, the right to give and withhold consent lies with the parents, but nonetheless that assumes that the parents have the best interests of the child at heart which isn’t always the case.’ (GP7)*

Therefore, “clearly it’s not the children’s fault” (GP15) if children defaulted on appointments or had poor outcomes, and quality markers must be able to take these factors into account. The unique characteristics of children also evoked anxiety amongst some participants who did not feel comfortable addressing certain medical conditions in children for fear that it may inadvertently bring attention to a child’s medical problems with potentially adverse outcomes.

> *‘Eating disorders I suppose again, a sort of relatively commoner thing in children. And you know, their body mass index the recording of that would be [pause] … It would need to be handled with extreme sensitivity. I mean it has to be attempted to be handled with extreme sensibility and sensitivity in adults, but even more so in children.’ (GP6)*

'I think that's part of the thing that's holding back the National Obesity Observatory from actually having a policy on this. But it seems to me there are similarities with giving up smoking, in that sometimes just mentioning it as an issue may be a trigger for some changed behaviours. I don't know about that, but one can infer it may be helpful. And I'm hopeless at this, absolutely hopeless and I've not really found a good form of words. I'm so anxious about making children more self-conscious and [um] would therefore sort of pussy foot around it, with talking about exercise and that sort of thing, just as being a general good, but probably children are quite aware and their parents are well, some are aware, some are not.' (GP12)

Although the focus of these comments was on the vulnerability of children and the risk of inappropriate medicalisation of issues if quality markers were to be developed, it also brought to light some underlying issues in clinical confidence addressing some childhood medical problems.

4.4.4 Areas on which to focus marker development

The GPs raised a wide range of clinical conditions when asked to discuss the specific areas in which quality markers could be developed (Figure 4.2) yet no consensus emerged on any single condition as the most important. Appendix A.2 describes in greater detail the number of GPs that mentioned specific conditions for quality indicator development.

Figure 4.2: Condition specific issues mentioned by participants when discussing quality marker development for children in primary care

- Attention deficit hyperactivity disorder
- Asthma
- Cancer
- Cardiac conditions
- Cerebral palsy
- Chlamydia testing
- Coeliac disease
- Constipation
- Croup
- Cystic fibrosis
- Diabetes Mellitus
- Ear infections
- Eating disorder
- Eczema
- Epilepsy
- Febrile child
- Learning disabilities
- Meningitis
- Migraine
- Nutrition
- Obesity
- Postnatal education
- Pre-school wheeze
- Urinary tract infections

However, there was some agreement and substantial discussion about a number of generalist or cross-cutting issues: preventive health (including adolescent health), access to primary care, child protection, management of both chronic illness and acute illness (with substantial discussion on antibiotic prescribing), and staff training. In some, but not all, of these generalist areas the general practitioners were able to make specific suggestions for topics that could be used as quality indicators.

4.4.4.1 Preventive health

The major health promotion-related conditions which emerged as important were developmental screening, obesity, and adolescent health. In particular, GPs stated that changes to the role of the health visitor have raised questions regarding the responsibilities in developmental screening. The health visitor acted as a liaison with individuals in the field, such as in school, with social services, and with parents. GP11 referred to health visitors as "trusted advisors" or "what society used to have…the wise woman" and felt their role was essential and should be re-affirmed.

Figure 4.3 sets out the specific indicators suggested by GPs which might be used to assess quality in this area. Most were related to structure and process measures with few related to outcomes.

Figure 4.3: Quality indicators suggested in the area of preventive health

Adolescent health

- Contraception has been discussed with each patient after giving post-coital contraception.
- Every sexual health related consultation in under 18 year olds has included discussions on basic contraception and testing, explored child protection issues and recorded the discussion in the patient record.
- During all consultations with an adolescent, GPs had taken the opportunity to meet with them without their parents present to ensure they are aware they can return without their parents.

Developmental screening

- The height and weight of children has been measured annually and plotted on a growth chart.
- Dietary issues have been adequately addressed (evidenced by completion of a dietary questionnaire at key developmental points).
- Child developmental screening checks have been completed, including physical examination, social evaluation and school performance.
- Appropriate health promotion has been carried out with evidence of appropriate discussion of diet, healthy eating, exercise, smoking, alcohol, sexual health and teenage pregnancies.

Obesity

- A register is kept of children with a body mass index (BMI) over a certain number.
- For children with raised BMI, evidence that the GP has arranged education classes about obesity and given parents advice (referring them to a dietician or having a dietician assess their home and giving the whole family advice).

Immunisation

- In children that fail to arrive for immunisations, evidence that general practitioners have followed-up and recorded parents reasons for non-attendance.

4.4.4.2 Access to care

Many physicians discussed the importance of good accessibility, both in terms of children consulting general practice and access to secondary care for GPs when they need to refer children. The ease of access to primary care appointments varied. These variations were based on different practice policies and case-mix which led to varying access to face-to-face clinical assessments.

> *'…in theory if people have got easy access to their own GPs, they shouldn't be pitching up at A&E and if the service they've got at their own GPs is easy to access and good then they shouldn't be choosing A&E.' (GP15)*

> *'I suppose if children turned up at the A&E department during a weekday with screaming earache, to give an extreme example. I don't think that happens, but I mean if that did happen it would be indicative of the fact or it might be very suggestive of the fact that they couldn't get an appointment to be seen in their practice quickly enough, and so the parents might be desperate enough to have to feel, well I've got to go to the only other place I can get, you know, I can't access my primary care team, so I'll have to go to the hospital.' (GP6)*

Participants conveyed how important it was for parents and children to access appropriately trained health care professionals. They also expressed frustration with the lack of secondary care support they often felt, citing many communication barriers. The importance of access emerged repeatedly when discussing specific conditions in children, but none of the specific suggestions for quality markers related to access.

4.4.4.3 Chronic illness

A number of GPs highlighted variation in the management of chronic conditions based on case-mix, personal level of comfort, and the availability of secondary care services. They thought there were certain '*at risk*' groups (e.g. epilepsy and diabetes) which would benefit from planned proactive care of unmet health care needs.

> *'...but if you got a kid with Crohn's or a kid with severe asthma or a kid with diabetes, they probably have huge numbers of psychological needs which GP's probably don't [manage] unless they hit us in the face as reports from school, health visitors, [when] things are going horribly wrong. I think they only ever get looked into when things have gone horribly wrong, or behaviours are changing or the child gets actually seriously psychologically unwell. But there are probably lots of other health needs that we're failing to pick up, although in adults, we screen for stuff. I don't think we do that in kids.' (GP4)*

They pointed out that most reactive care for acute self-limiting illnesses for children with chronic conditions was managed in general practice. While this highlighted the

skills required to recognise children at high-risk of complications from minor acute illness, it was also an opportunity to provide proactive care. To assist in managing this group of patients, participants suggested generic or template markers for their care:

> *'In paediatrics you could have a register of those [children] with significant medical history and you could have an indicator saying, 'These children should be reviewed annually and these checks undertaken' like we do with the mental health checks in adults. That would, in those children, be quite easy to identify because we have them in the 'at risk' groups. Flu for example, so you know, those would be on particular 'at risk' group which we could target more specifically.' (GP3)*

> *'If we started to produce markers which would bring forward a group that we wouldn't see otherwise, for example learning disabled children. We would invite them to come to an appointment, and they want to come, and it gives you an opportunity, not when they're sick, just to review things, so hopefully we will see where [there] may be a problem with coordination of care. That potentially may have advantages. Get to know the family better. Maybe the parents learn to trust the GP, rather than necessarily always relying on the secondary care colleague.' (GP9)*

However, apart from these examples of the feasibility of identifying and targeting quality indicators for '*at risk*' children, the general practitioners did not propose any specific quality indicators for the care of chronic illness. Mental health in particular was mentioned by a number of participants as an area of importance, but discussion elicited concern about the difficulty of the issue rather than any specific quality indicators which could be set.

4.4.4.4 Acute illness

Acute illnesses were considered the "bread and butter" of general practice with "good ways of managing them, which include good safety netting and good advice to parents" (GP4) but few specific indicators were suggested. Antibiotic prescription was the one potential quality marker widely discussed in this area, but views differed. It was frequently mentioned, although some GPs expressed concern over using

antibiotic prescription as a marker, saying that it "might be a good marker for teaching academic practice [but] I don't think it's necessarily a good marker for teaching clinical practical medicine" (GP18). There was a tension between what is regarded as 'right' at the population level and a GP's clinical intuition with an acutely unwell child in their consulting room. Often the issue seemed more related to managing parents' and carers' expectations than with the appropriateness of prescribing. GP19, who practices in a suburban area of high deprivation and with a large population of ethnic minorities, outlines:

> *R: 'We are a high prescribing practice for antibiotics. The problem we have is there are strategies to get round this, which we haven't successfully employed. I think there's quite a high ethnic patients here, South Asian, and it's very difficult to try and tell them that they don't need antibiotics. They think you're withholding treatment… So we always struggle with that. We have run campaigns and so forth and at the end of the day it's very difficult. We find it is a pressure to withhold prescribing antibiotics unless you get some, it depends, if the parents are not at all happy and something goes wrong, you are in a lot of trouble, particularly in paediatrics you find. So it's a very difficult area. Even in MK Doc where you get some quite tough doctors you find you still get a high prescribing for antibiotics as well. The doctors tend to err on the side of caution. If you've got a good record with a patient, with the parents, and you know, that there is some margin of leeway if things go wrong that they will work on things, you're much more likely not to prescribe. That's one of the advantage of [being] a GP, a lot of my patients if I know them well enough they'll know that I'm work in their best interests and so forth. But on the whole we tend to struggle with this. We have had various campaigns. It's come down over years, but it's still quite high.*
>
> *I: Yes, yes, it's difficult.*
>
> *R: I'm not sure of it as marker, because you could argue that the patient, the parents are so concerned, they have a low threshold to bring in their children, it shows concern for the children and their well being. So I'm not necessarily sure that high antibiotics… I'm sure there are studies in public health medicine that show a link, but I'm sure you could also argue that the parents are so concerned about their child at the early stages just to have them checked and they are so willing to fight for something like that, it shows that they possibly are good parents to the children.' (GP19)*

There were also concerns about the consequences of failing to treat a potentially serious infection in its early stages.

The participants expressed frustration with the quality of care for acute illness delivered out-of-hours which often related to antibiotic prescriptions, but no consensus emerged on a specific quality marker. Instead, the three specific quality indicators proposed in relation to acute illness related to safety netting, dipstick testing for urinary tract infection, and management of croup (Figure 4.4).

Figure 4.4: Suggested quality indicators for management of acute illness

- There is documented evidence that parents of all children seen with acute illness have received appropriate safety-netting advice.
- At least 99% of children with symptoms consistent with urinary tract infection have had a urine dipstick test completed.
- Croup has been managed according to national guidance.

4.4.4.5 Staff training

The importance of training emerged as a key theme. Many participants stated the current system for GPs should be improved as there is considerable variability in exposure to paediatrics and it has become increasingly difficult for trainees to acquire a paediatric training post. One GP trainer felt trainees appeared concerned with completing newborn and six-week checks due to the lack of clinical experience. There are also differences in the exposure between adults and paediatric medicine in training. With no guarantee of the high quality training schemes required, some of the participants cast doubt on the ability of future GPs to recognise and assess sick children.

'So one concern, I would say, I am probably with the Royal College of Paediatrics and Child Health and I do think that there is a danger that some trainees coming through may not be getting enough exposure to paediatrics.' (GP3)

'Some GPs will come in [to general practice] with no paediatric experience at all, whilst essentially virtually no doctor will come into general practice without ever working with adult populations.' (GP9)

Not only was proper training thought to be important, but a number of GPs also expressed the view that the assessment of the quality and outcome of training was inadequate: "just having the certificate is really all that's needed" (GP10). GP1 felt that if the problem with training continued, there would be a "loss of confidence in the ability of GPs to perform safely and effectively with kids." However, although there was an emergent consensus to suggest that quality markers focused on training could play an important role, no specific quality indicators were put forward.

4.4.4.6 Child protection

In nearly all interviews, child protection was discussed as an important area to develop quality markers, which required elements of access, training, communication, and structure to function effectively. The importance of training and ensuring staff were aware of their responsibilities arose particularly often. GPs were also frustrated with the difficulty communicating with Social Services and felt that these difficulties undermined the effectiveness of child protection initiatives. The only two suggestions in the area of practice organisation related to child protection through planned follow-up and review of regular attenders and appointment defaulters (Figure 4.5)

Figure 4.5: Quality indicators for child protection

- In children who default on an appointment, there is evidence of an annual review in general practice.
- Children who have consulted more than five times per year should be reviewed.

4.5 Discussion

4.5.1 Main findings

Most of the GPs interviewed supported the development and implementation of quality markers for children: they were seen as important for assessing the current standard of care and improving its future quality. The main difficulty GPs perceived in the introduction of quality indicators was the likelihood that they would be judged on outcomes over which they felt powerless to influence. The GPs pointed out many external influences which determine outcomes in child health, influences that are independent of the quality of primary care. They therefore expressed conflicting views, being both enthusiastic for indicators focusing on outcomes rather than care processes while also expressing concern that many health outcomes bear no relation to the quality of their care.

There was an emergent consensus that out-of-hours care for children was problematic. Concerns included the rising incidence of emergency hospital admissions, and the GPs shared the view that there was a particular need for quality indicators in this area. However, the GPs expressed more concern than enthusiasm for the use of ambulatory care sensitive conditions as quality indicators, citing a wide range of issues that contributed to unplanned hospital admissions irrespective of primary care quality. The

GPs did suggest a range of potential indicators but there was no emergent consensus on which should be prioritised. Most suggested indicators related to the process of care rather than health outcomes. The majority of specific indicators related to preventive care, particularly adolescent health and developmental screening.

4.5.2 Limitations

The intention of this qualitative study was to recruit a maximum variation rather than representative sample. While the participants were recruited just from the Thames Valley, and only 1 in 9 of those contacted agreed to participate, the study nevertheless succeeded in sampling a range of views. Data saturation was reached with 20 interviews and the final sample included a broad range of GPs serving diverse practice populations (including inner-city areas with a multi-ethnic patient mix). However, most GPs interviewed had a special interest in child health and many participants had completed a Diploma of Child Health or additional training in paediatrics. It is therefore possible that the study did not identify some views held only by GPs without such enthusiasm who may have been more strongly opposed to the idea of quality markers for care of children.

While respondent validation or triangulation were not used to check the data identified, deviant or negative views were explored. The first two transcripts were independently coded but a second person did not review all other coded transcripts to ensure the codes matched the themes generated, nor did my supervisors read the full transcripts. Participating GPs were aware that I was a doctoral student from the Department of Primary Care Health Science, supervised by academic GPs, and conducting research on quality indicators in children. This may have affected their

responses, since they may have been less willing to criticise quality markers or to discourage the use of paediatric indicators. On the other hand, my personal characteristics as a non-UK based student may have resulted in more candid responses since GPs were possibly less concerned to '*show support'* for quality indicators and about criticising a system that has increased practice income. Indeed, several deviant or negative cases were identified that reflected this viewpoint. With my clinical experience from Canada, I was also able to ask follow-up questions that perhaps would not have been posed by a UK based researcher (such as those relating to alternate fee-for-service payment models). The face-to-face nature of the interviews helped establish a rapport with participants that may have encouraged forthright responses; however it also potentially limited the response rate given the greater time commitment required. Telephone interviews may thus have prompted a higher rate of response.

It would have been informative to seek the views of parents and other health professionals (e.g. health visitors, practice nurses, and reception staff) as well as GPs but this was not possible given the time and logistic constraints of the programme of work for this thesis. The possible divergence of views would certainly have required a much larger study and perhaps separate studies for parents and other professionals. It could also be argued that I should have sought the views of children themselves. However, dealing with the age range would have required specific skills and techniques that are outside the scope of my training. Qualitative studies involving children are particularly challenging and require specialised supervision which was not available to me.

The interviews provided a range of perspectives on the topic of quality indicators but lacked depth for specific conditions. Unlike other studies that have focused on individual conditions (such as conjunctivitis (14) or obesity (15)) it generated few specific proposals for quality indicators. I might have elicited more focused discussion if I had presented NICE guidance on the management of childhood conditions to GPs and explored issues around developing quality markers (like Turner *et al.* (16) for obesity) though this would only have been feasible by pre-selecting specific conditions that would have prejudiced the elicitation of GPs' views.

4.5.3 Generic issues raised by the GPs

4.5.3.1 Should indicators focus on clinical outcomes?

There was an expressed preference for quality markers based on outcomes rather than on structures and processes. However, when pressed to suggest possible markers, GPs often went on to say, paradoxically, that the quality of primary care has little influence on important health outcomes. Consequently, many of the specific quality measures proposed by GPs related to process rather than outcome. This paradox has also been also reported by researchers in the US who note that the development of outcome-based quality markers for children is particularly challenging because children's health is affected by so many issues other than the quality of medical care.(17) Similar concerns were expressed by primary care practitioners in response to the new NICE guideline on managing child obesity: practitioners felt their involvement would have little impact given the multi-factorial causes of obesity.(16) Quality indicators targeted on clinical outcomes will clearly not have the professional support of GPs unless they perceive a direct link between their care and the clinical outcome.

4.5.3.2 Do quality indicators need to be evidence-based and have GP support?

A number of GPs expressed their lack of support for quality indicators if they were required to collect data "for its own sake." GPs supported indicators only where they felt there was good evidence linking performance of the action with improved clinical outcome. This is an issue in many clinical areas in paediatrics that lack robust evidence which demonstrates that process measures improve clinical outcomes: recording of BMI and measurement of vital signs in febrile children are two such examples that appear in NHS guidance. Maisey *et al.* reported similar observations from qualitative interviews with 12 GPs and nurses and suggested QOF advisers "may wish to ensure that the evidence-base for newly recommended care is not only robust, but understood to be so by practitioners in order to avoid cynicism."(18) This is supported by a meta-analysis of 128 studies completed by Deci *et al.* which concludes that providing rewards for activity that is perceived as having no value can undermine intrinsic motivation.(19) However, the view that quality indicators will be ineffective if they lack professional support has been challenged by Campbell *et al.* (20), who suggest that GPs pursue financial incentives irrespective of motivation and professional alignment.

These contrasting views are more consistent than they may at first appear. Campbell is probably correct where the quality indicator is restricted to routine mundane tasks that require little self-motivation. The evidence from psychological studies supports the notion that for routine mundane tasks, externally regulated motivation (i.e. behaviour due to reward or punishment, or *controlled motivation*) performs as well as internally regulated motivation (i.e. behavior due to alignment with goals and values, or *autonomous motivation*).(21) However, many clinical tasks and interactions with

children are neither routine nor mundane (e.g. interacting with the parent and child sympathetically to elicit the clinical history and conduct an effective examination) and require substantial internal motivation to achieve a good outcome. Moreover, there is direct evidence from the Quality Outcome Framework that providing a financial incentive for some activities can have a negative impact on other non-incentivised activities which also impact on care quality.(22) Therefore, a strong case can be made in most instances (whenever the clinical action linked to the indicator is neither routine nor mundane) for aligning quality indicators with clinical evidence and professional opinion to encourage internalisation of motivation and minimise professional cynicism.

4.5.3.3 Do quality indicators increase social inequality?

A number of participants raised the potential for quality markers to increase social inequality, in one case citing the Inverse Care Law.(13) While the potential is clear for financial incentives based on quality markers to penalise under-achievement caused more by the social deprivation of the practice population rather than the quality of clinical practice (e.g. teenage pregnancy or smoking rates), published evidence based on existing QOF markers shows very little systematic difference in achievement of targets in practices in relation to the population deprivation index.(23, 24)

4.5.4 Indicators based on unplanned hospital admissions

The general practitioners' views on the use of emergency hospital admissions for ambulatory care sensitive conditions as a quality indicator were consistently negative. While they recognised the escalating rate of emergency paediatric admissions in the

UK as a problem, and also acknowledged the potential contributory role of out-of-hours primary care, they felt such admissions were due to numerous factors over which GPs have little control. In particular, many expressed the view that children depend on parents and caregivers to access health care services and provide appropriate medical care and that parents have more impact on hospital admission rates than clinical management in primary care. This view is consistent with one US study conducted by Flores *et al.* which found parents' "failure to pay greater attention to medication-related issues as the single most common reason for children's avoidable hospitalisations."(25) Yet one could argue that parents' lack of knowledge or attention could be due to poor communication or instructions by primary care staff. The balance of opinion expressed was that emergency admissions could not be used as a quality indicator of the care provided by an individual practitioner (or practice) but only as a measure of the overall quality primary care system. It is worth noting, however, that the GPs said they valued looking at individual cases when an event occurred for quality improvement.

Nevertheless, the 2012/13 QOF contract includes three '*Quality and Productivity*' markers focused on emergency admissions to hospital: practices are required to review their admissions, compare the data with regional practices, and develop three care pathways which aim to avoid such admissions.(26) While they do not specifically focus on children, some of the care pathways developed may include paediatric conditions. These new markers highlight the discrepancy between what GPs say they want as indicators with the broader priorities and issues facing the NHS. Several GPs suggested looking at inappropriate A&E attendances for commonly managed childhood conditions (e.g. acute otitis media) in general practice as a marker of poor

quality. Indeed the 2012/13 QOF contract includes three '*Quality and Productivity*' markers focused on A&E attendances (similar to the emergency admission markers): practices are required to review their A&E attendances, compare the data with regional practices, and develop proposals to improve access to reduce such attendances.(26) Some proposals may focus on paediatric conditions but there is scope to develop more precise indicators.

4.5.5 Indicators for preventive health

4.5.5.1 Childhood obesity

The management of childhood obesity emerged in several interviews and GPs raised two main issues: the potential workload associated with giving dietary advice to families and the lack of evidence for the effectiveness of any primary-care led intervention. As stated above, the GPs predicted that proposed indicators that lack robust supporting evidence would be met with professional resistance. Indeed, while indicators for childhood obesity have been questioned as potential QOF indicators (15), the NICE QOF Indicator Programme considered developing indicators for obesity but the advisory committee felt there was insufficient information on intervention effectiveness.(27) The lack of incentives to treat obesity has also been cited elsewhere as a reason primary care practitioners did not prioritise child obesity management despite the presence of NICE guidelines.(16) However, GPs also expressed concern about discussing sensitive topics, such as children's weight, and the anxiety associated with potentially damaging children's self-confidence. This should not be a barrier to improving quality of care and additional training indicators may need to be focused on improving GPs' communication with children.

4.5.5.2 Developmental screening and health promotion

Developmental screening emerged as an important area for quality indicator development in the view of the GPs despite the progressive shift from child health surveillance to child health promotion in the UK.(28) In the US, primary care practitioners (usually a paediatrician) assess children frequently for developmental screening, and the adherence to these checks are often used as quality indicators.(29) In the UK, on the other hand, children see a GP for a 6-8 week development check with little further planned proactive contact; health visitors complete the rest. There is evidence from one study that increasing health visiting time in deprived areas reduces rates of acute hospital admissions.(30) However, the shortage of health visitor positions and their busy workloads lead to a marked inconsistency in service provision offered to families (31), so quality indicators related to their performance are only likely to improve care quality if they help address the staffing shortage or facilitate alternative solutions to providing care. Further work is needed to explore this issue in greater detail and to determine how the specific indicators proposed by the GPs could be implemented, perhaps integrating standards outlined in the Healthy Child Programme given that most of the tasks suggested would likely be undertaken by health visitors.

4.5.6 Indicators for patient access and staff training

The potential to develop quality indicators for access to care was mentioned by a number of participants. Although this has been a major focus of primary care reform in the UK over the past decade (which included the introduction of '*Advanced Access*' and setting a target that general practice had to provide an appointment within 48 hours), success in addressing access barriers has been modest (32) (and has reduced

continuity of care (22)). Lack of easy access to primary care may partly explain the rise in A&E visits for children in England.(33) However, access is not an issue specific to children and development of any quality marker would need to avoid adverse consequences for other age groups.

Most of the discussion about training focused on general practitioners and many participants felt the training of future GPs must be improved if they are to retain public confidence in their ability to provide care for children. This is consistent with the concerns about GPs' ability to diagnose serious illness highlighted in the UK confidential child death enquiry which looked into role of primary care in a number of child deaths. Where primary care was actively involved, the enquiry found avoidable factors in one-fifth of child deaths, citing "failure to recognise and manage severe infection" as the most common.(34) Failures in each step in the clinical management of sick children were identified as avoidable factors including patient history, physical exam, treatment, and referral. Certain initiatives have already commenced to address these concerns such as the RCGP First5 Initiative, which focuses on supporting newly qualified GPs during their first five years in practice.(35) (The five pillars of the First5 are: 'connecting with the college', 'facilitating networks', 'supporting revalidation', 'career mentorship', and 'continuing professional development'). The challenge in developing quality indicators in this area is, as one participant pointed out, the weak link between attendance at training and improved performance. The quality indicator would either have to be based on direct assessment of competencies in managing acute unwell children or be based on a clinical outcome (e.g. missed cases of serious illness), raising the same issues of multiple contributory factors already discussed.

4.5.7 Indicators for chronic care

While participants suggested several quality markers for specific chronic conditions, no consensus emerged about the most important. However, there is a potential to use quality markers as a mechanism to target specific groups of children at high-risk of ill-health. One participant specifically suggested such an approach by setting a quality indicator for the follow-up of children who fail to attend appointments; another suggested flagging children that consulted over five times in one year. It is clearly feasible to develop quality markers for '*at risk*' children (e.g. with epilepsy or diabetes) to ensure they have a planned proactive review of their care (as suggested by others (36)). Such an '*aggregate*' indicator, structured similar to those for adults with learning disorders, would ensure consistency of care for children with uncommon conditions. It would also allow GPs to actively manage childhood conditions without requiring a detailed knowledge of each condition. Recent evidence from the US suggests that high levels of continuity of care and adherence to well-child-care reduced hospital admissions in young children with chronic conditions.(37) Differences in the US health care system limit the generalisability of the findings to the UK but elements of the intervention may be helpful in formulating indicators focused on the care of children with chronic conditions in UK general practice.

4.5.8 Indicators for acute care

While many GPs discussed acute illness, few specific quality indicators were suggested. Most acute illnesses do not require investigations in primary care. Urinary tract infections, however, require appropriate testing since they often present with non-specific signs and symptoms and the consequences of delayed diagnosis are serious.(38) A quality indicator for appropriate dipstick testing was put forward. In

the viral season, croup overwhelms both primary and secondary care: ensuring this infection is managed according to national guidance in the community was recommended as a marker of quality. But for all acute illnesses, the importance of safety-netting cannot be under-emphasised.(39) Developing a quality indicator focused on appropriate safety netting is feasible but, if not designed carefully, might become a '*tick-box*' marker.

A few participants expressed frustration with the quality of care delivered in the out-of-hours setting and suggested that this should be a priority area for developing quality indicators. For example, they argued that clinicians in out-of-hours settings prescribe antibiotics to children too freely, thus undermining the GPs' efforts to manage minor illnesses without antibiotics. This has been demonstrated by Dutch out-of-hours primary care, with antibiotic prescribing indicators focused on acute conditions in children such as pneumonia and urinary tract infections.(40) However, several GPs interviewed questioned the use of generic antibiotic prescribing rates as a marker of quality, arguing that the prescribing rates fail to take into account parental expectations and increase the risk of failing to treat serious bacterial sepsis. This professional anxiety should probably be addressed by piloting before national roll-out.(41)

4.6 Conclusions

There was support amongst the GPs interviewed for the development of quality markers for the care of children in UK general practice. GPs felt quality indicators were important to ensure consistent care is delivered to children and to ensure its

future quality. However, indicators targeting childhood conditions that lack robust evidence will meet with professional resistance even if financially reimbursed. Markers are more likely to be successful in driving quality improvement, and need less financial incentivisation, if they encourage internalisation of motivation and minimise professional cynicism.

GPs flagged up a number of challenges that need to be addressed if measurable indicators are to be developed that are within the direct control of primary care. Despite an expressed preference for markers focused on clinical outcomes, GPs were concerned they would be judged on outcomes which they felt powerless to influence (e.g. childhood obesity). Outcome based indicators will not have professional support unless GPs perceive a direct link between their care and the clinical outcome. While there was some concern about indicators potentially increasing social inequality, recent evidence from the Quality and Outcomes Framework shows little variation related to deprivation, suggesting that indicators can in fact reduce social inequality. Indicators could further reduce inequalities by targeting specific groups of children at high-risk of ill-health to ensure they have a planned proactive review of their care.

General practitioners recognised the importance of reducing admissions to hospital for ambulatory care sensitive conditions (those which are commonly managed in primary care) but felt these admissions were outside their control. They highlighted the multiplicity of issues that affected whether a child was admitted to hospital, including caregivers' anxiety and limited health care facilities. GPs felt that unplanned hospital admissions could not be used as a quality indicator for individual practitioners or surgeries. Yet the 2012/13 Quality and Outcomes Framework contract

includes markers focused on emergency admissions, highlighting the discrepancy between GPs' preferences for indicators and broader NHS priorities. There is scope to develop more precise indicators which may address both GPs' concerns and broader health care system issues.

GPs suggested a range of potential quality indicators which could be prioritised, but there was no emergent consensus. Childhood obesity arose in numerous interviews but the lack of evidence for appropriate management and GPs' concern about discussing sensitive topics hindered indicator support. Despite the reduced emphasis on child health surveillance in UK primary care, health promotion and developmental screening emerged as an important topic. However, it is unclear to whom or how this care should be delivered, and further work is needed to explore this issue in greater detail. Issues with accessibility continued to be a focus of concern amongst GPs: some suggested looking at inappropriate A&E attendances for commonly managed childhood conditions (e.g. acute otitis media) as a marker of poor quality and there is scope to develop paediatric specific indicators. Participants felt that improving the training of GPs should be the focus of quality improvement: indicators should not only prioritise training standards but also assess adequate knowledge and skills. The quality of care delivered in the out-of-hours setting was flagged by a number of participants as being sub-optimal, particularly relating to issues such as the prescription of antibiotics. Markers should be prioritised to ensure consistency of care in this setting (e.g. appropriate safety netting advice).

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Chapter 5: Emergency admissions to hospital for paediatric ambulatory care sensitive conditions in England

5.1 Introduction

General practitioners' views on care quality and on the areas that should be prioritised for the development of quality indicators, are likely to be well informed but they will not be impartial. An alternative, and less partial, perspective is provided by unplanned admissions to hospital for "*ambulatory care sensitive conditions*" (ACSCs).(1) ACSCs are a set of conditions where the frequency of hospital admission is thought to be inversely related to the quality of primary care. If the admission rate for an ambulatory care sensitive condition is high, then the quality of primary care for that condition is probably inadequate. Thus, development of a quality indicator for this condition should perhaps be prioritised.

While it is important to look at absolute admission rates, it is also pertinent to consider measures of variation in admissions for ACSCs. A certain amount of variation is appropriate (reflecting population characteristics in each area) and desirable (improvements in care occur through innovation), but high levels of variation suggest that quality of care is less than optimal. Identifying ambulatory care sensitive conditions with high levels of variation can provide further evidence from which areas of care might be prioritised for quality indicator development.

A database of Hospital Episode Statistics (HES) data for England is held at the Unit of Health-Care Epidemiology at the University of Oxford. It was therefore possible for me to access this database and undertake an analysis of childhood admissions. However, both clinical and coding practice in the UK and North America are not

identical and it was first necessary to modify the methodology developed in the United States to enable its application to childhood admissions in the UK.

5.2 Aims and objectives

The overall aim of the research reported in this chapter was to identify areas in which the quality of primary care delivered to children in England may be less than optimal, thus determining which areas should be prioritised for the development of quality indicators. This research was conducted by exploring unplanned (i.e. emergency) hospital admissions for ambulatory care sensitive conditions. The specific objectives were:

1. To define a set of ambulatory care sensitive conditions and the associated diagnostic codes used in HES data for England that would be applicable to children aged less than 15 years.

2. To determine which ambulatory care sensitive conditions are associated with high rates of emergency admission of children to hospital.

3. To determine which ambulatory care sensitive conditions are associated with substantial local area variation in the rate of emergency admissions.

4. To determine whether high rates of emergency admission for these conditions, (or local area variation in admission rate) varied according to the age of the

child. This would help determine which quality indicators should be age-specific.

5. To explore recent time-trends in emergency admission of children to hospital in order to identify: a) temporal associations with organisational changes that might have impacted on care quality, since such organisational changes might be an issue for indicator development; and b) the trajectory in rates of admission. Rates with an upward trajectory over time may indicate issues which merit prioritisation.

5.3 Methods

5.3.1 Data source

The data on admissions were drawn from Hospital Episode Statistics (HES) and included all admissions to NHS hospitals in England. Mid-year population counts were obtained from the Office of National Statistics (ONS). The Unit of Health-Care Epidemiology (UHCE) at the University of Oxford built the file used in this analysis based on the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) codes. The data available from the UHCE was limited to HES; no primary care or A&E consultation data was available which restricted the analysis to the secondary care setting.

Most of the HES data generated and used for this analysis were based on episodes of care defined as '*continuous inpatient spells*' (CIPS) which referred to the continuous time a patient spent in hospital from admission to discharge, regardless of any within-

hospital transfers. When individual children were admitted more than once, each admission was counted. Linkage of the UHCE database also enabled the calculation of '*person-based admission rates*' which are based on counting each person once, regardless of his or her number of admissions, in the one-year period. Both CIPS and person-based admission rates were used in the analyses. Files were built that included only emergency admissions to hospital: other types of admissions were excluded (i.e. elective, maternity and hospital deliveries) because the objective was to analyse those unplanned admissions in which primary care could have played a role.

The data files included all emergency admissions of children in England between 1 April 1998 and 31 December 2010. The initial analyses (the analysis of geographical variation and the report provided to the expert panel described in Chapter 6) were conducted using data for the financial years 1 April 1998 to 31 March 2009. However, most analyses presented in this chapter are based on data from 1 January 1999 to 31 December 2010 unless otherwise specified. Ethics approval was obtained from the NHS research ethics committee by the UHCE (reference number 04/Q2006/176). Results from this chapter have been published in *Archives of Disease in Childhood*.(2)

5.3.2 Modification of ACSC methodology for use in England

5.3.2.1 Selection of conditions

The choice of specific conditions and codes were based on the Purdy *et al.* (3) literature review and analysis of ACSCs relevant to NHS practice in England. To be selected, the conditions had to be childhood health problems routinely managed in UK primary care which had relevant management guidelines published by NICE or SIGN (to support quality indicator development). Of Purdy's 19 conditions, eight of

relevance to children were selected: asthma, dehydration and gastroenteritis, diabetes, urinary tract infection (UTI), lower respiratory tract infection (LRTI), epilepsy, upper respiratory tract infection (URTI), and vaccine-preventable diseases.

For most analyses, the eight conditions were grouped into: 1) vaccine-preventable conditions; 2) acute self-limiting infections (i.e. LRTI, URTI, UTI and gastroenteritis); and 3) acute exacerbations of chronic conditions (i.e. asthma, diabetes and epilepsy) as described by Caminal *et al*. (4). The codes for vaccine-preventable conditions are restricted to immunisations that are routinely delivered to all children in primary care (measles, mumps, tetanus, polio and rubella). The codes do not include conditions for which vaccines are given only to selected children at high risk of specific diseases. The conditions excluded from Purdy's list were: angina, cellulitis, congestive heart failure, chronic obstructive pulmonary disease, dental conditions, gangrene, hypertension, iron-deficiency anaemia, nutritional deficiency, pelvic inflammatory disease and perforated/bleeding ulcer.(3)

5.3.2.2 Selection of ICD-10 codes

Purdy re-defined the ACSCs by ICD-10 codes commonly used in the NHS; most were derived from Dr Foster Intelligence and the NHS Institute for Innovation and Improvement.(3) To derive a set of paediatric-specific codes which had strong clinical validity to primary care practitioners, two GPs reviewed the codes in order to exclude those specific to adults. The GPs also suggested the inclusion of some additional codes which might be more common in childhood admissions for the specific conditions. Two experts in HES analysis and ICD coding from the UHCE (Michael Goldacre, Emeritus Professor of Public Health; and Valerie Seagroatt, University

Statistician) also reviewed the codes and suggested the addition of some non-specific '*unspecified'* sub-codes. Overall, these recommendations resulted in the exclusion of one code from epilepsy (i.e. O15 eclampsia) since it was not relevant to children, and the inclusion of 23 additional codes (LRTI, 6; gastroenteritis; 9; UTI, 5; URTI, 1; and diabetes, 2). The changes from Purdy's 'common NHS subset' of codes are outlined in Appendix B.1.

5.3.2.3 Sensitivity analyses and generation of final coding set

Sensitivity analyses were completed to assess how the results were impacted by varying the ICD codes from Purdy's recommended ACSC set. It was anticipated that adding the non-specific '*unspecified'* sub-codes could be important: not only would inclusion of these codes potentially change the absolute estimate of the admission rate for an ACSC, their inclusion could also impact the interpretation of trends over time (if specificity of coding changed over time). Where 4-digit ICD-10 codes were specified, the effect of each 4-digit diagnostic code within the 3-digit ICD-10 code was evaluated to ensure that the exclusion of large unspecified groups did not adversely affect the results (e.g. specifying only J18.0 and J18.1 rather than J18).

In December 2011, the Department of Health published the 'NHS Outcomes Framework 2012/13' which specified reducing unplanned hospital admissions in children for specific long-term conditions (i.e. asthma, diabetes, and epilepsy) and lower respiratory tract infections.(5) Although these conditions were already included in Purdy's ACSC dataset, only for asthma were the ICD codes used to define the condition precisely the same (see Appendix B.2). These coding differences resulted in substantial variation in the estimates of the number of admissions. For example, the

removal of the '*convulsions not otherwise specified*' code by the NHS Outcomes Framework reduced the estimated number of epilepsy admissions to one-quarter of its original number. In contrast, the estimate of the number of admissions for diabetes was doubled by including the specific code for diabetes '*without complications*' and the estimate of admissions for LRTI was increased three-fold by including a code for bronchiolitis.

Although these sensitivity analyses showed the potential impact of coding variation, alignment with the NHS Outcome Framework was not as relevant to the objectives of this chapter than comparability with other research. Therefore the only amendment to Purdy's coding applied in the final analysis was the inclusion of those additional '*unspecified*' sub-codes (described above) for each condition (in order to decrease the possibility that the time-trend analysis could be biased by changes in coding precision). The ACSC codes used in this thesis are listed in Table 5.1; Appendix B.3 provides a written description of each code.

Table 5.1: List of final ICD-10 codes used to define ACSCs (derived from Purdy et al. (3))

Ambulatory care sensitive condition	ICD-10 codes
Acute infections	
Dehydration and gastroenteritis	E86 K52.2 K52.8 K52.9 A02.0 A04 A07.2 A08.0 A08.1 A08.3 A08.4 A08.5 A09
Lower respiratory tract infections	J10 J11 J12.0 J12.1 J12.2 J12.8 J12.9 J13 J14 J15.3 J15.4 J15.7 J15.9 J16.0 J16.8 J18
Upper respiratory tract infections	H66 H67 J02 J03 J04.0 J06 J31.2
Urinary tract infections	N10-N12 N13.6 N15.9 N30.0 N30.8 N30.9 N39.0
Chronic conditions	
Asthma	J45 J46
Diabetes	E10.0–E10.8 E11.0–E11.8 E12.0–E12.8 E13 E14
Epilepsy	G40 G41 R45
Other	
Vaccine-preventable diseases	A35-A37 A80 B05 B06 B16.1 B16.9 B18.0 B18.1 B26 G00.0 M01.4

5.3.3 Analysis

Descriptive analyses were used to summarise the trends in rates and counts for hospital admissions for ACSCs in children. The data were analysed in five age bands (less than 1, 1-4, 5-9, 10-14 and all children under 15 years) for all emergency admissions, groups of ACSCs (i.e. vaccine-preventable conditions, acute infections and chronic conditions) and individual ACSCs. Length of stay was calculated by subtracting the admission date from the discharge date of each episode of continuous inpatient care; it was divided into treatment lengths of less than 1 day, 1-<2 days, 2-<3 days and greater than 3 days. HES data do not include time of admission and discharge: length of stay was calculated as '*zero'* (reported as <1 day) if a child was admitted and discharged on the same calendar day.

For analyses of geographical variation, standardised admission rates (SARs) were calculated for each of the 352 local authorities (LA) in England using the indirect method of standardisation and the total English population as the standard; admissions to hospital do not follow a normal distribution therefore the mean of the (natural) logarithm of SARs was determined and the antilog presented. This geometric mean is less influenced by very large values (as would be expected in some LAs) hence more accurate; this also explains why the SARs presented in the analysis related to variation are generally smaller than the crude rates reported.

The amount of variation in the condition-specific standardised admission rates between local authority areas was assessed by calculating McPherson's co-efficient for the systematic component of variation (SCV) – the variance of the (natural) logarithm of the SARs excluding the random component attributable to Poisson

variability.(6) The McPherson SCV is not only scale-independent but, unlike the regular co-efficient of variation (standard deviation divided by mean), takes better account of the unequal contributions to variance resulting from the differing population size of each area. However, as the SCV can only be interpreted as a comparative measure, the ratio of the SAR at the 90th and 10th percentiles are also reported to give some direct indication of the magnitude of the variation in admission rates between local areas excluding extreme outliers.

The analysis was completed with the assistance of Valerie Seagroatt, University Statistician with the UHCE at the University of Oxford, who extracted the relevant data with PASW Statistics for Windows Version 18.0 and provided me with a database showing the number of childhood admissions and population at risk by year, ACSC condition and age group. For the analysis of geographical variability, she also provided variables showing the standardised admission ratio (geometric mean and 90/10 ratio); total variance of the SAR and percentage attributable to Poisson variability; and the systematic co-efficient of variation. I conducted all further analyses in Microsoft Excel 2007. Except for time-trends, data from multiple years were combined to increase precision.

5.3.4 Out-of-hours care

I also sought to determine whether particular out-of-hours care providers were associated with higher rates of admissions for ACSCs in children. In 2010, I sent a Freedom of Information (FOI) request to all 130 PCTs (of 151) that were co-terminous with LAs to identify the following information for 2006-07 and 2007-08: 1) the provider of out-of-hours care; 2) whether the provider is classified as local GPs,

GP co-operatives (i.e. small private organisations), or large commercial deputising organisations; and 3) the number of practices that opted out of providing this care. After numerous reminders, 128 of the 130 PCTs responded and their responses are summarised in Table 5.2. The number of surgeries per PCT varied but in 70% of PCTs, all GP practices opted out of providing out-of-hours care.

Table 5.2: Provider of out-of-hours care in 128 PCTs from 2006-2008

PCT Information	**2006-2007**	**2007-2008**
Out-of-hours care provider		
NHS/PCT	24 (18.8%)	24 (18.8%)
Small private organisation	55 (43.0%)	55 (43.0%)
Commercial deputising service	18 (14.1%)	19 (14.8%)
NHS/PCT and small private organisation	15 (11.7%)	15 (11.7%)
NHS/PCT and commercial deputising service	7 (5.5%)	7 (5.5%)
Small private organisation and commercial deputising service	5 (3.9%)	4 (3.1%)
All three providers	4 (3.1%)	4 (3.1%)
Number of general practices		
Mean (range)	54 (11-147)	54 (11-137)
Median (IQR)	52 (35-66)	52 (34-66)
Number of general practices providing out-of-hours care		
Mean (range)	7 (0-130)	7 (0-130)
Median (IQR)	0 (0-1)	0 (0-1)
PCTs with 0 practices providing out-of-hours care	90 (70%)	89 (70%)
PCTs with 1-4 practices providing out-of-hours care	16 (13%)	18 (14%)
PCTs with ≥5 practices providing out-of-hours care	22 (17%)	21 (16%)

Further consultation with GPs in the department established that this information in isolation was insufficient for use as an explanatory variable. Rather, it was important to determine whether GPs employed in these organisations were local (i.e. familiar with the health care services and patient population), or non-local. Therefore, to ascertain this information, I designed a Doctors.net.uk electronic survey that was administered to all PCTs sampled. Unfortunately, the results were inconclusive, and this analysis was not pursued further in this programme of work.

5.4 Results

5.4.1 Admission rates for ambulatory care sensitive conditions

5.4.1.1 Admission rates for different ACSCs in England

The total number of admissions in 2007-10 for all ACSCs was 769 513 (21.3 per 1000). Table 5.3 shows that most of these admissions were for the four acute infections (URTIs, LRTIs, UTIs and gastroenteritis) rather than the chronic conditions (asthma, diabetes and epilepsy). The high admission rate for acute infections (15.5 per 1000) was due mostly to URTIs (7.3 per 1000) and gastroenteritis (5.4 per 1000); LRTIs and UTIs accounted for only one-fifth of admissions. The majority of admissions for chronic conditions were for asthma and epilepsy which were both 10-fold more common reasons for admission than diabetes. There were only 615 admissions for vaccine-preventable conditions (0.07 per 1000).

Table 5.3: Emergency admissions for ACSCs in children under 15 years, 2007-10

Condition	Total admissions	Admissions/year (mean)	Admission rate/1000/year (mean)[1]
Gastroenteritis	195 334	48 834	5.4
LRTI	57 599	14 400	1.6
URTI	262 510	65 628	7.3
UTI	45 823	11 456	1.3
Acute infections (total)	*561 266*	*140 317*	*15.5*
Asthma	98 681	24 670	2.7
Diabetes	8757	2189	0.2
Epilepsy	98 350	24 588	2.7
Chronic conditions (total)	*205 788*	*51 447*	*5.7*
Vaccine-preventable conditions	*2459*	*615*	*0.07*
All ACSC (total)	*769 513*	*192 378*	*21.3*

Note: [1] Admission rate based on 2008 population.

5.4.1.2 International comparison of admission rates

The emergency admission rates for childhood ACSCs in England are compared with rates from Australia (7) and the United States (8, 9) in Table 5.4. While differences in coding preclude precise comparisons, admissions for most acute infections (i.e. URTIs, UTIs and gastroenteritis) are considerably higher in England. In particular, gastroenteritis admissions are 5-fold higher than those in the US and 16-fold higher than those in Australia. Admissions for LRTIs are also 5-fold higher in England than in Australia, but lower than in the US. In contrast, England has the lowest admission rate for vaccine-preventable conditions.

For chronic conditions, no consistent pattern is evident. England had the highest epilepsy admission rates but the lowest diabetes admission rates. English asthma admission rates were half those in Australia but almost double those in the US.

Table 5.4: Admission rates for ACSCs in England, Australia and United States

	England *National* *Age 0-14*	**Australia** *Victoria* *Age 0-14 (7)*	**United States** *South Carolina* *Age 0-17 (8)*		**United States** *National* *Age 0-17 (9)*
Condition[a]	***2007-10***	***2009-10***	***1995, M***	***1995, F***	***2009***
Asthma	2.7	5.6	2.9	1.8	1.5
Diabetes	0.2	0.5	0.3	0.5	0.3
Epilepsy	2.7	1.8	0.7	0.6	-
Gastroenteritis and dehydration	5.4	0.3	1.1 (1.5)[b]	1 (1.5)[b]	1.0
LRTI	1.6	0.3	3.9	3	-
URTI	7.3	3.2	0.9	0.8	-
UTIs	1.3	1	0.2	1.1	0.4
Vaccine-preventable conditions	0.07	0.14	0.3	0.2	-

Notes: M, male; F, female. [a] Severe ear-nose-throat (ENT) infections included as URTIs; Influenza and pneumonia included as LRTIs. [b] The study reports gastroenteritis and dehydration separately – the rate reported is for gastroenteritis only (the rate for dehydration is given in parentheses).

5.4.1.3 Illness severity on admission

The only proxy for illness severity in the HES database is length of stay after admission; this is presented in Table 5.5. The ACSCs with the highest emergency admission rates, URTIs and gastroenteritis, also had the highest rates of short-term admissions for less serious illness. In 2007-10, 89% and 83% of admissions of URTIs and gastroenteritis respectively were for less than 2 days, suggesting few children had a severe illness.

The ACSC condition with the highest emergency admission rate for serious illness (3+ day stay) was LRTI, although perhaps surprisingly the rates of 3+ day admissions for the other infections was comparable to those for epilepsy and asthma. Although emergency admissions for diabetes were less common than for the other chronic conditions, the distribution of length of stay suggests that a substantial proportion were for serious illness.

Table 5.5: Emergency admissions for ACSCs in children under 15 years by length of stay, 2007-10

	Admissions/year (mean)				***Admission rate/1000/year (mean)[1]***			
Condition	*<1 day*	*1-<2 days*	*2-<3 days*	*3+ days*	*<1 day*	*1-<2 days*	*2-<3 days*	*3+ days*
Gastroenteritis	24 883	15 815	4603	3533	2.8	1.8	0.5	0.4
LRTI	2885	3307	2945	5263	0.3	0.4	0.3	0.6
URTI	40 054	18 420	4126	3027	4.4	2.0	0.5	0.3
UTI	4069	2312	1868	3207	0.5	0.3	0.2	0.4
Acute infections (total)	*71 891*	*39 854*	*13 542*	*15 030*	*8.0*	*4.4*	*1.5*	*1.7*
Asthma	8302	9651	3989	2728	0.9	1.1	0.4	0.3
Diabetes	226	672	567	724	0.03	0.07	0.06	0.08
Epilepsy	10 310	9066	2336	2876	1.1	1.0	0.3	0.3
Chronic conditions (total)	*18 838*	*19 389*	*6892*	*6328*	*2.1*	*2.2*	*0.8*	*0.7*
Vaccine-preventable conditions	*195*	*133*	*71*	*216*	*0.02*	*0.01*	*0.01*	*0.02*

Note: [1] Admission rate based on 2008 population.

5.4.2 Geographical variation in ACSC admission rates

The relative variation in rates of emergency admission for individual ACSCs is summarised in Table 5.6. The two infections associated with the highest absolute emergency admission rates (URTIs and gastroenteritis) also had the highest systematic component of variation whether based on all admission episodes or the number of children admitted at least once during the year. The SCV for vaccine-preventable conditions was also high, but this is in the context of a much smaller absolute admission rate. In contrast, there was substantially (3-fold) less variation in admission rates for UTI and LRTI.

Diabetes, the chronic condition with the lowest emergency admission rate, had a higher SCV than the other chronic conditions when based on individual admissions but not when repeat admissions of the same child were taken into account.

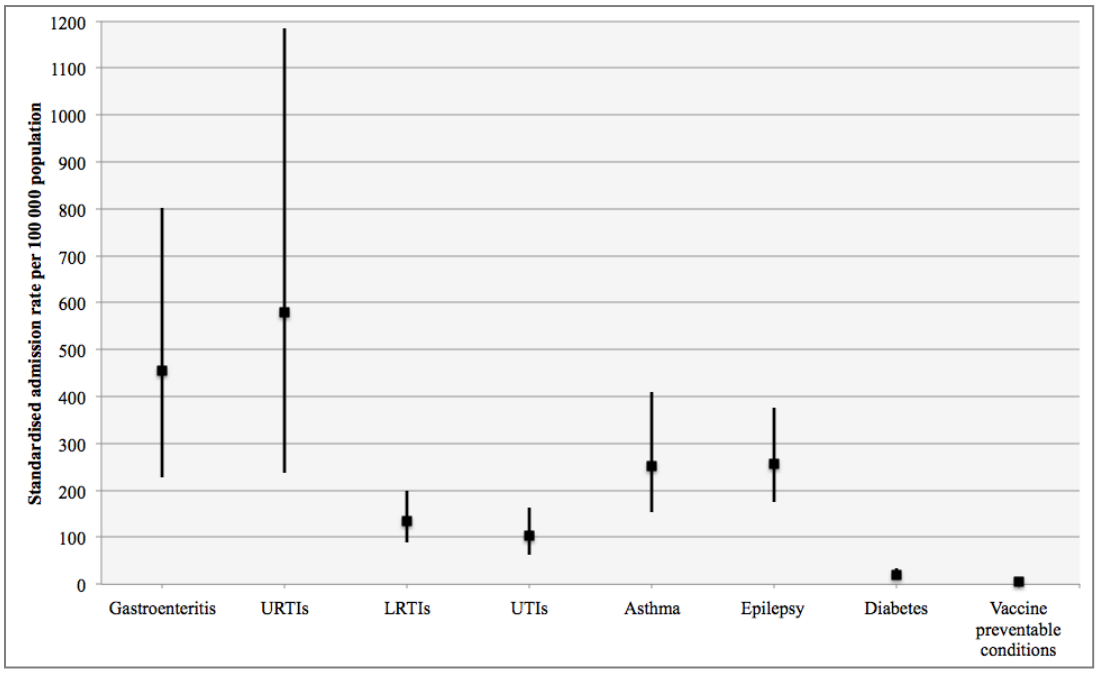
Table 5.6: Variation in emergency admission rate for ACSCs in children under 15 years, 2004-08

	Emergency admissions		Children with at least one emergency admission/year	
Condition	*Standardised Admission Rate (SAR)*[1]	*McPherson's co-efficient (SCV)*[2]	*Standardised Admission Rate (SAR)*[1]	*McPherson's co-efficient (SCV)*[2]
URTI	580.0	35.7	539.4	33.5
Gastroenteritis	454.3	21.3	420.4	20.0
Epilepsy	257.8	9.1	198.3	7.8
Asthma	251.2	12.7	201.1	10.6
LRTI	134.8	9.7	125.5	9.4
UTIs	103.5	12.2	93.0	11.0
Diabetes	20.4	19.4	15.9	10.2
Vaccine-preventable conditions	6.1	33.4	5.6	28.1

Notes: [1] SAR, geometric mean standardised admission rates per 100 000. [2] SCV, McPherson's co-efficient for the systematic component of variation (SCV multiplied by 100).

Figure 5.1 shows the same thing in an easier to interpret format by presenting directly the variability about mean admission rate for each condition. The plot is conservative as the extreme outliers are omitted – the range shown is between the admission rates in local authority areas on the 10th and 90th centiles. Unlike the SCV, the range is not independent of the absolute admission rate but it does show very clearly the more than 5-fold range in admission rates for URTIs and the more than 3.5-fold range for gastroenteritis.

Figure 5.1: Mean and range of 90th and 10th percentile standardised admission rates (emergency admissions) for ACSCs, 2004-08



5.4.3 Does the rate of ACSC admissions vary by age?

Children less than 5 years accounted for 82% of all acute ACSC admissions in 2007-10 (Table 5.7). The two infections associated with the highest absolute emergency admission rates (URTIs and gastroenteritis) also had the highest age-specific admission rates in the under 1 and 1-4 age group suggesting the majority of these infections were in young children. Diabetes admission rates peaked in older children (particularly the 10-14 group which represented 65% of all diabetes admissions) while most epilepsy and vaccine-preventable conditions admissions were in children less than 5 years.

Table 5.7: Emergency admissions for ACSCs in children under 15 by age group, 2007-10

	Admissions/year (mean)				Admission rate/1000/year (mean)[1]			
Condition	*<1 year*	*1-4 year*	*5-9 year*	*10-14 year*	*<1 year*	*1-4 year*	*5-9 year*	*10-14 year*
Gastroenteritis	17 712	22 877	5180	3065	26.5	9.3	1.8	1.0
LRTI	2947	7718	2516	1219	4.4	3.1	0.9	0.4
URTI	19 330	35 998	7087	3213	29.0	14.6	2.5	1.1
UTI	4544	3578	2007	1327	6.8	1.5	0.7	0.4
Acute infections (total)	*44 533*	*70 171*	*16 790*	*8824*	*66.7*	*28.5*	*5.9*	*2.9*
Asthma	415	11 941	7819	4496	0.6	4.9	2.8	1.5
Diabetes	93	241	422	1434	0.1	0.1	0.2	0.5
Epilepsy	3539	13 294	4238	3517	5.3	5.4	1.5	1.2
Chronic conditions (total)	*4047*	*25 476*	*12 479*	*9447*	*6.1*	*10.4*	*4.4*	*3.1*
Vaccine-preventable conditions	*344*	*164*	*59*	*49*	*0.5*	*0.07*	*0.02*	*0.02*

Note: [1] Admission rate based on 2008 population.

5.4.4 Trends in emergency admission rates

Table 5.8 shows that the total numbers of emergency admissions for ambulatory care sensitive conditions rose 13% (from 171 953 to 194 634; 18.3 to 21.3 per 1000) between 1999 and 2010. The increase was only in acute conditions (25% increase) – the emergency admission rate for chronic conditions actually fell by 7.7% overall (Table 5.8). However, this overall decline was driven by a substantial 19% fall in asthma admissions.

While the number of emergency admissions for vaccine-preventable conditions fell even more substantially (64%), the absolute number of admissions and hence impact on overall rate is small. The number of emergency admissions for epilepsy remained unchanged but, in contrast, emergency admissions for diabetes increased by 12%, 15% if expressed as a rate per 1000 children in the population.

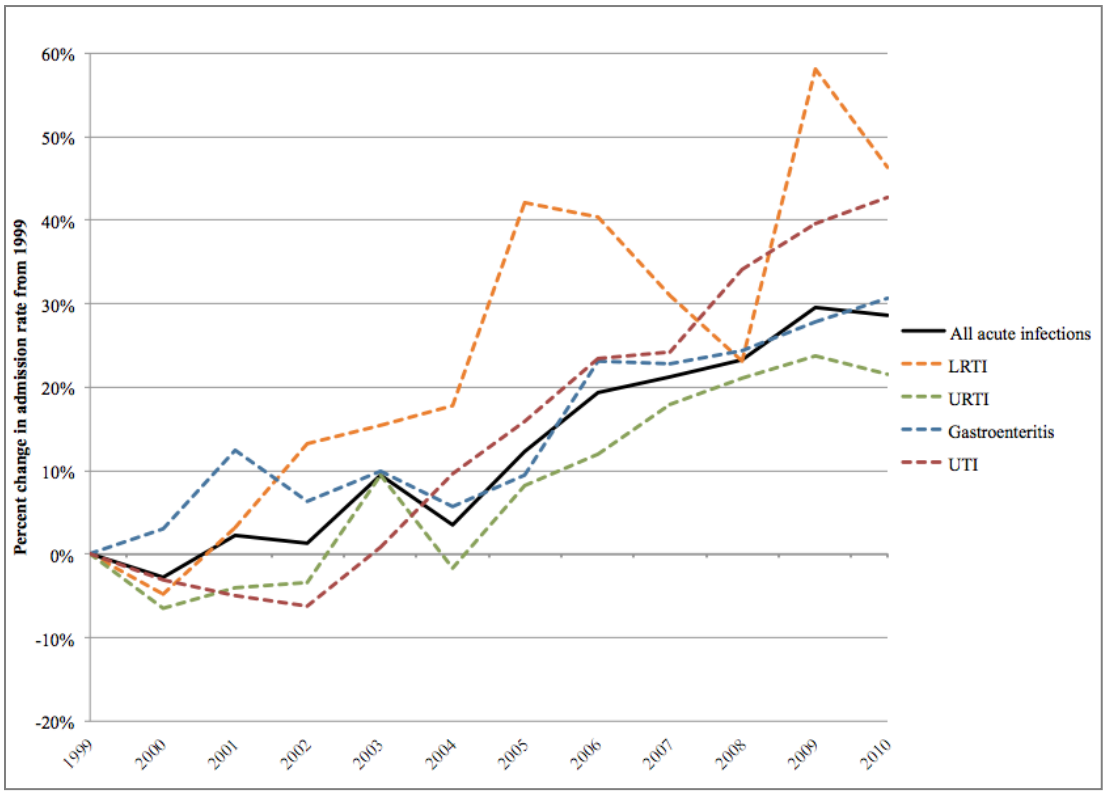
Table 5.8: Emergency admissions for ACSCs in children from 1999-2010

Condition	Admissions/year		Cumulative percentage change[1]	Admission rate/1000/year		Cumulative percentage change[2]
	1999	*2010*		*1999*	*2010*	
Gastroenteritis	40 120	50 958	+27.0	4.3	5.6	+30.6
LRTI	10 708	15 231	+42.2	1.1	1.7	+46.3
URTI	56 286	66 505	+18.2	6.0	7.3	+21.5
UTI	8799	12 208	+38.7	0.9	1.3	+42.7
Acute infections (total)	*115 913*	*144 902*	*+25.0*	*12.3*	*15.8*	*+28.6*
Asthma	29 197	23 667	-18.9	3.1	2.6	-16.6
Diabetes	1951	2176	+11.5	0.21	0.24	+14.7
Epilepsy	23 838	23 504	-1.4	2.53	2.57	+1.4
Chronic conditions (total)	*54 986*	*49 347*	*-10.3*	*5.8*	*5.4*	*-7.7*
Vaccine-preventable conditions	*1054*	*385*	*-63.5*	*0.1*	*0.04*	*-62.4*
Total	*171 953*	*194 634*	*+13.2*	*18.3*	*21.3*	*+16.4*

Notes: [1] (count in 2010 – count in 1999)/(count in 1999) x 100. [2] (rate in 2010 – rate in 1999)/(rate in 1999) x 100.

Figure 5.2 illustrates graphically the sharp increase in emergency admission rates for the four ACSC infections since 2004. The timing of this rise is contiguous with the implementation of the A&E 4-hour wait target (i.e. time from patient arrival in A&E to decision to admit or discharge should be <4 hours) in 2003-04 and the introduction of the new GP contract in 2004 (allowing GPs to opt-out of providing out-of-hours care). Overall, the rates of admission for the four acute infections rose by 29% (12.3 to 15.8 per 1000). There was some difference in the rate of increase for the individual acute infections (URTIs 22%, LRTIs 46%, UTIs 43% and gastroenteritis 31%) but the consistency and sustained nature of the increase is the striking feature of the graph.

Figure 5.2: Percentage change since 1999, expressed as cumulative change from 1999, in rates of admissions of children for acute infections, 1999-2010



5.5 Discussion

5.5.1 Main findings

5.5.1.1 What conditions generate the highest volume of admissions?

Acute infections generated the highest volume of admissions for ambulatory care sensitive conditions between 2007 and 2010. In particular, URTIs (7.3 per 1000) and gastroenteritis (5.4 per 1000) were the reason for 60% of admissions. Asthma and epilepsy were also common reasons for admissions, together accounting for one-quarter of admissions.

5.5.1.2 What conditions are associated with admission for more severe illness?

LRTI was the ACSC associated with admissions for more serious illness (3+ day stay). A substantial proportion of diabetes admissions were also severe. Most admissions for UTIs and vaccine-preventable conditions were either minor (same day admission and discharge) or severe (3+ day stay).

5.5.1.3 Does international comparison suggest that England performs poorly in any specific areas?

International comparison of admission rates for ACSCs suggests that the NHS in England performs poorly in managing acute infections. Admission rates for URTIs and gastroenteritis in England were several times higher than in Australia and the United States. Higher epilepsy admissions rates also raise the possibility of poor performance. However, such international comparisons need to be interpreted with caution for the reasons set out in section 5.5.2.3.

5.5.1.4 Does the extent of geographical variation suggest quality problems in any specific areas?

The extent of geographical variation suggests quality problems in the management of URTIs and gastroenteritis, the two infections associated with the highest absolute admission rates. Even when extreme outliers are omitted there is more than 5-fold and 3.5-fold range in admission rates for URTIs and for gastroenteritis respectively. Although the rate of admissions for vaccine-preventable conditions was lower than for the other ACSCs, it showed substantial geographical variation.

5.5.1.5 Should quality indicators be age-specific?

Most admissions for acute infections were in children less than 5 years suggesting quality indicators for this ACSC should be age-specific. This was also evident for vaccine-preventable conditions and epilepsy. Admissions rates for diabetes peaked in older children therefore indicators should focus on this age group unlike asthma where no clear age-specific pattern was observed.

5.5.2 Robustness of data

5.5.2.1 How robust are the HES data on ACSC emergency admissions?

The robustness of any analysis is limited by possible variation in data completeness and the consistency of coding but I am not aware of any major changes in coding or completeness which would impact the findings. Rather, the accuracy of HES coding has improved in recent years (as described by Burns *et al.* (10)). The inclusion of non-specific '*unspecified'* codes minimised the possible risk of changes over time being attributable to changes in coding practice.

National HES data does not include the time of day that children are admitted which precludes conclusions on specific conditions that are primarily admitted out-of-hours. It is also likely that the admission rate is driven in part by the number of medical A&E department attendees which Sands *et al.* report to have increased between 1997 and 2007.(11)

The significant number of admissions in the study period, and limitations in HES data, precluded evaluating the appropriateness of each individual admission, such as evaluating clinical (e.g. vital signs) and social factors (e.g. parental characteristics)

that prompted the decision to hospitalise. While the HES analysis took account of age and change in population size, the only way to adjust for indices of social deprivation (which have been previously correlated with hospitalisation by Roos *et al.* (12) and others) is through geographical analysis by applying the deprivation index of the geographical area in which the admission occurred. The index of multiple deprivation was included in preliminary analyses but significantly added to the complexity and time required to conduct the data analysis. As this study was completed in collaboration with the UHCE and relied on their support and methodological assistance it was decided to defer further analysis of deprivation.

5.5.2.2 How robust are the ACSCs used in the analysis?

Unplanned admission for ACSCs is an indicator of quality at the level of the health care system in aggregate. Admission to hospital for a child, particularly for a short stay, may be necessary and important to observe an illness trajectory or to help resolve an acute social problem as described by Hill.(13) The eight conditions used for this analysis have been widely used to measure the quality of primary care in Europe (3, 4), Australasia (14), North America (8, 9, 15-17), and by international organisations (e.g. OECD).(18) Four of these conditions have been adopted as outcome indicators in the NHS Outcomes Framework 2012-13 in relation to unplanned emergency admissions.(5)

5.5.2.3 How robust is the international comparison?

International comparisons of emergency admission rates for ACSC are necessarily crude, particularly as differences in coding preclude precise comparisons. It is difficult to compare absolute admissions rates between countries due to differences in

health care systems; each country's admission rates are based on multiple factors including disease prevalence, patient expectations, medical legal system, coding practices, health care funding and clinical threshold. However, such comparisons provide an approximate assessment of the ability of the primary care system to manage such conditions and give an indication of whether the rate is '*good'* or '*poor'*.

5.5.2.4 How robust is the time-trend analysis?

The inclusion of the additional codes used in the NHS specified by Purdy (including the non-specific '*unspecified'* codes) means that observed changes over time are unlikely to be due to changes in coding practice. However, it is difficult to interpret temporal relationships because two of the potentially most important changes – the gradual enforcement of the A&E 4-hour wait target and the new GP contract which allowed GPs to opt-out of providing out-of-hours – happened co-incidentally in 2004.

There are also several factors correlated with increased hospitalisation in children which were not evaluated (e.g. deprivation (12), ethnicity (1), insurance status (19), sex (20) and characteristics of parents, particularly with young children (21)). Parental factors, combined with more children being brought for assessment to both primary care clinics and direct to hospital, may be overloading the system and have little to do with the quality of primary care. Better public education and information dissemination may have led to an increase in consultations due to better awareness of the potential red-flag symptoms. Therefore, robust conclusions on the impact of organisational changes in the NHS are not possible.

5.5.3 Implications of the time-trends and variation analysis

5.5.3.1 Which issues appear to be getting worse or resolving over time?

The emergency admission rates for acute infectious ACSC appear to be getting worse over time: they rose 29% between 1999 and 2010. In particular, LRTI and UTI admission rates increased by 46% and 43% respectively. The admission rate for diabetes also increased 15% over the time period suggesting a worsening in care quality.

The overall admission rate for chronic conditions fell by 7.7%. This was driven by a 17% fall in asthma admission rates which suggests an improvement in care quality. Similarly, the number of vaccine-preventable conditions fell substantially from 1054 in 1999 to only 385 in 2010 (64%) inferring improved immunisation coverage.

5.5.3.2 Have the NHS organisational changes been associated with changes in ACSC admissions?

Over the past decade, there have been several major structural reforms to the NHS in England. The timing of the rise in emergency admissions for acute infectious ACSC is co-incidental with the gradual enforcement of the A&E 4-hour wait target between 2000 and 2004 (23% of patients waited over 4-hours in 2002 which dropped to 5% in 2004).(22) The rise in emergency admissions is also concurrent with the introduction of the new GP contract in 2004. This contract allowed GPs to opt-out of providing out-of-hours care, and now only 10% of GPs provide this care and the responsibility has shifted to NHS Primary Care Trusts who contract with a range of public and private providers.(23) Saxena and colleagues (24) suggest that the new contract has influenced the rise in emergency admissions in children although, as mentioned

previously, such robust conclusions are not possible. A list of possible contributory factors is listed in Table 5.9.

Table 5.9: List of potential causes of rise in short-term hospital admissions

▪ Increase in number of children being taken to primary care for assessment.
▪ Decrease in thresholds in primary care for referral of children to hospital.
▪ Increase in the number of parents being advised by National Health Service (NHS) Direct to take their child straight to hospital.
▪ Increase in the number of parents taking their child straight to hospital without first seeking NHS advice elsewhere.
▪ Decrease in willingness of parents and carers of children to care for them at home when they have minor self-limiting complaints.
▪ Decrease in willingness of parents and carers of children to tolerate uncertainty.
▪ Increase in decisions to admit rather than further observe in order to reach the 4 hour emergency department wait target.
▪ Decrease in exposure to (and training for) triage of children with potentially serious illness during general practitioner training.
▪ Decrease in hospital clinicians' ability to triage effectively or to accept risk.
▪ Unintended financial incentives created by contracts and payment tariffs that reward admission.
▪ Introduction of rapid diagnostic technologies without clear understanding of their diagnostic value in situations where disease prevalence is low.
▪ Decrease in the length of stay of children admitted because of more rapid and effective treatment in short-stay units for acute conditions such as asthma and mild dehydration (from gastroenteritis).

Reproduced from: Gill PJ, Goldacre MJ, Mant D, Heneghan C, Thomson A, Seagroatt V, et al. Increase in emergency admissions to hospital for children aged under 15 in England, 1999–2010: national database analysis. *Arch Dis Child*. 2013;98:328-34.

Other organisational changes in the study period include the introduction of NHS Direct, a protocol-led telephone service. There is some evidence that this service encourages the parent to take the child to see a doctor and may advise parents to seek hospital care directly. Data from the South Central region of England 2007 showed that 41% of calls for children to NHS Direct resulted in advice to see a doctor that day and 14% were sent directly to secondary care compared with less than 5% of children who are seen by a GP out-of-hours.(25) The commissioning of walk-in centres may have further fragmented care across multiple providers.

New models of acute paediatric care, such as short stay units and emergency outpatient consultations have emerged, partly in response to the 4-hour wait target (described by Coon *et al.* (26)). These models may have lowered the threshold for admission by increasing the efficiency with which acute problems such as asthma and dehydration are managed. These models may have also decreased the length of stay, thereby increasing the number of very short-term admissions.

5.5.3.3 Is geographical variation a useful marker of care quality?

For geographical variation to be a useful marker of care quality, there must be a certain level, after adjusting for variation that is related to social deprivation, where variation is considered unwarranted and implies poor care. Unfortunately such cut-off points are not available, and Diehr *et al.* (27) warned that McPherson's co-efficient (systematic component of variation) can only be used to compare conditions with similar admissions rates (as prevalence can affect the SCV value). Therefore, geographical variation can only provide one more indication of care quality at the health care system level, adding substance to other findings (such as absolute admission rates and international comparison). Variation must be explored and the local areas with extremely high and extremely low rates investigated. These investigations will determine whether variation is desirable, reflecting improvements in care through innovation, or if it is unwarranted.

5.5.4 Are the results of this ACSC analysis consistent with other evidence about care quality?

5.5.4.1 Level of immunisation coverage to prevent serious illness?

The high variation in admission rates for vaccine-preventable conditions are consistent with other evidence about care quality in England. The recently published 'Atlas of Variation' for English children identified high variation in the percentage of children who did not receive vaccinations against 'diphtheria, tetanus, pertussis, polio, and *Haemophilus influenzae type b*' (DTaP/IPV/Hib vaccine), pneumococcal disease, and measles, mumps and rubella.(28) The confidential enquiry into child deaths also found that where immunisation records were available, only 59% of children were fully vaccinated.(29) Regarding the treatment of children with chronic disease, the enquiry found a failure to vaccinate despite specific requests from secondary care.

LRTI was the ACSC condition with the highest emergency admission rate for serious illness (3+ day stay). Poor influenza vaccine uptake in '*at risk'* children (e.g. those with chronic medical conditions) may have led to high admission rates for influenza and secondary bacterial infections. Baguelin *et al.* estimated that hospitalisation for influenza is five times more likely in at risk children versus non at risk children aged 0 to 4 years (214 versus 42 per 1000) and twelve times more likely in children aged 5 to 14 years (67 versus 6 per 1000).(30) The peaks in admissions in Figure 5.2 may reflect fluctuations in the severity of influenza seasons.

5.5.4.2 Quality of management of acute self-limiting infection such as URTIs?

Saxena *et al.* (24) reported that URTIs are one of the main reasons children under the age of 10 are admitted to hospital. Evidence about care quality suggests many

admissions for acute self-limiting infections are unnecessary and put children at risk of hospital-acquired infections, medical errors, drug reactions and emotional trauma as described by Flores *et al*. (31). Yet the risk of death from these infections is low. The number of deaths of children aged 1-14 years fell by 36% in England and Wales during the study period (from 1581 in 1999 to 1006 in 2010).(32) Between 1996 and 2004, Jit and colleagues only identified 3 deaths in England due to a primary diagnosis of rotavirus and 16 deaths due to a primary diagnosis of gastroenteritis in children under 5.(33) Yet gastroenteritis indicators evaluated in the UK (34), US (35) and the Netherlands (36) reported low adherence to appropriate care standards.

The risk of serious deterioration for acute self-limiting infections is also small. In the 10-year period from 2000-2010, Koshy *et al.* reported that admissions for acute pharyngitis and tonsillitis in children increased 76% without any major change in admissions for peritonsillar abscesses (a marker of severity).(37) This rise in admissions cannot be attributed to inappropriately conservative antibiotic management that results in more serious infections. Schneider-Lindner and colleagues found antibiotic prescribing rates in UK general practice increased 41% from 2000-2007 which they attributed to additional prescriptions of second and third generation penicillins to children less than 5 years old.(38)

5.5.4.3 Quality of management of urinary tract infections?

Adherence to indicators developed for urinary tract infection management in primary care was only 53% in UK general practice (34) (comparable with 48% in US children (35) and 66% in Dutch out-of-hours clinics (39)). While it is true that most children with UTIs have an uncomplicated course, a small but important sub-group develop

renal scarring or dysfunction.(40) Early diagnosis and treatment with antibiotics is critical to avoid such unwanted outcomes: delayed treatment by more than 48 hours after fever onset increases the risk of renal scarring by up to 50%.(41) Delayed treatment may also result in clinical deterioration in children such that they are admitted for longer (e.g. for IV antibiotics when early oral antibiotics would have been effective). Indeed, UTIs were associated with more severe illness (3+ day stay) in the study period. Recognising the consequences of diagnostic failure and the need to improve care quality, NICE developed guidance in 2007 to improve early detection and management of UTIs.(42)

5.5.4.4 Quality of management of chronic conditions?

Asthma admissions fell in the study period, a trend consistent with observational evidence collected by Millett *et al.* (43), suggesting asthma admissions also fell in England after the smoke-free legislation was implemented in 2007. But Fuhrman *et al.* (44) suggested that up to two-thirds of admissions to hospital for asthma were in poorly-controlled patients who were not prescribed appropriate medication, given action plans, or followed up properly.

Diabetes admission rates were highest in children aged 10-14 and the distribution of length of stay suggests that a substantial proportion were for serious illness. These findings are consistent with a national audit of paediatric diabetes care in the UK which found four-fifths of children had HbA1c levels outside the specified threshold, 1 in 11 children had a DKA episode in the previous year, and only 4% received care as outlined in the appropriate guidelines.(45) Nordly *et al.* used outcome indicators to determine that the quality of diabetic care in 1335 Danish children was poor.(46)

Recent evidence suggests that the incidence of recorded epilepsy diagnosis in children in primary care is decreasing: annual incidence has fallen from 167 to 93 per 100 000 from 2001-2008.(47) Yet unplanned admissions for epilepsy changed little in the study period which suggest that while fewer children have epilepsy, they are frequently admitted. Further, findings from the confidential enquiry into child deaths described by Harnden and colleagues, identified deficiencies in the care quality of epileptic children.(29)

5.5.5 What relevant quality indicators have been developed?

5.5.5.1 QIs for the common infectious ACSCs

There are indicators developed for common infectious conditions in primary care such as the quality indicator set published by the NPCRDC (outlined in Chapter 2) which includes indicators for acute otitis media, acute diarrhoeal disease, URTIs and UTIs.(48) The National Quality Measures Clearinghouse also includes several sets of paediatric indicators for these conditions which could be modified for use in the UK (e.g. acute gastroenteritis, otitis media and otitis externa) (49) but would likely need updating to ensure they comply with current evidence-based (i.e. NICE) guidelines.

Giesen *et al.* (39) developed a general practice indicator set for Dutch out-of-hours, and this set included child markers. For example, one indicator focused on appropriate antibacterial treatment for patients that presented with complicated UTIs with signs of tissue invasion, outlining first line and second line therapy. When assessed in 289 patient contacts, the indicator was adhered to in 66% of cases with missing values in only 2.4% of records. Similar UK markers could be developed which focus on the

early identification and treatment of UTIs in children to reduce the number of severe hospitalisations.

Engels *et al.* (50) developed an indicator set for general practice management in European primary care; a few of these markers focused on access to care, such as ensuring patients have rapid access to out-of-hours service. A recent study by O'Loughlin and colleagues on unplanned re-attendance rates in A&E found that most patients present directly to hospital rather than consult primary care.(51) The authors recommend focusing on "parents who bypass primary care resources" to reduce these rates.(51) Indicators, like those developed by Engels, could potentially address why parents bring their children to hospital as this may reflect inadequate access to out-of-hours care.

5.5.5.2 QIs for the chronic ACSCs

The striking reduction in hospital admissions mentioned earlier with the passing of smoke-free legislation, described by Millett *et al.* (43), suggests that targeting indicators on smoking cessation for young asthmatic children may reduce hospitalisations in older children. One QOF indicator targets smoking in patients with asthma aged between 14 and 19.(52) Additional indicators could focus on assessing the smoking status of parents and siblings, and educating them on the potential harm in children.

Diabetes and epilepsy QOF markers, unlike asthma, are adult specific. There is some evidence (from the US) that high levels of well-child-care and continuous care reduced hospital admissions for young children with chronic conditions.(16)

Indicators focused on proactive primary care for these children may have a similar effect in the UK. While the Beal *et al.* review found few markers for children with chronic conditions (53), indicators could be designed from UK guidance (like those developed in Denmark for paediatric diabetes (46)).

5.5.5.3 QIs for immunisation and preventive health

Quality indicators developed for child immunisations both in the UK and elsewhere (such as those previously described in the 'Atlas of Variation' (28)) could be implemented in UK primary care. Indicators have also focused specifically on '*at risk'* children who have a higher probability of poor outcomes if not vaccinated (e.g. higher hospitalisation rates for influenza).(48) Specifically prioritising indicators on this population could potentially reduce unplanned hospital admission rates.

5.6 Conclusions

Acute infections generated the highest volume of admissions for ambulatory care sensitive conditions between 2007 and 2010, particularly URTIs and gastroenteritis. International comparison, although necessarily crude, also suggests that admission rates for URTIs and gastroenteritis were several times higher than in Australia and the United States. Previously developed indicators focused on these conditions could be used in UK general practice but may need updating to adhere to evidence-based guidance.

The extent of geographical variation suggests quality problems in the management of URTIs and gastroenteritis. Vaccine-preventable conditions also had substantial

geographical variation, consistent with evidence from the 'Atlas of Variation'. To reduce variation, immunisation indicators could focus on '*at risk'* children who have a higher probability of poor outcomes if not vaccinated.

LRTI was the ACSC associated with admissions for more serious illness (3+ day stay); many admissions for UTIs were also severe. Markers could be developed which focus on the early identification and treatment of UTIs in children to reduce the number of severe hospitalisations.

The admission rate for diabetes increased 15% over the time period suggesting a worsening in care quality. A substantial proportion of these admissions were for 3 days or more (suggesting more severe illness), with rates highest in older children. Quality indicators should therefore focus on this age group. There were also large numbers of admissions for asthma and epilepsy. Further consideration should be given to develop indicators focused on the proactive management of children with chronic conditions (which could be developed from UK national guidance).

The emergency admission rates for acute infectious ACSCs appear to be getting worse over time: they rose 29% between 1999 and 2010 with particularly large rises in LRTI and UTI admission rates. Although there was a clear escalation in admission rates around the time of the new GP contract (which allowed GPs to opt-out of providing out-of-hours care), other changes are likely to have contributed to the rise in admissions. Nevertheless, indicators focused on out-of-hours care quality could begin to address the wider issue of how parents access acute care for their children in a setting of universal health care and unpick why they frequently bypass primary care.

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Chapter 6: Prioritising areas for quality marker development in children

6.1 Introduction

The Nominal Group Technique (NGT) is an objective prioritisation technique which provides participants equal opportunities to contribute and builds on the reflections of others to reach consensus.(1) It was used with a nationally convened panel of GPs (with specific expertise in child health) to select eight clinical areas to prioritise quality marker development that were: 1) important to UK general practice; 2) representative of a range of conditions treated; and 3) feasible to measure.

6.2 Aims and objectives

The overall aim of the research reported in this chapter was to identify the clinical areas of child primary care for which national experts thought quality markers should be developed. The specific objectives were:

1. To recruit a panel of general practitioners with specific expertise in child health, and with representation from England, Scotland, Wales, and Northern Ireland.

2. To convene a meeting of the expert panel in order to generate professional consensus on the clinical areas of child primary care for which it is most important to develop quality indicators.

6.3 Methods

6.3.1 Study design

The Nominal Group Technique is a consensus methodology that uses a highly structured format to prioritise responses from an expert group.(2) As Van de Ven and Delbecq have outlined (1), the NGT is particularly useful in areas prone to subjective judgements. Murphy *et al.* (3) reported that the NGT performed better than informal group methods; in particular, it was superior to other structured consensus methods (e.g. Delphi technique) for idea generating. Gallagher *et al.* (4) described its use in general practice in 1993 and Guttmann *et al.* (5) used the NGT to prioritise topics for quality indicator development in paediatric emergency care.

Murphy *et al.* (3) recommended a panel size of between 6 and 12 on the basis that the reliability and validity is low when the panel is smaller than six while larger panels can impair equal participation and create logistical challenges. They also suggested that diversity of panel membership usually improved performance as long as participants did not express extreme views and provoke conflict.

The NGT process described by Gallagher is divided into several specific steps, outlined in Table 6.1. In addition, the Hutchings *et al.* (6) review suggests that groups participating in formal consensus methods are more likely to produce judgements consistent with the research evidence if they are provided with a literature review summarising that evidence. Participants were therefore provided with written information before the meeting (Appendix C.1). At the outset of the meeting, a summary of this information was provided in an oral briefing before the question was outlined to participants (similar to the methodology used by Guttmann *et al.* (5)).

Table 6.1: Outline of steps in Nominal Group Technique

1. Question: After welcoming participants and explaining the purpose and specific steps of the Nominal Group Technique (NGT), participants are presented with the specific question.
2. Silent idea generation: Each panel member is asked to spend 5 minutes writing comments in response to the question on paper. No discussion between group members is permitted.
3. Listing of ideas: Each person is asked in turn to share one item they have written during the silent period. Each point is written down verbatim on a flip board. Participants are encouraged to '*hitch-hike*' on other ideas by writing down new ideas. Members do not have to contribute at each opportunity and participants may skip their turn and respond later. When the ideas have been exhausted, the step is complete. The moderator of the NGT ensures that there is no debate or discussion during the listing of items.
4. Discussion and clarification of ideas: Once all items are recorded, there is a moderated 30-45 minute discussion clarifying, elaborating, or disputing the items to ensure each item listed is mutually exclusive. Once an item is listed, it may not be eliminated, but new items can be suggested. The discussion proceeds, one item at a time, until all items have been reviewed.
5. Selecting the top eight items: The panel members select the top eight items that they consider the most important and write it on paper.
6. Ranking the top eight items: Each panel member ranks their top eight items in order of priority (highest priority 1 to lowest 8) where the highest priority item is equal to eight points and the lowest priority item is equal to one point.
7. Break: The results of the vote are collected during a break period and summarised.
8. Active discussion: The group's top eight items are presented in order of most points and a moderated discussion about the nature and content of the '*top eight*' items occurs to discuss their thoughts on those items included or excluded. Items may also be modified.
9. Re-ranking: Each panel member re-ranks their '*top eight*' items in order of priority (highest priority 1 to lowest 8) where the highest priority item is equal to eight points and the lowest priority item is equal to one point.
10. Consensus: Final list of top eight items are presented to the panel. If consensus is not achieved, several rounds of ranking may follow.

Note: Reproduced from Gill PJ, Hewitson P, Peile E, Harnden A. Prioritizing areas for quality marker development in children in UK general practice: extending the use of the nominal group technique. *Fam Pract*. 2012;29(5):567-75.

Modified from: Gallagher M, Hares T, Spencer J, Bradshaw C, Webb I. The nominal group technique: a research tool for general practice? *Fam Pract*. 1993;10(1):76-81.

The Proportionate Review Sub-Committee of the South West London 4 Research Ethics Committee reviewed the project and deemed it service development (not requiring approval from a Research Ethics Committee). The study was funded by the RCGP Scientific Foundation Board as part of a grant awarded for this thesis (Ref. SFB-2010-03). Results from this chapter have been published in *Family Practice*.(7)

6.3.2 Expert panel

Previous work has suggested that the output of formal consensus methods is more likely to be accepted when it is generated by a group perceived to be credible.(3) Since a key aim of my research was to develop a set of quality indicators which could be adopted as part of the general practice Quality and Outcome Framework in the UK, an expert panel of GPs with a special interest in child health was recruited with the assistance of my supervisor (Dr Anthony Harnden, who, at the time, was the RCGP Child Health Clinical Champion). Panellists were sought with a variety of backgrounds (such as RCGP Council, NICE guideline development, NICE QOF Programme Indicator Committee, medical education, and child protection) and were at varying stages in their respective careers. Most were clinically practicing GPs at the time of the meeting.

Invitation letters were sent by email on 7 February 2011 to 13 GPs identified: 12 responded and agreed to participate in the panel (one GP did not respond after one reminder email). One panel member cancelled two days prior to the meeting due to a personal health crisis and Dr Harnden agreed to take his place. The panel members are described in Table 6.2 and include GPs from England (n=9), Scotland (n=1), Northern Ireland (n=1) and Wales (n=1).

Table 6.2: List of expert panel

Name	Location	Description
Dr Janice Allister	Peterborough	RCGP Child Health Clinical Champion (2011-) Secretary of Primary Care Child Safeguarding Forum at Stockport Primary Care Trust
Dr Chris Boardman	Scotland	RCGP First5 Lead in North East Scotland
Dr James Cave	Berkshire	NICE guideline development, practice based commissioning, Editor of *Drugs and Therapeutics Bulletin*
Dr Dick Churchill	Nottingham	Chair of RCGP Adolescent Primary Care Society Clinical Associate Professor, University of Nottingham
Dr Duncan Keeley	Oxford	Editorial Adviser for the *BMJ* (1999-2001), member of the Oxford Tropical Research Ethics Committee
Dr Maeve Lambe	Northern Ireland	RCGP Northern Ireland Council NICE QOF Indicator Programme Committee
Dr Tonia Myers	East London	GP partner, Handsworth Medical Practice, London
Prof Ed Peile	Warwick	Professor Emeritus of Medical Education, Warwick Medical School
Dr Phil Rayner	Nottingham	Medical education, vocational training RCGP Board, Vale of Trent Faculty
Dr Peter Saul	Wales	GP Associate Dean, Cardiff University Chair and Welsh Council Representative, RCGP
Dr Clare Taylor	Birmingham	NIHR In-Practice Fellow First5 Clinical Lead at RCGP, Deputy Editor of *InnovAiT*
Dr Anthony Harnden	Oxford	University Lecturer, University of Oxford RCGP Child Health Clinical Champion (2010-2011)

6.3.3 Preparatory material and panel briefing

The written material provided to panel members prior to the face-to-face meeting described the study objectives and summarised the key preliminary thesis findings. Also, to illustrate how the topics selected in the NGT will be used for indicator development, sample quality indicators were included for each priority area in the RCGP Child Health Strategy.(8) Dr Harnden reviewed the material and provided input on the level of detail, time required to read and clarity of objectives.

The panel met for one day on 10 June 2011 at the RCGP Headquarters in London. I moderated the meeting and was a non-voting member. After introductions by each panel member, I completed a PowerPoint presentation which covered the topics outlined in Table 6.3.

Table 6.3: Topics presented to expert panel

- Childhood conditions and themes which emerged as important from qualitative interviews with GPs (outlined in Chapter 4)
- Analysis of emergency hospital admissions for paediatric ambulatory care sensitive conditions (outlined in Chapter 5)
- Analysis of the common reasons for childhood consultations in UK general practice described in Gill *et al.* (9)
- Key findings from the child death confidential enquiry into the role and quality of UK primary care described in Harnden *et al.* (10)

The NGT methodology was explained to the panellists who were then given the opportunity to ask questions and to clarify any points of uncertainty.

6.3.4 Implementation of the NGT process

6.3.4.1 Question

The panellists were asked to answer the following question: '*What are three clinical areas or topics that should be prioritised for quality marker development?*'

The term 'clinical areas or topics' was used, rather than 'conditions' as the latter would exclude potentially important topics like child protection. A discrete number of topics (i.e. three) was included in the question to drive panellists towards prioritising – Guttmann *et al.* (5) also selected three. The panellists were instructed that the clinical areas chosen should be: 1) important to UK general practice; 2) representative of a

range of conditions treated in general practice; and 3) feasible to measure. They were asked to keep in mind the RCGP Child Health Strategy to ensure conditions were representative of various aspects of care. No further guidance was given on how broad or narrow their focus should be at this stage.

6.3.4.2 Generation of clinical areas

In response to the question posed to panel members, five minutes were allocated for the GPs to write responses on a single sheet a paper; no discussion or interaction was permitted. Then, using the '*recorded round-robin*' technique described by Van de Ven and Delbecq (11), I asked each participant one-by-one to share an item which I then recorded verbatim on a large flip board. Members did not have to contribute at each opportunity and could skip their turn and respond later if desired (there was no '*pressure*' to continue contributing). This process continued until panellists had no further items to suggest.

I moderated a 30-45 minute discussion which focused on clarifying, elaborating on, or disputing the items listed to ensure each was mutually exclusive and described precisely. Items could not be removed but new ones could be suggested, or a new wording offered. Items were not changed unless the GP who suggested the item approved. The discussion proceeded one item at a time until all items were reviewed and the list was deemed acceptable to the expert panel. This step proved difficult due to the large number of lengthy items. The panel thus took a brief 10-minute recess to allow the items to be typed and presented on a PowerPoint slide.

6.3.4.3 Initial ranking and moderated discussion

The panel members were instructed to select the top eight items they considered the most important from the list and to write it on paper. Then, each member was asked to rank their list of eight items in order of priority where the highest priority item was equal to eight points and each subsequent item equal to one less point (points = 9 – item rank). Each of the panel members therefore allocated 36 priority points giving an aggregate total of 432 (36 x 12). The panel members handed their anonymised result to me before the meeting adjourned for lunch. I tabulated the results during the break period in a Microsoft Excel 2007 spread sheet. All responses were kept confidential since the status of participants, and their subsequent responses, can influence group decisions.(3)

The group re-convened and I presented the results on an overhead projector. The items were ranked in order of most points by total sum and included the anonymised individual scores of each panel member: this allowed the panellists to see the sum score along with the spread of responses. Providing participants with a frequency distribution avoids arbitrary value judgements on which summary measures to use because other measures, like mean, are sensitive to extreme values; this is recommended by Murphy *et al.* (3).

The top eight items were then discussed. Unlike the clarification of item phase, this was an open discussion where panellists were encouraged to express their viewpoints. They discussed their thoughts on the items included or excluded and modified items to ensure they were sufficiently distinct. As moderator, I focused the group to review each relevant item and ensured each panellist had the opportunity to speak.

6.3.4.4 Re-ranking and final priority list

After the moderated discussion, each panel member was instructed to re-rank their eight items in order of priority based on the same scoring criteria outlined above. The panel adjourned for a break while I collected the results and entered them into a Microsoft Excel 2007 spread sheet.

The results were presented in order of most points along with individual scores of each panellist. I moderated an open discussion with the group to determine whether the top eight items indeed represented the most important areas. (If consensus is not achieved, several further rounds of ranking may follow. In this instance, further ranking was not required.) One panellist had to leave the meeting early but sent his final rankings the following day.

6.4 Results

6.4.1 Clinical areas initially identified

The panel generated 33 items, 30 of which were retained after the panellists went through and aggregated those that were deemed similar; they are listed in Table 6.4.

Table 6.4: Clinical areas identified prior to ranking

1) Profile of child-specific training of the professionals in the primary care organisations/providers
2) Safe and cost effective prescribing and promoting concordance
3) Recognition and management of child safeguarding and child protection
4) All children should have access to full immunisation
5) GP training in acute illness
6) Recorded observation of child well-being in infancy, school-aged and preschool
7) Embedding prevention and early intervention in general practice with specific reference to healthy child programme
8) Identifying acute sick child, on-going process, involvement with other agency including best practice including documentation, safety netting, consultation for acute illness
9) Detection, information gathering and management including clear pathways and signposting for primary care of mental health problems in young people
10) Access to primary health care professional in children presenting with an acute illness
11) Evidence-based management of common childhood conditions (e.g. asthma, eczema, constipation, encopresis and enuresis) and appropriate referral
12) Early recognition of serious illness in children (infectious disease and non-infectious disease)
13) Assessment of child and carer friendliness of consultation and practice organisations
14) Child and young people representation and feedback on consultation
15) Structured assessment of the febrile child
16) Primary care involvement in chronic disease monitoring and management
17) Provision of health promotion information (vaccination, drugs, alcohol, sex)
18) Coordination of care for children with complex disorders
19) Identification of children with needs who do not come
20) Continuity of care and smooth transitions
21) Effective and coordinated practice activity in the prevention of obesity
22) Access issues for young people especially contraception
23) Proactive smoking cessation advice for parents
24) Education and support for parents and carers to optimise child health and development by the practice
25) Evidence for multi-professional cooperation and communication in the care of children
26) Appropriate involvement of the child in decisions and respect for preferences
27) Training for 6-week check and knowledge of normal child development
28) Active whole practice engagement in child protection
29) Improving health outcomes by encouraging early return to school
30) Communication with children

Note: Reproduced from Gill PJ, Hewitson P, Peile E, Harnden A. Prioritizing areas for quality marker development in children in UK general practice: extending the use of the nominal group technique. *Fam Pract*. 2012;29(5):567-75.

Several common themes were identified: health promotion (n=7), training (n=3), child safeguarding and child protection (n=3), management of acute illness (n=4), communication with children and parents (n=4), and care of children with chronic conditions (n=3). Some items narrowly focused on care delivered by GPs while others

related to broader issues such as the organisation of care and communication with other professionals outside of primary care.

6.4.2 First round ranking and moderated discussion

Detailed results of the first round ranking are shown in Appendix C.2. Four clinical areas were not ranked by any panel members (#14, #17, #18, and #23) and four were only ranked by one (#5, #6, #20, and #26). The top eight clinical areas had a combined total of 280 priority points out of a possible 432 (65%) but there was no clear numeric separation between the top-eleven items: the eighth item had 17 points while the ninth had 16 and the tenth had 15.

Most participants felt the results were not representative of the eight most important topics in child health; I moderated a discussion which explored this lack of consensus. In particular, I focused on items where: 1) several panellists failed to rank an item that was in the top eight; 2) one panel member ranked an item as high priority but it was not selected in the top eight; and 3) items were poorly ranked yet several panel members felt they were important (e.g. one panellist commented that failure to prioritise health promotion would reflect poorly on GPs and the profession).

The panel members unanimously modified nine items which were merged into four (Table 6.5). Several were felt to be redundant. For example, item #4, #7, and #21 focused on health promotion and prevention therefore item #7 was modified to: '*Embedding prevention and early intervention in general practice with specific reference to Healthy Child Programme (e.g. obesity and immunisation)'*. Similar

decisions were facilitated for items on GP training, child protection and safeguarding, and child friendliness and communication.

Table 6.5: Summary of original and modified items (#7, #27, #3, #13)

Original item	Modified item
Health promotion and prevention	
All children should have access to full immunisation (#4)	Embedding prevention and early intervention in general practice with specific reference to Healthy Child Programme (e.g. obesity and immunisation) (#7)
Embedding prevention and early intervention in general practice with specific reference to Healthy Child Programme (#7)	
Effective and coordinated practice activity in the prevention of obesity (#21)	
General practitioner training	
General practitioner training in acute illness (#5)	General practitioner training for acute illness, 6-week check and knowledge of normal child development (#27)
Training for 6-week check and knowledge of normal child development (#27)	
Child protection and safeguarding	
Recognition and management of child safeguarding and child protection (#3)	Whole practice involvement in the recognition and management of child safeguarding and child protection (e.g. missed appointments) (#3)
Active whole practice engagement in child protection (#28)	
Child friendliness and communication	
Assessment of child and carer friendliness of consultation and practice organisations (#13)	Assessment of child and young person and carer friendliness of consultation and practice organisations (#13)
Communication with children (#30)	

Note: Reproduced from Gill PJ, Hewitson P, Peile E, Harnden A. Prioritizing areas for quality marker development in children in UK general practice: extending the use of the nominal group technique. *Fam Pract*. 2012;29(5):567-75.

There was debate on the two highest ranked items, #8 and #12, which both related to acute illness in children (Table 6.6). Most panellists felt they were similar, and if they ranked one, they did not rank the other (eight panellists ranked only one). But others ranked both because they considered them sufficiently different or feared neither would be selected. These GPs felt item #8 focused on the management of common acute illnesses in children and the overall processes which should be in place to ensure high quality care; item #12, however, was narrowly interpreted to refer to early

diagnosis of serious illnesses. The issue could not be resolved by consensus so the panellists then voted whether to combine the two items: eight voted in favour and four opposed. These results mirrored the first round ranking results.

Table 6.6: Summary of original and modified item (#12)

Original item	Modified item
Acute and serious illness	
Identifying acute sick child, on-going process, involvement with other agency including best practice including documentation, safety netting, consultation for acute illness (#8)	Early recognition of potentially serious illness in children including identifying acute sick child, on-going process, involvement with other agency including best practice, documentation, safety netting, consultation for acute illness (#12)
Early recognition of serious illness in children (infectious disease and non-infectious disease) (#12)	

Note: Reproduced from Gill PJ, Hewitson P, Peile E, Harnden A. Prioritizing areas for quality marker development in children in UK general practice: extending the use of the nominal group technique. *Fam Pract*. 2012;29(5):567-75.

6.4.3 Results of final ranking

The results of the second-round of ranking (of the 24 clinical areas as redefined by the moderation process) are shown in Table 6.7. The top eight items selected had a combined total of 359 points (83%) with a clear cut-off between the eighth and ninth ranked items. All panellists ranked item #3 (child safeguarding) and 11 panellists ranked three items (#7, #9, and #12). The ninth ranked item, which related to training of professionals in primary care organisations (#1), was rated the most important priority area by two GPs; this item was similar to #27. Panellists may have ranked only one item related to training for no panellist ranked both (and only four GPs ranked item #27 while eight or more GPs ranked all other highly rated items).

The top ranked area focused on the early identification of potentially serious illness in children which had 82 of a possible 96 points; 15 points more than the second item.

However, three panellists also felt access to primary care for acutely unwell children (#10) was important which ranked tenth. Unlike the first round rating in which eight GPs ranked item #8 or #12, all three panellists who ranked access also ranked item #12; these GPs clearly felt the specific issue of access merited greater attention and was mutually exclusive. Two items were highly ranked by a single panel member: involving children in decision making (#26) and chronic disease monitoring (#16).

Table 6.7: Results of final (round 2) ranking by the 12 panel members

Rank	Item	1	2	3	4	5	6	7	8	9	10	11	12	*Sum*
1	Early recognition of potentially serious illness in children including identifying acute sick child, on-going process, involvement with other agency including best practice, documentation, safety netting, consultation for acute illness (#12)	8	8	8	8	8	6	-	7	8	6	7	8	*82*
2	Whole practice involvement in the recognition and management of child safeguarding and child protection (e.g. missed appointments) (#3)	6	4	7	7	5	8	8	3	5	2	5	7	*67*
3	Detection, information gathering and management including clear pathways and signposting for primary care of mental health problems in young people (#9)	5	-	5	3	6	7	4	1	4	5	4	1	*45*
4	Embedding prevention and early intervention in general practice with specific reference to healthy child programme (e.g. obesity and immunisation) (#7)	1	5	4	4	4	3	7	4	-	8	2	2	*44*
5	Evidence-based management of common childhood conditions (e.g. asthma, eczema, constipation, encopresis and enuresis) and appropriate referral (#11)	-	7	3	6	1	-	6	2	6	4	1	5	*41*
6	Assessment of child and young person and carer friendliness of consultation and practice organisations (#13)	-	2	-	1	2	5	5	6	7	1	3	3	*35*
7	Safe and cost effective prescribing and promoting concordance (#2)	-	3	1	-	3	-	2	5	2	3	-	4	*23*
8	General practitioner training for acute illness, 6-week check and knowledge of normal child development (#27)	7	-	-	5	-	-	3	-	-	7	-	-	*22*
9	Profile of child specific training of the professionals in the primary care organisations/providers (#1)	-	-	-	-	-	-	-	8	-	-	8	-	*16*

10	Access to primary health care professional in children presenting with an acute illness (#10)	3	6	6	-	-	-	-	-	-	-	-	-		*15*
11	Continuity of care and smooth transitions (#20)	-	-	-	-	7	1	-	-	-	-	-	-		*8*
12	Primary care involvement in chronic disease monitoring and management (#16)	-	1	-	-	-	-	-	-	-	-	6	-		*7*
13	Evidence for multi-professional cooperation and communication in the care of children (#25)	2	-	2	-	-	-	-	-	3	-	-	-		*7*
14	Education and support for parents and carers to optimise child health and development by the practice (#24)	-	-	-	-	-	4	1	-	1	-	-	-		*6*
15	Appropriate involvement of the child in decisions and respect for preferences (#26)	-	-	-	-	-	-	-	-	-	-	-	6		*6*
16	Structured assessment of the febrile child (#15)	4	-	-	-	-	-	-	-	-	-	-	-		*4*
17	Recorded observation of child well-being in infancy, school aged and preschool (#6)	-	-	-	-	-	2	-	-	-	-	-	-		*2*
18	Identification of children with needs who do not come (#19)	-	-	-	2	-	-	-	-	-	-	-	-		*2*
19	Child and young people representation and feedback and on consultation (#14)	-	-	-	-	-	-	-	-	-	-	-	-		*0*
20	Provision of health promotion information (vaccination, drugs, alcohol, sex) (#17)	-	-	-	-	-	-	-	-	-	-	-	-		*0*
21	Coordination of care for children with complex disorders (#18)	-	-	-	-	-	-	-	-	-	-	-	-		*0*
22	Access issues for young people especially contraception (#22)	-	-	-	-	-	-	-	-	-	-	-	-		*0*
23	Proactive smoking cessation advice for parents (#23)	-	-	-	-	-	-	-	-	-	-	-	-		*0*
24	Improving health outcomes by encouraging early return to school (#29)	-	-	-	-	-	-	-	-	-	-	-	-		*0*

Note: Reproduced from Gill PJ, Hewitson P, Peile E, Harnden A. Prioritizing areas for quality marker development in children in UK general practice: extending the use of the nominal group technique. *Fam Pract*. 2012;29(5):567-75.

In final discussion, the panel members felt the eight priority items (shaded grey in Table 6.7) were representative of the most important areas of child health in general practice. The group discussed which conditions should be the focus of item #11 relating to the evidence-based management of common childhood conditions. One GP suggested a '*layering'* approach by first looking at asthma before focusing on less common conditions such as enuresis, and then shifting focus to more complex

conditions. Another GP suggested focusing on the top conditions in general practice based on the RCGP surveillance data presented.

6.5 Discussion

6.5.1 Main findings

The expert panel prioritised eight clinical areas to focus paediatric indicator development: early recognition of serious illness, whole practice involvement in safeguarding, health promotion, mental health, evidence-based management of common conditions, child and carer friendliness, safe and cost-effective prescribing, and general practitioner training. These priority areas cover a broad range of topics in primary care ranging from common conditions to the identification of rare but serious illnesses.

The general practitioners struggled to balance the breadth of the clinical areas and were overly inclusive in the rankings. Instead of concentrating on increasing the precision and focus of the items, the GPs seemed reluctant to prioritise. This reluctance to prioritise suggests that the GPs were uncertain which areas were the most important or that they were uncertain about which topics should be left out.

6.5.2 Potential limitations of the consensus study methodology

6.5.2.1 Did the panel composition affect the priority areas?

The panel was composed exclusively of GPs which limited the perspective to one professional group in a field where teamwork is important. As GPs are primarily responsible for QOF achievement, they were considered the most appropriate

individuals to form the expert panel for this thesis. While Hutchings *et al.* (6) recommends multi-specialty groups over single-specialty groups for consensus development methods, the effect of group membership on NGT results was inconclusive. Furthermore, Hutchings cautions on generalising findings on panel composition because of differences in topics, differences categorising judgements, and underlying variability in ratings.(6)

Involving other clinicians (e.g. community paediatricians) may have broadened the areas discussed. Health visitors and nurses, who work closely with GPs, would likely have suggested similar issues; managers may have focused on organisational structures. The addition of any of these groups of people may have changed the group dynamic and the wording of the priority areas (such that they were narrower or broader). But there is a risk that no consensus may be reached with a diverse panel, particular in complex topics (as Pastrana *et al.* (12) found in palliative care).

The panel was composed of GPs with a range of clinical experience, including academia and policy, and those working on the frontline. But there was a bias towards '*expert'* over '*ordinary'* GPs. This was consistent with the methodology used by Marshall *et al.* in selecting Fellows by Assessment of the RCGP (13) and reflected the panel selection process (i.e. informed by RCGP Child Health Clinical Champion). The predominance of expert GPs likely altered the final set of priority areas selected. Full-time clinically oriented GPs may have prioritised topics that were more in touch with frontline clinical practice (e.g. access and continuity of care) and that differ from the RCGP priority areas.

Patients were excluded. The original developers of the NGT recommended panel members communicated in the same or '*common*' language.(1, 4) Further, it would have been difficult to identify and recruit the appropriate patient representatives given the wide age range and broad variety of conditions seen in general practice.

6.5.2.2 Are the results from a single NGT valid?

Only a single NGT study was completed. By completing multiple NGTs, the reproducibility of the priority areas selected could be evaluated.(1) It may have been possible to complete multiple NGTs throughout the UK with local groups of GPs and health care professionals rather than facilitate a single face-to-face meeting in London. Hares *et al.* (14), for example, conducted multiple NGTs with patients and professionals to explore views about diabetic care.

Previous studies which looked at multiple NGTs completed with groups of similar composition found minimal difference in the results.(6) Lloyd-Jones *et al.* (15) used the NGT to develop a questionnaire in medical education; while only 5% of the class was involved, the items generated were largely representative of the entire class. While it is possible that priority areas generated by another NGT study may be slightly different, this was minimised by providing the panel with detailed research evidence to ensure judgements were consistent with the evidence (which was recommended by Hutchings *et al.* (6)). Further, six topics were included in the RCGP Child Health Strategy which suggested they have strong face validity with GPs across the UK; however this is not surprising given at least eight panel members were actively involved in the RCGP.

Rather than complete multiple NGTs, it may have also been possible to validate the NGT priority areas using the Delphi technique. For example, a large number of UK-wide health care professionals, including GPs, nurses, health visitors, A&E physicians, public health physicians, and paediatricians, could have ranked the topics in order of importance. The lack of face-to-face meeting and convenience of the postal survey suggests it would be possible to get a large number of responses. It would also be possible to compare ranking by profession, unpicking whether GPs prioritise similar or different areas to other professionals. However, it is unclear whether all topics initially suggested in the NGT should be included, or only the final eight chosen (as the output would vary considerably). Similar to the NGT, there is also a risk that no consensus may be reached with a diverse panel.(12)

6.5.2.3 Do the results of the NGT represent consensus or the average view?

One criticism of formal consensus techniques is whether they indeed generate consensus or report the average view. Lancaster and colleagues (16) applied this criticism to the NGT where items are voted and ranked by the expert panel. Presentation of the results by total sum and the individual scores allowed the participants to compare the '*sum*' score with the '*consensus*' or how many individuals ranked the item. Showing results by spread is recognised as the most objective method to feedback to the panel, least prone to arbitrary decision of which summary measure to use.(3)

The active discussion phase was difficult to moderate as it closely resembled a focus group: personal agendas and opinions dominated. The one hour allocated was insufficient which created a sense of urgency to ensure all items were discussed.

There was no consensus to merge two serious illness items but this was resolved with a vote. Groups working under time pressure tend to focus on task completion which usually results in their initial preference having a greater influence than the careful consideration of information.(3) If more time had been allocated, these two items regarding serious illness might not have been combined. However, time pressure has a marginal effect on the consensus process and it was unlikely that more time would have changed the results.

6.5.2.4 How did the question affect the priority areas selected?

The panel focused on broad topics rather than precise and narrowly-defined ones; this likely reflected the structure of the question. As Van de Ven and Delbecq describe (1), a properly-worded question is necessary to guide the group towards consensus: it must not be too narrow (and fail to tease out alternative viewpoints) or too broad (and be too all-encompassing to be useful). As this thesis seeks to broaden the potential indicators used in children (and move away from narrow condition focused measurement), a broader question was chosen. Consequently, the panel had no incentive to increase the precision of items suggested and ranked, and overly specific items were generally excluded.

6.5.2.5 Can 'group-think' explain the results?

The concept '*group-think'*, or the "tendency for group members to seek concurrence" as described by Murphy *et al.* (3), may explain why the priority areas were selected, and why they mirrored the RCGP Child Health Strategy. Perhaps GPs wanted to ensure they prioritised topics deemed important by the wider health care community and felt they were representing the RCGP who funded the study. The panel's perceived '*responsibility*' to the profession seemed more salient than their personal

views, or the topics informed by the evidence, and this perceived responsibility drove the items selected. Indeed after the first round ranking, some panellists were concerned when topics that were perceived to be important (e.g. health promotion) were excluded. Failure to prioritise these items would reflect poorly on the profession (and by proxy the panel). Having the current RCGP Child Health Clinical Champion as one of the panel members likely influenced the panel ratings but this was not anticipated nor planned.

6.5.3 Are the priority areas consistent with evidence where care needs improvement?

6.5.3.1 Recognition of potentially serious illness

The panel chose the early recognition of serious illness as the most important topic. Serious illness also dominated the discussion phase after the first round ranking. Recognition of serious illness in children is clearly a particularly salient topic for GPs; many fear missing a potentially life-threatening infection. GPs may only see one or two cases of meningitis in their career and when they do, only half are appropriately referred to hospital from primary care.(17) Prioritisation of this area reinforces the findings from Chapter 5 which suggests LRTIs and UTIs may be responsible for the large number of prolonged hospitalisations for severe infections. But this area includes other serious illnesses such as epilepsy and diabetes which are also uncommon in children (and recent evidence suggests the incidence of some are falling (18)) but they may present first to primary care.

6.5.3.2 Detection and management of mental health

The ‘World’s Mental Health Survey Initiative’ found mental disorders that progress into adulthood frequently presented by the age of 14.(19) Mental health problems are

also common in primary care: the prevalence of psychiatric disorders in children aged 5-15 is approximately 10%.(20) However, Sayal *et al.* reported that many paediatric patients with problems are not recognised in general practice (21) and previous indicator development for UK primary care mental health services did not focus on children and young people.(22) Recently, Sayal and colleagues developed markers for mental health.(23)

6.5.3.3 Child protection and child safeguarding

Child safeguarding was ranked second in the NGT. The large number of panel members who were involved in safeguarding probably influenced this high ranking. But studies suggest that 4% of UK children experience maltreatment each year.(24) The statutory responsible for safeguarding lies with GPs and the panel felt this topic should be the focus of indicator development.

6.5.3.4 Management of common conditions

The most common childhood conditions in primary care are acute self-limiting infections and skin conditions.(9, 25) It is therefore unsurprising that the panel prioritised the evidence-based management of these conditions. The selection of this topic emphasised the importance of best practice and appropriate referral. Many primary care indicator sets were based on common conditions (outlined in Chapter 2), like those developed by RAND (26) and the NPCRDC (27) but the recorded quality of care delivered was variable.(28, 29) Appropriate management often required medications and the panel prioritised safe and cost-effective prescribing. This topic is important: medications tested in adults may not be safe or effective in children (30) but prescriptions are frequently used off-label or unlicensed in paediatrics.(31) While

some QOF markers focused on repeat prescriptions, the panel felt these were insufficient.

6.5.3.5 Health promotion

The panel listed a large number of health promotion items despite the historical shift in the opposite direction in the UK (unlike the United States).(32) Their concern is consistent with research evidence: there is high variation in admission rates for vaccine-preventable conditions (outlined in Chapter 5) and high variation in the percentage of children who did not receive vaccinations against DTaP/IPV/Hib, pneumococcal disease and MMR.(33) There is also a need to improve care for other childhood conditions such as obesity: lack of incentives have been cited as a reason primary care practitioners did not prioritise child obesity management.(34)

6.5.3.6 General practitioner training

Concerns about GP training are not new: the RCGP has been trying to increase the length of post-graduate training from three to four years to address these concerns. In April 2012, the RCGP put forward the educational case for enhanced and extended GP training which highlighted "improved care for children and young adults" as a key outcome.(35) The case was endorsed by Medical Education England in September 2012 (36) and was supported by the Department of Health.(37) The implementation strategy is currently under development and proposes that all GP trainees should "receive specialist-led training in child health and mental health problems."(36) But this topic is complicated and, as outlined in Chapter 4, GPs have pointed out the weak link between attendance at training (or arguably longer training) and improved performance. This topic was also salient to panel members, many of whom were

involved in medical education and GP training (including the RCGP First5 Clinical Lead (38)).

6.5.4 Which important areas were not prioritised?

6.5.4.1 Children with complex needs and adolescent health

While the panel suggested multiple chronic disease management topics, none were selected despite criticisms that QOF excluded children from potentially relevant indicators (e.g. diabetes and epilepsy). Adolescent health was also not included. Yet both areas were included in the RCGP Child Health Strategy and were flagged by primary care practitioners. The failure to prioritise these topics suggests such management is variable and based on GPs' level of comfort (and probably secondary care support). The focus, as evidenced by the top priority area, is on diagnosing such children (rather than managing them). However this may reflect an aversion to prioritise topics that are more difficult to address and require a greater amount of work for the GP.

6.5.4.2 Access to primary care

Access to primary care for children presenting with an acute illness was the tenth most important item rated by GPs. The potential to develop indicators for access to care was mentioned in a number of interviews with GPs. O'Loughlin *et al.* (39) also found most patients presented directly to hospital (i.e. 'bypass primary care') and suggested focusing on these parents to reduce unplanned re-attendance rates in A&E. However, access to primary care is a complicated issue; it has been the focus of previous primary care reform, but such reform has met with limited success. This

might explain why this item was not rated higher.(40) Alternatively, access may be encompassed in the broadly defined priority area focused on serious illness.

6.5.4.3 Admissions for ambulatory care sensitive conditions

The panel, despite evidence presented from Chapter 5, did not prioritise admissions for ambulatory care sensitive conditions. This reinforces the consistently negative views expressed by GPs on using ACSCs as quality indicators, as outlined in Chapter 4. However, while emergency hospital admissions were not explicitly selected, they did form an important component of individual priority areas such as the recognition of serious illness (e.g. LRTIs) and the management of common conditions (e.g. asthma).

6.5.5 What are the implications of the priority areas for QI development?

6.5.5.1 QIs for specific clinical conditions

US-based research groups have developed indicators focused on the early diagnosis of potentially serious infections (e.g. meningitis and pneumonia).(28) When these markers were transferred to UK general practice, many were excluded because of differences in the two health care systems (particularly related to over- and under-investigation).(13) Indeed, there is a risk that over-investigation and referral, (common criticisms of US health care) will overwhelm hospital services and secondary care. Therefore, specific indicators, informed by this earlier work, will need to focus on diagnosis, investigation and referral for serious illness in children with UK specific guidance (i.e. NICE). These indicators must also include other serious illnesses like diabetes and epilepsy.

The wording of the evidence-based management of common conditions priority area is particularly broad and poorly defined (i.e. what is the definition of common?) which will have implications on the feasibility of a pragmatic indicator set. The panel supported focusing on conditions identified in the RCGP surveillance data (e.g. skin conditions) as important. The literature review in Chapter 2 did not identify previously developed indicators for conditions such as enuresis or constipation but NICE guidelines on the management of these conditions could be used easily. Quality indicators for safe prescribing in children can also be drafted from guidelines. Recently, Stienen *et al.* (41) published a set of indicators for paediatric constipation (which have yet to be validated) that could inform further work.

6.5.5.2 QIs for child friendly practice

Patient feedback is collected under the current QOF contract but is not specific to children and young people. The panel suggested four items which addressed communication with children and parents but prioritised assessing the friendliness of consultations and practice organisations (which aligned with the RCGP Child Health Strategy (8)). However, GPs (Chapter 4) worry that developing markers in these '*soft'* areas will make clinical care mechanistic and fail to fulfill the intended purpose. Many US-based quality indicator sets include measures that focus on paediatric evaluation of health care delivery (e.g. Child and Adolescent Health Measurement Initiative); I may need to modify these indicators for use in the UK.

6.5.5.3 QIs for child protection and GP training

There are no previously developed indicators which focus on child protection and GP training that can be readily implemented in UK general practice. Recommendations from the recently published NICE guidance on suspecting child maltreatment (42) and

the RCGP Toolkit for ‘Safeguarding Children and Young People in General Practice’ (43) could be used for indicator development. Similarly, the pillars outlined in the RCGP First5, such as supporting revalidation or continuing professional development, could be modified for use as a training quality indicator.

6.6 Conclusions

The panel identified eight areas to focus quality indicator development which cover a broad range of topics in primary care including the early recognition of serious illness, whole practice involvement in safeguarding, health promotion, mental health, evidence-based management of common conditions, child and carer friendliness, safe and cost-effective prescribing, and general practitioner training.

The topics are consistent with evidence that indicates where care needs improvement and are representative of the RCGP Child Health Strategy. The topics will thus have strong face validity with GPs. Other important topics which merit greater attention were left out, in particular the care of children with complex needs, adolescent health, access to primary care and hospital admission for ambulatory care sensitive conditions.

The priority areas are also broader than desired. The panel members struggled to balance the breadth of the clinical areas and were overly inclusive in the rankings. They seemed reluctant to select specific areas. This indicated they were either uncertain which areas were the most important, or uncertain which topics should be left out.

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Chapter 7: Development of draft evidence-based indicators

7.1 Introduction

The previous chapter describes how the Nominal Group Technique was applied to define priority clinical areas for quality marker development. This chapter defines the next step in the process: developing a set of draft indicators for each area.

The clinical trial evidence outlining the effectiveness of health care interventions in each area was sought by identifying systematic reviews in the Cochrane Library. Expert opinion on optimal quality care, whether or not trial evidence-based, was sought by identifying national guidelines (issued by NICE in England and SIGN in Scotland) on best practice in delivering care. Most of the 64 NICE and 15 SIGN guidelines are disease-focused so it was first necessary to identify those guidelines which could have relevance to the care of children. Each of the 48 potentially relevant guidelines contained on average 77 specific recommendations which could underpin a quality indicator.

A modified version of the iterated consensus rating procedure was used to sieve the evidence from the 396 Cochrane systematic reviews and 3680 guideline recommendations potentially relevant to children. The final outcome was 67 draft statements defining high quality care for children, the achievement of which could be used as a quality indicator. Standards, which quantified the actual level of fulfilment with the indicator, were not defined as this step is usually completed after pilot testing. The evidence underpinning these draft statements was assessed using GRADE methodology. The process of selecting a final set of quality indicators from these 67 draft statements is described in Chapter 8.

7.2 Aim and objectives

The overall aim of the research reported in this chapter was to develop potential evidence-based quality indicators in the priority areas (identified by the NGT process described in Chapter 6) for assessment in the final phase of the study. The specific objectives were:

1. To identify systematic reviews of the effectiveness of health care interventions relevant to the primary care of children.

2. To identify the UK national guidelines (SIGN and NICE) relevant to the primary care of children.

3. To identify specific recommendations within these SIGN and NICE guidelines with the potential to be expressed as quality statements for the care of children in primary care.

4. On the basis of the recommendations and evidence identified, to draft a set of statements that define good quality care which could be used as potential quality indicators in each of the priority areas.

5. To rate the evidence underpinning each of these statements using GRADE methodology.

7.3 Methodology

7.3.1 Identification of relevant systematic reviews

7.3.1.1 Decision to limit search to Cochrane reviews

I sought to complete a systematic overview of systematic reviews of interventions for the management of childhood conditions in primary care in order to identify those topics which are supported by trial evidence of effectiveness. Initially, I planned to include both Cochrane and non-Cochrane reviews and sought the support and methodological expertise of the Cochrane Effective Practice and Organisation of Care (EPOC) Group in conducting the search. Unfortunately, EPOC declined to support the proposed review title, saying that it did not fit within their remit of directly improving delivery of health services. Given the workload involved in proceeding without EPOC support, I accepted instead an offer from Prof Terry Klassen, the Cochrane Child Health Field (CCHF) Co-Coordinator, to access the CCHF Reviews Register. This register lists all Cochrane systematic reviews that, when initially registered, intended to include children (0-18 years of age) or studied an intervention intended to improve the health and wellbeing of children.(1) Although focusing only on existing Cochrane reviews had the disadvantage of narrowing my search field, these reviews are recognised as methodologically rigorous and of higher quality than non-Cochrane reviews.(2)

To access the register, I spent July 2010 at the University of Alberta (Edmonton, Canada) with the CCHF team. The search terms used to develop the CCHF Reviews Register are described by Bow *et al.* (1). The original register included all studies identified in Issue 2, 2009 of the *Cochrane Database of Systematic Reviews* (*CDSR*)

and I updated the register in Issue 8, 2010. Results from this chapter have been published in *PLoS ONE*.(3)

7.3.1.2 Identifying reviews relevant to primary care

The updated CCHF register contains 1183 titles. I sought to identify those reviews relevant to the management of childhood conditions in primary care or those which evaluated interventions that could be administered in the primary care setting by a health care provider (screening for early detection of disease, diagnosis of conditions, initiation of treatment, referral to secondary care, and on-going monitoring in primary care). In this context, '*primary care setting*' included general or family practice, ambulatory care, paediatric outpatient clinics, paediatric assessment units, or emergency departments. School-based interventions, public health programmes, orthodontic and specialist dental procedures, and interventions delivered during pregnancy or by specialist nurses were excluded. Reviews that focused only on children aged less than one month were also excluded as the majority of neonatal interventions would be delivered in secondary and tertiary care. At the time of the search, only reviews of interventions were included in the database; diagnostic and prognostic reviews were not yet included.

To pilot and refine the process of identifying reviews relevant to primary care, three reviewers (myself, Kay Wang and Anthony Harnden) screened a sample of 100 abstracts independently. Subsequently, two reviewers (myself and KW) screened independently all potentially relevant reviews in a 3 stage process: 1) all 1183 abstracts were assessed; 2) the full text of the 429 reviews which could not be excluded on the basis of the abstract were read in full; and 3) the 396 reviews which

met the inclusion criteria were categorised according to whether the review had identified primary studies in children and whether these studies included interventions relevant to the delivery of primary care. Disagreement was resolved by consensus or consultation with a third reviewer (AH or DM) at all stages. The PRISMA Flow Diagram is included in Appendix D.1.

7.3.2 Identification of relevant UK national guidelines

National guidelines (NICE and SIGN) are used by the NICE QOF Indicator Programme in the UK (4) and by similar agencies in other countries such as the Netherlands (5) as a basis for deriving quality indicators. I sought to identify NICE and SIGN guidelines that: 1) were relevant to one of the priority areas identified by the NGT process described in the previous chapter; and 2) included child-specific recommendations relevant to primary care. Guidelines were excluded from consideration if they focused on patients 16 years and older or focused primarily on public health and commissioning rather than clinical care. The search was completed in November 2011 and updated in February 2012.

I extracted the following information from all 79 potentially relevant guidelines: title, date (issued and updated), planned review date, relevant documents (i.e. full and clinical guideline, quick reference, evidence table, key priorities, audit criteria, quality standards or implementation advice), population (adult, paediatric or mixed) and number of recommendations. I made the initial judgement on inclusion and exclusion, providing the data extracted to my supervisors (AH/DM). We discussed all borderline cases and the final list of 48 included guidelines reflected a clear consensus (Appendix D.2).

7.3.3 Extraction of recommendations

The 48 guidelines selected made a total of 3680 specific recommendations about optimal care delivery. About half (1817) were clearly not related to children or to primary care and were not considered further. This left 1863 recommendations of potential relevance and a modified version of the iterated consensus rating procedure, described by Campbell *et al.* (6), was used to identify those recommendations with quality indicator development potential. This process was undertaken by an expert panel following the method used by Westert *et al.* (7) to develop indicators in Dutch primary care. As recommended by Wollersheim *et al.* (8), the expert panel consisted of three people, all of whom were GPs with academic appointments in the Oxford Department.

I moderated four 2-hour meetings between December 2011 and March 2012 where the panel reviewed the 1863 guideline recommendations using the iterated consensus rating procedure. Each priority area was reviewed in turn. For each meeting, I prepared a package of documents which included a summary of the recommendations extracted from guidelines relevant to the priority area. The panel was asked to work by consensus, iteratively selecting recommendations which met the following 5 criteria: 1) the recommendation made a precise statement about what constitutes high-quality care; 2) it defined a standard against which care quality could be measured; 3) all elements of the recommendation (such as the children to whom it applied) were clearly defined; 4) achievement of the implied quality standard was measurable (preferably abstractable from the primary care clinical record); and 5) the implied quality standard was attributable to actions in primary care (as recommended by Lester and Campbell (9)). If there were no relevant NICE or SIGN guidelines relating

to a priority area, or no recommendations were selected, the panel was asked to consider whether any statement about optimal care quality could be made in that area and could thus form the basis of an evidence-based quality indicator. Trial evidence from the Cochrane reviews was taken into consideration when applicable.

7.3.4 Drafting of potential QIs

Recommendations made in guidelines are seldom expressed in a form that directly translates into a statement about care quality which could then form the basis of a quality indicator. This is in part a matter of deciding precisely how the recommendation should be expressed so that its achievement is a necessary condition for good quality care. It is also related to the appropriate standard set for a quality indicator where 100% adherence is often not appropriate. However, standards are best set *after* indicators are developed once sufficient information is obtained from pilot implementation studies. (It can also be political: negotiators set the national standards for QOF.) For these reasons, specifying standards was outside the scope of my thesis.

There was also substantial overlap between some recommendations (e.g. where similar recommendations had been selected from SIGN and NICE guidelines) and an imbalance in the number of recommendations relating to each of the selected areas. Recommendations were therefore considered by area with the objective of avoiding overlap (as recommended by Campbell and colleagues (4)) and ensuring that a range of potential quality indicators was drafted for each priority area. No absolute target was set for the number of draft quality indicators although it was recognised that the quality of the final stage (described in Chapter 8) would be prejudiced if the number

of draft quality indicators it had to consider was as high as the original number of recommendations selected.

The translation of the selected guidelines into a series of draft quality indicators was therefore undertaken as a 5-step process with iteration (mainly between myself and members of the expert panel), particularly at steps 2 and 5, described in Figure 7.1.

Figure 7.1: Translation of selected guideline recommendations into draft QIs

Step 1	The recommendations were grouped by the priority clinical areas selected in the previous chapter. As some areas had few recommendations, and there was some overlap, I grouped the priority areas 'child and carer friendliness', 'safe and cost-effective prescribing' and 'GP training' as '*general practice management'*. For brevity and to avoid confusion, the priority area 'evidence-based management of common conditions' is renamed '*routinely managed conditions*'.
Step 2	Where no relevant NICE or SIGN recommendations had been identified for a specific area, supplementary searches were completed to identify other proposed quality indicators based on the panel's recommendations (e.g. RCGP Training Standards). Panel members that participated in the NGT process described in the previous chapter were also contacted for suggestions.
Step 3	To inform the drafting process, exemplar quality indicators were identified from three sources: i) the AHRQ National Quality Measures Clearinghouse website (10); ii) the list of quality indicators for UK general practice developed by Marshall *et al.* (11); and iii) the list paediatric indicators developed by RAND (12). I also searched PubMed for newly published indicators where the above sources contributed no useful exemplars.
Step 4	I checked if the recommendations made had been associated with specific audit criteria in the NICE/SIGN guideline.
Step 5	In the light of steps 2-4, I articulated the selected recommendations as quality indicators, expressing the population of children to whom the indicator should apply (as described by Guttmann *et al.* (13)). In each case, the iterative discussions focused mainly on clarity, precision and feasibility of application of the quality indicator in clinical practice. For some indicators, an additional note was included (e.g. specifying symptoms and signs of Coeliac disease).

A number of the draft quality indicators included the word '*All*'. This did not imply that the specified care applied to 100% of patients (i.e. standard of 100%) but rather that like QOF, patients could be exception reported. Where the indicator specified

'*Percentage'* this intended to quantify the clinical activity without specifying whether low or high achievement implied poor or good care.

7.3.5 Review of evidence-base for each draft QI

The quality of the evidence supporting each indicator was assessed using a modified version of the GRADE (Grading of Recommendations Assessment, Development and Evaluation) evidence profile system described by Guyatt *et al.* (14). Most guidelines did not use GRADE. Therefore, existing evidence ratings were converted using the sources described in the guidelines and the Cochrane reviews identified.

I created a template for each guideline topic based on the GRADE Pro Cochrane tool. I extracted the evidence that informed the recommendation, including number of studies, study design, design detail, year range, number of patients, effect size and overall NICE or SIGN evidence statement. Cochrane reviews identified in section 7.3.1 were used to provide evidence and the expert panel also suggested relevant articles. After reviewing the evidence and evaluating the specific factors described by the GRADE system which decrease (e.g. inconsistent study findings) or increase (e.g. large measure of effect) the quality of evidence described by Balshem *et al.* (15), I assigned a GRADE rating based on the outcome selected which was either: 1-*very low* (i.e. expert consensus); 2-*low*; 3-*moderate*; or 4-*high*. If there was uncertainty regarding the evidence, I discussed it with one of my supervisors (AH) and if unresolved, I assigned a rating of 1 (expert consensus).

I classified each indicator either as measuring structure, process or outcome (as described by Donabedian (16)). I created a summary profile for each indicator which

included the following information: numerator, denominator, rationale supporting indicator, references from guideline, additional references or supporting information, type of care (i.e. structure [S], process [P] or outcome [O]), NICE or SIGN evidence rating, GRADE rating, outcome of interest and previously developed indicators that were relevant.

7.4 Results

7.4.1 Evidence garnered from Cochrane reviews

Of the 1183 systematic reviews in the Cochrane Child Health Field register, 396 were relevant to children in primary care (Appendix D.1). Over half (n=216) of the reviews focused on drug interventions and less than half (n=192) had any relevance to the priority areas selected by the panel (further information about the reviews is detailed in Appendix D.3). Only 24 reviews provided specific evidence to underpin the draft indicators selected by the iterative consensus procedure which are listed in Table 7.1; a full summary of the other 168 reviews is given in Appendix D.4.

Table 7.1: Cochrane systematic review titles relevant to recommendations selected which provided evidence for the draft indicators (n=24)

Condition	Total (n)	Cochrane reviews which provided evidence for indicators	
		No.	*Review title(s)*
Antibiotic use	10	2	1) Antibiotics for the common cold and acute purulent rhinitis 2) Delayed antibiotics for respiratory infections
Attention deficit hyperactivity disorder	5	1	1) Amfetamine for attention deficit hyperactivity disorder in people with intellectual disabilities
Asthma	78	5	1) Beclomethasone for asthma in children: effects on linear growth 2) Educational interventions for asthma in children 3) Interventions for educating children who are at risk of asthma-related emergency department attendance 4) Written action plans for asthma in children 5) Written individualised management plans for asthma in children and adults
Autism / developmental delay	8	3	1) Intervention for childhood apraxia of speech 2) Speech and language therapy interventions for children with primary speech and language delay or disorder 3) Speech therapy for children with dysarthria acquired before three years of age
Constipation	2	2	1) Lactulose versus Polyethylene Glycol for Chronic Constipation 2) Stimulant laxatives for constipation and soiling in children
Depression	5	1	1) Selective serotonin reuptake inhibitors (SSRIs) for depressive disorders in children and adolescents
Immunisations	16	1	1) Patient reminder and recall systems to improve immunisation rates
Nocturnal enuresis	7	3	1) Alarm interventions for nocturnal enuresis in children 2) Drugs for nocturnal enuresis in children (other than desmopressin and tricyclics) 3) Tricyclic and related drugs for nocturnal enuresis in children
Otitis media	16	3	1) Antibiotics for acute otitis media in children 2) Grommets (ventilation tubes) for hearing loss associated with otitis media with effusion in children 3) Identification of children in the first four years of life for early treatment for otitis media with effusion
Urinary tract infections	5	3	1) Antibiotics for acute pyelonephritis in children 2) Long-term antibiotics for preventing recurrent urinary tract infection in children 3) Modes of administration of antibiotics for symptomatic severe urinary tract infections

7.4.2 UK national guidelines of potential relevance to children

Of the 79 guidelines identified (64 NICE and 15 SIGN), 48 were relevant including 37 NICE and 11 SIGN. They are summarised by priority areas in Table 7.2 (listed Appendix D.2). Several topics had both NICE and SIGN guidance. Most guidelines

were relevant to the early recognition of serious illness, health promotion, and routinely managed conditions.

Table 7.2: List of relevant NICE and SIGN guidelines (n=48)

Priority areas	Relevant guidelines (n)
Early recognition of serious illness	15
Child protection/safeguarding	2
Mental health	7
Health promotion	10
Routinely managed conditions	14
General practice management	0
Total	*48*

7.4.3 Recommendations selected with QI development potential

From the 48 guidelines, a total of 3680 recommendations were extracted; 1817 were discarded as not relevant to children in primary care (usually focused on adults or different settings, such as the inpatient setting) leaving 1863 to be reviewed by the expert panel. After four meetings, the panel identified 123 recommendations that represented good quality care and could potentially be articulated as quality indicators, listed in Table 7.3 by priority area.

Table 7.3: Number of recommendations reviewed and selected by expert panel

	NICE and SIGN recommendations (n)	
Priority area	*Reviewed*	*Selected*
Early recognition of serious illness	538	33
Child protection/safeguarding	122	3
Mental health	462	28
Health promotion	273	8
Routinely managed conditions	468	51
General practice management	0	0
Total	*1863*	*123*

The 13 guidelines from which no recommendations were selected are described in Appendix D.5. Eight focused on health promotion: in most cases, the recommendations were lacking in the necessary specificity to be implemented as quality indicators or the outcomes suggested as quality markers were attributable to actions outside primary care. In some cases, it was uncertain which professional group held primary responsibility for delivering the specified care (i.e. public health, schools or primary care). The panel only selected NICE recommendations for two topics with duplicate guidance (epilepsy and atopic eczema).

7.4.4 Changing recommendations into QIs

The 5-step drafting process reduced the 123 selected recommendations to 67 quality indicators. Table 7.4 shows the derivation of the indicators by priority area. The indicators for the three priority areas with many recommendations (early recognition of serious illness, mental health and routinely managed conditions) were all derived from NICE and SIGN recommendations while the general practice management indicators were derived mainly from other sources. The specific NICE and SIGN recommendations, and where relevant, the audit criteria that were used to draft the 56 indicators derived directly from the guidelines are summarised in Appendix D.6.

Table 7.4: Number and derivation of QIs by priority area

Priority area	Number of initial recommendations selected	Quality indicators		
		Derived from recommendations	*Derived from other sources*	*Total*
Early recognition of serious illness[1]	33	14	0	14
Child protection / safeguarding	3	4	2	6
Mental health	28	12	0	12
Health promotion[2]	8	4	2	6
Routinely managed conditions	51	21	0	21
General practice management	0	1	7	8
Total	*123*	*56*	*11*	*67*

Note: [1] Two recommendations from this priority area were used to draft a health promotion indicator (#6; diabetes immunisation) and a general practice management indicator (#12; antibiotic prescriptions).
[2] One recommendation from this priority area was used to draft a routinely managed condition indicator (#61; management of colic).

7.4.5 Draft QIs by priority area and evidence rating

7.4.5.1 Early recognition of serious illness

Twelve indicators drafted that are supported by expert consensus are listed in Table 7.5. Few Cochrane reviews were relevant. Indicator #1 on safety netting was suggested by the panel and articulated from four recommendations (and informed by Almond *et al.* (17)); an additional safety netting indicator (#15) was also drafted for bronchiolitis, a major burden on health care services. Three indicators focused on investigations for diabetes (#4, #5) and gastroenteritis (#7) while two specified documentation of the clinical exam in young acutely unwell children (#8, #10). Five recommendations on the management of UTIs in children referred to specific NICE tables and were articulated into a single comprehensive indicator (#14). Three Cochrane reviews provided evidence for UTI treatment in the NICE guideline but not for the specific indicator drafted.(18-20)

Two indicators had a GRADE evidence rating of >1 (Table 7.6). A systematic review of 6 observational studies reported the symptoms and signs children with Coeliac disease presented with at diagnosis (21) which provided weak evidence for indicator #3. Children with a feverish illness usually do not require a chest x-ray; a single RCT showed that 522 children aged 2 months to 5 years with clinical pneumonia had similar recovery rates regardless of whether or not they had chest radiography.(22)

Table 7.5: List of draft serious illness indicators with very low evidence (n=12)

No.	Indicator	Source	Type	Evidence	
				Comment	*GRADE*
1	There should be a clear record of management, investigations and safety netting advice for all children who present with the same complaint ≥3 times without a clear diagnosis.	(22-24)	P	Expert consensus	1
2	All children aged 2 years and older with a new squint should be referred urgently for assessment.	(23)	P	1 retrospective observational study in hospital; expert consensus	1
4	All children with symptoms and/or signs that may be associated with Type I diabetes should have clearly documented evidence of glucose assessment.	(25)	P	1 SR; indirect evidence; expert consensus	1
5	All children newly presenting with secondary enuresis should have clearly documented evidence of glucose assessment.	(25, 26)	P	1 SR; indirect evidence; expert consensus	1
7	All children 5 years and younger with gastroenteritis with "blood and/or mucus in stool" or compromised immune status should have "stool microbiological investigations."[1]	(27)	P	8 observational studies, none relevant to diagnosis in UK; expert consensus	1
8	All children 5 years and younger with gastroenteritis should have hydration status clearly documented.	(27)	P	1 SR, 1 observational study; indirect evidence; expert consensus	1
9	All children with a first non-febrile seizure should have clearly documented evidence of referral to secondary care for further assessment.[2]	(28)	P	2 observational studies (adults); high risk of bias; indirect evidence	1
10	All children 5 years and younger with feverish illness should have documented evidence of vital sign measurements.	(22)	P	Expert consensus	1
13	All neonates ≥37 weeks (gestational age) with jaundice lasting ≥14 days or neonates <37 weeks (gestational age) with jaundice lasting ≥21 days should have clearly documented evidence of conjugated bilirubin measurement.[3]	(29)	P	2 case series, 1 retrospective chart review for ≥14 days; expert consensus ≥21 days; indirect evidence	1
14	All children with urinary tract infections should be treated and investigated according to the NICE guideline tables.	(30)	P	Expert consensus	1
15	All parents/caregivers of children with acute bronchiolitis should be provided with information about recognising clinical deterioration and instructions for re-assessment by a clinician.	(24)	P	Expert consensus	1
16	All children at risk of familial hypercholesterolaemia should have serum lipids measured by age 10.	(31)	P	Expert consensus	1

Notes: SR, systematic review. [1] NICE 'Management of acute diarrhoea and vomiting due to gastroenteritis in children under 5' guideline audit criterion #1.(27)
[2] NICE 'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care' guideline audit criterion #1.(28)
[3] NICE 'Recognition and treatment of neonatal jaundice' guideline audit criteria #12.3.(29)

Table 7.6: List of draft serious illness indicators with ≥2 GRADE evidence rating (n=2)

				Research evidence			GRADE	
No.	**Indicator**	**Source**	**Type**	*Guidelines*	*Cochrane*	*Other*	*Comment*	*Rating*
3	All children with symptoms and/or signs that may be associated with Coeliac disease should be investigated with serological testing.	(21)	P	SR of 30 observational studies; 6 studies in children of symptoms/signs at diagnosis (21)	-	(32)	6 observational studies; weak evidence	2
11	Percentage of children 5 years and younger with feverish illness presenting in primary care that had a chest x-ray.	(22)	P	1 SR of 1 RCT (n=522); similar recovery rates with or without chest x-ray (22)	(33)[1]	-	1 high quality RCT from South Africa; indirect evidence	3

Note: [1] Single relevant Cochrane review cited in NICE guideline withdrawn (assessed as out of date; not identified in systematic overview).

7.4.5.2 Child protection/safeguarding

The evidence supporting child protection recommendations was limited and all indicators were consensus-based (Table 7.7). Two indicators focused on "looked-after children and young people" as vulnerable populations (#17, #18).(34) The panel suggested review of frequent A&E attenders in primary care (#19) and clearly documented evidence that diagnosed child maltreatment cases were discussed adequately and investigated (#20) after reviewing the NICE guideline. Audit criteria #3 and #5 were used to articulate indicator #21 and #65 respectively.

Table 7.7: List of draft child protection/safeguarding indicators (n=6)

				Evidence	
No.	**Indicator**	**Source**	**Type**	*Comment*	*GRADE*
17	All "looked-after children and young people" should be clearly identified in the general practitioners summary record.[1]	-	S	Expert consensus	1
18	All "looked-after children and young people" should have an annual review in primary care and an updated personal health record.[1]	(34)	P	Expert consensus	1
19	All children and young people that presented ≥3 times to emergency department in last 12 months should be reviewed in primary care.	(35)	P	Expert consensus	1
20	All children who the practitioner suspects neglect should have evidence that a clear and recorded course of action was taken.	-	P	Expert consensus	1
21	All relevant staff should know the "named or designated professionals for safeguarding children." [2]	(35)	S	Expert consensus	1
65	All "relevant staff must have been on child protection/safeguarding children training in line with local policy." [3]	(35)	S	Expert consensus	1

Notes: [1] "Looked-after children and young people" are defined by NICE as: "those looked-after by the State where the Children Act 1989 applies, including those who are subject to a care order or temporarily classed as looked-after on a planned basis for short breaks or respite care."(34)
[2] Modified NICE 'When to suspect child maltreatment' guidance audit criterion #3.(35)
[3] NICE 'When to suspect child maltreatment' guidance audit criterion #5.(35)

7.4.5.3 Mental health

There were 12 indicators for mental health which focused on depression, eating disorders, post-traumatic stress disorder, alcohol misuse, autism and ADHD. The indicator of antidepressants prescription was the only one to have a GRADE rating >1 (#24). A Cochrane review reported children and young people prescribed selective serotonin reuptake inhibitors (SSRI) antidepressants had a increased risk of suicide-related outcomes (36) and 4 moderate quality RCTs on fluoxetine described by NICE provided weak evidence of the safety and efficacy profile of these medications (Table 7.8).(37)

Table 7.8: List of draft mental health indicator with ≥2 GRADE evidence rating (n=1)

				Research evidence			**GRADE**	
No.	**Indicator**	**Source**	**Type**	*Guidelines*	*Cochrane*	*Other*	*Comment*	*Rating*
24	Antidepressant medications should not be initiated by general practitioners for children and young people with depression.	(37)	P	4 RCTs [1] (n=576) (37)	Suicide related outcome, 9 studies (RR=1.7, 95% CI 1.1-2.7) (36)	-	4 moderate quality RCTs; post-hoc analysis (risk of bias); uncertainty about outcome measure (indirect)	2

Note: [1] Only listed RCTs of fluoxetine, the only antidepressant indicated for treatment of paediatric depression in the UK.

Eleven other indicators were drafted (Table 7.9) which included a mental health safeguarding indicator (#22). NICE suggested a stepped approach to manage children and young people with depression (37); indicator #23 was drafted from three recommendations to focus specifically on high-risk patients. Two indicators focused on screening children '*at risk'* for eating disorders (#25) and monitoring those patients diagnosed in primary care (#26).

Three self-harm recommendations were drafted into indicator #28 while the expert panel suggested indicator #29 to identify children with alcohol misuse problems. Indicators #30 and #31 are derived from the NICE guidance on autism but are based mainly on expert opinion. Although there is Cochrane evidence to suggest that speech and language therapy interventions are effective for children with delays (38), the reviews on interventions for childhood apraxia of speech and dysarthria in children less than 3 years did not identify any relevant studies (i.e. empty).(39, 40) There are some published studies describing the potential adverse effects of medication for ADHD (including weak evidence from one Cochrane review (41)), but no other trial evidence was found to support the proposed prescribing and monitoring framework (#33).

Table 7.9: List of draft mental health indicators with very low evidence (n=11)

No.	Indicator	Source	Type	Evidence	
				Comment	*GRADE*
22	All "children and young people with" mental health conditions "who do not attend follow-up appointments" in hospital or primary care should be contacted by their general practitioner.[1]	(37, 42)	P	Expert consensus; information derived from multiple studies	1
23	All adolescents with depression, "high recurrent risk of acts of self-harm" or "suicide or significant on-going self-neglect" should be referred for further assessment.[2]	(37)	P	Expert consensus	1
25	All children with eating disorders should have growth and development monitored annually using an age-appropriate tool.	(43)	P	Expert consensus	1
26	All children at risk of eating disorders should be screened for by asking at least one simple validated question.	(43)	P	3 observational studies on adult patients	1
27	All children that are involved in a severe "traumatic event treated in an emergency department should" be contacted by their general practitioner to assess for post-traumatic stress disorder.[3]	(44)	P	Expert consensus	1
28	All children that self-harm should have a clearly documented assessment and be referred immediately for further assessment.	(45)	P	Expert consensus	1
29	All children and young people who present to the emergency department with alcohol misuse should be referred for further assessment.	(46)	P	Expert consensus	1
30	All children with suspected autism should be referred for further assessment with a referral letter that includes information from family and from multi-professional agencies (e.g. education).	(47, 48)	P	Expert consensus	1
31	All children 3 years and older with "regression in language" or "any age with regression in motor skills" should be referred for further assessment.[4]	(47, 48)	P	Expert consensus	1
32	Stimulant medication for the treatment of attention deficit hyperactivity disorder should not be initiated by general practitioners.	(49, 50)	P	Expert consensus	1
33	All children taking methylphenidate, atomoxetine or dexamfetamine should have clearly documented monitoring in primary care.	(49, 50)	P	Expert consensus	1

Note: [1] NICE 'Depression in children and young people' guideline recommendation 1.5.1.2.(37)

[2] NICE 'Depression in children and young people' guideline recommendation 1.3.2.3.(37)

[3] NICE 'Post-traumatic stress disorder (PTSD): The management of PTSD in adults and children in primary and secondary care' guideline recommendation 1.1.4.2.(44)

[4] NICE 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum' guideline recommendation 22.(47)

7.4.5.4 Health promotion

Four health promotion indicators focused on immunisations, particularly in populations known to have incomplete vaccine schedules. Indicator #36 targeted children eligible for Hepatitis B immunisation (Table 7.10) which was similar to previously developed indicators.(11, 12) Evidence from NICE guidance suggests early interventions in high-risk patients increases vaccination rates and are cost-effective.(51) Evaluation of the UK national screening programme demonstrates it reduces Hepatitis B infection in at-risk patients.(52)

Table 7.10: List of draft health promotion indicator with ≥2 GRADE evidence rating (n=1)

				Research evidence			GRADE	
No.	**Indicator**	**Source**	**Type**	*Guidelines*	*Cochrane*	*Other*	*Comment*	*Rating*
36	All children eligible for targeted Hepatitis B immunisation should have a complete and up-to-date immunisation record.[1]	(51)	P	2 ITS studies, 3 cohort studies; 4 reported intervention effective (51)	-	(11, 12, 52)	5 observational studies; 1 UK study effective; negative findings from low-quality ITS study	2

Notes: ITS, interrupted time-series.

[1] Patients eligible for targeted Hepatitis B immunisation are those whom mother is Hepatitis B positive or who's parents have Hepatitis B.(51)

The three other immunisation indicators are described in Table 7.11. The Department of Health recommends children with Type 1 Diabetes receive an annual influenza immunisation (#6).(25) Adolescents frequently miss recommended vaccines and are the focus of indicator #34. Immunisations are particularly important for '*at risk'* children (i.e. medical condition or social situation which increase the risk of complications e.g. splenectomy) and Harnden *et al.* (42) found they have poor documentation of immunisations (#35). A Cochrane review provided indirect

evidence to support these indicators: patient reminder and recall systems improve childhood immunisation rates (OR, 1.5; 95% CI, 1.3-1.7).(53) All four draft immunisation indicators were reviewed with a GP who sits on the Joint Committee on Vaccination and Immunisation (JCVI).

The panel felt that it was the GP's responsibility to ensure that the Guthrie test and the newborn hearing assessment are completed at the 6-8 week check-up (#37). The implications of missed diagnoses are serious (e.g. hypothyroidism). The panel suggested indicator #38 for obesity.

Table 7.11: List of draft health promotion indicators with very low evidence (n=5)

				Evidence	
No.	**Indicator**	**Source**	**Type**	*Comment*	*GRADE*
6	All children with Type I diabetes aged 6 months and older should have documented evidence of being offered annual influenza immunisation.	(25)	P	Expert consensus	1
34	All children aged 15 should have their immunisation record reviewed and updated.	(51)	P	Expert consensus	1
35	All '*at risk*' children and young people should have received eligible immunisations and have a complete and up-to-date immunisation record.[1]	-	P	Expert consensus	1
37	All children should have their Guthrie test and newborn hearing test results reviewed at the 6-8 week check-up.	(54)	P	Expert consensus	1
38	All practices should have appropriate growth charts including body-mass index (BMI) measurement in children.	-	S	Expert consensus	1

Note: [1] '*At risk*' patients refers to patients with chronic disease (e.g. splenectomy, chronic medical condition, looked-after register, etc.).

7.4.5.5 Routinely managed conditions

Two asthma indicators are supported by strong evidence (Table 7.12). A Cochrane review reported that written action plans reduce the number of acute care visits, with symptom-based plans better than peak-flow based plans.(55) One review (withdrawn

in 2011) found written individualised management plans have limited evidence of effectiveness (56) but another review found that self-management plans reduce mean number of asthma exacerbations.(57) These reviews supported the SIGN recommendation for annual asthma review (#40). There is also evidence from Cochrane that inhaled corticosteroids have a significant effect on growth, leading to a 1.5 cm decrease in growth per year, so children should be on the lowest possible dose.(58)

Indicator #45 determined whether asthmatic children seen in secondary care had a follow-up appointment. A Cochrane review found asthma educational interventions for these children significantly reduced subsequent hospitalisation and acute care visits.(59)

Cochrane evidence showed that polyethylene glycol (PEG) is superior to lactulose for the treatment of chronic constipation (60) but the optimal method of prescribing and follow-up remains unclear.(61) Indicator #47 specifies that children should be treated with PEG for initial maintenance therapy, similar to a new set of indicators developed by Stienen *et al.* (62). Both the Cochrane reviews and a NICE network meta-analysis provide low-quality evidence that alarms should be offered as first-line treatment for nocturnal enuresis.(26, 63) Additional reviews suggest that anticholinergic (64) and tricyclic medications (65) should not be used as first line therapy to manage nocturnal enuresis unless under specialist guidance.(26) The three nocturnal enuresis indicators (#53, #63, #64) are based on NICE audit criteria.(26)

A Cochrane review found no evidence that early surgical intervention with tympanostomy tubes had a significant effect on development in children with persistent otitis media with effusion (OME).(66) However, children with persistent bilateral OME or with developmental problems required a hearing assessment (#56).(67, 68) Two indicators focused on antibiotic prescribing. The statement that most children with uncomplicated respiratory tract infections (e.g. common cold) do not require antibiotics is supported by evidence from two Cochrane reviews (69, 70). The evidence is considered by NICE (71), who recommend a delayed prescribing protocol should be used (#57). Indicator #55 is based on a meta-analysis showing that antibiotics do not alter the course of uncomplicated acute otitis media (AOM) infections.(72)

Table 7.12: List of draft routinely managed conditions indicators with ≥2 GRADE evidence rating (n=10)

				Research evidence			GRADE	
No.	**Indicator**	**Source**	**Type**	*Guidelines*	*Cochrane*	*Other*	*Comment*	*Rating*
40	All children with asthma should have an annual review with documented height and evidence of lowest possible dose of inhaled corticosteroids.	(73)	P	1 SR (73)	Head-to-head written action plan comparison; symptom-based superior to peak-flow (0.73, 0.55-0.99) in reducing number of acute visits (5 studies, 353 patients) (55-57)	-	3 Cochrane SRs; moderate quality evidence; indirect evidence	3
45	All children and young people admitted or seen in secondary care for an asthma exacerbation should be assessed within 30 days in primary care.	(73)	P	1 RCT; 1 cohort study (73)	A&E visits (RR 0.73; 0.65-0.81; 17 studies); hospitalisation (RR 0.79; 0.69-0.92; 18 studies) (59)	-	SR of 17 RCTs; high quality evidence	4
47	All children with idiopathic constipation should be treated with polyethylene glycol (e.g. Movicol) for initial maintenance therapy.	(61)	P	2 RCTs; 3 observational studies (1 retrospective, 2 prospective) (61)	Stool frequency per week higher with PEG than lactulose, 3 studies, n=227 (Mean difference, 1.57; 95% CI, 0.36, 2.77) (60)	(62)	Cochrane SR; PEG effective but unclear method of prescribing and follow-up	2
53	All children with nocturnal enuresis should be offered an alarm as first-line treatment.[1]	(26)	P	Network meta-analysis (26)	Alarm better than control, RR=0.39 (0.33-0.45); 14 studies, 574 children (63)	-	Weak evidence; study limitations; indirect evidence	2
63	Percentage of patients with nocturnal enuresis without daytime symptoms prescribed anticholinergic medications alone.[2]	(26)	P	Network meta-analysis (26)	1 RCT (64)	-	Weak evidence; possible side-effects; indirect evidence	2
64	All children with nocturnal enuresis should not be prescribed tricyclic medications in primary care.[3]	(26)	P	Network meta-analysis (26)	Effective but high relapse; potentially lethal adverse effects of drugs if overdose (65)	-	Weak evidence; lethal adverse effects; indirect evidence; study limitations	2

57	Percentage of patients with uncomplicated respiratory tract infection prescribed antibiotics.	(71)	P	7 RCTs (n=1843) (71)	No change in persistent symptoms, 2 RCTs, n=449 (RR, 1.36; 95% CI, 0.59-3.15) (69); No change in re-consultation rate in delayed vs immediate antibiotics, 2 RCTs, n=799 (OR, 1.04; 95% CI, 0.55-1.98) (70)	-	7 RCTs; moderate quality evidence; imprecise effect	3
55	Percentage of patients with acute otitis media prescribed antibiotics.	(67, 71)	P	8 RCTs (67) 3 RCTs (n=758 children) (71)	10 RCTs, n=2928 children; 78% of AOM episodes settle spontaneously; NNT=16, NNH=24 (72)	(74, 75)	10 RCTs; moderate quality evidence; indirect evidence	3
56	All children 3 years and older with "persistent bilateral otitis media with effusion" or "any age with speech and language, developmental or behavioural problems" should be referred for hearing assessment.[4]	(67, 68)	P	1 RCT (referral); 1 SR of 13 RCTs (developmental problems); 1 SR of 27 observational studies (natural history) (67, 68)	5 RCTs, n=458; benefits of early intervention compared with watchful waiting small (but children had audiometry to rule out hearing loss) (66)	(75)	1 RCT; 2 SRs; imprecise effect; indirect evidence	2
61	All children with colic should not be prescribed dicycloverine (dicyclomine).	(54)	P	5 RCTs; effective (RR, 0.46; 95% CI, 0.33-0.60) but 9/177 infants had side effects (breathing difficulties, coma) (54)	-	-	5 RCTs; strong evidence of adverse effects	4

Notes: WAP, written action plans. NNT, number needed to treat. NNH, number needed to harm.

[1] NICE 'The management of bedwetting and nocturnal enuresis in children and young people' guideline audit criterion 3: "An alarm should be offered as the first-line treatment to children or young people with bedwetting."(26)

[2] NICE 'The management of bedwetting and nocturnal enuresis in children and young people' guideline audit criterion 8: "An anticholinergic alone should not be used for the management of bedwetting in children or young people without daytime symptoms", and 9: "An anticholinergic combined with imipramine should not be used for the treatment of bedwetting in children or young people."(26)

[3] NICE 'The management of bedwetting and nocturnal enuresis in children and young people' guideline audit criterion 10: "Tricyclic antidepressants should not be used as a first-line treatment for bedwetting in children or young people."(26)

[4] SIGN 'Diagnosis and management of childhood otitis media in primary care' guideline recommendation 4.2.2.(67)

Eleven other indicators are described in Table 7.13, including five indicators for asthma. Two focus on asthma diagnosis: one for young children under 5 years (#41) and the other for 5-12 year olds (#39). Both are supported by expert consensus.(73) While there is no trial evidence for which asthma medication delivery devices should be used preferentially, the panel felt children should be prescribed a spacer (#42). They also suggested that children using large numbers of rescue inhalers should be reviewed (#44) since they are "*at risk of fatal or near fatal asthma*."(73) There is strong trial evidence that early oral corticosteroids reduce hospital admission rates in children who present to A&E with acute asthma.(76) Expert consensus suggested these patients should be actively reviewed in primary care (#43).

Four indicators on atopic eczema were drafted, three based on the stepped approach to management.(77) While there is no published evidence on optimal strategies for treating eczema, the panel felt that GPs should prescribe emollients first before moving to other therapies (#48). The panel were also concerned about the prolonged use of potent steroids unless under the guidance of specialist care (#49) and about the routine use of oral antihistamines (#50) (both indicators based on NICE audit criteria). The prompt diagnosis of eczema herpeticum was the focus of indicator #51.

Indicator #52, by differentiating between primary and secondary enuresis, sought to rule out patients who may present with Type I Diabetes; nocturnal enuresis in an otherwise healthy child has been recorded as an early symptom of diabetes (but there is no evidence that clearly recorded assessment improved detection).(78) Appropriate investigations for children with acute allergic reactions were the focus of indicator #54.

Table 7.13: List of draft routinely managed conditions indicators with very low evidence (n=11)

No.	Indicator	Source	Type	Evidence	
				Comment	*GRADE*
39	All children aged 5-12 years with asthma should have documentation of reversibility using peak flow measurement or spirometry.	(73)	P	Expert consensus	1
41	All children with asthma aged 5 years or less should have clearly documented basis for diagnosis.	(73)	P	Expert consensus	1
42	All children with asthma should be prescribed a spacer.[1]	(73)	P	Expert consensus	1
43	All children with an acute asthma exacerbation who are prescribed short-duration oral steroids should be reviewed within 5 days.	(73)	P	Expert consensus	1
44	All children who are using excessive beta-agonists should be reviewed in primary care.	(73)	P	Expert consensus	1
48	All children with atopic eczema should be prescribed emollients.[2]	(77)	P	Expert consensus	1
49	Percentage of children with atopic eczema prescribed moderate/very potent steroids for >14 days.[3]	(77)	P	Expert consensus	1
50	Percentage of patients with atopic eczema prescribed oral antihistamines.	(77)	P	Expert consensus	1
51	All children with atopic eczema with suspected eczema herpeticum should be referred urgently for further assessment.	(77)	P	Expert consensus	1
52	All children with nocturnal enuresis should have a clearly recorded assessment which differentiates between primary and secondary enuresis.	(26)	P	Expert consensus	1
54	All children with an acute allergic reaction to a food substance should be referred for appropriate investigations.	(79)	P	Expert consensus	1

Notes: [1] SIGN 'British Guideline on the Management of Asthma' audit criterion: "Audit the percentage of patients using a spacer device for mild to moderately severe exacerbations."(73)
[2] NICE 'Management of atopic eczema in children from birth up to the age of 12 years' guideline audit criterion 8: "Percentage of children prescribed emollients."(77)
[3] NICE 'Management of atopic eczema in children from birth up to the age of 12 years' guideline audit criterion 11: "Percentage of children with atopic eczema experiencing flares in vulnerable sites such as axillae and groin using moderate or potent topical corticosteroids for longer than 14 days."(77)

7.4.5.6 General practice management

Three outcome indicators were articulated: number of admissions to hospital for acute asthma exacerbations (#46), emergency hospital admissions (#58), and A&E attendances (#59). These were not derived from UK guidance and were instead informed by the background literature review, the expert panel, and the findings discussed in Chapter 5. The GP panel also suggested indicator #62. There were no

recommendations relevant to child carer friendliness; a US indicator identified was modified (#60).(80) Two training indicators (#66, #67) were derived from the RCGP curriculum document '*Care of Children and Young People*' (81) with the assistance of a NGT panel member (Prof Ed Peile).

Table 7.14: List of draft general practice management indicators (n=7)

				Evidence	
No.	**Indicator**	**Source**	**Type**	*Comment*	*GRADE*
46	Number of children and young people admitted to hospital for acute asthma exacerbation.	-	O	Expert consensus	1
58	Number of emergency admissions for children in previous 12-month period.	-	O	Expert consensus	1
59	Number of Accident and Emergency attendances for children in previous 12-month period.	-	O	Expert consensus	1
60	"Parent's/guardian's overall rating of their" satisfaction with general practitioners care of their child.[1]	(80)	P	Expert consensus	1
62	All children on long-term prescriptions should have an annual review in primary care.	-	P	Expert consensus	1
66	All general practitioners should have completed an update course in paediatrics within a 2-year period.	(81)	S	Expert consensus	1
67	Number of general practitioners with additional training in paediatrics (e.g. Diploma of Child Health).	(81)	S	Expert consensus	1

Note: [1] Similar to indicator from CAHPS Clinician & Group Survey Child Primary Care Questionnaire 2.0: "Patients' satisfaction with care: parent's/guardian's overall rating of their child's doctor."(80)

A third, more general antibiotic indicator which focused on antibiotic prescriptions for children under 5 years of age that present with a feverish illness without a clear diagnosis (Table 7.15) was suggested. This antibiotic indicator was supported by weak evidence from two systematic reviews (#12).

Table 7.15: List of draft general practice management indicators with ≥2 GRADE evidence rating (n=1)

				Research evidence		GRADE	
No.	**Indicator**	**Source**	**Type**	*Guidelines*	*Cochrane*	*Comment*	*Rating*
12	Percentage of children 5 years and younger with feverish illness presenting in primary care that are prescribed oral antibiotics.	(22)	P	1 RCT, 2 SRs of observational studies (22)	-	1 RCT, 2 SRs of observational studies; weak evidence	2

7.5 Discussion

7.5.1 Contribution of evidence from Cochrane reviews

Of the 396 Cochrane systematic reviews identified as relevant to primary care in the Cochrane Child Health Field database, only 24 provided evidence relevant to the draft quality indicators. This reflects both the limitations of the Cochrane Library and the dearth of clinical studies relevant to paediatric primary care available for synthesis.

The objective of the systematic overview was to determine which of the health care interventions identified by the Cochrane Collaboration had evidence of effectiveness. Although the number and content of Cochrane reviews are only a proxy for clinical trials and the overall evidence-base, in many areas of primary care for children there is a notable absence of trials that demonstrate the effectiveness of intervention. This lack of evidence hinders the development of evidence-based quality indicators.

7.5.1.1 Limitations of the Cochrane database

At the time of the analysis (2010) the Cochrane Child Health Field database focused exclusively on reviews of clinical trials assessing the effectiveness of health care interventions. A number of the priority areas, particularly early recognition of serious illness, had a strong diagnostic element. Although diagnostic processes can be characterised as interventions, and assessed in randomised clinical trials, much of the necessary evidence to underpin clinical practice (e.g. measures of diagnostic performance such as sensitivity and specificity) comes from observational studies. Such studies were seldom included in any of the Cochrane reviews. For example, the key studies were not identified for diagnostic accuracy of testing for Coeliac disease in primary care relevant to quality draft indicator #3.(82)

Several reviews combined data on adults and children in conducting their meta-analyses. Children differ from adults in physiology, biology, and developmental processes, and modifying evidence from the treatment of adults to be applied to the treatment of children can lead to ineffective or even unsafe medical care.(83) There are potentially important differences in the efficacy and safety of interventions between children and adults (84) and for a number of cases this meant that the combined data had little utility. For example, one review found a modest benefit of intranasal steroids for treatment of acute sinusitis. However, the review combined trials with wide age groups (8-76 years) in the meta-analysis, thus concealing potential differences.(85)

Cochrane reviews are expected to be updated every two years (86) yet 56% of the reviews were last assessed as up-to-date prior to 2008 (as of August 2010), nearly

20% greater than the 38% reported by Bow *et al.* (1). Of reviews considered out-of-date, two were last updated in 1998. Several authors have reiterated the importance of developing mechanisms to identify when reviews need updating and channeling resources to ensure they are updated as new evidence emerges. However, there is clearly significant progress to be made.(87) Finally, clinicians and researchers identify topics for Cochrane reviews based on clinical uncertainty, practice variation or research interests which may not correlate with burden of illness.

7.5.1.2 Lack of primary studies to review

The lack of controlled trials in child health is well documented.(88) This scarcity can be attributed to a variety of reasons, including ethical concerns, particularly regarding informed consent, parent/care giver reluctance to participate, and recruitment challenges to meet adequate sample sizes. The need for higher quality clinical trials in children led to the launch of the StaR Child Health initiative in 2009 to improve the calibre of paediatric research (83), which has since published several standards.(89)

A UK study of the clinical activities (e.g. investigations, prescriptions, referrals) of community paediatricians in 1999 found that 47% had evidence of effectiveness based on high quality studies.(90) There were notable differences between the type of clinical activity and the evidence for effectiveness: 53% of prescriptions were supported by evidence yet accounted for 4% of clinical activities while there was no evidence underpinning the counselling/advice interventions that represent 13% of clinical activity.(90) This is consistent with the over-representation of reviews of drug interventions in the CCHF database, reflecting that 69% of all paediatric controlled trials assess drug products.(88) This in turn reflects research funding in both the

commercial and non-commercial sectors.(91) Others have reported a weak correlation between disease burden and funding of research by public institutions.(92)

Unfortunately, only a small proportion of the evidence from drug trials was helpful. For example, nearly one-quarter of all reviews focused on asthma but only five provided relevant evidence. Many of the studies reviewed described head-to-head comparisons for asthma medications and the study results do not inform clinical practice in primary care. While some reviews provided evidence from hospital practice which can be extrapolated to primary care (e.g. the review showing that early oral corticosteroid use in children with acute asthma in emergency departments reduces admission rates (76)), few studies had been carried out in a primary care setting and could provide direct evidence of clinical efficacy and cost-effectiveness (and the responsiveness of patients to therapy).

It is therefore most likely that the principal reason for this disappointing absence of informative Cochrane reviews is the fact that there has only been a limited number of primary studies that could be reviewed. This reinforces previous research by Klassen *et al.* (93) and Martinez-Castaldi *et al.* (94) suggesting there is insufficient evidence specific to children in certain topic areas. Detailed reading of those trials synthesised by Cochrane also reinforces Glasziou and colleagues' observation that lack of primary research is often compounded by poor reporting.(95, 96) In many cases, if the interventions assessed (including the study population and context) had been better described, the value of the evidence for setting a quality indicator for clinical practice would have been greatly enhanced.

7.5.2 Evidence from national guidelines

The limitations of the Cochrane reviews in providing an adequate evidence-base for indicator development increased the importance of the evidence gleaned from the national guidelines substantially. The guidelines reflect professional opinion on the best clinical practice but the extent to which the specific recommendations made were evidence-based was very variable. Moreover, many (in some guidelines, most) of the recommendations were made in such imprecise terms that it was impossible to use them to construct a quality indicator.

7.5.2.1 Which clinical areas were underpinned by strong evidence?

The clinical areas in which the guideline recommendations were supported by the strongest evidence were appropriate antibiotic prescribing, asthma management, and interventions for nocturnal enuresis and idiopathic constipation. These were also clinical areas with a large number of Cochrane reviews.(3)

Unfortunately, most recommendations relevant to children and young people in primary care were based on weak evidence or expert consensus because no relevant studies were identified in the NICE or SIGN systematic review or those studies which were identified were either: 1) not applicable to the UK setting; 2) completed on adults and extrapolated to children; or 3) had serious methodological limitations.

Some topics in particular were only supported by weak evidence, such as the mental health recommendations (e.g. stepped management of depression, autism, post-traumatic stress disorder, and self-harm). Recommendations for non-drug interventions (e.g. referral) also had little evidence and were derived from expert

consensus. While several clinical areas had minimal evidence to support the recommendations within guidelines, there were also important topics in some priority areas that did not have any NICE/SIGN guidelines (such as the recognition of acute surgical conditions, including appendicitis and learning disorders).

7.5.2.2 Quality of UK national guidance

I followed the method used by Giesen *et al.* (5) in developing Dutch primary care indicators. This method did not require a formal assessment of the quality of each guideline using an appraised tool (e.g. AGREE tool). Instead, the GRADE quality assessment was undertaken only on the draft quality indicators derived from the recommendations extracted from the guidelines. However, overall the expert panel felt the quality of recommendations was poor: few were clinically relevant and many were poorly worded. The selection of 123 recommendations of 1863 reviewed, and the eventual drafting of 67 indicators, is in itself evidence of the utility of the recommendations in setting quality indicators applicable to UK general practice. The SIGN guidelines were consistently more useful than the NICE guidelines in drafting indicators.

7.5.3 Robustness of the process for identifying recommendations with QI potential

7.5.3.1 How does this approach compare with that used by the NICE QOF Indicator Programme?

In order to draft potential quality indicators, I used a similar approach to the NICE QOF Indicator Programme which only develops markers from previously published national guidance.(97) I felt this methodology would have strong face validity to most clinicians and thus used recommendations created specifically for the UK health care

system. Several other researchers employ the guideline-based technique to develop markers: a recent systematic review by Kotter *et al.* (98) found 48 such studies. Prior to the widespread development of NICE and SIGN guidelines, Marshall *et al.* (11) commissioned a group of over 20 expert GPs to complete systematic reviews on the top 20 most common conditions in primary care. Each GP also suggested a list of indicators for UK general practice. Replicating this methodology would have been unfeasible for my thesis but I did refer to several of these indicators to help indicator drafting.

7.5.3.2 How robust is the iterated consensus rating procedure?

The iterated consensus rating procedure has been used before to select key recommendations from evidence-based guidelines for indicator development.(8) However, it is possible that important recommendations were missed or that one person biased the decision to include or exclude statements. I tried to minimise this possibility by ensuring all recommendations were adequately discussed. However, the panel composition will have affected the results: all were white male GPs over the age of 50 years from Oxfordshire. They had a good grasp of the evidence base but their concerns do not represent the experience and practice of all UK primary care practitioners; nor are they likely to reflect accurately the priorities of the new Clinical Commissioning Groups.

7.5.4 Robustness of process for drafting potential QIs

7.5.4.1 How robust is the articulation of indicators?

The articulation of draft indicators from the selected recommendations was informed by several sources including previously developed indicators and NICE and SIGN

audit criteria. To ensure the indicator set was coherent and precisely defined (as suggested by Campbell *et al.* (4)), some recommendations were not translated into indicators. These omissions were made in order to minimise duplication and maximise feasibility. The precise wording of each indicator was also reviewed by my supervisor (AH) to ensure they had strong face validity. However, some important topics may not have been drafted into indicators, and recommendations were modified during the articulation phase. These were only draft indicators and it was anticipated that they would be refined further during the consensus study described in Chapter 8.

7.5.4.2 How robust is the quality of evidence rating?

The GRADE rating relied on evidence identified in guidelines and Cochrane reviews. The link in guidelines between strength of evidence and recommendations has been frequently described as unclear.(99) It was, in fact, quite difficult to identify evidence that supported the recommendations, particularly in NICE guidelines. SIGN guidelines, on the other hand, clearly linked each specific statement to supporting studies. The way evidence was rated was also inconsistent across NICE guidelines. Most SIGN guidelines were less than 100 pages but NICE guidelines frequently exceeded 500 pages with additional appendices and supporting documents. The publication dates for the guidelines varied, as did the date of the literature review. These variations were minimised by searching for additional high quality studies if the evidence seemed out of date. NICE and SIGN guidelines focused on the UK setting and may have excluded studies from other settings; as the focus of this thesis is to develop UK markers, this is of marginal concern.

As this work was conducted for a doctoral thesis, I undertook the GRADE quality of evidence rating alone. However, whenever the most appropriate GRADE evidence rating was unclear, I discussed it with my supervisor (AH) and rated the evidence as level 1 if there was any uncertainty. While I attempted to specify a single key outcome as the basis for each GRADE rating, this was often difficult since the outcomes specified in the studies were seldom the outcome of clinical importance for primary care practitioners (and this problem is worse in paediatric research (100)). Ultimately, the evidence rating required a clinical judgement and upon further reflection, I may have modified the rating (likely more critically with a lower rating).

7.5.5 How do the draft QIs compare with topics considered by the NICE QOF Indicator Programme?

7.5.5.1 Early recognition of serious illness

The NICE QOF Indicator Programme chronic disease recommendations targeted on-going management rather than early recognition and diagnosis. For example, the NICE epilepsy indicators focus on comprehensive care plans and appropriate referral for poorly controlled patients yet epilepsy is difficult to diagnose and misdiagnosis occurs in approximately 25% of cases.(28) Therefore, an epilepsy-related indicator was drafted which specified appropriate referral for children with a first non-febrile seizure. Similarly, the GP panel prioritised a quality indicator focusing on the diagnosis of Coeliac disease, reflecting evidence that the major problem in primary care is not appropriate treatment but under-diagnosis. The QOF programme focused on which high-risk patients should be selectively tested.

7.5.5.2 Routinely managed conditions

Atopic eczema in children was reviewed but no quality indicator was recommended by NICE. In contrast, five recommendations concerned with management of atopic eczema were selected by the GP panel and four precise indicators were articulated for specific management stages.

The NICE advisory committee supported developing indicators for appropriate antibiotic prescribing for self-limiting RTIs in primary care but they deferred making a decision until they received further evidence. This seems surprising, given the Cochrane review evidence that antibiotics in children have little impact on symptom resolution (69) and delaying prescription does not increase re-consultation rate.(70) The GP panel felt the evidence was sufficient to support a single draft indicator based on the percentage of patients with an uncomplicated RTI prescribed an antibiotic.

One of the thirteen indicators piloted in the new NICE programme focused on ensuring patients have had an asthma review and an assessment of control using the 3 Royal College of Physicians questions.(4) However, this indicator is similar to current indicators already included in QOF and the panel drafted additional asthma indicators that focus on asthma identification (which was excluded by the committee) and hospital admissions.

7.5.5.3 Health promotion

The expert panel did not select any specific recommendations related to obesity for indicator development (although one indicator was suggested). Several NICE advisory committee meetings focused on the development of obesity indicators

specifically, but they were also unable to formulate any indicators for QOF despite the lack of incentives to manage childhood obesity.(101) This has already been highlighted in Chapter 4 and by Turner *et al.* (102). Although there is Cochrane evidence supporting obesity interventions in children (103), there appear to be no clear concept of '*what works'* in UK primary care, particularly in children, and the impact of measuring weight has been questioned.

No smoking related recommendations were suggested by the panel or developed into draft indicators. Smoking indicators for adults are already included in QOF but, after reviewing the results from piloting, the NICE committee did not support an indicator based on creation of smoking registers including children aged 14 years and older. This was mainly because of ethical concerns with obtaining valid and reliable data from adolescents who may consult with their parents or guardians.

7.6 Conclusions

The process of developing draft evidence-based quality indicators is labour-intensive and difficult. Neither the 396 Cochrane reviews nor the 1863 recommendations extracted from existing UK national guidelines with some relevance to the care of children delineated a strong evidence-base for most of the areas of clinical practice prioritised by the expert panel. Only 6 of the 67 draft quality indicators were supported by evidence rated GRADE level 3 or 4.

Nevertheless all 67 probably do reflect a broad consensus in the UK on what constitutes high quality clinical practice. The precise wording of each draft quality

indicator also reflects the articulation of similar quality markers developed by others, in some cases wording revised after experience of implementation. Chapter 8 reports the next and final stage in my research programme – the process of selecting about 26 of the 67 draft indicators on the basis of their perceived validity, feasibility of implementation and potential impact on the quality of primary care delivered to children in the UK.

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Chapter 8: Selecting quality indicators for the care of children in UK general practice

8.1 Introduction

The RAND Appropriateness Method is a formal consensus development technique that uses expert opinion and scientific evidence to generate consensus.(1) It is the methodology used by NICE to develop indicators for consideration in the Quality and Outcome Framework.(2, 3) This methodology was used to generate professional consensus on which indicators outlined in Chapter 7 are valid and feasible in UK general practice.

The final wording of many of the indicators was influenced by consideration of how the quality indicator could be implemented in clinical practice. While careful and precise wording is a necessary condition for successful implementation, it is not sufficient. The terms used often need further explanation, the anticipated data sources need to be stated, and the numerator and denominator need to be precisely defined. The rationale for the indicator also needs to be articulated in a format understandable to policy makers, health service managers and the clinicians whose performance is being assessed. This chapter also describes the process of creating detailed measurement profiles which outlined how the indicators could be pilot tested and appropriate standards defined.

8.2 Aims and objectives

The overall aim of the research reported in this chapter was to identify a sub-set of quality indicators that could be implemented in UK general practice to improve the quality of primary care for children. The specific objectives were:

1. To use formal consensus development methods to optimise the content and wording of the original 67 draft indicators.

2. To identify a sub-set of quality indicators agreed by consensus to have face validity and that are feasible to measure in UK general practice.

3. To draft a document providing a technical specification for each of the 26 selected indicators to submit to NICE and other relevant stakeholders.

8.3 Methods

8.3.1 Study design

The RAND Appropriateness Method is the most rigorous and widely-used methodology to generate professional consensus on quality indicators.(4) It was described by Naylor as the "only meticulously tested and systematic method for leavening limited evidence with expert opinion and inference" (5) and was used by the NICE QOF Indicator Programme.(2, 3) The RAND method consists of two rounds of anonymous questionnaires. Panel members rate each indicator on a set of 'a priori' statements using a 9-point Likert scale. Indicators are discussed at a face-to-face meeting to identify points of uncertainty and to modify wording. Then, the indicators

are re-rated and only those determined by the majority to be highly rated are included. As outlined in Chapter 7, Murphy and colleagues (6) recommended a panel size of between 6 and 12 on the basis that the reliability and validity is low when the panel is smaller than six while larger panels can create logistical challenges for the meeting.

The Proportionate Review Sub-Committee of the South West London 4 Research Ethics Committee reviewed the project and deemed it service development (not requiring approval from a Research Ethics Committee). The study was funded by the RCGP Scientific Foundation Board as part of a grant awarded for this thesis (Ref. SFB-2010-03).

8.3.2 Expert panel

The NICE QOF Indicator Programme appoints a 10-person panel made up of frontline GPs and GPs with a special interest in areas under consideration.(3) Since a key aim of this thesis was to develop a set of indicators that could potentially be implemented as part of QOF, I adopted a similar approach and invited members of the panel that participated in the initial NGT process to participate. Two of the original 12 GPs were unable to attend (JC and PR) but they were still able to participate in the questionnaire. The Scottish representative (CB) had moved to England, so a currently practicing Scottish GP with an interest in child health was invited to attend instead (FM). My supervisor (AH) did not participate as he was involved in indicator development. I invited one additional member with specific expertise in child protection (DJ), who completed the questionnaire but was unable to attend the meeting. Appendix E.1 lists the 13 GPs who completed the online questionnaire and the 10 that attended the meeting and completed the second rating.

8.3.3 Implementation of the RAND Appropriateness Method

8.3.3.1 Phase 1 – Postal questionnaire

I used the online survey tool SurveyMonkey (www.surveymonkey.com) to create and distribute the questionnaire. I designed a survey template over several months and discussed the layout and organisation with departmental colleagues for feedback. I also sent a pilot survey to a Canadian colleague, Dr Antonia Stang, who had recently completed a similar study to develop indicators for paediatric emergency care, building on work from Guttmann *et al.* (7).

The literature review in Chapter 2 identified *validity* and *feasibility* as the most important characteristics to develop quality indicators. Therefore, for each indicator listed, the expert panel was asked to rate the extent to which they agreed on a 9-point Likert scale (1 = strongly disagree, 9 = strongly agree) with the following statements:

- *Validity*: the indicator is a marker of high quality care for children in UK general practice

- *Feasibility*: the indicator can be collected and measured in UK general practice

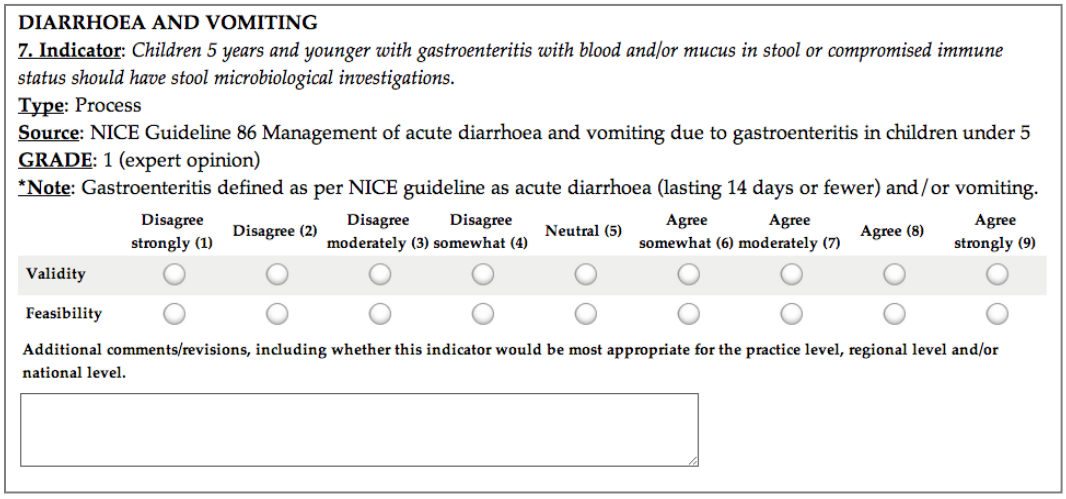
The questionnaire included a comment section in which GPs were encouraged to offer wording modifications, explain why markers were excellent or poor, and suggest new indicators. This helped flag potential problems which were discussed at the face-to-face meeting. Unlike NICE, I did not include *clarity* (i.e. "whether the indicator is expressed in clear, precise and unambiguous language" (2)) since I felt that validity

and the comment section adequately addressed this intention; Marshall *et al.* (8) also only used validity and necessity to record (i.e. feasibility).

As a previous study has shown that panels were more likely to produce judgements consistent with the evidence when provided with a literature review (9), I provided GPs with the GRADE evidence rating and referenced the source material. It was impractical to provide paper copies of all the research papers supporting each indicator but most evidence could be easily accessed from the NICE and SIGN guidelines. Both of which are readily available to GPs.

The layout of the questionnaire, using indicator #7 as an example, is shown in Figure 8.1. I also sent the panel a supplementary document listing the indicators and references.

Figure 8.1: Sample layout of online questionnaire



DIARRHOEA AND VOMITING

7. Indicator: *Children 5 years and younger with gastroenteritis with blood and/or mucus in stool or compromised immune status should have stool microbiological investigations.*

Type: Process

Source: NICE Guideline 86 Management of acute diarrhoea and vomiting due to gastroenteritis in children under 5

GRADE: 1 (expert opinion)

***Note**: Gastroenteritis defined as per NICE guideline as acute diarrhoea (lasting 14 days or fewer) and/or vomiting.

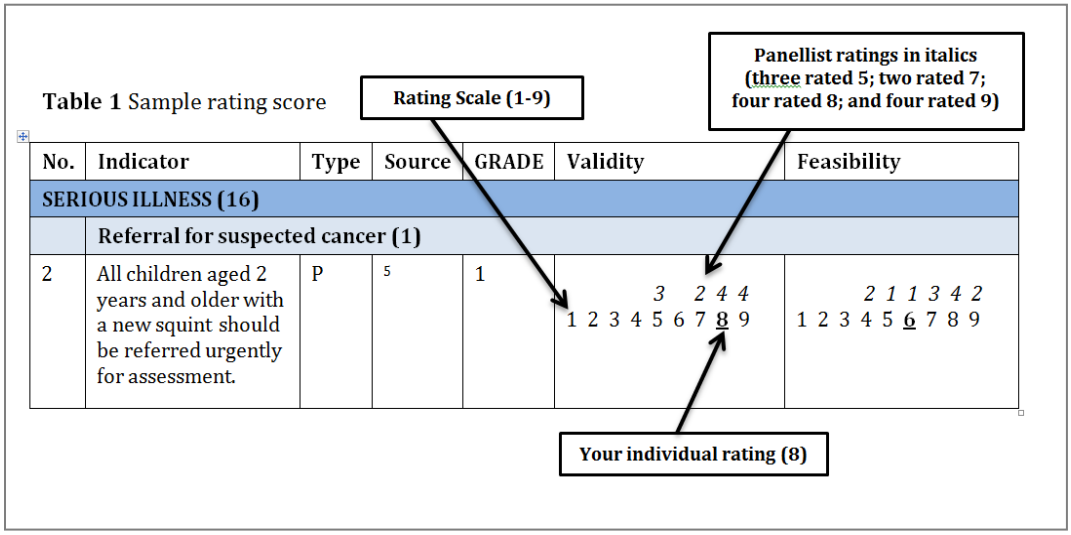
	Disagree strongly (1)	Disagree (2)	Disagree moderately (3)	Disagree somewhat (4)	Neutral (5)	Agree somewhat (6)	Agree moderately (7)	Agree (8)	Agree strongly (9)
Validity	○	○	○	○	○	○	○	○	○
Feasibility	○	○	○	○	○	○	○	○	○

Additional comments/revisions, including whether this indicator would be most appropriate for the practice level, regional level and/or national level.

Each panel member was sent a summary of their individual ratings along with the anonymised ratings of all other participants. The format in which these data were

presented is shown in Figure 8.2, using indicator #2 as an example. Participants were also given a summary of what had been written in the "additional comments" box for each indicator.

Figure 8.2: Sample rating score provided to panellists after Phase 1



8.3.3.2 Phase 2 – Face-to-face meeting

At the panel meeting, the discussion first focused on general feedback from the first round rating. This was followed by a moderated discussion to identify areas of uncertainty, clarify why indicators did not achieve consensus and modify wording. The discussion allowed participants to suggest new alternative indicators for draft indicators they felt to be inadequate. The meeting was audio recorded to ensure the modifications made were accurate.

8.3.3.3 Final rating and analysis

Shortly after the face-to-face meeting, the participants who attended the meeting were sent the modified quality indicators, including two newly suggested indicators (69 in total). They were again asked to rate each indicator for validity and feasibility and, in

addition, to comment whether or not each indicator would be applied most appropriately at the practice, regional and/or national level (reflecting discussion during the meeting).

8.3.4 Operationalisation of the selected indicators

8.3.4.1 Ascertaining what was required

I conducted a search of the technical appendices used to specify measurement and other technical parameters for quality indicators in Quality and Outcomes Framework Guidance for 2012/13, the NICE Menu of Indicators, NICE Quality Standards, the NHS Outcomes Framework 2012/13, the NHS Information Centre Compendium of Health Indicators, the NHS Atlas of Variation, and the AHRQ.(10-14)

I did not attempt to undertake a search to specify READ codes and these were not included in the technical specifications unless they were explicitly suggested by panel members (such as child safeguarding (15)). It would not have been feasible to specify READ codes in the time available for completion of the thesis. My supervisor (AH) also advised me that it was more realistic, and perhaps more appropriate, for the coding specification to be completed in liaison coding experts at a later stage of implementation (as is current practice in the NICE QOF indicator testing protocol which is done with the NHS Information Centre (3)).

8.3.4.2 Drawing up the technical specification

The technical content was guided by the literature review mentioned above. The required content also guided the format to some extent, but as I intended the technical specification document to be accessible to clinician stakeholders as well as policy

makers (and QOF panels are largely populated by general practitioners), I chose to provide a level of detail similar to that provided in the 2012/13 QOF Guidance which was intended mainly for GPs. This allowed me to summarise the key technical details for each indicator on one side of A4. Where possible, I used consistent language from the QOF Guidance which would be familiar to UK primary care professionals.

There is no standard list of measurement or other technical parameters that need to be specified as part of the process of policy review or implementation in UK primary care. However, there are many common features and most technical appendices report the 9 parameters listed in Table 8.1. As this list would sometimes exclude key implementation issues that had been flagged by members of the expert panel, particularly when they were highly specific to a given indicator, the technical specification I adopted includes a tenth '*other issue*' category provided as an additional note.

Table 8.1: Measurement parameters for quality indicators

Parameter	Explanation
Rationale	Short summary outlining why the indicator is important.
Definitions	Detailed information on how the indicator can be measured, including indicator description, construction and reporting format. The indicator construction specifies numerator and denominator required to quantify the indicator, including the specific age range and READ codes (if readily available). Language consistent with QOF Guidance detailing how indicators are implemented was used where possible.
Data source	Specific sources used to collect data which may include Quality Management and Analysis System (QMAS) and manual searches of clinical records.
Technical issues	Issues that may hinder feasibility of indicator.
Type of care	Indicator classified according to measurable items of care, either as structure, process or outcome.
Level	Applicability of indicator to practice, regional or national level.
GRADE	GRADE quality of evidence rating based on sources identified in NICE and SIGN guidelines and additional high quality literature. If uncertainty, indicators were assigned 1 (expert consensus).
Source clinical guideline	NICE or SIGN guideline recommendation used to articulate quality indicator.
Other source information	Additional references, guidelines or policy documents used to inform indicator.

8.3.4.3 Collating the expert feedback

Members of the GP panel were invited to review the measurement parameters and provide feedback on operational issues to ensure pertinent information required to capture the appropriate care was included; this was also done by Woodman *et al.* (15). Those GPs who agreed were sent a small number of indicators to review; 3-4 panellists reviewed indicators for each priority area. Of the 12 GPs invited, 11 responded and were each sent between 4 and 13 indicators to review.

8.4 Results

8.4.1 Consensus study

8.4.1.1 Overall panel selections

Of the 69 indicators assessed in the final rating, 26 were unanimously rated ≥7 on validity and ≥6 on feasibility (the criterion set as the minimum level of agreement for consensus) (Table 8.2). However, only four had a GRADE evidence rating higher than 1: #3, #12a, #47, and #56. The mean rating for the final modified indicators was higher than for the original draft indicators: the mean validity score increased from 7.1 to 7.9 while the feasibility score increased from 6.8 to 7.4. While 30 indicators were rated 3 or less by ≥1 panel members in the first round, this dropped to seven in the final rating.

Table 8.2: Summary of priority areas and indicators selected

Priority areas	No. of indicators	No. of indicators selected (%)
Early recognition of serious illness	15	7 (47%)
Child protection/safeguarding	6	4 (67%)
Mental health	12	4 (33%)
Health promotion	6	1 (17%)
Routinely managed conditions	21	6 (29%)
General practice management	9	4 (44%)
Total	*69*	*26 (38%)*

Note: The panel suggested one new indicator for early recognition of serious illness and general practice management after Phase 1.

8.4.1.2 Early recognition of serious illness

Table 8.3 outlines the seven selected indicators. Some markers were originally worded too broadly; both indicator #3 and #4 were changed to specify precise symptoms and signs. Other indicators required an additional note of clarification (e.g. for indicator #3, it was thought important to clarify that the serological test must be

completed whilst remaining on gluten-containing diet). Indicator #2 was changed to specify it applied to a new onset '*fixed squint'*. The panel suggested that indicator #2 and #13 (neonatal jaundice) were not valid for assessment of individual practice performance, since the health professionals mainly responsible are employed by NHS Trusts rather than general practitioners; they suggested instead that these indicators should be applied at a regional level.

Table 8.3: Serious illness indicators selected: median (range) ratings for validity and feasibility (n=7)

		Phase 1 (n=13)		**Phase 2 (n=10)**	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
2	Children with a new onset fixed squint should be assessed and referred urgently when appropriate.	8 (5-9)	7 (4-9)	8 (7-9)	8 (7-9)
3	Children with "chronic or intermittent diarrhoea" and/or faltering growth should be investigated with "serological testing for Coeliac disease."[1]	7 (3-9)	5 (2-9)	8.5 (7-9)	8 (7-9)
4	Children newly presenting with polydipsia, polyuria and/or weight loss should have clearly documented evidence of glucose assessment.	9 (4-9)	8 (4-9)	9 (8-9)	9 (8-9)
5	Children newly presenting with secondary enuresis should have clearly documented evidence of glucose assessment.	8 (3-9)	8 (5-9)	8.5 (7-9)	8.5 (8-9)
7	Children 5 years and younger with gastroenteritis with "blood and/or mucus in stool" or compromised immune status should have "stool microbiological investigations."[2]	8 (6-9)	7 (2-9)	8 (7-9)	7.5 (6-9)
9	Children with a first non-febrile seizure should have clearly documented evidence of referral to secondary care for further assessment.	9 (7-9)	8 (6-9)	9 (8-9)	8.5 (8-9)
13	Neonates ≥37 weeks (gestational age) with jaundice lasting ≥14 days or neonates <37 weeks (gestational age) with jaundice lasting ≥21 days who present to the general practitioner should have clearly documented evidence of conjugated bilirubin measurement.[3]	8 (2-9)	8 (2-9)	8 (7-9)	8 (6-9)

Note: 1 NICE 'Recognition and assessment of coeliac disease' guideline recommendation 1.1.1.(16)
[2] NICE "Management of acute diarrhoea and vomiting due to gastroenteritis in children under 5" guideline audit criterion #1.(17) [3] NICE 'Recognition and treatment of neonatal jaundice' guideline audit criterion #12.3: "Babies with a gestational age of 37 weeks or more with jaundice lasting more than 14 days, and in babies with a gestational age of less than 37 weeks and jaundice lasting more than 21 days: conjugated bilirubin should be measured."(18)

Most indicators were rejected because of feasibility concerns (Table 8.4). While there was strong validity support for safeguarding indicator #1, it was thought to be "virtually impossible to audit." Indicator #11 had a median validity score of 6: while the panel agreed that few children with feverish illness require a chest x-ray, and over use of x-rays may therefore indicate poor quality care, it would be impossible to ascertain responsibility for test ordering.

Indicators #10, and the newly suggested indicator #10a, were the focus of intense discussion on documentation and measurement of vital signs, reflecting the very wide range of ratings (from 1 to 9) awarded. There was less variability in rating indicator #14, but a number of participants thought that the NICE guideline on managing UTIs was controversial. The participants felt these NICE guidelines were often at odds with regional protocols, the views of local consultants, and the local availability of imaging facilities. Narrowing the focus of indicator #16 to patients with a family history of familial hypercholesterolaemia, removing the age specification, and changing the wording to '*offer'* did not alter the panel rating on its feasibility.

Table 8.4: Serious illness indicators rejected: median (range) ratings for validity and feasibility (n=8)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
1	There should be a clear record of management and safety netting advice for children who present with the same complaint ≥3 times without a clear diagnosis.	9 (2-9)	8 (2-9)	8.5 (7-9)	7 (2-9)
8	Children 5 years and younger with gastroenteritis should have hydration status clearly documented.	8 (1-9)	8 (4-9)	9 (5-9)	8 (3-9)
10	Children 5 years and younger with feverish illness should have documented evidence of vital sign measurements.	8 (5-9)	7 (1-9)	7.5 (4-9)	8 (2-9)
10a[1]	General practitioners should have a low threshold for measuring and recording vital signs in children 5 years and younger with a feverish illness.	-	-	8.5 (1-9)	5.5 (2-9)
11	Percentage of children 5 years and younger with feverish illness presenting in primary care that had a chest x-ray.	4 (1-9)	5 (1-9)	6 (2-9)	7 (2-9)
14	Children with urinary tract infections should be managed according to the NICE guideline tables.	8 (2-9)	8 (6-9)	8 (5-9)	7 (4-9)
15	Parents/caregivers of children with acute bronchiolitis should be provided with information about recognising clinical deterioration and instructions for re-assessment by a clinician.	8 (4-9)	6 (2-9)	8 (6-9)	7.5 (3-9)
16	Children with a family history of familial hypercholesterolaemia should be offered serum lipids measurement.	6 (4-9)	6 (4-9)	8 (7-9)	6 (3-8)

Note: [1] Articulated by panel at face-to-face meeting.

8.4.1.3 Child protection/safeguarding

The panel selected two thirds of the child protection/safeguarding indicators (Table 8.5) with minimal wording changes. Indicator #21 was modified to specify that relevant staff should also know the practice lead and the contact details of the named safeguarding professional. GPs suggested indicator #65 for the regional level.

Table 8.5: Child protection/safeguarding indicators selected: median (range) ratings for validity and feasibility (n=4)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
17	"Looked-after children and young people" should be clearly identified in the general practitioner's summary record.[1]	8 (7-9)	8 (4-9)	8.5 (7-9)	8 (7-9)
20	Children about whom a practitioner suspects neglect or abuse should have evidence that a clear and recorded course of action was taken.	9 (7-9)	8 (4-9)	9 (8-9)	8.5 (7-9)
21	Relevant staff should know the practice lead and the contact details for the "named/designated professionals for safeguarding children."[2]	9 (6-9)	8 (3-9)	8 (8-9)	8 (7-9)
65	All "relevant staff must have been on child protection/safeguarding children training in line with local policy."[3]	8 (6-9)	8 (4-9)	8 (7-9)	8 (6-9)

Note: [1] NICE 'Promoting the quality of life of looked-after children and young people' guideline.(19)
[2] Modified NICE 'When to suspect child maltreatment' guidance audit criterion #3.(20)
[3] NICE 'When to suspect child maltreatment' guidance audit criterion #5.(20)

Some panel members felt indicator #18 was not feasible currently due to poor information sharing with social care. These panel members flagged issues with data integration between primary care and emergency departments that limited the feasibility of indicator #19.

Table 8.6: Child protection/safeguarding indicators rejected: median (range) ratings for validity and feasibility (n=2)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
18	"Looked-after children and young people" should have an annual review and an updated personal health record.[1]	7 (1-9)	8 (1-9)	8 (5-9)	8 (4-9)
19	Children and young people that have presented ≥3 times to emergency department in last 12 months should be reviewed in primary care.	7 (4-9)	7 (3-8)	8 (6-9)	7 (5-9)

Note: [1] NICE 'Promoting the quality of life of looked-after children and young people' guideline.(19)

8.4.1.4 Mental health

The panel selected four mental health indicators which focused on depression, self-harm, developmental delay, and ADHD (Table 8.7). The phrase '*discussed with specialist colleague*' was added to indicator #23, and the specification from indicator #33 that monitoring should be done in primary care was removed.

Table 8.7: Mental health indicators selected: median (range) ratings for validity and feasibility (n=4)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
23	Adolescents with depression who have moderate or high risk factors, "high recurrent risk of acts of self-harm or suicide" or "significant on-going self-neglect" should be referred for further assessment or discussed with a specialist colleague.[1]	8 (6-9)	6 (3-9)	8 (8-9)	7.5 (6-9)
28	Children that self-harm should have a clearly documented assessment and management plan.	7 (2-9)	6 (2-9)	8 (8-9)	8 (7-9)
31	Children 3 years and older with "regression in language" or "any age with regression in motor skills" should be referred for further assessment.[2]	8 (6-9)	8 (6-9)	8 (8-9)	8 (7-9)
33	Children taking methylphenidate, atomoxetine or dexamfetamine should have clearly documented monitoring.	8 (1-9)	7 (2-9)	8 (7-9)	8 (7-9)

Note: [1] NICE 'Depression in children and young people' guideline recommendation 1.3.2.3.(21)
[2] NICE 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum' guideline recommendation 22.(22)

The eight rejected indicators are described in Table 8.8. Panel members flagged concerns about reliability of data integration between primary care, secondary care and A&E; indicators #27 and #29 were modified accordingly but rejected. Both indicators on eating disorders were rejected: indicator #26 was revised to narrow the scope to children with type I diabetes and young women with menstrual disorders, but no consensus could be reached on a feasible wording. Indicator #32 was very highly

rated in both phases and was only rejected because one panel member rated it 5 for feasibility and consensus was not achieved.

Table 8.8: Mental health indicators rejected: median (range) ratings for validity and feasibility (n=8)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
22	"Children and young people with" mental health conditions "who do not attend follow-up appointments" in hospital or primary care should be contacted by their general practitioner.[1]	8 (1-9)	7 (1-9)	8 (4-9)	7 (6-9)
24	Antidepressant medications should not be initiated by general practitioners for children and young people with depression.	8 (3-9)	8 (4-9)	8 (5-9)	8 (6-9)
25	Children with eating disorders should have growth and development monitored at least annually using an age-appropriate tool.	8 (5-9)	6 (4-9)	8.5 (4-9)	7.5 (4-9)
26	Children and young people with type I diabetes and young women with menstrual disorders should be asked at least one simple validated question to screen for eating disorders.	7 (4-9)	7 (1-9)	7 (4-9)	7 (2-9)
27	Children whose general practitioner has been notified that they have been involved in a severe acute traumatic event should be contacted to assess for post-traumatic stress disorder.	4 (1-9)	4 (2-9)	7 (3-9)	6 (3-8)
29	Children and young people with identified alcohol misuse should have a clearly documented assessment and management plan.	7 (1-9)	4 (1-9)	8 (6-9)	7 (5-9)
30	Children with suspected autism should be referred for further assessment with a referral letter that includes information from family and from multi-professional agencies (e.g. education).	6 (2-9)	4 (2-9)	7.5 (5-9)	7 (5-9)
32	Stimulant medication for the treatment of attention deficit hyperactivity disorder should not be initiated by general practitioners.	9 (7-9)	9 (8-9)	8.5 (7-9)	8.5 (5-9)

Note: [1] Modified from NICE 'Depression in children and young people' guideline recommendation 1.5.1.2.(21)

8.4.1.5 Health promotion

Only a single indicator was selected which was unanimously rated in both rounds (Table 8.9).

Table 8.9: Health promotion indicator selected: median (range) ratings for validity and feasibility (n=1)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
6	Children with Type I diabetes aged 6 months and older should have documented evidence of being offered annual influenza immunisation.	8 (7-9)	8 (7-9)	9 (7-9)	9 (7-9)

The five rejected indicators, omitted mostly for feasibility concerns, are outlined in Table 8.10. Some felt the immunisation markers were more relevant to public health and raised issues of responsibility for care delivery. There was significant variation in opinion on indicator #37: Guthrie test and newborn hearing test results were generally not available to GPs in many places, and country-to-country differences were also highlighted (e.g. Wales hypothyroidism and cystic fibrosis). There was strong support for ensuring practices have access to appropriate growth charts (indicator #38) but again the indicator was rejected because one GP felt this was not feasible.

Table 8.10: Health promotion indicators rejected: median (range) ratings for validity and feasibility (n=5)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
34	Children aged 15 should have their immunisation record reviewed and updated.	8 (4-9)	6 (1-9)	8 (6-9)	6.5 (2-7)
35	Children and young people with underlying medical conditions should have received eligible immunisations and have a complete and up-to-date immunisation record.	8 (7-9)	8 (4-9)	8 (7-9)	7.5 (5-9)
36	Children eligible for targeted Hepatitis B immunisation should have a complete and up-to-date immunisation record.[1]	8 (2-9)	8 (5-9)	8 (6-9)	8 (6-9)
37	Children should have their Guthrie test and newborn hearing test results reviewed at the 6-8 week check-up.	8 (6-9)	8 (4-9)	8 (4-9)	6.5 (4-8)
38	Practices should have access to appropriate growth charts including body-mass index (BMI) measurement in children.	8 (7-9)	8 (2-9)	8.5 (7-9)	8 (5-8)

Note: [1] Patients eligible for targeted Hepatitis B immunisation are those whom mother is Hepatitis B positive or who's parents have Hepatitis B.(23)

8.4.1.6 Routinely managed conditions

One third of the indicators for routinely managed conditions were selected, dealing with asthma (n=2), nocturnal enuresis (n=2), idiopathic constipation, and persistent otitis media with effusion (Table 8.11). Although NICE guidance specifies that children with idiopathic constipation should be treated with polyethylene glycol (PEG) before other interventions (24), the panel felt strongly that this should not be prescribed without the parent being given advice on diet and fluid intake (#47).

Table 8.11: Routinely managed conditions indicators selected: median (range) ratings for validity and feasibility (n=6)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
41	Children with asthma aged 5 years or less should have clearly documented basis for diagnosis.	8 (3-9)	8 (3-9)	8 (7-9)	8 (6-9)
42	Children with asthma should be prescribed a spacer.	6 (2-9)	7 (5-9)	8.5 (8-9)	8.5 (7-9)
47	Children with idiopathic constipation should be treated with polyethylene glycol (e.g. Movicol) for initial therapy along with dietary and fluid advice.	8 (4-9)	7 (4-9)	8 (7-9)	7.5 (6-9)
52	Children with nocturnal enuresis should have a clearly recorded assessment which differentiates between primary and secondary enuresis.	8 (6-9)	8 (4-9)	8 (7-9)	8 (7-9)
56	Children 3 years and older with "persistent bilateral otitis media with effusion" or "any age with speech and language, developmental or behavioural problems" should be referred for hearing assessment.[1]	8 (5-9)	8 (4-9)	8 (8-9)	8 (7-9)
64	Children with nocturnal enuresis should not be prescribed tricyclic medications in primary care.	7 (3-9)	8 (3-9)	8 (7-9)	7.5 (6-9)

Note: [1] SIGN 'Diagnosis and management of childhood otitis media in primary care' guideline recommendation 4.2.2.(25)

The rejected indicators are listed in Table 8.12. Indicator #48 was rated highly but one GP felt it was "*motherhood and apple pie*" and rated it 2 for validity and feasibility. The panel also made several modifications to indicators that had been rejected: they removed a requirement to use the lowest possible inhaled corticosteroid dose in indicator #40; changed asthma review from 5 to 14 days in indicator #43; changed '*from prescription >14 days'* to '*repeat potent steroid prescription*' in indicator #49; and allowed any non-drug treatment, rather than specifying an alarm, for first line management of nocturnal enuresis in indicator #53. Despite being advised that the panel's task was not to define the standard that should be applied in implementing the quality indicator, some panel members argued that the word '*All'* in several indicators

did imply that a standard of 100% would be set; this word was therefore removed for the final rating. However, none of these changes were sufficient to produce consensus.

Table 8.12: Routinely managed conditions indicators rejected: median (range) ratings for validity and feasibility (n=15)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
39	Children aged 5-12 years with asthma should have documentation of reversibility using peak flow measurement or spirometry.	8 (3-9)	8 (6-9)	8 (6-9)	7.5 (6-8)
40	Children with asthma should have an annual review with documented height.	8 (4-9)	8 (6-9)	8 (3-9)	8 (6-9)
43	Children with an acute asthma exacerbation who are prescribed short-duration oral steroids should be reviewed within 14 days.	6 (2-9)	6 (2-9)	8 (7-9)	7.5 (5-9)
44	Children who are using excessive beta-agonists should be reviewed in primary care.	8 (6-9)	8 (6-9)	8 (6-9)	7.5 (6-9)
45	Children and young people admitted or seen in secondary care for an asthma exacerbation should be assessed within 30 days in primary care.	8 (4-9)	7 (4-9)	8 (5-9)	8 (5-9)
48	Children with atopic eczema should be prescribed emollients.	8 (7-9)	8 (6-9)	9 (2-9)	8 (2-9)
49	Percentage of children who have a repeat prescription of moderate/very potent topical steroids.	7 (5-9)	5 (4-9)	8 (7-9)	8 (5-9)
50	Percentage of children and young people with atopic eczema prescribed oral antihistamines.	6 (2-9)	6 (2-9)	5 (2-9)	5.5 (2-8)
51	Children with atopic eczema with suspected eczema herperticum should be referred urgently for further assessment.	8 (5-9)	8 (3-9)	8 (6-9)	8 (6-9)
53	Non-drug treatment (such as an alarm) should be first-line treatment for children with nocturnal enuresis whenever possible.	4 (1-9)	5 (1-8)	8 (4-9)	7 (5-9)
54	Children with an acute allergic reaction to a food substance should be referred for appropriate investigations.	8 (6-9)	8 (4-9)	8 (6-9)	8 (6-9)
55	Percentage of patients with acute otitis media prescribed antibiotics.	8 (1-8)	7 (4-9)	7 (2-8)	6.5 (4-8)
57	Percentage of patients with uncomplicated respiratory tract infection prescribed antibiotics.	8 (5-9)	8 (2-9)	7 (5-9)	6.5 (2-9)
61	Infants with colic should not prescribed dicycloverine (dicyclomine).	6 (3-9)	8 (3-9)	8 (4-9)	8 (4-9)
63	Percentage of children with nocturnal enuresis who do not have daytime symptoms prescribed anticholinergic medications in primary care.	7 (2-9)	7 (2-9)	7 (6-8)	7 (5-9)

8.4.1.7 General practice management

Four indicators were selected that focused on hospital admissions, reviewing children on long-term medications, GP training and good antibiotic stewardship (Table 8.13). The GP training indicator #66 was rated poorly in the first round and was modified extensively to focus on paediatric continuing professional development activities during re-validation. The panel suggested that indicators #46 and #66 would be most appropriately applied at a regional rather than practice level. There were strong opinions expressed at the face-to-face meeting about the validity of antibiotic prescribing indicator #12 and therefore indicator #12a was articulated and selected.

Table 8.13: General practice management indicators selected: median (range) ratings for validity and feasibility (n=4)

		Phase 1 (n=13)		**Phase 2 (n=10)**	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
46	Percentage of children and young people admitted to hospital for acute asthma exacerbation.	8 (4-9)	8 (3-9)	8 (7-9)	7.5 (6-9)
62	Children on long-term prescriptions should have an annual review in primary care.	9 (4-9)	9 (4-9)	8 (8-9)	8.5 (8-9)
66	General practitioners should document written reflection of their paediatric continuing professional development (CPD) activities undertaken within each 5 year re-validation cycle.	3 (1-8)	4 (1-9)	8 (7-9)	8 (6-9)
12a[1]	Antibiotic prescriptions in children should be accompanied by clearly documented rationale for this decision.	-	-	8 (7-9)	8 (6-9)

Note: [1] Articulated by panel at face-to-face meeting.

Table 8.14 lists the general practice management indicators that were rejected. Indicators #58 and #59, similar to the new QOF markers on unplanned hospital admissions and A&E attendances, were rejected because some GPs felt they reflected parental concern rather than the quality of primary care. Indicator #60, the only indicator for child and carer friendliness, was extensively modified but rejected.

Indicator #67 was also poorly rated after the first rating and significantly re-worded but still rejected.

Table 8.14: General practice management indicators rejected: median (range) ratings for validity and feasibility (n=5)

		Phase 1 (n=13)		Phase 2 (n=10)	
No.	**Indicator**	*Validity*	*Feasibility*	*Validity*	*Feasibility*
12	Percentage of children in a practice who have been prescribed oral antibiotics in the past year.	6 (2-9)	6 (2-9)	8 (5-9)	7.5 (5-9)
58	Unplanned admissions for children in previous 12-month period.	7 (4-8)	7 (4-9)	7.5 (6-9)	7.5 (6-9)
59	Accident and Emergency attendances for children in previous 12-month period.	6 (1-8)	7 (1-8)	8 (4-9)	8 (4-9)
60	Practices should have a mechanism by which to ascertain the views of children and young people and their parents/guardian with respect to their satisfaction with the care provided.	7 (5-9)	6 (3-9)	8 (6-9)	7.5 (6-9)
67	Practices should provide a publicly available account that demonstrates their practitioners' paediatric experience and training.	5 (1-9)	6 (1-9)	7 (4-8)	6.5 (4-8)

8.4.2 Operational issues identified by the panel

8.4.2.1 Level of care at which the indicator should be applied

A frequently recurring issue in the panel discussion was the level of care delivery at which the draft indicator should be applied: practice, regional or national. Several GPs echoed the views expressed in Chapter 4, asserting that while some indicators (such as hospital admissions and A&E attendances) were valid measures of quality at a health system level, it would be inappropriate to evaluate the quality of individual general practices. Interestingly, contrary to these concerns, more than half the panel felt that acute asthma admissions, emergency admissions and A&E attendances were appropriate for practice level measurement. This may reflect the new QOF '*Quality and Productivity'* markers (26) and the increasing focus on outcomes measures (e.g.

NHS Outcomes Framework); it also highlights discrepancies between panel comments and ratings, and between panel members themselves.

8.4.2.2 Availability of services

The panel drew specific attention to the issue of geographical variation in care provision. They emphasised in particular the lack of availability of NHS services that are outlined explicitly in the NICE/SIGN guidelines (e.g. CAMHS services). The indicators selected were modified where appropriate to try to ensure that the success of the indicator would be independent of the availability of these services; this should thus not be an implementation issue for the selected set. This emphasis was different to the NICE QOF Indicator Programme where the advisory committee was specifically instructed that "service provision should not be a deciding factor on which topics or guideline recommendations are put forward for further development, or on whether indicators should be approved by the Committee for publication in the NICE menu of indicators."(27) Campbell and colleagues (3) found that implementation issues arose when piloted indicators conflicted with local guidance. Addressing this issue early may thus reduce downstream problems.

8.4.2.3 Availability of data

The panel discussed data availability and the coding required for feasible indicator measurement. There may be a particular problem with the coding of mental health conditions in primary care records. The two selected mental health indicators directed at children at risk of self-harm depend on depression and previous self-harm incidents being adequately recorded and coded; one GP suggested articulating an additional indicator to ensure this was the case. Many health promotion indicators were rejected because of the perceived problem resulting from poor data integration and poor

communication with secondary care, schools, and social care; issues with data integration are described in detail by Kavanagh *et al.* (28). But other panellists felt that by identifying these areas as future quality indicators, it would incentivise '*bridging of silos'* and *drive* the development of the relevant information infrastructure (which happened in QOF). Indeed, the 'Report of the Children and Young People's Health Outcomes Forum' identified integrated care as particularly important.(29)

8.4.2.4 Individual responsible for providing care

While the care outlined in the draft quality indicators was seldom questioned, the specific individual responsible, or who *should* be responsible for actually delivering that care, was often unclear. The care of children is frequently shared; some GPs take an active role in managing children with specialised needs while others step back when strong secondary care support is present. Wang *et al*. (30) encountered a similar issue developing indicators for infants who were small at birth (less than 1500 grams). This feedback led to modifying several indicators to remove '*in primary care',* thereby ensuring care is delivered without specifying the precise location or professional. However, this introduces the risk that, by removing accountability, no one will take responsibility for delivering the specified care.

8.4.2.5 Clinically subjective denominators

Many of the quality indicators already used in QOF are based on measuring outcomes in a specific target patient group (e.g. diabetics). In this situation, the adequacy of the denominator for the quality indicator in itself depends on the diagnostic performance of the practice. This raises the operational issue of how to validate the diagnoses made to define the target group. For common chronic diseases, the denominator can be

validated against data on population prevalence. This is not feasible for uncommon conditions. Many of the draft indicators were rejected because the panel felt that it would not be operationally feasible to validate the denominator. However, this remains an issue for some of the indicators selected (e.g. referral for fixed squint). One panel member expressed unease with the first asthma indicator (which requires specification of the basis of diagnosis in children age less than 5 years). They suggested it might discourage GPs from diagnosing asthma in younger children which may be as harmful as over-diagnosis.

8.4.3 Technical specification of indicators

The full document which gives the technical specification for each of 26 selected indicators (structured according to the parameters listed in section 8.3.4) is included in Appendix E.2. The one-page summaries are grouped according to priority area and a brief summary and rationale is given for each area. As examples, the summary and rationale for the mental health indicators is shown in Figure 8.3 below and the one page summary for one of the mental health quality indicators is shown in Figure 8.4.

Figure 8.3: Rationale for mental health indicators

The burden of mental health problems in children is under recognised but growing. Poor recognition and treatment of mental health problems places stress on children and families which continues into adult life. Effective interventions are available yet they rely on timely detection and use. General practitioners can thus play an important role identifying and treating mental health problems.

Figure 8.4: Mental health indicator #4

Indicator	Children taking methylphenidate, atomoxetine or dexamfetamine should have clearly documented monitoring.
Rationale	Medications prescribed for attention deficit hyperactivity disorder may lead to reduced appetite and growth therefore monitoring is important to identify potential side effects.
Definitions	**Indicator description:** Proportion of children taking methylphenidate, atomoxetine or dexamfetamine that have clearly documented monitoring. **Indicator construction:** *Numerator* Number of children (0 – 18 years) taking methylphenidate, atomoxetine or dexamfetamine that have clearly documented monitoring. Prescriptions will be identified by appropriate READ Codes. Clearly documented monitoring of height and weight will be identified by looking at the primary care records. **Note*: Monitoring should include height and weight measurements every 6 months and plotted on a growth chart. *Denominator* All children (0 – 18 years) registered with a general practice taking methylphenidate, atomoxetine or dexamfetamine. **Indicator format** Raw numbers; percentage
Data source	QMAS; Local data collection
Technical issues	Specifying location of monitoring
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 72 recommendations 1.8.1.4 and 1.8.4.2 (2004, updated in 2012) SIGN guideline 112 recommendations 7.2.5 and 7.3.2 (2009)
Other source information	-
Other issues / note	Approximately 4% of boys and 1% of girls under 15 years are diagnosed with ADHD; 5% estimated prevalence (NICE CG72)

8.4.4 Future indicator development

The expert panel suggested numerous specific indicators to consider for future quality indicator development initiatives, several of which have been previously mentioned. One gap in the early recognition of serious illness priority area was acute surgical

conditions, such as pyloric stenosis, torsion of the testis and appendicitis, which are similarly as important as other serious illnesses. The panel also suggested several specific prescribing indicators for the following medicines: paracetamol, Vitamin D, melatonin, tetracyclines, and steroids. These topics were not included in the original draft set of indicators described in Chapter 7 for they did not have specific NICE and SIGN guidance developed.

8.5 Discussion

8.5.1 Main findings

There was consensus that the 26 quality indicators identified are valid markers of primary care quality and would be feasible to implement in UK general practice. The characteristics of each of the 26 selected indicators were further interrogated to generate detailed measurement profiles, outlining how they could be operationalised. However, this process flagged a number of issues that need to be addressed before the indicators can be implemented in clinical practice.

8.5.2 Limitations of the RAND Appropriateness Method

8.5.2.1 How did the panel composition affect the indicators selected?

Panel composition has been reported to have a specific effect on panel ratings (31) with representatives of '*the assessed'* usually more critical of quality markers. Hutchings *et al.* (31) recommended multi-specialty groups over single specialty groups because the former has a moderating effect on the panel differences. Campbell *et al.* (32) conducted a RCT to evaluate the effect of panel membership on the results of a Delphi survey of 176 indicators; the panels were either GPs only, managers only,

or mixed. They confirmed that mixed membership moderated the outcome: GPs alone were the most critical, rating the fewest performance criteria for inclusion (n=28) compared to managers alone (n=60). A Dutch study of GPs and specialists reported similar findings.(33) If the panel had been mixed, it is possible that a larger number of indicators would have been selected, although the requirement for consensus meant that a single voice could still have led to rejection.

The median rating awarded by this panel for most indicators was high, with convergence in the second round. This was consistent with the fact that the panel was a keen and interested group; most had participated in the earlier NGT process and were potentially '*attached*' to the project. This prior involvement may have led panel members to rate many indicators highly. A panel of non-expert GPs may have been more critical of the indicators and selected fewer for inclusion. However, the level of critical discussion at the face-to-face meeting was high, as evidenced by the many changes to wording and rejection of the majority of draft indicators.

8.5.2.2 Were the panel provided with sufficient evidence?

As mentioned in the method section, providing panel members with a literature review increases the likelihood that they will make judgements consistent with evidence.(31) The panel members were provided with the GRADE evidence rating for each indicator but were not given detailed evidence reviews. This was a pragmatic decision to avoid providing GPs with a large amount of reading material. It seems unlikely to have impacted substantially on their decision making for four reasons: 1) there were a number of subject experts on the panel who would have been aware of the evidence; 2) the panel chose a large number of indicators with low quality

evidence (i.e. GRADE = 1, or expert opinion) while rejecting those with high quality evidence; 3) most indicators were rejected on grounds of low feasibility rather than validity; 4) Raine *et al.* (9) found panel recommendations diverge from the evidence about 50% of the time even when the evidence is provided. At the face-to-face meeting, one GP said that quality of the evidence had no impact on his rating. Although this raises the question of whether or not the panel was fit for purpose, the GPs views are consistent with Raine and colleagues (9) observation that clinicians reject evidence they see as weak or irrelevant and are reluctant to accept lack of evidence as a reason to do nothing. The recent study by Bobrovitz *et al*. that looked at the factors influencing consensus group meetings reinforce these observations: their expert panel disputed 47% of the evidence provided.(34)

8.5.2.3 What were the main limitations of the face-to-face meeting?

It was not possible to discuss all indicators at the meeting due to time limitations; this was also an issue during the earlier NGT meetings to determine priority areas. Unlike the NGT, however, the discussion was less structured and certain topics dominated. As described by Murphy *et al.* (6), the status of participants, and their subsequent responses, did influence the group decisions. Panel members who were perceived by others as experts on certain topics did appear to influence the group's ultimate decision to select or reject indicators (and panel comments on the final rating support this observation) substantially. Wording changes suggested by dominant speakers may not have reflected true consensus and this may explain why some ratings decreased after the first round.

8.5.2.4 Were the rating criteria optimal?

The decision to select only those indicators which 100% of the panellists rated ≥7 on validity and ≥6 on feasibility was arbitrary. A more rigorous cut-off score for validity than feasibility was chosen as it was felt to be more important. This decision is in line with Marshall *et al.* (8). Not surprisingly, the reliability of selection decisions (i.e. the likelihood that another expert panel will reach the same decision) is increased when a higher median cut-off score of 8 of 9 is used.(35) All selected indicators had a median score of 8 or higher for validity on the final rating.

The decision to reject an indicator if any panel member gave it a rating below ≥7 on validity and ≥6 on feasibility did give substantial power to individual panellists whose views were more extreme. A number of indicators were rejected despite nine of the ten panellists awarding a score of 8 or 9 on both criteria. While this insistence on consensus must increase the likelihood that the selected indicators will be widely accepted by the GP community as having face validity, it also makes it likely that some potentially very important indicators might have been discarded. The indicators rejected should not be completely discarded; they should instead be the focus of future work to understand why they did not reach consensus and what improvements are needed. Many GPs asserted that the rejected indicators nonetheless highlight important learning points for clinicians.

8.5.3 What priority areas were not covered?

At least one indicator was selected for each priority area, but coverage was uneven with only one indicator for health promotion. There was also patchy coverage of individual clinical conditions with, for example, two indicators relating to nocturnal

enuresis but none to atopic eczema or eating disorders. This patchiness in large part reflected the final selection process.

8.5.3.1 Early recognition of serious illness

A substantial proportion of the time spent discussing the early recognition of serious illness indicators focused on documentation of vital signs in feverish children. While vital sign measurement is standard clinical practice in emergency settings, a survey of UK general practitioners reported that vital signs in young children were not measured often (with the exception of temperature).(36) Some panel members had strong beliefs on the potential consequences of such an indicator: they argued that a focus on measuring vital signs may be distracting and detract from a comprehensive assessment, such as observing how the child is moving around the room.(37) Many felt it is difficult to measure vital signs reliably in young children, and could lead to false positives and unnecessary admissions to hospital. I observed that approximately half the GPs indicated that they regularly recorded vital signs while the other half relied primarily on global assessment. There seemed to be a *demographic divide*: younger GPs were keen to measure and document vital signs which they thought important and a sign of good practice; older GPs felt this indicator illustrated how guidelines oversimplified a nuanced and complex clinical topic that could never be implemented in practice. With more time, it may have been possible to draft indicators for specific populations (i.e. less than 3 months) similar to those in the RAND QA Tools which focus on young children.(38) But given the level of disagreement, rejection of this marker was an appropriate outcome of the process regardless of whether or not the evidence suggests that measuring vital signs is necessary for optimal care.

The panel also rejected indicator #14 based on the NICE developed guidance to improve the early detection and management of urinary tract infections.(39) This issue is clinically important because early diagnosis and treatment of children with UTIs is critical to reduce the risk of renal scarring.(40) The hospital admissions analysis described in Chapter 5 reported that emergency admissions to hospital for UTIs were associated with more severe illness. However, panel members described these guidelines as controversial, contending that they conflicted with local policy and required imaging facilities that are available inconsistently. The indicator was therefore rejected on the grounds of feasibility of implementation rather than on validity.

The same issue of a low feasibility rating also led to the rejection of the only indicator on familial hypercholesterolaemia (indicator #16), a condition frequently missed in general practice (41) with a significant long-term effect on morbidity and mortality.(42) While many GPs felt this was an important topic, the indicator relied on identification of adult patients with a family history of familial hypercholesterolaemia. The GPs thought these histories would be poorly documented and first needed to be improved. This seems a very poor reason for rejection since the documentation of family history is an important part of the care quality pathway that needs to be improved.

8.5.3.2 Child protection/safeguarding

While the panel felt '*looked-after´* children needed to be clearly identified in the primary care summary record (#17) they did not support an annual review of these patients (#18). Multiple providers care for these children, particularly social care

services, but while this indicator may have been difficult to implement, it would have strengthened communication between professionals. The other rejected indicator (multiple presentations to A&E should prompt a review in primary care) was also rejected for feasibility issues. This is unfortunate; a US study cited in the NICE guideline found a strong link between multiple attendances for medical care and abuse.(20) The GPs cited unreliable and delayed communication from A&E repeatedly, factors which could make the indicator harder to achieve but would have probably detected a few cases of child maltreatment. The standard defined for these more involved indicators could be lower (accounting for these issues) without penalising practices.

8.5.3.3 Mental health

The panel rejected two-thirds of the mental health indicators. Most were rejected because of perceived poor validity and poor feasibility. Although the low validity ratings do reflect a weak evidence-base for the care of mental health in children, lack of evidence was not a barrier to selection in other areas. The spectrum of in-panel disagreement is reflected in the first phase scoring which ranged from 1 to 9 for three of the rejected indicators – indicators #22, #27, #29 for validity and indicators #22, #26, #29 for feasibility. Two rejected indicators, #24 and #32, stated that GPs should not initiate prescribing for depression and ADHD respectively. Both achieved high median scores of 8 or more for both validity and feasibility and were rejected because of isolated low scores awarded by one or two individuals. Again, this reflects the potential weakness of the consensus process if a high degree of consensus is demanded.

The decision on indicator #25 (monitoring of growth in children with eating disorders) was unusual because it was rated highly on validity but low on feasibility. This probably reflects the evidence. Certain groups are at a higher risk of developing eating disorders (e.g. young women with low BMI) but evidence shows the suggested screening tools do not work well (and are developed for adults).(43) Concerns about the potential negative impact of screening for and monitoring weight disorders were also described in the qualitative interview study in Chapter 4.

8.5.3.4 Health promotion

Two important immunisation indicators were rejected: immunisation status of adolescents, and Hepatitis B immunisation status in eligible patients. These were felt to be a '*systems problem*' rather than a '*primary care problem*' and raised a sensitive issue of responsibility for care delivery. This is precisely why this topic is important: the confidential enquiry into child deaths found a failure to vaccinate children with chronic diseases despite specific requests from secondary care.(44) The variation in admission rates for vaccine-preventable conditions in England (Chapter 5) and variation in the percentage of children who did not receive vaccinations (13) both reinforce the importance of immunisations and the consequences of inaction. Similar concerns led to the exclusion of the newborn screening indicator despite previously developed feasible markers which screen for congenital hypothyroidism and phenylketonuria.(38)

The rejection of indicators that have obvious clinical and public health importance bring to light the limitations of a selection process in which some of the panel have a financial interest. It is obviously not in GPs' principal interest to accept responsibility

for an outcome over which they have incomplete control. At the same time, it probably would be in the interest of UK children and the NHS if such immunisation indicators were implemented. This may be in part due to the poor understanding between an indicator and a standard. But there was obvious disagreement in the panel whereby some felt that identifying these areas as future quality indicators would incentivise '*bridging of silos'* and *drive* the development of the relevant information infrastructure. Yet a small number of panel members held strong viewpoints to the contrary (which likely reflected local issues).

Despite the importance placed on childhood obesity by the GPs interviewed in the qualitative study (Chapter 4), the panel did not select an obesity indicator. This is inconsistent with the lack of financial incentives to treat obesity which has been cited as a reason why GPs do not follow NICE guidelines and prioritise child obesity management.(45) Panel members cited copyright issues as a reason why it was not feasible for BMI growth charts to be used in NHS practice and suggested alternative indicators such as "practices should record weight and height using appropriate growth charts." However, they still rejected the guideline on the grounds of feasibility rather than validity. The panel might have pointed to the fact more cogently that the evidence supporting the effectiveness of primary care based interventions in managing child obesity is poor.(46)

8.5.3.5 Routinely managed conditions

The panel rejected 15 indicators for routinely managed conditions including all indicators for atopic eczema, food allergy and colic management. Three atopic eczema indicators (#48, #49, #51) achieved high median scores of 8 or more but were

rejected because of isolated low validity or feasibility scores. In particular, as mentioned in the results, one GP was strongly opposed to the indicator on emollient prescription. There was wide in-panel disagreement in the scoring of the indicator on oral antihistamines (#50) which was reflected in a phase 2 median score of 5 for validity and 5.5 for feasibility, the lowest score of the indicator set. Unlike mental health, not all low ratings reflect a poor evidence-base: the antibiotic prescribing indicators both had a GRADE evidence rating >1. There was considerable in-panel disagreement, evidenced by the spectrum of final scoring which ranged from 2 to 8 on validity for #55 (acute otitis media) and from 2 to 9 on feasibility for #57 (respiratory tract infections).

8.5.3.6 General practice management

Three outcome indicators were rejected, on unplanned admissions (#58), A&E attendances (#59) and number of prescribed antibiotics (#12), all of which are major issues for the NHS and have a negative impact on the care of children. These outcome indicators were rejected by the panel because some members felt strongly that the quality of care in general practice is not the main influence on these important outcomes. This may be correct, but it may still be in the interest of the NHS to rate care quality against these indicators.

The indicator focusing on ascertainment of satisfaction with care (#60) was not selected in the final indicator set despite being selected as a key priority issue in the NGT process. It was broadly supported, scoring a mean of 8 for validity, but was strongly opposed by one panel member who argued it lacked feasibility. Another GP suggested an indicator from the Picker institute questionnaire: “Environment, attitude

of receptionists and doctors, whether the doctor listened to the child and explained." Further work is needed to determine how this domain can be measured in UK general practice.

8.5.4 Observations from indicator operationalisation

8.5.4.1 Tension between individual rating and descriptive comments

I observed an interesting contradiction between the feasibility rating made by panel members in the RAND process and the descriptive comments when individuals were subsequently asked to comment in-depth. Despite rating indicators high on feasibility, many GPs were much more negative when asked to advise on exactly how an indicator could be operationalised. It appeared they had a bias towards *rating favourably* (as described by Hutchings *et al.* (31)) and did not reflect upon the actual clinical use, underestimating what was required. It is possible that GPs felt the indicator should be implemented in theory, or that it was feasible in their practice, but simply had not thought through the implications of scaling-up. Alternatively, GPs felt the indicator should *drive* feasibility and were simply reflecting factual concerns. This observation further highlights the importance of piloting indicators before implementation. It is also important to note, however, that while many panel members are content experts, they are not experts in coding (which is a further limitation of the methodology used): the issues identified may be minor when reviewed by technical coding experts as recommended by the NICE QOF Indicator Programme.(3)

8.5.4.2 Should operational issues have been considered earlier in the selection process?

The critical feedback from GPs questions whether operational issues were adequately addressed. While measurability was a key inclusion criteria in the iterated consensus

rating procedure (Chapter 7) and the RAND study, both steps relied on subjective GP judgements when objective assessment may have been more appropriate. For example, I could have audited a small number of local GP practices to examine the measurability of the 67 draft indicators, discarding ones difficult to measure (like Kirk *et al.* (47)) or tested the measurability in a clinical database (as recommended by AHRQ (14)). But both methods are not without limitations (prevalence and precise READ codes, respectively) and would have been difficult with the breadth of conditions and the time available to complete this programme of research. More importantly, placing greater weight on operational issues would have emphasised feasibility (i.e. *what is currently measurable?*) over importance (i.e. *what should be measurable?*). QOF led to changes in clinical practice and coding by *incentivising* those indicators that were not readily measurable. Similarly, I suggest that, rather than proposing a set of readily measurable indicators based on retrospective clinical practice, it is more efficient (in terms of clinically useful output) to pilot indicators selected on the attributes of validity and feasibility, and determine the barriers in clinical practice.

8.5.4.3 Can all the indicators selected be implemented in practice?

While further refinement and precision is required for the 26 draft indicators, most could be implemented: no issues flagged by GPs or identified in operationalisation are insurmountable. The '*QOF-like*' indicators – those which are readily measurable in QMAS – should face minor implementation barriers, in particular those focused on prescribing, and on conditions and care processes already specified in QOF, such as asthma or hospital admissions. Other indicators use the infrastructure already in place. For example, practices have systems to identify adults who decline vaccination (with

corresponding READ Codes), and it should therefore be easy to scale-up for children with Type 1 diabetes. By defining the appropriate READ Codes for recording concerns about child maltreatment in primary care, Woodman *et al.* (15) strengthened the impetus to implement the child safeguarding indicators. But some indicators could probably use a few additional rounds of iteration before implementation, such as those perceived to be largely free text coded (e.g. self-harm), those that may require an additional indicator to improve precision (e.g. depression), and those that require better data integration (e.g. neonatal persistent jaundice). The operationalisation profiles outlined in Appendix E.2 could use further refinement and input.

8.5.4.4 Why was so much scheduled "for future development"?

The selected indicators need to be prospectively pilot tested in UK general practices to tease out the issues flagged in the operationalisation process, such as timing of diagnostic tests and precise age groups. Pilot testing also ensures indicators measure appropriate care. I had planned this step in my original thesis proposal but unfortunately this was not feasible in the time available. Campbell *et al.* (3) articulated the process used by NICE in which indicator sets are evaluated for feasibility with experts in clinical coding, pilot tested, and evaluated by users using qualitative interviews. This process has revealed important unintended consequences of indicators; for example, a draft palliative care indicator was flagged as potentially causing harm to patients.(48) Given the comprehensiveness of the NICE pilot process, it is perhaps more appropriate that only those indicators with a high probability of implementation in UK general practice are tested. I plan to submit the draft indicators to NICE, outlining the detailed process used to draft them, and hope they would review and consider the indicators for pilot testing.

8.5.5 What gaps and weaknesses are exposed by drawing up the specifications?

8.5.5.1 Are some conditions too rare for quality measurement?

Defining the operationalisation parameters for the draft indicators reinforced the importance of prevalence. Some conditions are only encountered once or a few times in a GP's career. A challenge in quality marker development is balancing these rare but important conditions with common ones. Previous indicator initiatives, in particular the QOF, did not consider rare conditions.(49) However, the expert panel felt GPs should not '*wash their hands*' of rare disorders since they play an important role in identifying and managing all childhood illnesses. But one GP warned that the rarity of some disorders may make primary care clinicians skeptical about the whole indicator development process and this could result in unintended consequences. It may be that there should be two types of quality indicators; 1) those for common conditions, or typical *'QOFable'* indicators as described by Lester and Campbell (49); and 2) those for rare illnesses which focus on significant event analysis. While this would add a level of complexity to quality measurement, it would incentivise care improvement for those important conditions.

8.5.5.2 How to design quality indicators that measure care not already being delivered?

A frequent issue raised by GP experts was whether or not the indicators would only report care of those patients already receiving it. For example, for the self-harm indicator, there was a concern that it would only ensure those children that are coded as having self-harmed have a clearly documented assessment and management plan. However, the intention of the indicator is to detect those children that have self-harmed and are *not* receiving high quality care. Yet many of these children are not

receiving adequate care because they are not identified in the primary care record. This was a particular concern for conditions that are poorly defined or largely coded in free text (which would not be easily visible for other care providers). However, there was a clear and strong statement from several GPs that those indicators should *incentivise* better primary care. But the risk of unintended consequences is always present, and piloting will provide further answers.

8.6 Conclusions

The 26 selected quality indicators agreed by the expert panel have strong face validity and should be feasible to implement. At least one indicator was selected for each priority area, covering a number of individual topics, but the list is not without gaps, and coverage of individual conditions is patchy.

The selection criteria used, where a single panel member could reject an indicator, meant that GPs had considerable influence on the final indicator set. For some topics, this was clearly the case where indicator inclusion was certain except for one panellist rating. However, the panel rejected indicators which would have been difficult (but not necessarily unfeasible) to implement and perhaps over-emphasised '*low-hanging fruit*' (e.g. easily measurable targets). They were also inconsistent, selecting some indicators that required better data integration (e.g. neonatal jaundice) but rejecting others (e.g. immunisation).

Some panellists saw the study as a process for general practice to identify markers of excellence (i.e. *what should be feasible?)* but others seemed overly pragmatic (i.e.

what is feasible today?). There was a pre-occupation with QOF targets, and this discussion lost sight of the original aim to ultimately develop robust quality indicators for child health. Despite my best effort to clarify this distinction, this effect was more pronounced than I had anticipated.

There is a large gap between making recommendations for implementing quality indicators on one side of A4 that would be accessible to clinician stakeholders and policy makers, and operationalising the recommendations nationally in primary care. However, most of the quality indicators described in detail in this chapter can be implemented but would require clinical testing to determine the precise definitions required for valid quality indicator measurement.

8.7 References

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Chapter 9: Conclusion

9.1 Summary

9.1.1 Why did I start?

At the beginning of this programme of research, it was not possible to say with certainty if the quality of primary care delivered to UK children was adequate, poor, or excellent. Yet it was possible to determine the quality of adult primary care where indicators in the Quality and Outcomes Framework identified care gaps. This identification of care deficiencies prompted measurable improvements in quality and lives saved. Children were largely excluded from QOF at its inception in 2004 and from subsequent reorganisations. There was also insufficient information to identify how to achieve similar child health gains (or even whether they could be achieved in QOF). The principal objective of this thesis was thus to define a set of quality indicators that would be feasible to implement and have the potential to improve the quality of care provided for children in UK general practice, providing a set of tools to enable similarly effective quality gains for child health care.

9.1.2 Have things changed since I started in 2009?

Despite the identified deficiencies in the Quality and Outcomes Framework in 2009 and the concerns about the quality of children's care outlined in this thesis and elsewhere, little has changed. Children are still largely excluded from QOF in 2013 and pressure to take action is growing: the 2012 'Report of the Children and Young People's Health Outcomes Forum' called the situation a "completely inadequate reflection of the workload of general practice or the potential quality gains that could be achieved by improving primary care."(1)

9.1.3 What have I achieved?

In this thesis I have produced a set of 26 indicators which reflect the most important child health areas identified by primary care clinicians that align with GPs' internal motivation and professional values. I have used methodology consistent with NICE but not constrained by its narrow remit. This methodology broadened the focus to include other relevant domains of care delivery, such as child safeguarding and GP training. This research also includes indicators which prompt GPs to critically reflect on their actions (e.g. rationale for antibiotic prescribing), taking into account individual patient concerns. The indicators that were not selected by the expert panel should not be discarded but instead modified, stimulating further steps to refine quality marker tools to improve the quality of care of children in the UK.

9.2 Evidence-base in child health

9.2.1 Poor evidence-base, or lack thereof

One of the major impediments to developing indicators for children is the lack of high quality evidence. I was surprised by the extent to which paediatric clinical practice is based on expert consensus – only a fraction of the indicators selected are supported directly by research. Although NICE and SIGN guideline consensus statements are a form of low quality evidence (and the only evidence possible for some complex topics such as safeguarding), they cannot replace or deter the need for primary research. Without strong evidence it is difficult to generate consensus on indicators that highlight practice variability and the diversity of clinical medicine. In hindsight, it may have been more prudent to focus on a single clinical topic and compile all relevant evidence to develop care indicators that reflected the literature accurately

(such as To *et al.* (2) for asthma and Avery *et al.* (3) for prescribing). However, this approach would have narrowed the scope of the thesis considerably and I would need to justify *why* I had chosen a particular condition or area. The methodology used to map the applicability of Cochrane reviews to clinical practice (and to burden of illness (4)) can be replicated to ensure future research focuses on areas with a clinical impact to improve the evidence-base for children.

9.2.2 Would a stronger evidence-base have changed the outcome?

The results of the RAND study are based solely on the ratings made by the expert panel who were purported to integrate their professional experience and the research evidence. Would a stronger evidence-base have altered the panel decisions? It appears unlikely, since most panel members discarded the GRADE evidence rating and used their clinical expertise. This may be because GPs were only given the GRADE evidence rating rather than the detailed research evidence. However, some topics evoked a stronger response from GPs (e.g. atopic eczema) than others (e.g. idiopathic constipation). This may reflect the particular group of GPs, but it may also reveal an additional, but difficult to quantify, factor that prohibit certain topics from becoming indicators. Are certain paediatric conditions simply too diverse, irrespective of the evidence, to develop into indicators with strong face validity? Given that my panel included GPs with a special interest in child health, I can only speculate that this affect would be more pronounced in a random sample of GPs. Raine *et al.* (5) outline a clear methodology for how these factors can be investigated, perhaps using qualitative analysis techniques similar to Bobrovitz *et al*. (6).

9.2.3 What is the 'best' evidence?

The RCT has long been considered the gold standard for 'high quality' evidence. While clinical trials are desirable, they generally do not provide enough detailed information on how interventions can be applied in all patients and in all populations. This is in part due to (poor) reporting, and in part due to the complexity of medicine: not all patients respond uniformly to prescriptions or take medications according to the rigid schedules described in trials. An alternative is 'N of 1 trials' which provide evidence tailored to patients' unique characteristics, but these face many barriers and only apply to chronic conditions such as ADHD (as shown by Nickles *et al.* (7)). Hence, guidelines are necessary to contextualise data from trials for implementation, but these are not without their limitations. There must be a better, more systematic way forward. Large-scale pragmatic RCTs embedded in everyday clinical practice provide one opportunity, and the merits are described by Staa and colleagues who remarked optimistically that, "narrowly restricted studies with questionable external validity need not be the mean."(8) These trials, however, require health care professionals (and ethics committees) to acknowledge the uncertainty of clinical practice (and to overcome the 'God-complex' described by Archie Cochrane (9)) for which the profession may not be ready, particularly in paediatrics.

9.3 Reflecting on the methodological approach

9.3.1 Was the NGT necessary?

The Nominal Group Technique study resulted in eight broad clinical areas on which to focus indicator development, but the topic breadth did not make the process of indicator drafting straightforward. Some panel members suggested that it would have

been useful to simply select one clinical topic for each of the ten domains of the RCGP Child Health Strategy.(10) This may have been more efficient, asking the expert panel to select a single condition for each area to focus indicator development, and would also have allowed a more thorough interrogation of the research literature. Indeed, six of the eight NGT priority areas overlapped with the RCGP Strategy, and this helped triangulate the results to provide external evidence that they had some face validity. However, the approach suggested by panel members would have placed significant emphasis on the Strategy, a policy document created by the RCGP for its members, and it is possible this could have undermined the final indicator set, labelling it a product of the RCGP. The priority areas identified in the NGT were informed by research evidence and generated using a transparent methodology. The technique should increase the face validity to frontline clinicians but also risks being labelled as '*white tower*'. Nevertheless, the NGT could play an important role in future prioritisation processes by making them more objective and transparent, particularly with many local decisions required with the NHS reforms.

9.3.2 Participants and perspective taken

GPs are the only primary care professionals included in this thesis. They provided frontline perspectives, prioritised the most important topics and selected appropriate indicators. In essence, the quality indicators were developed *by* GPs *for* GPs, and this served as both a strength and a weakness. The indicators are in accordance with professional values, maximising face validity and increasing the likelihood they will be used in clinical practice. However, not all care delivered to children is completed by GPs; much is done by practice nurses, health visitors, and community paediatricians. The hospital setting (e.g. A&E) is also clearly relevant, and these

clinicians could have provided input on admissions for ambulatory care sensitive conditions. While the indicator set omits important areas of child health, it has broad GP support from the expert panel to progress to pilot testing. The integral role of GPs in the new clinical commissioning groups may increase the likelihood that the indicator set will be used in future initiatives.

It is also important to consider the type of GPs involved in this thesis, particularly the consensus studies. There is clearly a bias towards *'eminent'* GPs over *'coal-faced'* GPs; the overlap between the NGT priority areas and the Child Health Strategy supports this observation. This is not surprising given that the RCGP Child Health Clinical Champion suggested the panel members. Yet the low participation rate for the interview study described in Chapter 4 suggests that it would have been difficult to recruit full-time GPs. Moving forward, perhaps the best way to incorporate frontline perspectives is through pilot testing the indicators, as recommended by Campbell *et al.* (11), or through community-based studies. Alternatively, the Delphi technique may be the optimal method to involve busy GPs as it is convenient and does not require a face-to-face meeting.

An important omission from this programme of work is the voice of children and young people and their parents/carers. Unlike Sayal *et al.* (12), I did not take a patient or parent/caregiver led approach to indicator development and did not seek their views. While this approach was considered at the outset of my thesis, the necessary skills and training were not readily available to me. However, children and young person feedback from the 'Children and Young People's Health Outcomes Forum' provided support for some of the indicator topics (e.g. delayed diagnosis and training

of health care professionals).(1) Yet, other topics identified in the forum's report were not included in the indicator set, such as the transition of care for adolescents with chronic conditions. At the pilot study stage it should be possible to seek input from those patients who would be the most affected by the indicator. For example, a focus group study with parents/carers and children with ADHD could explore their views on the stimulant medication monitoring indicator to ensure the indicator aligns with important patient-oriented outcomes. Further, the NICE QOF indicator programme recently proposed that pilot testing for the 2013-16 contract may include acquiring patient views on quality indicators.(13) Future indicator development initiatives should involve children and young people from the outset (along with parents/carers) to ensure markers align with patients' priorities.

9.3.3 Role of the facilitator

In both the NGT and the RAND method, the facilitator plays an integral role and their characteristics affect the decisions made.(14) I facilitated both meetings because I felt impartial and independent, without a specific inclination or preference for certain topics that I thought should be included (and consequently, this kept the thesis scope too broad). However, it is important to reflect on the influence of my position as a researcher on the results. Drawing on concepts initially applied to ethnographic research (15), I could be considered, at face value, to be an *'outsider'* as a non-UK based student, without clinical experience in UK general practice, and from the academic '*white tower.*' Yet, as a medical trainee interested in primary care and affiliated with a general practice department, I could also be considered an '*insider.'*

My position, and the panel's perception of my position, likely affected the GPs contribution to the study with potential benefits and drawbacks. It is possible that the group was more likely to give honest input, free from concern that their input would clash or contradict a senior figure in the profession. Yet, they may have been less receptive to an *'outside'* moderator who was fairly junior and without clinical exposure to UK primary care. The panel may have been more respectful of the project because it was explicitly for a doctoral thesis rather than service development. Alternatively, they might not have taken the project as seriously because it is academic in nature and perhaps without definitive policy implications. It is also important to note that this research was not conducted in isolation: I had support and assistance by my supervisor (former RCGP Child Health Clinical Champion) for both meetings who occupied an *'insider'* role.

The literature on this topic illustrates that the dichotomy of '*insider'* or '*outsider'* is over-simplistic (as shown above), and most researchers occupy *'the space between'* as described by Dwyer and Buckle.(16) I believe that I occupied a space along the insider-outsider continuum. Positioning as an insider helped to successfully recruit an expert panel of UK-wide GPs (and to acquire study funding from the RCGP). It also meant that I could understand and relate to issues raised by GPs about clinical care, such as the difficult measuring vital signs in young children. Yet, I was clearly an outsider to QOF – I did not share GPs intimate experiences of the intricacies and complexities of a pay-for-performance system. However, this helped make explicit key issues that perhaps may not have been teased apart by an insider. Ultimately I believe (and hope) the influence of my position was positive and added a level of objectivity to the programme of research without taking away the perspectives of GPs.

9.3.4 Consensus, or importance?

One problem with seeking consensus is that it often reinforces current group beliefs and opinions rather than bringing to light what is necessary or important. Fundamental change often comes through '*paradigm shifts*' which make people feel uncomfortable by challenging the status quo. However, these changes often result in meaningful gains. In reference to the on-going debate about the merits of the NHS in the 1970s, Julian Tudor-Hart wrote about the culture shift required in medicine:

> "*The idealised, isolated doctor/patient relationship, that ignores the needs of other people and their claims on the doctor's time and other scarce resources, is incomplete and distorts our view of medicine….The ambition to practise this ideal medicine under ideal conditions still makes doctors all over the world leave those who need them most, and go to those who need them least.*"(17)

Over forty years later, the merits of the NHS are difficult to dispute. Upon reflection, perhaps rather than use '*validity*' and '*feasibility*' for the RAND method, I should have used '*importance*' or '*impact on children's health*' to identify which indicators would influence paediatric care in a meaningful way. Setting the criteria at unanimous meant that a single GP could de-rail the process and exclude an indicator (which was the case for several health promotion indicators). Nevertheless, this thesis was not conducted in isolation and I (tried to) balance importance with acceptability and feasibility. Given the current NHS reforms and the political nature of QOF, increasing the visibility and emphasis of child health irrespective of the topic or clinical area is arguably of equal importance, and perhaps some of these indicators have a reasonable chance of succeeding.

9.3.5 Overall approach – pragmatic, efficient or crude?

Given the complicated topic, pragmatic decisions were made throughout to keep the thesis feasible and not '*overly academic*'. The large number of potential topics meant it is likely some important ones were excluded, and there was not sufficient time for in-depth discussion of each clinical area. On one hand, this may have been more representative of real world clinical practice and decision-making where only the most salient topics are addressed; on the other hand, the limited discussion time may have prompted the group to glaze over topics that should be the focus of more work. It did have an element of efficiency and utility: NICE has only produced five Quality Standards relevant to children in the past three years (recently publishing standards on asthma, epilepsy and looked-after children, reaffirming their selection in the indicator set).(18) However, the number of topics listed on the NICE website scheduled as '*in development*' has rapidly expanded, but the methodology used is less robust than the QOF programme (and less so than the original guidance published in 2009) but has more stakeholder involvement.(19) Despite the importance of feasibility, I did not have time to test the indicators in clinical practice but the operationalising step should increase the likelihood that this will happen. Again, this may have been possible if I selected a single clinical topic.

9.4 Implications for future research

9.4.1 HES data, and linkage to primary care

The limitations of HES data precluded definitive conclusions on the hospital admissions analysis described in Chapter 5. In particular, lack of documentation of time of admission and discharge makes it difficult to distil the precise length of stay,

or to determine whether admissions are in-hours or out-of-hours. Other key data absent from HES are information on diagnostic investigations completed on admitted patients that would help differentiate which admissions are for investigations not available in primary care. It is also important to evaluate the whole care pathway by linking HES inpatient data with A&E and primary care. These links could identify primary care interventions that may reduce the chance of hospital admission. For example, a recent US study found children who miss over half of their well-child preventative care visits are at a two-fold increased risk of an ACSC admission than children who attend, rising to a three-fold risk in children with chronic conditions.(20)

9.4.2 Appropriateness and variation in hospital admissions

Future studies should evaluate the appropriateness of admissions for ACSCs to determine whether they are indeed *sensitive* to interventions in primary care (such as replicating the methodology used by Flores *et al.* (21)). It is also important to explore access-related issues, such as why parents with sick children are bypassing primary care (22) and whether many less than 24-hour admissions are for observation in short-stay units. The high levels of unexplained variation in hospital admissions is concerning. Variation can be appropriate, a sign of innovation and new modes of care delivery, but it can also be a marker of poor and inappropriate care. If variation persists despite adjusting for deprivation, investigating other variables may prove informative (i.e. age, sex, parental factors, size of hospital, presence of paediatric emergency department, and place of referral).

9.4.3 Quality indicator field testing

The recent joint paper 'Commissioning a Good Child Health Service' published by the RCGP, the RCPCH and the Royal College of Nursing outlines a *'hub-and-spoke'* model of care delivery with GPs at the centre (*hub*) linking up with other professionals (*spokes*).(23) Rather than pilot test indicators exclusively in general practice as recommended by Campbell *et al.* (11), the validity and feasibility of the indicators could be evaluated using the new '*hub-and-spoke'* model. For example, a Delphi study with a large number of UK-wide stakeholders (e.g. GPs, nurses, health visitors, A&E physicians, public health physicians, and paediatricians) could select the most important indicators. Then, these indicators could be rolled out in a coordinated multi-disciplinary fashion, potentially bridging professional boundaries and leading to integrated care for children.

9.5 Reflecting on the final quality indicator set

9.5.1 Potential health impact

NICE requires that indicators considered for inclusion in QOF target common conditions with a significant impact on morbidity/mortality and evidence of cost-effectiveness.(24) Clearly the goal of implementing quality indicators is to improve health, or lead to a '*health gain'* in the population to which they are applied. For many topics in adult medicine (e.g. diabetes), there is abundant literature to demonstrate intervention efficacy and cost-effectiveness. Yet, this is not easy in paediatrics given the poor evidence-base highlighted in this thesis. The application of these standards has resulted in the continued exclusion of children in QOF. It is a fruitless endeavour to continue applying these criteria to paediatric indicators, but it is possible to (not

exhaustively) explore some of the potential health gain achieved from the 26 indicators (described in Appendix E.2), both from a narrow '*QOF-lens'* and from a generalist context (section 9.5.2).

The health gain for most serious illness indicators is the early diagnosis of easily missed conditions (e.g. Coeliac disease (25) and Type 1 Diabetes (26)) which may improve quality of life and reduce complications (e.g. DKA). Mental health conditions are common (27) and poorly recognised in primary care.(28) The depression indicator will identify high-risk adolescents and ensure they are appropriately managed, potentially reducing unnecessary A&E visits and episodes of self-harm. Other indicators may minimise adverse effects in children prescribed stimulant medication for ADHD, a condition with an estimated prevalence of 5%.(29)

In 2008, there were 6300 paediatric medication related safety incidents (1) yet the 2013/14 QOF contract retired the medication review indicator.(30) Given children's reliance on parents/carers for medication adherence, and the potential fall in care quality with indicator retirement (31), the prescribing indicators may improve medication safety. Routinely managed conditions are common. For example, the childhood prevalence of idiopathic constipation varies from 5-30%.(32) Appropriate evidence-based management may reduce secondary care referral, leading to cost-savings for the NHS.

While the potential health gain for each indicator varies, with so few child-specific indicators in QOF, one could argue that *any* additional indicators, irrespective of the topic or condition, will lead to improvements in health for British children.

9.5.2 Medical generalism

The discussion of potential health gains highlights a salient tension between the patient-centred approach in primary care (bio-psychosocial) with the condition-specific (biomedical) quality indicators produced in this thesis. GPs are generalists who deliver care to patients of all ages and with various co-morbidities, often liaising with secondary care and addressing the social determinants of health. The importance of GPs as generalists was reinforced by the recent RCGP report 'Medical generalism: why expertise in whole person medicine matters.'(33) This report outlines how GPs can retain their essential generalist skill-set in the future.

Many important issues that relate to medical generalism, such as access and continuity of care, do not have relevant indicators in the final set. This exclusion reflects the methodological approach taken and the complexity of certain topics. The technical-rationale approach of formal consensus methods, where indicators are based on robust evidence and professional consensus, led to a fairly narrow list of indicators with a wide (and difficult to quantify) range of potential health gains (section 9.5.1). But this list also reflects practitioners' desire for indicators to be within their control and achievable, particularly if they may be used for performance assessment (e.g. QOF). I believe the exclusion of complex topics is probably appropriate. For example, a recent study by O'Loughlin *et al.* (22) found most patients with sick children present directly to A&E and bypass primary care, raising concerns about access to general practice. However, access issues are not unique to paediatrics. It is important to consider that a child-specific access indicator may have unintended consequences on other patients (and may in some ways, undermine the generalist approach by only focusing on a specific population).

Some of the 26 indicators, however, are broad in focus. For example, the GP training indicator, which specifies GPs should document paediatric CPD activities undertaken within each 5-year re-validation cycle, aligns with the concept of medical generalism. The antibiotic prescribing indicator emphasises the rationale for prescribing rather than simply the rate, encouraging GPs to reflect and justify their decision. Yet, there are clear gaps: no indicators focus on measuring patient centred care, carer friendliness, or patient involvement. The tension between the biomedical and bio-psychosocial approach to general practice requires continual reflection, and quality indicators (particularly '*QOF-like'* ones) are probably not suited to address the latter. In reality, any initiative can only ever focus on certain aspects of care to be valid and feasible, and trying to address both may be problematic.

9.5.3 Are the indicators measurable?

Lester and colleagues recently published qualitative interview study explores GPs' views eight years after QOF was introduced and suggests GPs are willing to take on new, more challenging indicators to improve patient care.(34) This was shown with the new rheumatoid arthritis indicators which, when piloted, *'pushed'* practices but were considered appropriate. GPs also wanted "greater professional involvement" in indicator development (34), echoing findings from the qualitative interview study described in Chapter 4 which suggests alignment of indicators with professional values will encourage internalisation of motivation. Therefore, while some of the 26 indicators in this thesis are *'QOF-like'*, many are not, and will, like the new rheumatoid arthritis indicators, push primary care teams to make them measurable. QOF is evolving and clinicians are embracing new opportunities to improve patient care.

9.6 What happens next?

"We cannot afford to rest on our laurels with the quality and outcomes framework."

- Barbara Starfield, 1932-2011 (35)

The output of this programme of research coincides with major organisational reform in the NHS, in particular the introduction of clinical commissioning groups in line with the new Health and Social Care Bill.(1) This research is also contemporaneous with a shift in UK policy from measuring processes and structures to measuring outcomes (with some suggesting a 'public health impact score' as an alternate measure of QOF effectiveness (36)). But there is a risk that by focusing on mortality reduction (a rare paediatric outcome), the exclusion of children will get worse. The large number of outcome indicators for children and young people in the 'NHS Outcomes Framework' that are classified as '*in development*' or lack a feasible data source is problematic (1) and reinforces the prospect that children will be again left out. Howe *et al.* emphasised that it was important *all* patients receive high quality care to 'recommended standards.'(37) These indicators, representative of a range of conditions treated in UK general practice, are one potential tool to ensure children receive the high quality care they deserve.

There are now five relevant child-specific NICE Quality Standards published and many topics currently in development (e.g. ADHD, depression, self-harm, eczema, headaches, and UTIs).(18) These standards are considered for inclusion in a 'commissioning indicator set' to be used by the new GP-led clinical commissioning groups.(38) NICE also suggests that clinicians use the quality statements for audit and to improve care delivery. However, it will not be easy for practitioners and commissioners to sift through hundreds of standards published on the NICE website.

Alternatively, practitioners and commissioners can use the 26 rigorously developed, primary care focused indicators produced in this thesis. These markers cover a breadth of important paediatric topics and can be used by frontline practitioners for quality improvement, similar to those markers developed by Marshall *et al.* (39) in 2001.

In the US, primary care indicators not only improved care (40) but were signed into law by President Obama in 2009 through the Children's Health Insurance Program Reauthorisation Act.(41) Bolder steps are needed to implement paediatric indicators in UK primary care. However, there is a large gap between making recommendations for implementing indicators and operationalising them nationally in UK primary care. The process of quality indicator development is also political and divisive. This was demonstrated by the original 2004 QOF indicators, and more recently by the 'Children and Young People's Outcome Forum' which largely excluded primary care despite explicitly stating its importance.(1) I plan to submit the draft indicators to NICE, outlining the important research findings, seeking the necessary support and infrastructure to pilot them. It is unlikely that NICE will consider and review all 26 indicators: some clearly fall outside their remit (e.g. training) and others require substantial refinement. To increase the likelihood that a few indicators may be implemented, I selected seven which I believe the NICE QOF Advisory Committee should consider for pilot testing.

Serious illness indicator 5, which focuses on referral for children with a non-febrile seizure to secondary care, has recently been developed into a NICE quality standard.(42) This reinforces the importance of the topic and adds weight to its case for piloting. The sole health promotion indicator targeting children with diabetes for

influenza immunisation is feasible, reinforced by Department of Health guidance, builds on existing QOF infrastructure, and will benefit '*at-risk'* children.(43) Mental health indicator 4 (stimulant medication monitoring), routinely management conditions indicator 3 (idiopathic constipation treatment) and practice indicator 2 (prescription medication review) have clear potential health gains (section 9.5.1), and should be measurable. These three indicators are particularly important after the retirement of prescribing indicators in the 2013/14 QOF contract.(30)

One area where there is strong consensus that indicators need to be urgently implemented is child safeguarding. The two selected child safeguarding indicators (1 and 2) have strong primary care support and the appropriate READ Codes for documenting child maltreatment concerns in primary care defined by Woodman *et al.* (44) outline how these indicators can be operationalised for pilot testing. The children's 'Outcomes Forum' also called for child safeguarding indicators (1), and there are no NICE quality standards in development for child safeguarding (or other published indicators).(18) If only a small number of markers can be put forward, perhaps these seven are the ideal candidates. We now have the opportunity for these indicators to impact quality.

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Appendices

Appendix A: Chapter 4 – Qualitative interview study

Appendix A.1: Proposed draft interview guide

1. Can you tell me about the care of children in general practice?
    a. What does it mean?
    b. Can you think of any examples?
2. What do you feel is the most important aspect of care in children in general practice?
    a. Can you give me any examples of that?
    b. Why do you think that?
3. There are several terms for quality measurement, such as "quality marker", "quality indicator" and "performance indicator." What do these terms mean to you?
4. What do you think characterises a good quality marker?
    a. Can you think of any examples of good quality markers?
    b. Why do you think these are good?
5. What do you think characterises a poor quality marker?
    a. Why do you think this?
    b. Do you have a particular experience of this?
    c. If no poor quality markers come to mind, are there any quality markers that are not as good as previously mentioned, and why?
6. Has the introduction of quality markers affected your interaction with patients?
    a. In what ways?
    b. Can you think of any examples?
7. Let's move on to think about quality markers and children. What does the term "quality marker" mean to you in regards to children?
    a. Is this very different to adults?
8. Do you think that the quality outcomes framework (QOF) or pay-for-performance quality markers system has affected the quality of care of children?
    a. Why? Why not?
9. In what ways could you see the quality outcomes framework (QOF) improving the quality of care for children in the UK?
    a. Can you expand on that?
10. Let's move on to think about specific conditions. What childhood conditions do you think should have quality markers in children?
    a. Why? What is it about these conditions?
    b. Can you think of any examples from your experience?
11. [Using topics listed in interview] Let's talk about one or two specific conditions. Can you tell me about some examples of quality markers and how they could be measured?
    a. Can you elaborate into some more detail?
    b. What do you think the barriers to the implementation of quality markers?
    c. How can they be improved?
    d. Examples?

12. What childhood conditions do you think should not have quality marker?
    a. Why/Why not?
13. What do you think is the best way to measure quality of care in children?
    a. Is this very different to quality marker in adults?
    b. Why/Why not?
14. How should quality markers in children be measured?
15. We are also looking at external markers of care outside of the general practice such as in the hospital and we would like to get feedback from GPs about what they think about them. Do you think that hospital admissions in children for certain conditions reflect a failure of primary care?
    a. What do you think about this?
16. Should there be quality markers based on hospital admissions?

Appendix A.2: Frequency by which general practitioners interviewed mentioned specific conditions for quality indicator development

Condition	Number of general practitioners
Management of acute illnesses	
Antibiotic prescriptions	5
Acutely unwell children	5
Constipation	2
Ear infections	2
Pre-school wheeze	2
Urinary tract infections	2
Croup	1
Febrile child	1
Meningitis	1
Migraine	1
Mild infectious diseases	1
Management of chronic conditions	
Asthma	8
Epilepsy	6
Type 1 Diabetes Mellitus	6
Mental health	5
Learning disabilities	4
Cardiac conditions	3
Eczema	3
Cystic fibrosis	2
Attention deficit hyperactivity disorder (ADHD)	1
Cancer	1
Cerebral palsy	1
Children with special needs	1
Coeliac disease	1
Eating disorders	1
Health promotion	
Immunisations	6
Obesity	6
Adolescent health	4
Health checks	4
Chlamydia testing	3
Sexual health	3
Nutrition	2
Teen pregnancy	2
Exercise/healthy lifestyle	1
Post-natal education	1
Organisation and structure of care	
Child protection / ‘at risk’ children	3
Accidental / non-accidental injury	2
Frequent consultations / missed appointments	2
Access to general practice	1
Confidentiality	1

Appendix B: Chapter 5 – Hospital admissions analysis

Appendix B.1: Disease codes associated with ACSC in common use in the NHS

Condition	ICD-10 codes	Changes from Purdy's 'common NHS subset'
Acute infections		
Dehydration and gastroenteritis	E86 K52.2 K52.8 K52.9 A02.0 A04 A07.2 A08.0 A08.1 A08.3 A08.4 A08.5 A09	Added A02.0 A04 A07.2 A08.0 A08.1 A08.3 A08.4 A08.5 A09
Lower respiratory tract infections	J10 J11 J12.0 J12.1 J12.2 J12.8 J12.9 J13 J14 J15.3 J15.4 J15.7 J15.9 J16.0 J16.8 J18	Added J12.0 J12.1 J12.2 J12.8 J12.9 J16.0
Upper respiratory tract infections	H66 H67 J02 J03 J04.0 J06 J31.2	Added J04.0
Urinary tract infections	N10 N11 N12 N13.6 N15.9 N30.0 N30.8 N30.9 N39.0	Added N15.9 N30.0 N30.8 N30.9 N39.0
Chronic conditions		
Asthma	J45 J46	N/A
Diabetes	E10.0–E10.8 E11.0–E11.8 E12.0–E12.8 E13.0–E13.8 E14.0–E14.8 E13.9 E14.9	Added E13.9 E14.9
Epilepsy	G40 G41 R56	Removed O15 (eclampsia)
Other		
Vaccine preventable diseases	A35 A36 A37 A80 B05 B06 B16.1 B16.9 B18.0 B18.1 B26 G00.0 M01.4	N/A

Appendix B.2: Differences in disease codes from NHS Outcomes Framework and Purdy

	No. of emergency admissions, 2010 (0-14 years)		
ACSC	*Purdy codes (modified)*	*NHS Outcomes Framework codes*	Main reason for change in number of admissions
Asthma	23 667	23 667	Same codes
Diabetes	2176	5128	Addition of E10.9 (Type 1 diabetes mellitus without complications) Addition of E11.9 (Type 2 diabetes mellitus without complications) Addition of E12.9 (Malnutrition-related diabetes mellitus without complications)
Epilepsy	23 504	7967	Removal of R56 (convulsions not otherwise specified)
LRTI	15 231	43 080	Addition of J21 (*Bronchiolitis*)

Appendix B.3: ICD-10 codes used to define ACSC in final analysis (Purdy's)

Ambulatory care sensitive condition	ICD-10 codes
Acute infections	
Dehydration and gastroenteritis	A02.0 Salmonella enteritis A04 Other bacterial intestinal infections A07.2 Cryptosporidiosis A08.0 Rotaviral enteritis A08.1 Acute gastroenteropathy due to Norwalk agent A08.3 Other viral enteritis A08.4 Viral intestinal infection, unspecified A08.5 Other specified intestinal infections A09 Diarrhoea and gastroenteritis of presumed infectious origin E86 Volume depletion K52.2 Allergic and dietetic gastroenteritis and colitis K52.8 Other specified non-infective gastroenteritis and colitis K52.9 Non-infective gastroenteritis and colitis, unspecified
Lower respiratory tract infections	J10 Influenza due to other identified influenza virus J11 Influenza, virus not identified J12.0 Viral pneumonia, not elsewhere classified J12.1 Respiratory syncytial virus pneumonia J12.2 Parainfluenza virus pneumonia J12.8 Other viral pneumonia J12.9 Viral pneumonia, unspecified J13 Pneumonia due to Streptococcus pneumonia J14 Pneumonia due to Haemophilus influenzae J15.3 Pneumonia due to streptococcus, group B J15.4 Pneumonia due to other streptococci J15.7 Pneumonia due to Mycoplasma pneumoniae J15.9 Bacterial pneumonia, unspecified J16.0 Pneumonia due to other infectious organisms, not elsewhere classified J16.8 Pneumonia due to other specified infectious organisms J18 Pneumonia, organism unspecified
Upper respiratory tract infections	H66 Suppurative and unspecified otitis media H67 Otitis media in diseases classified elsewhere J02 Acute pharyngitis J03 Acute tonsillitis J04.0 Acute laryngitis J06 Acute upper respiratory infections of multiple and unspecified sites J31.2 Chronic pharyngitis
Urinary tract infections	N10 Acute tubulo-interstitial nephritis N11 Chronic tubulo-interstitial nephritis N12 Tubulo-interstitial nephritis, not specified as acute or chronic N13.6 Pyonephrosis N15.9 Renal tubulo-interstitial disease, unspecified N30.0 Acute cystitis N30.8 Other cystitis N30.9 Cystitis, unspecified N39.0 Urinary tract infection, site not specified
Chronic conditions	
Asthma	J45 Asthma J46 Status asthmaticus
Diabetes	E10.0-E10.8 Insulin-dependent diabetes mellitus E11.0-E11.8 Non-insulin-dependent diabetes mellitus E12.0-E12.8 Malnutrition-related diabetes mellitus E13 Other specified diabetes mellitus E14 Unspecified diabetes mellitus
Epilepsy	G40 Epilepsy

	G41 Status epilepticus R56 Convulsions, not elsewhere classified
Other	
Vaccine preventable diseases	A35 Other tetanus A36 Diphtheria A37 Whooping cough A80 Acute poliomyelitis B05 Measles B06 Rubella [German measles] B16.1 Acute hepatitis B with delta-agent (coinfection) without hepatic coma B16.9 Acute hepatitis B without delta-agent and without hepatic coma B18.0 Chronic viral hepatitis B18.1 Chronic viral hepatitis B without delta-agent B26 Mumps G00.0 Haemophilus meningitis M01.4 Rubella arthritis

Appendix C: Chapter 6 – Nominal Group Technique

Appendix C.1: Background information sent to expert panel on 19 May 2011

Background

The care of children plays an important role in general practice. Children comprise approximately 20% of a general practitioner's patient population, represent 18% of consultations and children under 4 years have an average of 6 consultations per year with general practice.(1) In both developed and developing countries, the clinical care of children accounts for a large proportion of primary care. For example, in the UK, over 95% of patient contacts with NHS are made in primary care leading to an excess of 300 million per year (2), and consultations with children under 15 years represent 18% of all primary care consultations in the UK, 17% in the US and 12% in Australia.(1, 3, 4) A 10,000-patient general practice will expect to have 1,500 children under 16 years registered.(1)

However, less than 3% of the UK general practice pay-for-performance quality markers relate to them. Many of the existing clinical markers actively exclude children; for example, the diabetes and epilepsy markers only apply to adults. Several aspects of paediatric care remain outside the scope of Quality and Outcomes Framework (QOF) and now receive less priority and attention. The confidential enquiry into child deaths highlighted a number of areas where the primary care of children could be improved – recognition of serious illness, chronic disease management, children with disability, palliative care, and mental health of teenagers.(5) Both the '*Why Children Die'* report and Department of Health '*Healthy Lives, Brighter Futures*' strategy call for consideration and development of quality markers for children to be included within QOF.(5, 6)

Significant numbers of children are still living in poverty and inequalities in terms of access to healthcare remain in the UK. For example, recent changes in the delivery of primary care have led to an increase in Accident and Emergency presentations, short admissions, re-admissions and the number of unplanned hospitalisations in children.(7, 8) There is an urgent need to uniformly improve the quality of care of children in UK general practice.

Currently, there is a deficiency in the ability to measure the quality of care of children in general practice. Several country specific guidelines recommend quality measures based on a synthesis of evidence and consensus statements.(9-11) The National Service Framework (NSF) for Children, Young People and Maternity Services 2004 defined standards in ten headline categories, most of which have direct relevance to GPs.(12) In addition, the RCGP has been involved in developing quality standards for children, such as the RCGP Toolkit for Safeguarding Children and Young People in General Practice.(13) However, professional consensus in UK general practice regarding which quality markers should be used to evaluate the quality of care of children is lacking.

To our knowledge, there has been no consensus study in the UK involving GPs to develop quality markers for children in primary care. Several research groups have utilised consensus techniques to develop quality markers in certain clinical areas, such as angina, type II diabetes, asthma and cancer.(14-17) Future initiatives to develop

quality markers in primary care should involve GPs to ensure they are relevant, applicable and important to general practice. General practitioners, as front line health care professionals, should steer the development of quality markers for children primary care.

Quality markers in children

NICE, responsible for recommending indicators for QOF, defines a quality standard as a "set of specific, concise statements that: act as markers of high-quality, cost-effective patient care across a pathway or clinical area, covering treatment or prevention [and] are derived from the best available evidence".(18) Baker and Fraser developed the ideal characteristics of 'review criteria' or measures to evaluate the quality of care which are: "based on research evidence; prioritised according to strength of research evidence and influence on outcome; measurable–clear and precise; [and] 4) appropriate to the clinical setting."(19) In practice, quality markers can target structure, process and outcomes measures, in addition to disease, treatment and practice-based domains, such as practice-based health promotion programs.

Numerous challenges impede the development of quality markers for children in primary care which have been described in detail by Beal and colleagues.(20) Children are rapidly progressing through developmental stages and are constantly changing physically, emotionally, and cognitively. Quality measures for GPs will likely differ based on age or developmental stage of the child assessed in primary care. In addition, the epidemiology in children differs to adults. Most children are relatively healthy while special populations of children will have a wide array of various medical conditions. In comparison, adult patients share common co-morbidities, such as hypertension, diabetes and coronary artery disease. Finally, children are dependent on parents and caregivers involved in decision-making. Evaluating the care of children depends on information derived from multiple sources including caregivers, school and relatives, increasing the complexity of the role of the GP.(20)

High quality evidence-base

The first step to developing a framework to evaluate and improve the quality of care of children is the identification of the evidence base for interventions relevant to child health and primary care. Systematic reviews are the most comprehensive syntheses of information in healthcare (21) and represent a logical starting point to identify high quality evidence relevant to a broad clinical topic.

The number of systematic reviews published annually has steadily increased over the past decade.(22) In 2007 alone, 2,500 systematic reviews of research were published, with roughly 20% of them produced through the Cochrane Database of Systematic Reviews (CDSR).(23) The primary aim of the Cochrane Collaboration is to make available up-to-date syntheses of reliable evidence regarding the benefits and risks of health care interventions.(24) Cochrane systematic reviews are widely regarded as methodologically rigorous and of higher quality than non-Cochrane systematic reviews.(24-28) The CDSR therefore represents a sample of high quality studies to better understand the current state of the evidence base.

A previous review described the evidence available from child-relevant systematic reviews in the CDSR, yet it did not determine the evidence-base relevant to primary care(24) In addition no previous studies have compared the scope and number of systematic reviews published with the burden of illness in general practice. Therefore, we completed an overview of systematic reviews in the CDSR relevant to the management of childhood conditions in primary care and compared the topics and number of systematic reviews with the burden of childhood illness in primary care in Australia, Netherlands, UK and US.

We identified 396 relevant systematic reviews; 358 included primary studies on children while 251 undertook a meta-analysis. Most reviews (n=218, 55%) focused on chronic conditions and over half (n=216, 57%) evaluated drug interventions. Since 2000, the percentage of paediatric primary care relevant reviews only increased by 2% (7% to 9%) compared to 18% (10% to 28%) in all child relevant reviews.

Respiratory conditions are the most common reason for general practice consultations in children representing 23-32% of all consultations, of which 43% (n=147) of included reviews were relevant. There was a discrepancy between the burden of illness and the corresponding number of systematic reviews. For instance, despite representing over 15% of general practice consultations, only 7% (n=23) of reviews were relevant to skin conditions. In contrast, 12% (n=42) of reviews were on psychological conditions even though these only represent a relatively small proportion of consultations in Australian and Dutch general practice (2-3%). When evaluating specific diagnostic categories in greater detail, the study shows that despite asthma representing 3-5% of consultations in Australia, UK and US, it is the focus of 23% (n=78) of reviews. However, only 2% (n=8) of reviews were on injuries despite being the reason for 7-10% of consultations.

Although Cochrane systematic reviews focus on clinical trials and do not provide a comprehensive picture of the evidence base underpinning the management of children in primary care, the mismatch between the focus of the published research and the focus of clinical activity is striking. Clinical trials are an important component of the evidence base and the lack of trial evidence to demonstrate intervention effectiveness in substantial areas of primary care for children should be addressed. The findings have been submitted to the journal *PLoS ONE*.

Qualitative interviews

We completed 20 face-to-face semi-structured qualitative interviews with general practitioners in the Thames Valley on the quality of care of children in general practice. The interviews focused on general practitioners viewpoints on the care of children in UK general practice and on childhood conditions to focus quality marker development. We identified a maximum variation sample based on age, gender, urbanisation, and patient populations. The following section outlines the preliminary findings from the analysis on the quality of care in UK general practice.

> *"... without a measure, how do we know?" QM04*

> *"...because we've got no markers of it, or nobody's actually looked at it, how would we know? We think we're doing best practice but we have no idea." QM05*

Broadly speaking, GPs felt that the overall care of children in general practice is good, commenting on the robust nature of the NHS to respond to the acute needs of children and families. In particular, UK primary care is able to deliver good care in areas of high need.

However, a recurring theme amongst GPs was the variability of quality of care for children in general practice, including models of care, changing and heterogeneous role of health visitors, variability of GP trainee training schemes, discrepancies in health services available to children compared to adults, variation in the management of acute and chronic conditions and the lack of continuity of care. In the following section, we will summarise the range of perspectives of GPs on certain areas where the quality of care of children could be improved. In the interest of brevity, the section is not comprehensive and will not highlight the many examples of high quality of care in general practice. Subsequently, further findings from the study will be presented at the June 10th meeting.

Organisation and structure of care

The strength of UK general practice is universality, available to support families and children in need. However, several concerns were raised regarding the variability of access to allied healthcare services (e.g. psychological services and counselling), secondary care and out-of-hours. In children, there is a dependence on secondary care for the management of chronic conditions and reduced access to these services leads to reduced quality of care, patient and family anxiety and increased used of inappropriate services (e.g. out-of-hours and A & E). In particular, GPs have reduced access to secondary care resources compared to adults. The ease of access to primary care appointments varies based on different practice policies and case-mix leading to varying access to face-to-face clinical assessments. In addition, a tension seems to arise from access to a health care professional and continuity of care, particularly for acute illnesses.

The change to the structure of out-of-hours care led to several concerns amongst participants. The clinicians who work in these settings are often unfamiliar with the local population and availability of services, rely largely on telephone triage over face-to-face clinical assessment and lack the continuity of care with patients. As a result, relationships established with families can be undermined and eroded by contradictory advice in out-of-hours.

The deteriorating role of the health visitor and their removal from general practices has led to a gap in the care of certain populations of children. In particular, the health visitors play an instrumental role in vulnerable families, such as those that are ‘at risk’ for social reasons (e.g. traveller’s families, socially deprived) and who have greater health care needs. They are in a unique position to build relationships in areas where GPs cannot. On-going open and regular communication between health visitors and general practice facilitates high quality care to children and families, and where their role has diminished; the perception of care has suffered.

Certain participants felt that the relationship and interaction with secondary and tertiary care was exemplary, with good dialogue and clear management roles. However, several GPs expressed concerns regarding poor communication and the lack of accessibility to paediatricians, especially compared to adult medicine. Furthermore,

the difficulty in communicating with Social Services seemed profound, undermining the effectiveness of child protection initiatives.

> *"I think the accessibility of primary care, to react to childhood inter-current illness, is amazing: the fact that you do not have to pay to take your child to see a doctor when your child's got a chest infection is a huge bonus." QM08*

> *"...education that you don't need an antibiotic for everything. Because one thing that really pees me off is you look after them, you look after them, 'no you don't need this, you don't need that, you don't'... and then they go to the out-of-hours, and the out-of-hours say here's amoxicillin. And that just drives us mad. Because it just completely undermines what you've done up to that point. Yes, snotty nose, snotty nose, snotty nose, antibiotic in the out-of-hours. There's no need for an antibiotic." QM14*

> *"I think we could coordinate care between health services, GP and secondary care services, a lot better. I mean I think we're a long way apart from each other and increasingly getting I think, we are getting further rather than closer." QM09*

Clinical management

The management of acute infections in children forms a major part of primary care and GPs indicated that there lacks a system of monitoring the appropriate care of acute illnesses. Certain practices have excellent systems for recording vital signs of children that present with acute illnesses, where others lack templates or standardised methods. As a result, serial re-assessment leads to duplication of clinical information. Furthermore, the overall continuity of care for follow-up visits has deteriorated with the emphasis on access, which can inadvertently undermine the relationship of the primary care provider.

Participants felt that primary care's role in the management of chronic diseases varies based on case-mix and secondary care services. However, most care provided is reactive with minimal formalised proactive care. Concerns were raised regarding the burden of undiagnosed psychological and mental illnesses and the lack of available services. Secondary care tends to lead the management of chronic conditions in children; however care seems to shift to primary care during adolescence without clear communication pathways. In addition, GPs described the unmet healthcare needs of adolescents, the challenge of chronic disease management in this population and their accessibility to clinicians.

Overall, GPs acknowledged the decreased role of health promotion in general practice with the reduced role of health visitors. With the exception of immunisations, newborn and six-week checkups, little else are formalised. However, participants emphasised the rising prevalence of obesity and the undiagnosed co-morbidities in children with chronic diseases. Many important clinical areas for the care of children in general practice are not prioritised by government due to the lack of political will, such as sexual health, adolescent medicine and obesity.

> *"I mean I think the area, I do think, I think there's a lot of variability is acutely sick children."QM09*

"...but if you got a kid with Crohn's or a kid with severe asthma or a kid with diabetes, they probably have huge numbers of psychological needs which as GPs I think we probably don't, unless they hit us in the face as reports from school, health visitors, the things are going horribly wrong, you know, I think they only ever get looked into when things have gone horribly wrong, or behaviours are changing or the child gets actually, you know, seriously psychologically unwell, but there's probably lots of other health needs that we're failing to pick up, although in adults, we kind of screen for stuff. I don't think we do that in kids." QM04

Training

Participants felt the current training scheme for GPs was not sufficient. There is large variability in the exposure to paediatrics as training programs shift to encourage more time in general practice. Trainees appear to be concerned with completing newborn and six-week checks due to lack of clinical experience with children. Concerns were raised if trainees would be able to develop the skill set required to assess and recognise sick children, highlighting the difference in the exposure to adult medicine compared to paediatric medicine in training. Finally, primary care risks losing the confidence of the public if the quality of GPs is not exemplary.

"So one concern, I would say, I am probably with the Royal College of Paediatrics and Child Health and I do think that there's a danger that some trainees coming through may not be getting enough exposure to paediatrics."QM03

"Some GPs will come in with no paediatric experience at all, whilst essentially virtually no doctor will come into general practice without ever working with adult populations." QM09

"I do think it's really important that GPs are, that there's a real priority given to GPs having appropriate training in paediatric...it's becoming increasing difficult for GPs in training to get a training job, part of their training in general practice, in paediatrics. And if that continues to be a problem then it could cause great problems down the line with there being a loss of confidence in the ability of GPs to perform safely and effectively with kids." QM01

Further findings from the study, including the range of perspectives on which childhood conditions should be developed into quality markers, will be presented at the June 10th meeting.

Framework options to improve quality of care

To develop quality markers to evaluate and improve the care of children, we are asking the expert panel to select the appropriate framework to ensure that all the important aspects of care are recognised. Rather than developing a large number of comprehensive quality markers, we will focus on prioritising key clinical topics using a conceptual framework. There are several potential frameworks that could be utilised; however in the next section we present two examples: the RCGP Child Health Strategy (29) and King's Fund report on '*Improving the Quality of Care in General Practice*.'(30) Accompanying each framework, we have included examples of potential quality markers to illustrate how each could be utilised.

Please read through the following sections keeping in mind which framework, or individual components of each framework would be useful to prioritise quality marker topics at the June 10th meeting.

RCGP Child Health Strategy

In November 2010, the RCGP published a Child Health Strategy, acknowledging the vital importance of child health in general practice.(29) The introduction outlines the aims of the strategy:

> "*The strategy outlines key areas for development within clinical practice, highlights the standards and markers of good practice and suggests interventions to assist the delivery of quality services and continual quality development. To ensure that the RCGP aim of securing high quality care for children and young people delivered by GPs in primary care complements wider developments within the health care arena, the Child Health Strategy draws on the standards outlined in the National Service Frameworks for England and Wales as well as SIGN guidance where appropriate."(29)*

The ten key components in the framework are outlined in Table 1.

Table 1: Ten recommendations of RCGP Child Health Strategy

1. **Health promotion.** All parents, children and young people should have access to health promotion activities and a core health promotion programme to include immunisations, screening and early interventions which are delivered within a general practice setting.
2. **Supporting parents.** Every practice in partnership with health visitors and other skilled community staff should proactively support parents and help them to optimise the health of their children.
3. **Child friendly practice.** Practices should ensure that they are child and young-person friendly.
4. **Adolescents.** Every practice should help facilitate the transition of young people with chronic health problems from children's to adult services.
5. **Safeguarding.** All members of the practice team should be responsible for safeguarding children and young people and within each practice there should be a nominated professional child safeguarding lead to provide advice and promote awareness amongst every member of the practice.
6. **GP Training.** All GPs in training should have a sufficient amount of clinical exposure to sick children to ensure that they are competent in the assessment of the sick child.
7. **Palliative care.** Every practice should have an active role in the care of children and young people who choose to die in the community.
8. **Complex needs.** Every practice should be responsible for ensuring that all registered children or young people with complex needs are easily identified and have regular access to primary health care.
9. **Mental health.** All GPs should have training in the early recognition of mental health problems and all practices have access to services to support the psychological wellbeing of children, young people and their families.
10. **Prescribing/medicines.** Every practice should demonstrate evidence-based and cost-effective prescribing of medicines for children and young people.

Source: RCGP Child Health Strategy (29)

The Child Health Strategy comprehensively includes all the important aspects of general practice for children. Table 2 illustrates examples of potential quality markers in the literature that correlate to each standard, or that are developed from the RCGP Child Health Strategy.

Table 2: RCGP Child Health Strategy recommendations and examples of quality markers

Recommendation	Example of quality marker	Source
Health promotion	Weight should be measured at least once a year and plotted on a growth chart or be recorded with the age/gender percentile.	Mangione-Smith *et al.* 2007 (31)
Supporting parents	Parents whose children have special needs should be referred for a comprehensive needs assessment and advocacy.	Recommendation 2 (29)
Child-friendly practice	All practices should complete an annual evaluation on how they can facilitate appointments for specific groups of young people.	Recommendation 3 (29)
Adolescents	Between the ages of 11 and 18 years, all adolescents should have an annual visit at which risk assessment/preventive services were provided	Mangione-Smith *et al.* 2007 (31)
Safeguarding	All children that miss 3 or more appointments should be actively followed up, both in primary and secondary care.	Recommendation 5 (29)
GP Training	Each practice should carry out a primary care audit of the diagnosis of children and young people with a serious illness to form a component of revalidation of all GPs.	Recommendation 6 (29)
Palliative care	All children on palliative care should have an end of life care plan and agreements for joint safe and sustainable end of life care delivery, where this is out of hospital.	Recommendation 7 (29)
Complex needs	Children and young people who are disabled or who have complex health needs should receive coordinated, high quality child and family services.	Recommendation 8 (29) NSF Standard 8 (12)
Mental health	All children and young people who have mental health problems have access to timely, integrated, high quality multidisciplinary mental health services to ensure effective assessment, treatment and support, for them and their families.	Recommendation 9 (29) NSF Standard 9 (12)
Prescribing/ medicines	Antibiotics should only be prescribed in a patient with nasal congestion and pharyngitis if a rapid strep test or throat culture is obtained, or if there is evidence of a diagnosis of other bacterial infections.	Mangione-Smith *et al.* 2007 (31)

Source: The quality markers are developed from the RCGP Child Health Strategy (29) recommendations and the relevant NSF Standards (12) described in Strategy unless otherwise specified. Other markers are from previously published work by Mangione-Smith *et al.* (31).

The RCGP Child Health Strategy highlights the diverse and complex nature of child health.

King's Fund report on 'Improving the Quality of Care in General Practice'

In 2011, the King's Fund report on '*Improving the Quality of Care in General Practice*' was based on the findings of an independent inquiry.(30) This document will not discuss the findings but will present the framework used to evaluate general practice. Table 3 and 4 describe the domains outlined by the King's Fund to evaluate

quality in general practice, including the 'core services within general practice', the 'non-clinical aspects of general practice' and 'general practice as part of a wider system of care' (Table 4).(30)

Table 3: King's Fund 'core services provided within general practice'

- **Diagnosis.** A core focus of general practice is on the appropriate diagnosis of patients, including retrospective audit and significant event audit to assess and improve the quality of diagnosis.
- **Referral.** General practitioners' are patients' links to a broader health care system and play a role in ensuring that timely referrals are made, getting patients to the right destination and involving patients in decisions about referral options.
- **Prescribing.** Variation in prescribing between general practices is common and often due to the clinical case-mix of patients and socio-economic factors. There are opportunities for quality improvement through reducing medication errors and improving adherence.
- **Acute illness.** Appropriate and effective diagnosis and management of acute illnesses form a key aspect of high-quality care.
- **Long-term conditions.** A large proportion of general practitioners time is spent managing the care for patients with long-term conditions.
- **Health promotion.** General practice is at the bedrock of health promotion, ranging from childhood immunisations to smoking cessation advice.

Source: Modified from King's Fund report on '*Improving the Quality of Care in General Practice.*'(30)

Table 4: King's Fund 'non-clinical aspects of general practice' and 'general practice as part of a wider system of care'

Non-clinical aspects of general practice:

- **Access.** The ability to see your general practitioner and receive adequate primary care.
- **Continuity of care.** Enabling patients to see the same doctor and other clinical staff with whom they build a relationship over time.
- **Engagement and involvement of patients.** Engaging patients and carers to make decisions about their own health and supporting people to care for themselves is an important part of general practice.

General practice as part of a wider system of care:

- **End-of-life care.** General practice needs to be encouraged to support the co-ordination of health and social care to people at the end-of-life and to promote continuity of care.
- **Maternity care.** There is a need to re-skill GPs in maternity care and to develop a shared care approach with midwives (except for intrapartum care).
- **Health inequalities.** General practitioners have a key role in assessing the needs of local populations and in tackling health inequalities.

Source: Modified from King's Fund report on '*Improving the Quality of Care in General Practice*.'(30)

Table 5 highlights examples of potential quality markers that correlate to each King's Fund component of general practice (not markers from the King's Fund Report).

Table 5: King's Fund dimensions of general practice and examples of quality markers

Dimension	Example of quality marker	Source[1]
Diagnosis	If an infant or child presents with fever and symptoms/signs of an infection, either a urine culture should be performed or a urinalysis should be performed; if urinalysis is positive, a urine culture should be performed.	Mangione-Smith *et al.* 2007 (31)
Referral	If an infant presents with a fever and is toxic or at high risk, the infant should be hospitalised. (Applies to febrile infants 28 to 90 days old)	Mangione-Smith *et al.* 2007 (31)
Prescribing	Treatment for allergic rhinitis should include at least one of the following: recommendation for allergen avoidance, antihistamine, nasal steroids, nasal cromolyn.	Mangione-Smith *et al.* 2007 (31)
Acute illness	At least two of the following findings regarding hydration status should be recorded: general condition, appearance of eyes, presence or absence of tears, degree of oral moisture, degree of thirst, degree of skin turgor, or condition of anterior fontanelle.	Mangione-Smith *et al.* 2007 (31)
Long-term conditions	Any child with asthma who takes high doses of inhaled corticosteroids should have growth patterns monitored at least annually.	Mangione-Smith *et al.* 2007 (31)
Health promotion	All children that are overweight will receive health promotional material for the family.	-
Access	Any child that is ill should be seen on the same day in general practice.	-
Continuity of care	Management of chronic illnesses in primary care should be with the same general practitioner or health care professional.	-
Engagement / patient involvement	Patient surveys to families of young children should be conducted annually.	-
End-of-life care	All general practitioners will support families who wish for their children to die in the community.	-
Maternity care	The physician should make an accurate determination of gestational age.	Mangione-Smith *et al.* 2007 (31)
Health inequalities	Child that are at risk will be identified and provided with appropriate additional support.	-

Source: [1] Markers are from previously published work by Mangione-Smith *et al.* (31).

Conclusions

Thank you in advance for your participation in the study and we look forward to further discussion on 10 June 2011. Please contact at peter.gill@phc.ox.ac.uk should you require clarification of any of the above information.

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Appendix C.2: Results from Round 1 ranking

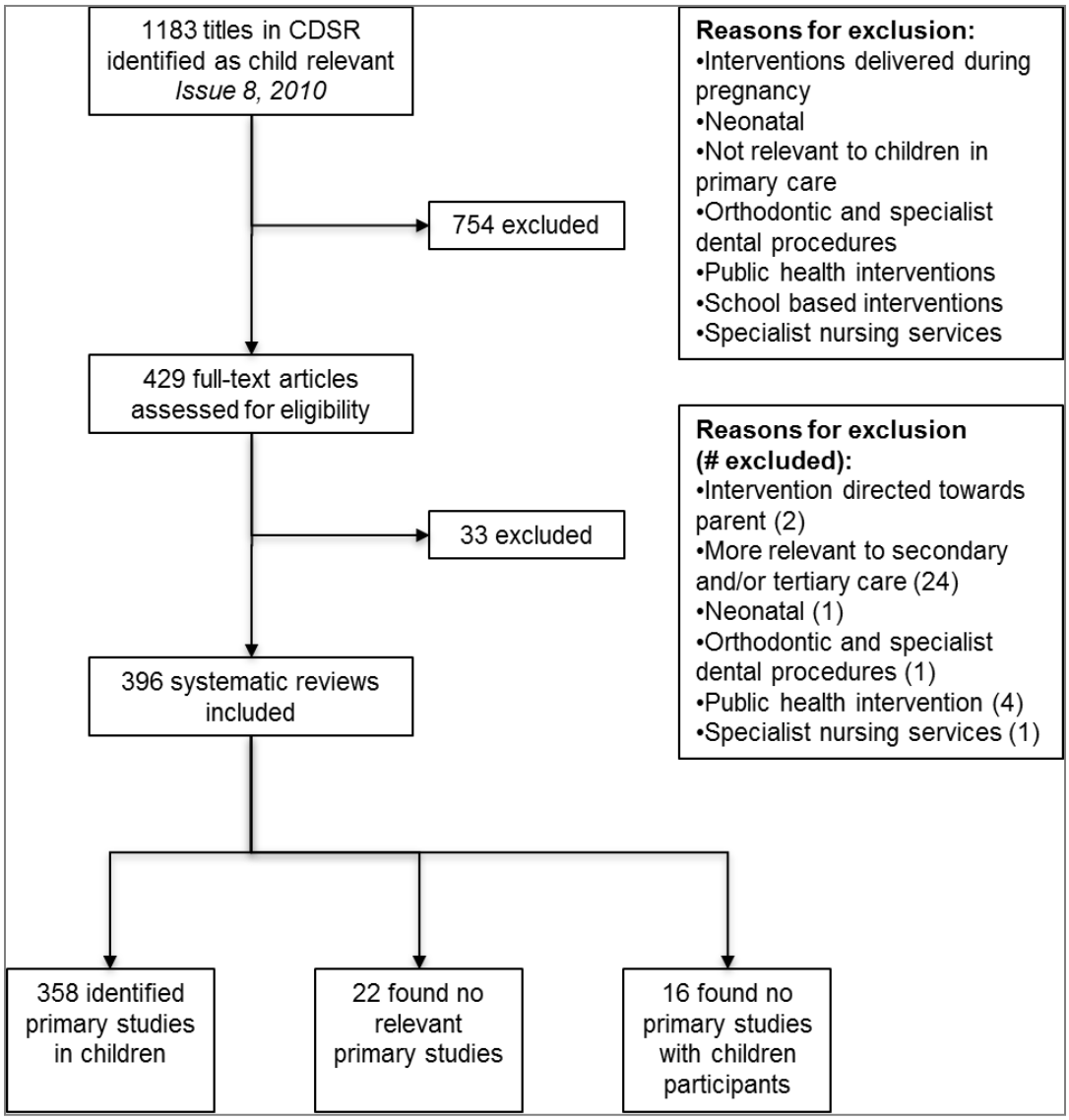
#	Item	1	2	3	4	5	6	7	8	9	10	11	12	*Sum*
12	Early recognition of serious illness in children (infectious disease and non-infectious disease)	7	-	8	4	8	4	-	7	5	7	-	7	*57*
8	Identifying acute sick child, on-going process, involvement with other agency including best practice including documentation, safety netting, consultation for acute illness	8	8	-	7	-	-	7	-	8	-	7	8	*53*
3	Recognition and management of child safe guarding and child protection	-	4	6	8	6	7	-	-	-	4	3	6	*44*
9	Detection, information gathering and management including clear pathways and signposting for primary care of mental health problems in young people	1	-	5	6	7	3	6	-	3	5	6	-	*42*
11	Evidence based management of common childhood conditions (e.g. asthma, eczema, constipation, encopresis and enuresis) and appropriate referral	-	7	-	5	5	-	-	-	4	3	-	1	*25*
2	Safe and cost effective prescribing and promoting concordance	-	3	3	-	3	-	1	6	1	2	-	2	*21*
28	Active whole practice engagement in child protection	-	-	4	-	-	8	-	3	6	-	-	-	*21*
1	Profile of child specific training of the professionals in the primary care organisations/providers	-	-	-	-	-	1	-	8	-	-	8	-	*17*
13	Assessment of child and carer friendliness of consultation and practice organisations	-	-	-	-	2	2	-	-	7	-	5	-	*16*
7	Embedding prevention and early intervention in general practice with specific reference to healthy child programme	4	-	-	-	1	-	-	-	-	8	2	-	*15*
10	Access to primary health care professional in children presenting with an acute illness	-	-	7	-	-	-	8	-	-	-	-	-	*15*
15	Structured assessment of the febrile child	6	6	-	-	-	-	-	-	-	-	-	-	*12*
24	Education and support for parents and carers to optimise child health and development by the practice	-	-	-	-	-	5	3	2	2	-	-	-	*12*
4	All children should have access to full immunisation	-	5	-	-	-	-	-	4	-	1	-	-	*10*
25	Evidence for multi professional cooperation and communication in the care of children	5	-	-	1	-	-	-	-	-	-	4	-	*10*
22	Access issues for young people especially contraception	2	2	-	-	-	-	5	-	-	-	-	-	*9*
27	Training for 6 week check and knowledge of normal child development	3	-	-	-	-	-	-	-	-	6	-	-	*9*
30	Communication with children	-	-	-	3	-	-	-	5	-	-	-	-	*8*
19	Identification of children with needs who do not come (DNA)	-	-	-	2	-	-	4	1	-	-	-	-	*7*
26	Appropriate involvement of the child in decisions and respect for preferences	-	-	-	-	-	6	-	-	-	-	-	-	*6*
6	Recorded observation of child well-being in infancy, school aged and preschool	-	-	-	-	-	-	-	-	-	-	-	5	*5*
21	Effective and coordinated practice activity in the prevention of obesity	-	1	-	-	-	-	-	-	-	-	-	4	*5*

20	Continuity of care and smooth transitions	-	-	-	-	4	-	-	-	-	-	-	-		*4*
29	Improving health outcomes by encouraging early return to school	-	-	1	-	-	-	-	-	-	-	-	3		*4*
16	Primary care involvement in chronic disease monitoring and management	-	-	2	-	-	-	-	-	-	-	1	-		*3*
5	GP training in acute illness	-	-	-	-	-	-	2	-	-	-	-	-		*2*
14	Child and young people representation and feedback and on consultation	-	-	-	-	-	-	-	-	-	-	-	-		*0*
17	Provision of health promotion information (vaccination, drugs, alcohol, sex)	-	-	-	-	-	-	-	-	-	-	-	-		*0*
18	Coordination of care for children with complex disorders	-	-	-	-	-	-	-	-	-	-	-	-		*0*
23	Proactive smoking cessation advice for parents	-	-	-	-	-	-	-	-	-	-	-	-		*0*

Note: Reproduced from Gill PJ, Hewitson P, Peile E, Harnden A. Prioritizing areas for quality marker development in children in UK general practice: extending the use of the nominal group technique. *Fam Pract*. 2012;29(5):567-75.

Appendix D: Chapter 7 – Drafting of evidence-based indicators

Appendix D.1: PRISMA Flow chart of study selection



Note: Reproduced from Gill PJ, Wang KY, Mant D, Hartling L, Heneghan C, Perera R, et al. The evidence base for interventions delivered to children in primary care: an overview of cochrane systematic reviews. *PLoS ONE*. 2011;6(8):e23051.

Appendix D.2: List of relevant NICE and SIGN guidelines (n=48)

Priority Area	Guidelines selected
Early diagnosis of serious illness (15)	▪ NICE. Diagnosis and management of Type 1 diabetes in children, young people and adults. 2004. ▪ NICE. Feverish illness in children - Assessment and initial management in children younger than 5 years. 2007. ▪ NICE. Identification and management of familial hypercholesterolaemia. 2008. ▪ NICE. Management of acute diarrhoea and vomiting due to gastroenteritis in children under 5. 2009. ▪ NICE. Recognition and assessment of coeliac disease. 2009. ▪ NICE. Recognition and treatment of neonatal jaundice. 2010. ▪ NICE. Referral guidelines for suspected cancer. 2005. ▪ NICE. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care (update). 2012. ▪ NICE. The management of bacterial meningitis and meningococcal septicaemia in children and young people younger than 16 years in primary and secondary care. 2010. ▪ NICE. Triage, assessment, investigation and early management of head injury in infants, children and adults. 2007. ▪ NICE. Urinary tract infection: diagnosis, treatment and long-term management of urinary tract infection in children. 2007. ▪ SIGN. Bronchiolitis in children. 2006. ▪ SIGN. Diagnosis and management of epilepsies in children and young people. 2005. ▪ SIGN. Early management of patients with a head injury. 2009. ▪ SIGN. Management of invasive meningococcal disease in children and young people. 2008.
Child protection / safeguarding (2)	▪ NICE. Guidance on when to suspect child maltreatment. 2009. ▪ NICE. Promoting the quality of life of looked-after children and young people. 2010.
Mental health (7)	▪ NICE. Alcohol use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence. 2011 ▪ NICE. Alcohol-use disorders - preventing the development of hazardous and harmful drinking. 2010. ▪ NICE. Core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder. 2005. ▪ NICE. Depression in children and young people: identification and management in primary, community and secondary care. 2005. ▪ NICE. Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. 2004. ▪ NICE. Post-traumatic stress disorder (PTSD): The management of PTSD in adults and children in primary and secondary care. 2005. ▪ NICE. Self-harm: The short-term physical and psychological management and secondary prevention of self-harm in primary and secondary care. 2004.
Health promotion (10)	▪ NICE. Brief interventions and referral for smoking cessation in primary care and other settings. 2006. ▪ NICE. Community-based interventions to reduce substance misuse among vulnerable and disadvantaged children and young people. 2007. ▪ NICE. Guidance for midwives, health visitors, pharmacists and other primary care services to improve the nutrition of pregnant and breastfeeding mothers and children in low income households. 2008. ▪ NICE. Guidance on differences in the uptake of immunisations (including targeted vaccines) in people younger than 19 years. 2009. ▪ NICE. Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children. 2006. ▪ NICE. One to one interventions to reduce the transmission of sexually transmitted infections (STIs) including HIV, and to reduce the rate of under 18 conceptions, especially among vulnerable and at risk groups. 2007. ▪ NICE. Postnatal care: Routine postnatal care of women and their babies. 2006.

	▪ NICE. Prevention of cardiovascular disease at the population level. 2010. ▪ NICE. Smoking cessation services in primary care, pharmacies, local authorities and workplaces, particularly for manual working groups, pregnant women and hard to reach communities. 2008. ▪ SIGN. Management of obesity. 2010.
Routinely managed conditions (14)	▪ NICE. Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults. 2008 ▪ NICE. Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. 2011. ▪ NICE. Diagnosis and assessment of food allergy in children and young people in primary care and community settings. 2011. ▪ NICE. Diagnosis and management of idiopathic childhood constipation in primary and secondary care. 2010. ▪ NICE. Management of atopic eczema in children from birth up to the age of 12 years. 2007 ▪ NICE. Prescribing of antibiotics for self-limiting respiratory tract infections in adults and children in primary care. 2008 ▪ NICE. Surgical management of children with otitis media with effusion (OME). 2008. ▪ NICE. The management of bedwetting and nocturnal enuresis in children and young people. 2010. ▪ SIGN. Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. 2007. ▪ SIGN. British Guideline on the Management of Asthma. 2011. ▪ SIGN. Diagnosis and management of childhood otitis media in primary care. 2003. ▪ SIGN. Management of atopic eczema in primary care. 2011. ▪ SIGN. Management of attention deficit and hyperkinetic disorders in children and young people. 2009. ▪ SIGN. Management of sore throat and indications for tonsillectomy. 2010.
General practice management	-

Appendix D.3: Characteristics of included Cochrane systematic reviews

Characteristic		N (%)[1]
Total		396 (100)
Authors identified primary studies[2]		358 (90.4)
Number of studies included	All included studies, median (range)	10 (1 – 144)
	Child only studies, median (range)	5 (0 – 144)
Number of participants included	All included studies, median (range)[3]	1428 (3 – 4 897 966)
	Child only participants, median (range)[4]	540 (0 – 3 141 224)
Methodological considerations	Meta-analysis completed	251 (70.1)
	Children (<18) only in meta-analysis	172 (48.0)
Date since last updated[5]	Before 2008	222 (56.3)
	Before 2005	66 (16.8)
	Before 2002	22 (5.6)
	Before 1999	2 (0.5)
Single intervention evaluated		343 (95.8)
Specific category of intervention[6]	Drug	216 (57.4)
	Complex	43 (11.4)
	Natural health product	34 (9.0)
	Device	20 (5.3)
	Vaccine	20 (5.3)
	Clinical	16 (4.3)
	Other	16 (4.3)
	Surgery	11 (2.9)
Type of care provided[7]	For chronic condition	218 (55.1)
	For acute condition	102 (25.8)
	Preventative	76 (19.2)

Notes: N, number of systematic reviews (unless otherwise indicated).
[1] Based on 358 SRs unless otherwise specified.
[2] 38 SRs did not find published studies (n=22) or include studies that had participants <18 (n=16).
[3] Based on 353 SRs, 5 SRs were unclear or did not specify total number of participants.
[4] Based on 351 SRs, 7 SRs were unclear or did not specify total number of participants.
[5] Based on 394 SRs, two SRs were classified as 'stable'.
[6] Based on 358 SRs that identified studies. If an SR had greater than one category of intervention, it was double counted (n = 15); total interventions evaluated is 376.
[7] Based on all 396 SRs.

Reproduced from Gill PJ, Wang KY, Mant D, Hartling L, Heneghan C, Perera R, et al. The evidence base for interventions delivered to children in primary care: an overview of cochrane systematic reviews. *PLoS ONE*. 2011;6(8):e23051.

Appendix D.4: Cochrane systematic review titles relevant to topics identified that did not provide evidence for draft indicators (n=168)

Condition	Reviews (n)	Cochrane reviews which did not provide evidence for QIs	
		No.	*Review title(s)*
Antibiotic use	10	8	1) Antibiotics for bronchiolitis in children 2) Antibiotics for community acquired pneumonia in adult outpatients 3) Antibiotics for community acquired pneumonia in children 4) Short-course versus long-course antibiotic therapy for non-severe community-acquired pneumonia in children aged 2 months to 59 months 5) Antibiotics for community acquired lower respiratory tract infections (LRTI) secondary to Mycoplasma pneumoniae in children 6) Azithromycin for acute lower respiratory tract infections 7) Short versus standard duration antibiotic therapy for acute streptococcal pharyngitis in children 8) Antibiotics for whooping cough (pertussis)
Attention deficit hyperactivity disorder	5	4	1) Family therapy for attention-deficit disorder or attention-deficit/hyperactivity disorder in children and adolescents 2) Homeopathy for attention deficit/hyperactivity disorder or hyperkinetic disorder 3) Meditation therapies for attention-deficit/hyperactivity disorder (ADHD) 4) Risperidone for attention-deficit hyperactivity disorder in people with intellectual disabilities
Asthma	78	73	*Adverse events / general* 1) Regular treatment with salmeterol for chronic asthma: serious adverse events 2) Regular treatment with salmeterol and inhaled steroids for chronic asthma: serious adverse events 3) Regular treatment with formoterol for chronic asthma: serious adverse events 4) Regular treatment with formoterol and inhaled steroids for chronic asthma: serious adverse events 5) Regular treatment with formoterol and an inhaled corticosteroid versus regular treatment with salmeterol and an inhaled corticosteroid for chronic asthma: serious adverse events 6) Regular treatment with formoterol versus regular treatment with salmeterol for chronic asthma: serious adverse events 7) Mono and multifaceted inhalant and/or food allergen reduction interventions for preventing asthma in children at high risk of developing asthma 8) Commercial versus home-made spacers in delivering bronchodilator therapy for acute therapy in children *Acute asthma* 9) Antibiotics for acute asthma 10) Combined inhaled anticholinergics and beta2-agonists for initial treatment of acute asthma in children 11) Corticosteroids for preventing relapse following acute exacerbations of asthma 12) Early emergency department treatment of acute asthma with systemic corticosteroids 13) Early use of inhaled corticosteroids in the emergency department treatment of acute asthma 14) Holding chambers (spacers) versus nebulisers for beta-agonist treatment of acute asthma

15) Inhaled magnesium sulfate in the treatment of acute asthma

Chronic asthma

16) Acupuncture for chronic asthma
17) Addition of anti-leukotriene agents to inhaled corticosteroids for chronic asthma
18) Addition of inhaled long-acting beta2-agonists to inhaled steroids as first line therapy for persistent asthma in steroid-naive adults and children
19) Addition of long-acting beta-agonists to inhaled corticosteroids for chronic asthma in children
20) Addition of long-acting beta2-agonists to inhaled steroids versus higher dose inhaled steroids in adults and children with persistent asthma
21) Anti-leukotriene agents compared to inhaled corticosteroids in the management of recurrent and/or chronic asthma in adults and children
22) Anticholinergic therapy for chronic asthma in children over two years of age
23) Beclomethasone at different doses for chronic asthma
24) Beclomethasone versus budesonide for chronic asthma
25) Beclomethasone versus placebo for chronic asthma
26) Budesonide at different doses for chronic asthma
27) Budesonide versus placebo for chronic asthma in children and adults
28) Calorie controlled diet for chronic asthma
29) Ciclesonide versus other inhaled steroids for chronic asthma in children and adults
30) Ciclesonide versus placebo for chronic asthma in adults and children
31) Combination fluticasone and salmeterol versus fixed dose combination budesonide and formoterol for chronic asthma in adults and children
32) Combination formoterol and budesonide as maintenance and reliever therapy versus inhaled steroid maintenance for chronic asthma in adults and children
33) Combination formoterol and inhaled steroid versus beta2-agonist as relief medication for chronic asthma in adults and children
34) Dietary marine fatty acids (fish oil) for asthma in adults and children
35) Dietary salt reduction or exclusion for allergic asthma
36) Family therapy for asthma in children
37) Feather versus non-feather bedding for asthma
38) Fluticasone at different doses for chronic asthma in adults and children
39) Fluticasone versus 'extrafine' HFA-beclomethasone dipropionate for chronic asthma in adults and children
40) Fluticasone versus beclomethasone or budesonide for chronic asthma in adults and children
41) Fluticasone versus placebo for chronic asthma in adults and children
42) Gastro-oesophageal reflux treatment for asthma in adults and children
43) Herbal interventions for chronic asthma in adults and children
44) High dose versus low dose inhaled corticosteroid as initial starting dose for asthma in adults and children
45) Holding chambers versus nebulisers for inhaled steroids in chronic asthma
46) Humidity control for chronic asthma
47) Inhaled corticosteroids versus sodium cromoglycate in

			children and adults with asthma 48) Inhaled short acting beta2-agonist use in chronic asthma: regular versus as needed treatment 49) Inhaled sodium cromoglycate for asthma in children 50) Intranasal corticosteroids for asthma control in people with coexisting asthma and rhinitis 51) Ionisers for chronic asthma 52) Ketotifen alone or as additional medication for long-term control of asthma and wheeze in children 53) Long-acting beta2-agonists as an inhaled corticosteroid-sparing agent for chronic asthma in adults and children 54) Long-acting beta2-agonists for chronic asthma in adults and children where background therapy contains varied or no inhaled corticosteroid 55) Long-acting beta2-agonists versus anti-leukotrienes as add-on therapy to inhaled corticosteroids for chronic asthma 56) Long-acting beta2-agonists versus placebo in addition to inhaled corticosteroids in children and adults with chronic asthma 57) Long-acting beta2-agonists versus theophylline for maintenance treatment of asthma 58) Macrolides for chronic asthma 59) Manual therapy for asthma 60) Nedocromil sodium for chronic asthma in children 61) Oral xanthines as maintenance treatment for asthma in children 62) Oxatomide for stable asthma in adults and children 63) Pet allergen control measures for allergic asthma in children and adults 64) Pressurised metered dose inhalers versus all other hand-held inhaler devices to deliver beta-2 agonist bronchodilators for non-acute asthma 65) Psychological interventions for children with asthma 66) Regular treatment with long acting beta agonists versus daily regular treatment with short acting beta agonists in adults and children with stable asthma 67) Selenium supplementation for asthma 68) Speleotherapy for asthma 69) Vitamin C supplementation for asthma *Exercise-induced bronchoconstriction* 70) Inhaled corticosteroids compared to placebo for prevention of exercise induced bronchoconstriction 71) Mast-cell stabilising agents to prevent exercise-induced bronchoconstriction 72) Nedocromil sodium for preventing exercise-induced bronchoconstriction 73) Nedocromil sodium versus sodium cromoglycate for preventing exercise-induced bronchoconstriction
Autism / developmental delay	8	5	1) Selective serotonin reuptake inhibitors (SSRIs) for autism spectrum disorders (ASD) 2) Risperidone for autism spectrum disorder 3) Music therapy for autistic spectrum disorder 4) Combined vitamin B6-magnesium treatment in autism spectrum disorder 5) Gluten- and casein-free diets for autistic spectrum disorder
Body dysmorphic / obsessive compulsive disorder	2	2	1) Pharmacotherapy and psychotherapy for body dysmorphic disorder 2) Behavioural and cognitive behavioural therapy for obsessive compulsive disorder in children and adolescents

Constipation	2	0	-
Depression	5	4	1) Exercise in prevention and treatment of anxiety and depression among children and young people 2) Psychological and/or educational interventions for the prevention of depression in children and adolescents 3) Psychological interventions for depression in adolescent and adult congenital heart disease 4) Tricyclic drugs for depression in children and adolescents
Diabetes	3	3	1) Exercise or exercise and diet for preventing type 2 diabetes mellitus 2) Metformin added to insulin therapy for type 1 diabetes mellitus in adolescents 3) Routine hospital admission versus out-patient or home care in children at diagnosis of type 1 diabetes mellitus
Eating disorders	1	1	1) Family therapy for anorexia nervosa
Eczema	7	7	1) Dietary exclusions for established atopic eczema 2) Disposable nappies for preventing napkin dermatitis in infants 3) Interventions to reduce Staphylococcus aureus in the management of atopic eczema 4) Probiotics for treating eczema 5) Psychological and educational interventions for atopic eczema in children 6) Topical pimecrolimus for eczema 7) Topical Vitamin A, or its derivatives, for treating and preventing napkin dermatitis in infants
Epilepsy	17	17	1) Acupuncture for epilepsy 2) Carbamazepine versus phenobarbitone monotherapy for epilepsy 3) Carbamazepine versus phenytoin monotherapy for epilepsy 4) Carbamazepine versus valproate monotherapy for epilepsy 5) Corticosteroids including ACTH for childhood epilepsy other than epileptic spasms 6) Drug management for acute tonic-clonic convulsions including convulsive status epilepticus in children 7) Early versus late antiepileptic drug withdrawal for people with epilepsy in remission 8) Ethosuximide, sodium valproate or lamotrigine for absence seizures in children and adolescents 9) Immediate-release versus controlled-release carbamazepine in the treatment of epilepsy 10) Lamotrigine versus carbamazepine monotherapy for epilepsy 11) Oxcarbazepine versus carbamazepine monotherapy for partial onset seizures 12) Oxcarbazepine versus phenytoin monotherapy for epilepsy 13) Phenobarbitone versus phenytoin monotherapy for partial onset seizures and generalized onset tonic-clonic seizures 14) Phenytoin versus valproate monotherapy for partial onset seizures and generalized onset tonic-clonic seizures 15) Psychological treatments for epilepsy 16) Rapid versus slow withdrawal of antiepileptic drugs 17) Traditional Chinese medicine for epilepsy
Familial hypercholest-erolaemia	1	1	1) Statins for children with familial hypercholesterolemia
Gastroenterit-is	7	7	1) Antibiotic treatment for travellers' diarrhoea 2) Antibiotics for treating salmonella gut infections 3) Antiemetics for reducing vomiting related to acute gastroenteritis in children and adolescents

			4) Oral versus intravenous rehydration for treating dehydration due to gastroenteritis in children 5) Probiotics for the prevention of pediatric antibiotic-associated diarrhea 6) Probiotics for treating infectious diarrhoea 7) Reduced osmolarity oral rehydration solution for treating dehydration caused by acute diarrhoea in children
Nocturnal enuresis	7	4	1) Complementary and miscellaneous interventions for nocturnal enuresis in children 2) Complex behavioural and educational interventions for nocturnal enuresis in children 3) Desmopressin for nocturnal enuresis in children 4) Simple behavioural and physical interventions for nocturnal enuresis in children
Obesity	1	1	1) Interventions for treating obesity in children
Otitis media	16	13	1) Adenoidectomy for otitis media in children 2) Antibiotics for the prevention of acute and chronic suppurative otitis media in children 3) Antihistamines and/or decongestants for otitis media with effusion (OME) in children 4) Autoinflation for hearing loss associated with otitis media with effusion 5) Grommets (ventilation tubes) for recurrent acute otitis media in children 6) Interventions for ear discharge associated with grommets (ventilation tubes) 7) Once or twice daily versus three times daily amoxicillin with or without clavulanate for the treatment of acute otitis media 8) Oral or topical nasal steroids for hearing loss associated with otitis media with effusion in children 9) Short course antibiotics for acute otitis media 10) Systemic antibiotics versus topical treatments for chronically discharging ears with underlying eardrum perforations 11) Topical analgesia for acute otitis media 12) Topical antibiotics without steroids for chronically discharging ears with underlying eardrum perforations 13) Ear drops for the removal of ear wax
Post-traumatic stress disorder	1	1	1) Combined pharmacotherapy and psychological therapies for post traumatic stress disorder (PTSD)
Urinary tract infections	5	2	1) Cranberries for treating urinary tract infections 2) Interventions for primary vesicoureteric reflux
Vaccines	16	15	1) Combined DTP-HBV-HIB vaccine versus separately administered DTP-HBV and HIB vaccines for primary prevention of diphtheria, tetanus, pertussis, hepatitis B and Haemophilus influenzae B (HIB) 2) Conjugate vaccines for preventing meningococcal C meningitis and septicaemia 3) Hepatitis B immunisation in persons not previously exposed to hepatitis B or with unknown exposure status 4) Immunoglobulins for preventing hepatitis A 5) Influenza vaccination in children being treated with chemotherapy for cancer 6) Pneumococcal conjugate vaccines for preventing otitis media 7) Pneumococcal conjugate vaccines for preventing vaccine-type invasive pneumococcal disease and X-ray defined pneumonia in children less than two years of age 8) Pneumococcal vaccine for asthma 9) Polysaccharide vaccines for preventing serogroup A meningococcal meningitis 10) Rotavirus vaccine for preventing diarrhoea

	11) Vaccines for measles, mumps and rubella in children 12) Vaccines for post-exposure prophylaxis against varicella (chickenpox) in children and adults 13) Vaccines for preventing influenza in healthy children 14) Vaccines for preventing influenza in people with asthma 15) Vaccines for preventing rotavirus diarrhoea: vaccines in use

Appendix D.5: NICE and SIGN guidelines with no recommendations selected (n=13)

Priority area	Guidelines with no recommendations selected
Early recognition of serious illness (n=3)	▪ NICE. The management of bacterial meningitis and meningococcal septicaemia in children and young people younger than 16 years in primary and secondary care. 2010. ▪ SIGN. Diagnosis and management of epilepsies in children and young people. 2005. ▪ SIGN. Management of invasive meningococcal disease in children and young people. 2008.
Health promotion (n=8)	▪ NICE. Brief interventions and referral for smoking cessation in primary care and other settings. 2006. ▪ NICE. Community-based interventions to reduce substance misuse among vulnerable and disadvantaged children and young people. 2007. ▪ NICE. Guidance for midwives, health visitors, pharmacists and other primary care services to improve the nutrition of pregnant and breastfeeding mothers and children in low income households. 2008. ▪ NICE. Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children. 2006. ▪ NICE. One to one interventions to reduce the transmission of sexually transmitted infections (STIs) including HIV, and to reduce the rate of under 18 conceptions, especially among vulnerable and at risk groups. 2007. ▪ NICE. Prevention of cardiovascular disease at the population level. 2010. ▪ NICE. Smoking cessation services in primary care, pharmacies, local authorities and workplaces, particularly for manual working groups, pregnant women and hard to reach communities. 2008. ▪ SIGN. Management of obesity. 2010.
Routinely managed conditions (n=2)	▪ SIGN. Management of atopic eczema in primary care. 2011. ▪ SIGN. Management of sore throat and indications for tonsillectomy. 2010.

Appendix D.6: Source NICE/SIGN recommendations and audit criteria used to draft quality indicators (n=56)

QI	NICE / SIGN	Guideline topic	Source	Recommendation	Audit criteria
1	NICE	Referral for suspected cancer	(1)	1.14.2, 1.14.5	-
	NICE	Feverish illness	(2)	1.4.1.4	-
	SIGN	Bronchiolitis in children	(3)	4.2.1	-
2	NICE	Referral for suspected cancer	(1)	1.14.32	-
3	NICE	Coeliac disease	(4)	1.1.1, 1.1.4	-
4	NICE	Type I Diabetes	(5)	1.1.2, 1.4.1	-
5	NICE	Type I Diabetes	(5)	1.1.2	2
	NICE	Nocturnal enuresis	(6)	1.3.8, 1.3.13	-
6	NICE	Type I Diabetes	(5)	2.11.1	-
7	NICE	Gastroenteritis	(7)	1.1.2.2	1
8	NICE	Gastroenteritis	(7)	1.2.1.3	2
9	NICE	Epilepsies	(8)	1.4.4C	1
10	NICE	Feverish illness	(2)	1.2.1.6	2
11	NICE	Feverish illness	(2)	1.4.2.1	2
12	NICE	Feverish illness	(2)	1.4.2.3	-
13	NICE	Neonatal jaundice	(9)	1.7.1	12.3
14	NICE	Urinary tract infections	(10)	1.1.1.1, 1.1.5.1, 1.2.1.2, 1.2.1.3, 1.3.1.9	-
15	SIGN	Bronchiolitis in children	(3)	4.2.1	-
16	NICE	Familial hypercholesterolaemia	(11)	1.1.5, 1.1.15, 1.1.16, 1.3.1.9	2
18	NICE	Looked-after children	(12)	20, 22	-
19	NICE	Child maltreatment	(13)	1.2.10	-
21	NICE	Child maltreatment	(13)	-	3
22	NICE	Depression	(14)	1.5.1.2	-
23	NICE	Depression	(14)	1.3.2.1, 1.3.2.2, 1.3.2.3	-
24	NICE	Depression	(14)	1.5.2.3	10
25	NICE	Eating disorders	(15)	1.1.5.2	4
26	NICE	Eating disorders	(15)	1.1.6.1, 1.1.6.2, 1.1.6.3	-
27	NICE	Post-traumatic stress disorder	(16)	1.1.4.2	-
28	NICE	Self-harm	(17)	1.9.1.10, 1.2.1.1, 1.2.1.2	8, 9
29	NICE	Alcohol use	(18)	1.3.7.1, 1.3.7.2	-
30	NICE	Autism	(19)	25 (1.3.5)	2
31	NICE	Autism	(19)	22 (1.3.2), 23 (1.3.3)	2
32	NICE	ADHD	(20)	6.8.3.5	-
	SIGN	ADHD	(21)	7.1	
33	NICE	ADHD	(20)	10.18.4, 10.18.11.2	-
	SIGN	ADHD	(21)	7.3.2	
34	NICE	Immunisations	(22)	2.1, 2.4	1, 7
36	NICE	Immunisations	(22)	6.2, 6.6	2, 4
37	NICE	Postnatal care	(23)	1.4.12, 1.4.14	-
39	SIGN	Asthma	(24)	2.1.3, 2.1.4, 2.1.5, 2.1.7, 2.1.8	-
40	SIGN	Asthma	(24)	2.6.1, 2.6.3, 4.2.3 (n=2), 8.1.2 (n=5)	-

41	SIGN	Asthma	(24)	2.1.1 (n=2), 4	-
42	SIGN	Asthma	(24)	5.5 (n=2)	-
43	SIGN	Asthma	(24)	6.8.4 (n=2)	-
44	SIGN	Asthma	(24)	4.1.1	-
45	SIGN	Asthma	(24)	8.2 (n=2)	-
47	NICE	Idiopathic constipation	(25)	1.4.2, 1.4.3, 1.4.8	8, 9, 14
48	NICE	Atopic eczema	(26)	1.5.1.1	4, 5, 6, 7
49	NICE	Atopic eczema	(26)	1.5.3.2, 1.5.3.7	10, 11
50	NICE	Atopic eczema	(26)	1.5.6.1	-
51	NICE	Atopic eczema	(26)	1.5.7.10	-
52	NICE	Nocturnal enuresis	(6)	1.3.1, 1.3.2	1
53	NICE	Nocturnal enuresis	(6)	1.8.1, 1.9.1, 1.9.2, 1.10.1, 1.10.2	3
54	NICE	Food allergy	(27)	1.1.5	5, 6, 7
55	SIGN	Otitis media	(28)	3.1.1	5.2
56	NICE	Otitis media	(29)	1.3.1	2, 3, 4, 5
	SIGN	Otitis media	(28)	4.2.2 (n=3)	5.2
57	NICE	Antibiotic prescribing	(30)	1.1.3, 1.1.7	2, 3
61	NICE	Postnatal care	(23)	1.4.38	-
63	NICE	Nocturnal enuresis	(6)	1.13.1	8, 9
64	NICE	Nocturnal enuresis	(6)	1.14.1	10
65	NICE	Child maltreatment	(13)	-	5

Notes: QI, quality indicator; ADHD, Attention deficit hyperactivity disorder.

Recommendations are numbered as identified in full NICE guideline or shortened 'clinical guideline' issued by NICE. SIGN, unlike NICE, do not number individual recommendations (or audit criteria); relevant guideline sections which recommendations were derived are listed along with the number of statements extracted from these sections in parentheses.

References

1. National Institute for Health and Clinical Excellence. Referral guidelines for suspected cancer. (Clinical guideline 27). London: National Institute for Health and Clinical Excellence, 2005.

2. National Institute for Health and Clinical Excellence. Feverish illness in children - Assessment and initial management in children younger than 5 years. (Clinical guideline 47). London: National Institute for Health and Clinical Excellence, 2007.

3. Scottish Intercollegiate Guidelines Network. Bronchiolitis in children. (Guideline No. 91). Edinburgh Scottish Intercollegiate Guidelines Network, 2006.

4. National Institute for Health and Clinical Excellence. Recognition and assessment of coeliac disease. (Clinical guideline 86). London: National Institute for Health and Clinical Excellence, 2009.

5. National Institute for Health and Clinical Excellence. Diagnosis and management of type 1 diabetes in children, young people and adults. (Clinical guideline 15). London: National Institute for Health and Clinical Excellence, 2004.

6. National Institute for Health and Clinical Excellence. The management of bedwetting and nocturnal enuresis in children and young people. (Clinical guideline 111). London: National Institute for Health and Clinical Excellence, 2010.

7. National Institute for Health and Clinical Excellence. Management of acute diarrhoea and vomiting due to gastroenteritis in children under 5. (Clinical guideline 86). London: National Institute for Health and Clinical Excellence, 2009.

8. National Institute for Health and Clinical Excellence. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. (Clinical guideline 20). London: National Institute for Health and Clinical Excellence, 2004.

9. National Institute for Health and Clinical Excellence. Recognition and treatment of neonatal jaundice. (Clinical guideline 98). London: National Institute for Health and Clinical Excellence, 2010.

10. National Institute for Health and Clinical Excellence. Urinary tract infection: diagnosis, treatment and long-term management of urinary tract infection in children. (Clinical guideline 54). London: National Institute for Health and Clinical Excellence, 2007.

11. National Institute for Health and Clinical Excellence. Identification and management of familial hypercholesterolaemia. (Clinical guideline 71). London: National Institute for Health and Clinical Excellence, 2008.

12. National Institute for Health and Clinical Excellence. Promoting the quality of life of looked-after children and young people. (Public health guidance 28). London: National Institute for Health and Clinical Excellence, 2010.

13. National Institute for Health and Clinical Excellence. Guidance on when to suspect child maltreatment. (Clinical guideline 89). London: National Institute for Health and Clinical Excellence, 2009.

14. National Institute for Health and Clinical Excellence. Depression in children and young people: identification and management in primary, community and secondary care. (Clinical guideline 28). London: National Institute for Health and Clinical Excellence, 2005.

15. National Institute for Health and Clinical Excellence. Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. (Clinical guideline 9). London: National Institute for Health and Clinical Excellence, 2004.

16. National Institute for Health and Clinical Excellence. Post-traumatic stress disorder (PTSD): The management of PTSD in adults and children in primary and secondary care. (Clinical guideline 26). London: National Institute for Health and Clinical Excellence, 2005.

17. National Institute for Health and Clinical Excellence. Self-harm: The short-term physical and psychological management and secondary prevention of self-harm in primary and secondary care. (Clinical guideline 16). London: National Institute for Health and Clinical Excellence, 2004.

18. National Institute for Health and Clinical Excellence. Alcohol use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence. (Clinical guideline 115). London: National Institute for Health and Clinical Excellence, 2011.

19. National Institute for Health and Clinical Excellence. Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. (Clinical guideline 128). London: National Institute for Health and Clinical Excellence, 2011.

20. National Institute for Health and Clinical Excellence. Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults. (Clinical guideline 72). London: National Institute for Health and Clinical Excellence, 2008.

21. Scottish Intercollegiate Guidelines Network. Management of attention deficit and hyperkinetic disorders in children and young people. (Guideline No. 112). Edinburgh: Scottish Intercollegiate Guidelines Network, 2009.

22. National Institute for Health and Clinical Excellence. Guidance on differences in the uptake of immunisations (including targeted vaccines) in people younger than 19 years. (Public health guidance 21). London: National Institute for Health and Clinical Excellence, 2009.

23. National Institute for Health and Clinical Excellence. Postnatal care: Routine postnatal care of women and their babies. (Clinical guideline 37). London: National Institute for Health and Clinical Excellence, 2006.

24. Scottish Intercollegiate Guidelines Network. British Guideline on the Management of Asthma. (Guideline No. 101). Edinburgh: Scottish Intercollegiate Guidelines Network, 2011.

25. National Institute for Health and Clinical Excellence. Diagnosis and management of idiopathic childhood constipation in primary and secondary care. (Clinical guideline 99). London: National Institute for Health and Clinical Excellence, 2010.

26. National Institute for Health and Clinical Excellence. Management of atopic eczema in children from birth up to the age of 12 years. (Clinical guideline 57). London: National Institute for Health and Clinical Excellence, 2007.

27. National Institute for Health and Clinical Excellence. Diagnosis and assessment of food allergy in children and young people in primary care and community settings. (Clinical guideline 116). London: National Institute for Health and Clinical Excellence, 2011.

28. Scottish Intercollegiate Guidelines Network. Diagnosis and management of childhood otitis media in primary care. (Guideline No. 66). Edinburgh: Scottish Intercollegiate Guidelines Network, 2003.

29. National Institute for Health and Clinical Excellence. Surgical management of children with otitis media with effusion (OME). (Clinical guideline 60). London: National Institute for Health and Clinical Excellence, 2008.

30. National Institute for Health and Clinical Excellence. Prescribing of antibiotics for self-limiting respiratory tract infections in adults and children in primary care. (Clinical guideline 69). London: National Institute for Health and Clinical Excellence, 2008.

Appendix E: Chapter 8 – RAND study

Appendix E.1: List of expert panel

Name	Location	Description	Phase 1	Phase 2
Dr Janice Allister	Peterborough	RCGP Child Health Clinical Champion (2011-); Secretary of Primary Care Child Safeguarding Forum at Stockport Primary Care Trust	Yes	Yes
Dr Chris Boardman	Hampshire	RCGP Board, Wessex Faculty; First5 Lead Experience	Yes	Yes
Dr James Cave	Berkshire	NICE guideline development, practice based commissioning, Editor of *Drugs and Therapeutics Bulletin*	Yes	No
Dr Dick Churchill	Nottingham	Chair of RCGP Adolescent Primary Care Society Clinical Associate Professor, University of Nottingham	Yes	Yes
Dr David Jones	Newcastle	GP for Child Protection and GP Advisor on Children and Family Services	Yes	No
Dr Duncan Keeley	Oxford	Editorial Adviser for the *BMJ* (1999-2001), Member of the Oxford Tropical Research Ethics Committee	Yes	Yes
Dr Maeve Lambe	Northern Ireland	RCGP Northern Ireland Council NICE QOF Indicator Programme Committee	Yes	Yes
Dr Faye McCleery	Scotland	GP with Special Training in Child Health	Yes	Yes
Dr Tonia Myers	East London	GP Partner, Handsworth Medical Practice, London	Yes	Yes
Prof Ed Peile	Warwick	Professor Emeritus of Medical Education, Warwick Medical School	Yes	Yes
Dr Phil Rayner	Nottingham	Medical education, Vocational training RCGP Board, Vale of Trent Faculty	Yes	No
Dr Peter Saul	Wales	GP Associate Dean, Cardiff University Chair and Welsh Council Representative, RCGP	Yes	Yes
Dr Clare Taylor	Birmingham	NIHR In-Practice Fellow; First5 Clinical Lead at RCGP, Deputy Editor of *InnovAiT*	Yes	Yes

Appendix E.2: List of operationalised quality indicators

Early recognition of serious illness in children (*SI*)

SI-1 (#3). Children with "chronic or intermittent diarrhoea" and/or faltering growth should be investigated with "serological testing for Coeliac disease."[1]
SI-2 (#4). Children newly presenting with polydipsia, polyuria and/or weight loss should have clearly documented evidence of glucose assessment.
SI-3 (#5). Children newly presenting with secondary enuresis should have clearly documented evidence of glucose assessment.
SI-4 (#7). Children 5 years and younger with gastroenteritis with "blood and/or mucus in stool" or compromised immune status should have "stool microbiological investigations."[2]
SI-5 (#9). Children with a first non-febrile seizure should have clearly documented evidence of referral to secondary care for further assessment.
SI-6 (#13). Neonates ≥37 weeks (gestational age) with jaundice lasting ≥14 days or neonates <37 weeks (gestational age) with jaundice lasting ≥21 days who present to the general practitioner should have clearly documented evidence of conjugated bilirubin measurement.
SI-7 (#2). Children with a new onset fixed squint should be assessed and referred urgently when appropriate.

Serious illness – rationale for inclusion of indicator
The recognition and management of serious illness plays an important role in primary care. The importance was highlighted in the UK confidential enquiry into child deaths which identified specific areas where the care of children with serious illness in primary care could improve. This was reinforced by the large number of guidelines developed by NICE and SIGN, as well as professional guidance issued by several professional bodies.

Further information
- NICE clinical guideline 86 (2009). Recognition and assessment of coeliac disease. http://guidance.nice.org.uk/CG86
- NICE clinical guideline 15 (2012). Diagnosis and management of type 1 diabetes in children, young people and adults. http://guidance.nice.org.uk/CG15
- NICE clinical guideline 111 (2010). The management of bedwetting and nocturnal enuresis in children and young people. http://guidance.nice.org.uk/CG111
- NICE clinical guideline 84 (2009). Management of acute diarrhoea and vomiting due to gastroenteritis in children under 5. http://guidance.nice.org.uk/CG84
- NICE clinical guideline 137 (2012). NICE. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care (update). http://guidance.nice.org.uk/CG137
- NICE quality standard 27 (2013). Quality standard for the epilepsies in children and young people. http://publications.nice.org.uk/quality-standard-for-the-epilepsies-in-children-and-young-people-qs27
- SIGN clinical guideline 81 (2005). Diagnosis and management of epilepsies in children and young people. http://www.sign.ac.uk/guidelines/fulltext/81/index.html
- NICE clinical guideline 98 (2010). Recognition and treatment of neonatal jaundice. http://www.nice.org.uk/CG98
- NICE clinical guideline 27 (2005). Referral guidelines for suspected cancer. http://www.nice.org.uk/CG027

[1] NICE 'Recognition and assessment of coeliac disease' guideline recommendation 1.1.1.(NICE CG86)
[2] NICE 'Management of acute diarrhoea and vomiting due to gastroenteritis in children under 5' guideline audit criterion #1 (NICE CG84)

Serious illness indicator 1 (#3)

Indicator	Children with "chronic or intermittent diarrhoea" and/or faltering growth should be investigated with "serological testing for Coeliac disease."
Rationale	Coeliac disease is a common and under-diagnosed in the UK. It can present with various symptoms and signs that should prompt a blood test by the primary care practitioner.
Definitions	**Indicator description:** Proportion of children with "chronic or intermittent diarrhoea" and/or faltering growth that were investigated with "serological testing for Coeliac disease."(NICE CG86) **Indicator construction:** *Numerator* Number of children (0 – 18 years) with "chronic or intermittent diarrhoea" and/or faltering growth that are investigated with "serological testing for Coeliac disease."(NICE CG86) Patients with "chronic or intermittent diarrhoea" and/or faltering growth will be identified by appropriate READ Codes. Whether serological testing was completed will be identified from the primary care records.(NICE CG86) **Note*: Serological testing may be completed in primary or secondary care. Patients with congenital IgA deficiency may have a false negative test if IgA-based tests used. Guidance should have been provided to patients that they must remain on a gluten-containing diet. ***Note*: Serological testing should be completed whilst remaining on a gluten-containing diet. *Denominator* All children (0 – 18 years) registered in a general practice with a coded diagnosis of "chronic or intermittent diarrhoea" and/or faltering growth.(NICE CG86) **Indicator format** Raw numbers; percentage
Data source	QMAS; Local data collection
Technical issues	Verifying tests completed if done outside of primary care Objectively defining chronic or intermittent diarrhoea, faltering growth Timing of serological test with clinical presentation
Type	Process
Level	Practice
GRADE	2 = low
Source guideline	NICE clinical guideline 86 recommendations 1.1.1 and 1.1.4 (2009, reviewed July 2012, update in progress)
Other source information	Jones R, Sleet S. *BMJ* 2009;338:a3058.
Other issues / note	Prevalence ranges from 0.5 to 1.9% (NICE CG86)

Serious illness indicator 2 (#4)

Indicator	Children newly presenting with polydipsia, polyuria and/or weight loss should have clearly documented evidence of glucose assessment.
Rationale	Certain clinical symptoms and signs are characteristic of Type I diabetes and should prompt immediate evaluation and ruling out of diabetes by primary care practitioner.
Definitions	**Indicator description**: Proportion of children who presented with polydipsia, polyuria and/or weight loss that have clearly documented evidence of glucose assessment. **Indicator construction:** *Numerator* Number of children (0 – 18 years) who presented with polydipsia, polyuria and/or weight loss that have clearly documented evidence of glucose assessment. Symptoms will be identified by appropriate READ Codes, and by completing an annual search to identify patients that may meet the criteria but are improperly coded. **Note*: Glucose assessment includes fingerprick blood test or urinalysis. *Denominator* All children (0 – 18 years) registered with a general practice with a coded diagnosis of new onset polydipsia, polyuria and/or weight loss. **Indicator format** Raw number; percentage
Data source	QMAS; local data collection
Technical issues	Symptoms are vague and may be poorly documented and/or coded Timing of glucose assessment with clinical presentation (same day)
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 15 recommendations 1.4.1 and 1.1.2 (2004, updated 2009, reviewed August 2011; update in progress)
Other source information	▪ Usher-Smith JA et al. *BMJ* 2011;343:d4092 ▪ Ali K et al. *BMJ* 2011;342:d294 ▪ RCPCH. Growing up with diabetes: children and young people with diabetes in England. Research report. London: The College, 2009.
Other issues / note	England: diabetes occurs 1 in 450 children (97% Type 1 diabetes) (*BMJ* 2011;342:d294) Incidence 26/100 000 per year; prevalence 186/100 000 (0 – 17 year olds); England: >23 000 diabetic children (RCPCH 2009)

Serious illness indicator 3 (#5)

Indicator	Children newly presenting with secondary enuresis should have clearly documented evidence of glucose assessment.
Rationale	Certain clinical symptoms and signs are characteristic of Type I diabetes and should prompt immediate evaluation to rule out diabetes.
Definitions	**Indicator description**: Proportion of children who newly presented with secondary enuresis that have clearly documented evidence of glucose assessment. **Indicator construction:** *Numerator* Number of children (0 – 18 years) who newly presented with secondary enuresis that have clearly documented evidence of glucose assessment. Secondary enuresis will be identified by appropriate READ Codes, and by completing an annual search to identify patients that may meet criteria but are improperly coded. **Note*: Glucose assessment includes fingerprick blood test or urinalysis. *Denominator* All children (0 – 18 years) registered with a general practice with a coded diagnosis of secondary enuresis. **Indicator format** Raw number; percentage
Data source	QMAS; local data collection based on NICE audit criterion #2 (NICE CG111)
Technical issues	Symptoms are vague and may be poorly documented and/or coded Timing of glucose assessment with clinical presentation (same day)
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 15 recommendations 1.4.1 and 1.1.2 (2004, updated 2009, reviewed August 2011; update in progress) NICE clinical guideline 111 recommendations 1.3.8 and 1.3.13 (2010, review decision update expected October 2013)
Other source information	▪ Usher-Smith JA et al. *BMJ* 2011;343:d4092 ▪ Ali K et al. *BMJ* 2011;342:d294 ▪ RCPCH. Growing up with diabetes: children and young people with diabetes in England. Research report. London: The College, 2009.
Other issues / note	**Note*: Nocturnal enuresis in an otherwise well child has been recorded as an early symptom of diabetes. England: diabetes occurs 1 in 450 children (97% Type 1 diabetes) (*BMJ* 2011;342:d294) Incidence 26/100 000 per year; prevalence 186/100 000 (0 – 17 year olds); England: >23 000 diabetic children (RCPCH 2009)

Serious illness indicator 4 (#7)

Indicator	Children 5 years and younger with gastroenteritis with "blood and/or mucus in stool" or compromised immune status should have "stool microbiological investigations."
Rationale	Most children with gastroenteritis have common self-limiting infections that do not require investigations; however in certain circumstances stool microbiological investigations are important to diagnose and/or rule out underlying pathology, especially in '*at risk'* children.
Definitions	**Indicator description:** Proportion of children 5 years and younger with gastroenteritis with "blood and/or mucus in stool" or compromised immune status that had "stool microbiological investigations." **Indicator construction:** *Numerator* Number of children (0 – 5 years) who presented with gastroenteritis with "blood and/or mucus in stool" or compromised immune status that have "stool microbiological investigations." Gastroenteritis will be identified by appropriate READ Codes, and by completing an annual search to identify patients that may meet criteria but are improperly coded. **Note*: Gastroenteritis defined as per NICE guideline as acute diarrhoea (lasting 14 days or fewer) and/or vomiting.(NICE CG84) *Denominator* All children (0 – 5 years) registered with a general practice with a coded diagnosis of gastroenteritis with "blood and/or mucus in stool" or compromised immune status. **Indicator format** Raw number; percentage
Data source	QMAS; local data collection based on NICE audit criteria 1.1 and 1.2 (NICE CG84)
Technical issues	Identifying patients with compromised immune status Location of record of stool microbiological investigations Timing of stool investigations with clinical presentation (same day)
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 84 recommendations 1.1.2.2 (2009, reviewed July 2012)
Other source information	▪ Van Damme P et al. *J Infect Dis* 2007;195 Suppl 1:S4-S16 ▪ Ogilvie I et al. *BMC Infect Dis* 2012;12:62
Other issues / note	Annual incidence of gastroenteritis in UK approximately 5.8/100 mostly presenting to primary care (5/100 per year) (*J Infect Dis* 2007;195 Suppl 1:S4-S16) "Approximately 10% of children younger than 5 years presented to healthcare services with gastroenteritis each year."(NICE CG84)

Serious illness indicator 5 (#9)

Indicator	Children with a first non-febrile seizure should have clearly documented evidence of referral to secondary care for further assessment.
Rationale	Misdiagnosis frequently occurs in children with epilepsy therefore prompt referral in children with non-febrile seizures is important.
Definitions	**Indicator description:** Proportion of children with a first non-febrile seizure that have clearly documented evidence of referral to secondary care for further assessment. **Indicator construction:** *Numerator* Number of children (0 – 18 years) who had a first non-febrile seizure that have clearly documented evidence of referral to secondary care for further assessment. Non-febrile seizure will be identified by appropriate READ Codes, and by completing an annual search to identify patients that may meet the criteria but are improperly coded. *Denominator* All children (0 – 18 years) registered with a general practice with a coded diagnosis of a first non-febrile seizure. **Indicator format** Raw number; percentage
Data source	QMAS; local data collection; A&E data
Technical issues	Ensuring all patients with non-febrile seizure are documented, particularly if they first present to A&E
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 137 recommendations 1.4.4C (2004, updated 2012) SIGN clinical guideline 81 (2005) Similar to newly developed NICE quality statement 1 for epilepsy ▪ "Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation."(NICE QS27)
Other source information	-
Other issues / note	Prevalence 5-10 cases per 1000 (NICE CG137) Practice of 2,000 patients will have 10-20 patients with epilepsy on treatment with 1-2 new cases per year (NICE CG137)

Serious illness indicator 6 (#13)

Indicator	Neonates ≥37 weeks (gestational age) with jaundice lasting ≥14 days or neonates <37 weeks (gestational age) with jaundice lasting ≥21 days who present to the general practitioner should have clearly documented evidence of conjugated bilirubin measurement.
Rationale	Prolonged jaundice in infants should be taken seriously and adequately investigated to rule out serious underlying causes.
Definitions	**Indicator description:** Proportion of neonates ≥37 weeks (gestational age) with jaundice lasting ≥14 days or neonates <37 weeks (gestational age) with jaundice lasting ≥21 days who presented to the general practitioner and have clearly documented evidence of conjugated bilirubin measurement. **Indicator construction:** *Numerator* Number of neonates ≥37 weeks (gestational age) with jaundice lasting ≥14 days or neonates <37 weeks (gestational age) with jaundice lasting ≥21 days who presented to the general practitioner and have clearly documented evidence of conjugated bilirubin measurement. Prolonged neonatal jaundice will be identified by appropriate READ Codes, and by completing an annual search to identify patients that may meet the criteria but are improperly coded. *Denominator* All neonates ≥37 weeks (gestational age) with jaundice lasting ≥14 days or neonates <37 weeks (gestational age) with jaundice lasting ≥21 days registered with a practice who presented to the general practitioner. **Indicator format** Raw numbers; percentage
Data source	QMAS; local data collection based on NICE audit criteria 12 and 12.3 (NICE CG98) for 'Care of babies with prolonged jaundice' Two related audits mentioned in NICE report could be linked: ▪ National Neonatal National Audit Programme (NNAP) ▪ Paediatric Intensive Care Audit Network (PICANet) Regional data collection from public health agencies
Technical issues	Integrating the data sources for measurement; accurate timing of length of jaundice and gestational age
Type	Process
Level	Practice / Regional
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 98 recommendation 1.7.1 (2010, review update decision date May 2013)
Other source information	-
Other issues / note	Common in term (60%) and preterm (80%) (NICE CG98)

Serious illness indicator 7 (#2)

Indicator	Children with a new onset fixed squint should be assessed and referred urgently when appropriate.
Rationale	Retinoblastoma is a serious form of childhood cancer that can present in children with a new squint or change in visual acuity. There should be a low threshold to rule out retinoblastoma in primary care.
Definitions	**Indicator description:** Proportion of children that presented with a new onset fixed squint that were assessed and referred urgently when appropriate. **Indicator construction:** *Numerator* Number of children (0 – 6 years) with a new onset fixed squint that were assessed and referred urgently when appropriate. New onset fixed squint will be identified by appropriate READ Codes, and by completing an annual search to identify patients that may meet the criteria but are improperly coded. '*When appropriate'* will be determined by clinical review of all notes of patients that present with fixed squint. Most children with retinoblastoma are diagnosed by the age of 6 (PubMed Health) while 80% of cases occur before by the age of 4 (NICE CG27) and 95% will be diagnosed by the age of 5 (*Br J Ophthalmol* 2009;93:33-37) therefore will be relevant for children aged 0 – 6 years. *Denominator* All children (0 – 6 years) registered with a general practice with a coded diagnosis of new onset fixed squint. **Indicator format** Raw numbers; percentage
Data source	QMAS; local data collection and secondary care registries (e.g. optometrists, ophthalmologists, etc.); regional cancer registries with retrospective audit
Technical issues	Accurate and reliable coding for '*when appropriate*'; potentially re-structure to clinical review of new onset fixed squint cases given low prevalence
Type	Process
Level	Regional / practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 27 recommendations 1.14.32 (2005, update in progress expected March 2014)
Other source information	▪ MacCarthy et al. *Br J Ophthalmol* 2009;93:33-37 ▪ Ahrensberg JM et al. *Br J Gen Pract* 2012;62(600):e458-65 ▪ Dommett RM et al. *Br J Cancer* 2012;106(5):982-7
Other issues / note	Frequency <1 in 15 000; 40-50 per year in UK (NICE CG27) Strabismus occurs in up to 5% of population (*Ophthalmic Epidemiol* 2005;12(4):243-50)

Child protection/safeguarding (*Safe*)

Safe-1 (#20). Children about whom a practitioner suspects neglect or abuse should have evidence that a clear and recorded course of action was taken.
Safe-2 (#21). Relevant staff should know the practice lead and the contact details for the "named/designated professionals for safeguarding children."[3]
Safe-3 (#17). "Looked-after children and young people" should be clearly identified in the general practitioner's summary record.[4]
Safe-4 (#65). "All relevant staff must have received child protection/safeguarding children training in line with local policy."[5]

Child protection/safeguarding – rationale for inclusion of indicator
General practitioners play a unique role in safeguarding due to their close relationships with families and ability to observe the complex social dynamic over several consultations. Yet recent evidence suggests that child maltreatment cases are under recorded in primary care. There have been numerous guidelines published articulating the responsibilities and the role of general practitioners in safeguarding and its importance is reflected by the RCGP publishing "*Safeguarding Children and Young People: A Toolkit for General Practice*." (last updated 2011; http://www.rcgp.org.uk/clinical-and-research/clinical-resources/child-and-adolescent-health/safeguarding-children-toolkit.aspx)

Further information

- NICE clinical guideline 89 (2009). Guidance on when to suspect child maltreatment. http://www.nice.org.uk/CG89
- NICE public health guideline 28 (2010). Promoting the quality of life of looked-after children and young people. http://www.nice.org.uk/PH28
- Royal College of General Practitioners 2011. Safeguarding Children & Young People A Toolkit for General Practice. http://www.rcgp.org.uk/clinical-and-research/clinical-resources/child-and-adolescent-health/safeguarding-children-toolkit.aspx
- Royal College of Paediatrics and Child Health on behalf of the contributing organisations 2010. Safeguarding children and young people: roles and competencies for healthcare staff. http://www.rcpch.ac.uk/system/files/protected/page/Safeguarding%20Children%20and%20Young%20people%202010.pdf
- General Medical Council 2012. Protecting children and young people: The responsibilities of all doctors. http://www.gmc-uk.org/guidance/ethical_guidance/13257.asp

[3] NICE 'When to suspect child maltreatment' guidance audit criterion #3.(NICE CG89)
[4] NICE 'Promoting the quality of life of looked-after children and young people' guidance.(NICE PH28)
[5] NICE 'When to suspect child maltreatment' guidance audit criterion #5.(NICE CG89)

Safeguarding indicator 1 (#20)

Indicator	Children about whom a practitioner suspects neglect or abuse should have evidence that a clear and recorded course of action was taken.
Rationale	All confirmed cases of child maltreatment should be fully investigated by GPs and have evidence that steps were appropriately followed. "In sharing concerns about possible abuse or neglect, you are not making the final decision about how best to protect a child or young person."(GMC Protecting Children and Young People)
Definitions	**Indicator description:** Proportion of children about whom a practitioner suspects neglect or abuse that have evidence that a clear and recorded course of action was taken. **Indicator construction:** *Numerator* Number of children (0 – 18 years) registered with a general practice about whom a practitioner suspects neglect or abuse that have evidence that a clear and recorded course of action was taken. Patients with suspected neglect or abuse will be identified by an appropriate READ Codes outlined in the RCGP Multisite Audit "Level 3: Consensus recommended coding list" (e.g. 'child is cause for concern, 13If'; 'family is cause for concern, 13Ip'; 'social worker involved, 13G4'; 'child in care, 13IB'; 'health visitor visits, 13G2') and by completing an annual search to identify patients that may meet the criteria but are improperly coded. Patients with longstanding maltreatment issues should be coded from date the issues were first known. *Denominator* All children (0 – 18 years) registered with a general practice about whom a practitioner suspects neglect or abuse. Time frame bounded by READ Code 'Child no longer vulnerable' (13lW) which specifies that the period of concern has now ended. **Indicator format** Raw number; percentage
Data source	Local data collection; QMAS
Technical issues	Determining when the period of observation ends, or when GP '*suspects'*
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 89 (2009, no update required August 2012)
Other source information	▪ Woodman et al. *Br J Gen Pract* 2012;62(600):e478-e86 ▪ RCGP Multisite Audit: Recording concerns about child maltreatment in primary care databases. www.clininf.eu/maltreatment ▪ General Medical Council (GMC). Protecting children and young people: The responsibilities of all doctors. 2012-Jul-10
Other issues / note	-

Safeguarding indicator 2 (#21)

Indicator	Relevant staff should know the practice lead and the contact details for the "named/designated professionals for safeguarding children."
Rationale	Each practice should have a named lead for child safeguarding and the staff should be aware of who this person is and have their contact details.
Definitions	**Indicator description:** Proportion of relevant staff who know the practice lead and the contact details for the "named/designated professionals for safeguarding children."(NICE CG89) **Indicator construction:** *Numerator* Number of practice-employed staff that know the practice lead and the contact details for the "named/designated professionals for safeguarding children."(NICE CG89) Each practice has an identified Practice Safeguarding Lead and deputy as outlined in the RCGP Safeguarding Children & Young People A Toolkit for General Practice. Each staff member should know the contact information for the lead and deputy. *Denominator* All practice-employed staff. **Indicator format** Raw number; percentage
Data source	Local data collection from practice records, audit criterion 3 (NICE CG89)
Technical issues	Defining relevant staff
Type	Structure
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 89 audit criterion 3 (2009, reviewed August 2012) ▪ "All relevant staff must know who are their named or designated professionals for safeguarding children."
Other source information	▪ Woodman et al. *Br J Gen Pract* 2012;62(600):e478-e86 ▪ RCGP Safeguarding Children & Young People A Toolkit for General Practice 2011. RCGP and National Society for the Prevention of Cruelty to Children (NSPCC). ▪ RCGP Multisite Audit: Recording concerns about child maltreatment in primary care databases. www.clininf.eu/maltreatment ▪ General Medical Council (GMC). Protecting children and young people: The responsibilities of all doctors. 2012-Jul-10
Other issues / note	-

Safeguarding indicator 3 (#17)

Indicator	"Looked-after children and young people" should be clearly identified in the general practitioner's summary record.
Rationale	Children and young people that are looked-after should be clearly identified to ensure adequate clinical assessment and high quality care. Each practice should complete an annual review to ensure all "looked-after children and young people" are properly identified.(NICE PH28)
Definitions	**Indicator description:** The practice can produce a register of "looked-after children and young people."(NICE PH28) **Indicator construction:** *Numerator* "Looked-after children and young people" (0 – 18 years) registered with a general practice who are clearly identified in the general practitioner's summary record.(NICE PH28) "Looked-after children and young people" will be identified by appropriate READ Codes outlined in the RCGP Multisite Audit "Level 3: Consensus recommended coding list" (e.g. 'child in care, 13IB'; 'foster care, 8GE7'; 'fostering medical examination, 6982'; 'child lives with another relative, 13Ic'; 'child lives with unrelated adult, 13Iu') and by completing an annual search to identify patients that meet the criteria but are improperly coded. *Note: "Looked-after children and young people" are defined by NICE public health guidance 28 as: "those looked-after by the State where the Children Act 1989 applies, including those who are subject to a care order or temporarily classed as looked-after on a planned basis for short breaks or respite care."(NICE PH28) *Denominator* All "looked-after children and young people" (0 – 18 years) registered with a general practice.(NICE PH28) **Indicator format** Raw number, percentage
Data source	Local data collection in each practice; QMAS; health visitor notes; Red Book; Social care registry or local databases
Technical issues	Verifying correct information; integrating data sources
Type	Structure
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE public health guidance 28 recommendations 20, 21, 22 and 23 (2010, next review October 2013)
Other source information	▪ Woodman et al. *Br J Gen Pract* 2012;62(600):e478-e86 ▪ RCGP Multisite Audit: Recording concerns about child maltreatment in primary care databases. www.clininf.eu/maltreatment ▪ General Medical Council (GMC). Protecting children and young people: The responsibilities of all doctors. 2012-Jul-10
Other issues / note	NICE guidelines indicate that "accurate and up-to-date personal health information has significant implications for the immediate and future wellbeing of children and young people during their time in care and afterwards." (NICE PH28)

Safeguarding indicator 4 (#65)

Indicator	"All relevant staff must have been on child protection/safeguarding children training in line with local policy."
Rationale	Recent evidence suggests that child maltreatment cases are under recorded in primary care yet general practitioners are in an important position to identify and respond to families where maltreatment might be considered. Further, many primary care practitioners have not received adequate child protection training.
Definitions	**Indicator description:** The practice can produce a register of "relevant staff who have been on child protection/safeguarding children training in line with local policy."(NICE CG89) **Indicator construction:** *Numerator* Number of practice-employed non-clinical and clinical staff including partners that have completed "child protection/safeguarding children training in line with local policy."(NICE CG89) Each individual practice will determine the appropriate level (1-6) of competence required for each staff member. The levels and the specific training requirements are outlined in the RCPCH report Safeguarding children and young people: roles and competences for healthcare staff intercollegiate report published in 2010 with GPs being considered Level 3 (agreed by RCGP 2012). *Denominator* All practice-employed non-clinical and clinical staff including partners employed in a general practice. **Indicator format** Raw number; percentage
Data source	QMAS; Local data collection
Technical issues	-
Type	Structure
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 89 audit criterion 5 (2009, reviewed August 2012) ▪ "All relevant staff must have been on child protection/safeguarding children training in line with local policy."
Other source information	▪ Woodman et al. *Br J Gen Pract* 2012;62(600):e478-e86 ▪ RCGP Safeguarding Children & Young People A Toolkit for General Practice 2011. ▪ RCGP Multisite Audit: Recording concerns about child maltreatment in primary care databases. www.clininf.eu/maltreatment ▪ RCPCH, et al. Safeguarding children and young people: roles and competences for healthcare staff London, 2010. ▪ General Medical Council (GMC). Protecting children and young people: The responsibilities of all doctors. 2012-Jul-10
Other issues / note	**Note*: Based on audit criterion #5 in NICE Guidance on when to suspect child maltreatment (NICE CG89).

Mental health problems in young people (*MH*)

MH-1 (#23). Adolescents with depression who have moderate or high risk factors, "high recurrent risk of acts of self-harm or suicide" or "significant on-going self-neglect" should be referred for further assessment or discussed with a specialist colleague.[6]
MH-2 (#28). Children that self-harm should have a clearly documented assessment and management plan.
MH-3 (#31). Children 3 years and older "with regression in language" or "any age with regression in motor skills" should be referred for further assessment.[7]
MH-4 (#33). Children taking methylphenidate, atomoxetine or dexamfetamine should have clearly documented monitoring.

Mental health – rationale for inclusion of indicator

The burden of mental health problems in children is under recognised but growing. Poor recognition and treatment of mental health problems places stress on children and families which continues into adult life. Effective interventions are available yet they rely on timely detection and use. General practitioners can thus play an important role identifying and treating mental health problems.

Further information

- NICE clinical guideline 28 (2005). Depression in children and young people: identification and management in primary, community and secondary care. http://www.nice.org.uk/CG28
- NICE clinical guideline 16 (2004). Self-harm: The short-term physical and psychological management and secondary prevention of self-harm in primary and secondary care. http://www.nice.org.uk/CG16
- NICE clinical guideline 128 (2011). Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. http://www.nice.org.uk/CG128
- SIGN clinical guideline 98 (2007). Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. http://www.sign.ac.uk/guidelines/fulltext/98/index.html
- NICE clinical guideline 72 (2008). Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults. http://www.nice.org.uk/CG72
- SIGN clinical guideline 112 (2009). Management of attention deficit and hyperkinetic disorders in children and young people. http://www.sign.ac.uk/guidelines/fulltext/112/index.html

[6] NICE 'Depression in children and young people: identification and management in primary, community and secondary care' guideline recommendation 1.3.2.3.(NICE CG28)

[7] NICE 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum' guideline recommendation 22.(NICE CG128)

Mental health indicator 1 (#23)

Indicator	Adolescents with depression who have moderate or high risk factors, "high recurrent risk of acts of self-harm or suicide" or "significant on-going self-neglect" should be referred for further assessment or discussed with a specialist colleague.
Rationale	Patients with depression should be managed according to the stepped-care model which "draws attention to the different needs that depressed children and young people have – depending on the characteristics of their depression and their personal and social circumstances – and the responses that are required from services."(NICE CG28)
Definitions	**Indicator description:** Proportion of adolescents with depression who have moderate or high risk factors, "high recurrent risk of acts of self-harm or suicide" or "significant on-going self-neglect" that were referred for further assessment or discussed with a specialist colleague.(NICE CG28) **Indicator construction:** *Numerator* Number of children (5 – 18 years) with depression who have moderate or high risk factors, "high recurrent risk of acts of self-harm or suicide" or "significant on-going self-neglect" that were referred for further assessment or discussed with a specialist colleague.(NICE CG28) Depression and risk factors will be identified by READ Codes, and by completing an annual search to identify patients that may meet the criteria but are improperly coded. Require documentation in record that patients were referred or evidence of communication with specialist colleague. **Note:* Moderate risk factors refer to depression with >2 other risk factors; depression where >1 family members have history for depression; failure to respond to treatment for mild depression "after 2–3 months; moderate or severe depression; signs of a recurrence of depression in those who recovered" from depression; "unexplained self-neglect >1 month"; active suicidality; referral requested by patient or parent/caregiver.(NICE CG28) *Denominator* All children (5 – 18 years) registered with a general practice with depression who have moderate or high risk factors, "high recurrent risk of acts of self-harm or suicide" or "significant on-going self-neglect."(NICE CG28) **Indicator format** Raw number; percentage
Data source	Local data collection; QMAS; regional data from CAMHS
Technical issues	Coding risk factors and assessment/discussion with colleague
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 28 recommendations 1.3.2.2 and 1.3.2.3 (2005, reviewed 2011)
Other source information	Vallance AK et al. *Prim Health Care Res Dev* 2011;12(4):301-9
Other issues / note	Prevalence 1-3% in 12-month period (NICE CG28)

Mental health indicator 2 (#28)

Indicator	Children that self-harm should have a clearly documented assessment and management plan.
Rationale	Children that self-harm require a full assessment to evaluate the risk of suicide and associated mental illness and provide appropriate interventions which may include referral to a specialist.
Definitions	**Indicator description:** Proportion of children that self-harm that have a clearly documented assessment and management plan. **Indicator construction:** *Numerator* Number of children (8 – 18 years) that self-harm that have a clearly documented assessment and management plan. Self-harm will be identified by READ Codes, and by completing an annual search to identify patients that may meet the criteria but are improperly coded (e.g. presented to A&E). Clearly documented assessment and management plan will be outlined in the record. **Note*: Assessment includes family/social situation and child protection issues. *Denominator* All children (8 – 18 years) registered with a general practice that have self-harmed. **Indicator format** Raw number; percentage
Data source	Local data collection; QMAS; A&E data
Technical issues	Correctly identifying self-harm behaviour which may require new READ codes or standardised list of codes (similar to child maltreatment) Identifying patients that presented to A&E – notes review
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 16 recommendations 1.2.1.1, 1.2.1.2 and 1.9.1.10 (2004, reviewed February 2012, next review date February 2015)
Other source information	-
Other issues / note	Survey of 12 529 children aged 5-15: 1.3% had tried to harm themselves (NICE CG16)

Mental health indicator 3 (#31)

Indicator	Children 3 years and older "with regression in language" or "any age with regression in motor skills" should be referred for further assessment.
Rationale	Regression in any developmental milestone is an important red flag that must prompt referral to a specialist for further evaluation. Recognition and detection of autism ensures that children and young people receive adequate support and education, increasing the likelihood of positive outcomes long-term and reducing the impact on family members.
Definitions	**Indicator description:** Proportion of children 3 years and older "with regression in language" or "any age with regression in motor skills" that were referred for further assessment.(NICE CG128) **Indicator construction:** *Numerator* Number of children with "regression in language" (3 – 18 years) or "with regression in motor skills" (0 – 18 years) that were referred for further assessment.(NICE CG128) Regression in language, motor skills will be identified by appropriate READ Codes, and by completing an annual search to identify patients that meet the criteria but are improperly coded. Documentation of referral in records. *Denominator* All children registered with a general practice "with regression in language" (3 – 18 years) or "with regression in motor skills" (0 – 18 years).(NICE CG128) **Indicator format** Raw number; percentage
Data source	QMAS; Local data collection consistent with several relevant audit criteria including time to and composition of diagnostic assessment, communicating results and follow-up appointment with autism team (NICE CG128) Notes from health visitors and referral agencies (e.g. CAMHS)
Technical issues	Integrated data sources
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 128 recommendations 1.3.2 and 1.3.3 (2011) SIGN guideline 98 recommendation 3.2.1 (2007)
Other source information	-
Other issues / note	Prevalence of autism >1% (NICE CG128)

Mental health indicator 4 (#33)

Indicator	Children taking methylphenidate, atomoxetine or dexamfetamine should have clearly documented monitoring.
Rationale	Medications prescribed for attention deficit hyperactivity disorder may lead to reduced appetite and growth therefore monitoring is important to identify potential side effects.
Definitions	**Indicator description:** Proportion of children taking methylphenidate, atomoxetine or dexamfetamine that have clearly documented monitoring. **Indicator construction:** *Numerator* Number of children (0 – 18 years) taking methylphenidate, atomoxetine or dexamfetamine that have clearly documented monitoring. Prescriptions will be identified by appropriate READ Codes. Clearly documented monitoring of height and weight will be identified by looking at the primary care records. **Note*: Monitoring should include height and weight measurements every 6 months and plotted on a growth chart. *Denominator* All children (0 – 18 years) registered with a general practice taking methylphenidate, atomoxetine or dexamfetamine. **Indicator format** Raw numbers; percentage
Data source	QMAS; Local data collection
Technical issues	Specifying location of monitoring
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 72 recommendations 1.8.1.4 and 1.8.4.2 (2004, updated in 2012) SIGN guideline 112 recommendations 7.2.5 and 7.3.2 (2009)
Other source information	-
Other issues / note	Approximately 4% of boys and 1% of girls under 15 years are diagnosed with ADHD; 5% estimated prevalence (NICE CG72)

Health promotion (*HP*)

HP-1 (#6). Children with Type I diabetes aged 6 months and older should have documented evidence of being offered annual influenza immunisation.

Health promotion – rationale for inclusion of indicator

Health promotion is a cornerstone of primary care, particularly for children with chronic conditions. Despite being primarily managed in secondary care, children with diabetes will present frequently to the general practitioner for routine care of acute self-limiting illnesses. These visits provide unique opportunities to ensure children with Type 1 Diabetes have their annual influenza immunisation.

Further information

- NICE clinical guideline 15 (2012). Diagnosis and management of Type 1 diabetes in children, young people and adults. http://guidance.nice.org.uk/CG15

Health promotion indicator 1 (#6)

Indicator	Children with Type I diabetes aged 6 months and older should have documented evidence of being offered annual influenza immunisation.
Rationale	Children with Type I Diabetes are at an increased risk of serious illness or death if they contract influenza. Primary care practitioners should ensure these children are offered annual immunisation against influenza.
Definitions	**Indicator description:** Proportion of children aged 6 months and older with Type I diabetes who have documented evidence of being offered annual influenza immunisation. **Indicator construction:** *Numerator* Children aged 6 months and older with a coded diagnosis of Type I diabetes who have documented evidence of being offered annual influenza immunisation in the preceding year. Type 1 Diabetes will be identified by appropriate READ Codes; similarly with receipt of annual influenza immunisation. Notes review of free text in clinical records will likely be required to determine whether immunisation was not given but offered, which should be manageable considering the small number of patients with Type 1 Diabetes in each practice. *Denominator* All children aged 6 months and older registered with a general practice with a coded diagnosis of Type I diabetes. **Indicator format** Raw number; percentage
Data source	QMAS; Local data collection
Technical issues	Identifying when patients were offered immunisation but did not receive it or chose not to receive it
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 15 recommendation 2.11.1 (2004, updated 2009, decision in August 2011 to update guideline; in progress)
Other source information	▪ Department of Health. Seasonal flu plan: Winter 2012/13. 3 May 2012. ▪ Joint Committee on Vaccination and Immunisation. JCVI statement on its position on the annual influenza vaccination programme. 16 Nov 2011
Other issues / note	England: diabetes occurs 1 in 450 children (97% Type 1 diabetes) (*BMJ* 2011;342:d294) Incidence 26/100 000 per year; prevalence 186/100 000 (0 – 17 year olds); England: >23 000 diabetic children (RCPCH 2009)

Routinely managed conditions (*Routine*)

Routine-1 (#41). Children with asthma aged 5 years or less should have clearly documented basis for diagnosis.
Routine-2 (#42). Children with asthma should be prescribed a spacer.
Routine-3 (#47). Children with idiopathic constipation should be treated with polyethylene glycol for initial therapy along with dietary and fluid advice.
Routine-4 (#52). Children with nocturnal enuresis should have a clearly recorded assessment which differentiates between primary and secondary enuresis.
Routine-5 (#64). Children with nocturnal enuresis should not be prescribed tricyclic medications in primary care.
Routine-6 (#56). Children 3 years and older with "persistent bilateral otitis media with effusion" or any age with "speech and language, developmental or behavioural problems" should be referred for hearing assessment.[8]

Routinely managed conditions – rationale for inclusion of indicator
General practitioners play an important role managing common childhood conditions, such as asthma, idiopathic constipation, nocturnal enuresis and otitis media. Usually self-limiting, appropriate management and assessment for these conditions is important to ensure prompt resolution and to reduce unnecessary referral to secondary care and attendances to A&E.

Further information

- SIGN clinical guideline 101 (2011). British Guideline on the Management of Asthma. http://www.sign.ac.uk/guidelines/fulltext/101/index.html
- NICE quality standard 25 (2013). Quality standard for asthma. http://guidance.nice.org.uk/QS25
- NICE clinical guideline 99 (2010). Diagnosis and management of idiopathic childhood constipation in primary and secondary care. http://guidance.nice.org.uk/CG99
- NICE clinical guideline 111 (2010). The management of bedwetting and nocturnal enuresis in children and young people. http://www.nice.org.uk/cg111
- NICE clinical guideline 60 (2008). Surgical management of children with otitis media with effusion (OME). http://guidance.nice.org.uk/CG60
- SIGN clinical guideline 66 (2003). Diagnosis and management of childhood otitis media in primary care. http://www.sign.ac.uk/guidelines/fulltext/66/index.html

[8] SIGN 'Diagnosis and management of childhood otitis media in primary care' guideline recommendation 4.2.2.(SIGN 66)

Routinely managed conditions indicator 1 (#41)

Indicator	Children with asthma aged 5 years or less should have clearly documented basis for diagnosis.
Rationale	Asthma diagnosis requires confirmation of reversibility which cannot be definitively completed in children less than 5 years. Recorded diagnosis of asthma before this age should include a clear description of the basis for diagnosis.
Definitions	**Indicator description:** Proportion of children aged 5 years or less with asthma that have clearly documented basis for diagnosis. **Indicator construction:** *Numerator* Number of children aged 5 years or less with asthma who have clearly documented basis for diagnosis. Asthma will be identified by READ Codes. Clearly documented basis for diagnosis will be identified by READ codes or notes evaluation which may include symptoms/sign of asthma, trial of treatment with clear evidence of clinical improvement, investigations that ruled out other causes of conditions and/or referral to specialist. *Note: As per the SIGN guideline, documentation should include "presence of key features in the history and examination [and] careful consideration of alternative diagnoses."(SIGN 101) *Denominator* All patients aged 5 years or less registered with a general practice with a coded diagnosis of asthma. **Indicator format** Raw number, percentage
Data source	QMAS; Local data collection
Technical issues	Appropriate READ codes for basis of diagnosis as they will include symptoms/sign, trial of treatment, investigations and/or referral
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	SIGN guideline 101 recommendations 2.1.1, 2.1.8 and 4 (2008, revised 2011) Similar to NICE indicator: ▪ "The percentage of patients with asthma who have had an asthma review in the preceding 15 months that includes an assessment of asthma control using the 3 RCP questions."(NICE NM23) Similar to newly developed NICE quality statement 1 for asthma: ▪ "People with newly diagnosed asthma are diagnosed in accordance with BTS/SIGN guidance."(NICE QS25)
Other source information	-
Other issues / note	Over 1 million British children with asthma (Asthma UK)

Routinely managed conditions indicator 2 (#42)

Indicator	Children with asthma should be prescribed a spacer.
Rationale	Spacers are highly effective inhaler devices used for the delivery of asthma-related medications. SIGN indicates they are the preferred option for patients with asthma that is mild to moderate in particular; therefore each patient with asthma should be prescribed a spacer.
Definitions	**Indicator description:** Proportion of children with asthma that are prescribed a spacer. **Indicator construction:** *Numerator* Number of children (5 – 18 years) with asthma that are prescribed a spacer. Asthma will be identified by appropriate READ Codes. Spacers will be identified by the BNF code to be searched in the appropriate database and confirmation of prescription should have been reviewed during annual asthma review. *Denominator* All children (5 – 18 years) registered with a general practice with a coded diagnosis of asthma. **Indicator format** Raw number, percentage
Data source	QMAS; Local data collection extracted from practice audit looking for prescriptions for asthmatic patients and audit criteria for inhaler devices: ▪ "Audit the percentage of patients in whom there is a record of satisfactory inhaler technique."(SIGN 101) ▪ "Audit the percentage of patients using a spacer device for mild to moderately severe Exacerbations."(SIGN 101)
Technical issues	Appropriate READ codes; time frame
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	SIGN guideline 101 recommendations 5.2.2, 5.5 and 6.8.2 (2008, revised 2011)
Other source information	-
Other issues / note	Over 1 million British children with asthma (Asthma UK)

Routinely managed conditions indicator 3 (#47)

Indicator	Children with idiopathic constipation should be treated with polyethylene glycol for initial therapy along with dietary and fluid advice.
Rationale	Idiopathic constipation is common and becomes chronic in over one-third of children. It is frequently referred to secondary care and appropriate treatment should begin with a trial therapy of polyethylene glycol.
Definitions	**Indicator description:** Proportion of children with idiopathic constipation that were treated with polyethylene glycol for initial therapy along with dietary and fluid advice. **Indicator construction:** *Numerator* Children (0 – 18 years) with a coded diagnosis of idiopathic constipation that were treated with polyethylene glycol for initial therapy along with dietary and fluid advice. Idiopathic constipation will be identified by READ Codes. Polyethylene glycol will be identified by the BNF code to be searched in appropriate database. Dietary and fluid advice will be identified from practice notes. **Note: The NICE guidance provides non-BNFC recommended doses for all age groups but notes the following: "At the time of publication (May 2010) Movicol Paediatric Plain is the only macrogol licensed for children under 12 years that includes electrolytes. It does not have UK marketing authorisation for use in faecal impaction in children under 5 years, or for chronic constipation in children under 2 years. Informed consent should be obtained and documented."(NICE CG99) *Denominator* All children (0 – 18 years) registered with a general practice with a coded diagnosis of idiopathic constipation. **Indicator format** Raw numbers; percentage
Data source	QMAS; Local data collection from NICE audit criteria 8, 9 and 14 (NICE CG99)
Technical issues	Identifying READ codes for idiopathic constipation and any constipation
Type	Process
Level	Practice
GRADE	2 = low
Source guideline	NICE clinical guideline 99 recommendations 1.4.2, 1.4.3 and 1.4.8 (2010, review decision date May 2013)
Other source information	▪ Stienen JJ et al. *Eur J Pediatr* 2011;170(12):1513-9 ▪ Lee-Robichaud H et al. *Cochrane Database Syst Rev* 2010;7;(7):CD007570.
Other issues / note	**Note*: Quality indicator similar to that developed in Stienen JJ et al (*Eur J Pediatr* 2011;170(12):1513-9) Prevalence varies from 5-30% (NICE CG99)

Routinely managed conditions indicator 4 (#52)

Indicator	Children with nocturnal enuresis should have a clearly recorded assessment which differentiates between primary and secondary enuresis.
Rationale	It is important to differentiate between primary and secondary enuresis in children that present with nocturnal enuresis due to the higher chance of being diagnosed with serious conditions such as Type I Diabetes, urinary tract infection or child maltreatment.
Definitions	**Indicator description:** Proportion of children with nocturnal enuresis that have a clearly recorded assessment which differentiates between primary and secondary enuresis. **Indicator construction:** *Numerator* Number of children (0 – 18 years) with a coded diagnosis of nocturnal enuresis that have a clearly recorded assessment which differentiates between primary and secondary enuresis. Nocturnal enuresis will be identified by appropriate READ Codes. Clearly recorded assessment includes assessing for possible medical, emotional or physical triggers, and characterising the pattern of bedwetting (i.e. frequency, timing, fluid intake, daytime symptoms, etc.). Secondary enuresis defined by NICE: "Bedwetting that has occurred after a child has been dry at night for more than 6 months."(NICE CG111) *Denominator* All children (0 – 18 years) registered with a general practice with a coded diagnosis of nocturnal enuresis. **Indicator format** Raw numbers; percentage
Data source	QMAS; local data collection extracted from NICE practice audit #1 looking for specific information with a clearly recorded assessment (NICE CG111)
Technical issues	Appropriate READ codes
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	NICE clinical guideline 111 recommendations 1.3.1 and 1.3.2 (2010, review decision date October 2013)
Other source information	▪ Usher-Smith JA et al. *BMJ* 2011;343:d4092 ▪ Ali K et al. *BMJ* 2011;342:d294
Other issues / note	Prevalence of nocturnal enuresis (depending on whether defined as >1 or >2 nights/week) varies by age but highest in younger children (5 years old, 8-15%) (NICE CG111)

Routinely managed conditions indicator 5 (#64)

Indicator	Children with nocturnal enuresis should not be prescribed tricyclic medications in primary care.
Rationale	Tricyclic medications are inappropriate to use as first line therapy for treatment of nocturnal enuresis; they have a high relapse rate and potentially lethal adverse effects if overdosed. More effective therapies, namely alarm interventions, are more appropriate for first line treatment.
Definitions	**Indicator description:** Proportion of children with nocturnal enuresis that have a prescription for tricyclic medications. **Indicator construction:** *Numerator* Number of children (0 – 18 years) with a coded diagnosis of nocturnal enuresis that have a prescription for tricyclic medications. Nocturnal enuresis and tricyclic prescriptions will be identified by appropriate READ Codes. *Denominator* All children (0 – 18 years) registered with a general practice with a coded diagnosis of nocturnal enuresis. **Indicator format** Raw numbers; percentage
Data source	QMAS; local data collection extracted from NICE practice audit #10, "Tricyclic antidepressants should not be used as a first-line treatment for bedwetting in children or young people."(NICE CG111)
Technical issues	Appropriate READ codes
Type	Process
Level	Practice
GRADE	2 = low
Source guideline	NICE clinical guideline 111 recommendation 1.14.1 and audit criterion 10 (2010, review decision date October 2013)
Other source information	Glazener CM et al. *Cochrane Database Syst Rev* 2003;(3):CD002117
Other issues / note	Prevalence of nocturnal enuresis (depending on whether defined as >1 or >2 nights/week) varies by age but highest in younger children (5 years old, 8-15%) (NICE CG111)

Routinely managed conditions indicator 6 (#56)

Indicator	Children 3 years and older with "persistent bilateral otitis media with effusion" or "any age with speech and language, developmental or behavioural problems" should be referred for hearing assessment.
Rationale	Children with "persistent bilateral otitis media with effusion" beyond the age of 3 or with developmental problems require a specialist assessment to evaluate whether an intervention is indicated.(SIGN 66)
Definitions	**Indicator description:** Proportion of children 3 years and older with "persistent bilateral otitis media with effusion" or "any age with speech and language, developmental or behavioural problems" that are referred for hearing assessment.(SIGN 66) **Indicator construction:** *Numerator* Number of children with a coded diagnosis of "persistent bilateral otitis media with effusion" (3 – 18 years) or "speech and language, developmental or behavioural problems" (0 – 18 years) that are referred for hearing assessment.(SIGN 66) "Persistent bilateral otitis media with effusion" and "speech and language, developmental or behavioural problems" will be identified by the appropriate READ Codes. Referral for hearing assessment will be identified by READ codes or notes evaluation. (SIGN 66) *Denominator* All children registered with a general practice with a coded diagnosis of "persistent bilateral otitis media with effusion" (3 – 18 years) or a coded diagnosis of "speech and language, developmental or behavioural problems" (0 – 18 years). (SIGN 66) **Indicator format** Raw numbers; percentage
Data source	QMAS; local data collection using audit criteria 2, 3, 4 and 5 from NICE (NICE CG60) and SIGN referral criteria for hearing assessments (SIGN 66)
Technical issues	Feasible data extraction; READ codes
Type	Process
Level	Practice
GRADE	2 = low
Source guideline	NICE clinical guideline 60 recommendations 1.3.1 (2008, no update required in 2011, review date February 2014) SIGN guideline 66 recommendation 4.2.2 (2003, updated 2012)
Other source information	Browning GG et al. *Cochrane Database Syst Rev* 2010;(1):CD001801
Other issues / note	-

General practice management (*Practice*)

Practice-1 (#46). Percentage of children and young people admitted to hospital for acute asthma exacerbation.
Practice-2 (#62). Children on long-term prescriptions should have an annual review in primary care.
Practice-3 (#12a). Antibiotic prescriptions in children should be accompanied by clearly documented rationale for this decision.
Practice-4 (#66). General practitioners should document written reflection of their paediatric continuing professional development (CPD) activities undertaken within each 5 year re-validation cycle.

General practice management – rationale for inclusion of indicator
Primary care can effectively manage chronic conditions and thereby minimise the number of unplanned hospital admissions for chronic illnesses (e.g. asthma). Measuring rates of asthma hospitalisations helps to identify where improvements in care are required. Around one-fifth of children have a chronic condition that may warrant the continuing use of prescription medications. Appropriate annual review by primary care practitioners can ensure children on these long-term medication prescriptions are effective with minimal adverse effects. Evidence supporting the efficacy of antibiotics for common viral infections is weak, and high rates of prescriptions lead to antimicrobial resistance. GPs should provide a clear rationale where antibiotic treatment is provided, which can be appropriate for numerous reasons.

Primary care is continually evolving, and accordingly GPs require regular updating of their knowledge base. The 2010 RCGP Child Health Strategy emphasised the importance of maintaining professional competencies such as the ability to "demonstrate the key skills and competencies required, maintain standards and regularly review their performance."[9] Continuing professional development can play a key role to help facilitate this process.

Further information
- SIGN clinical guideline 101 (2011). British Guideline on the Management of Asthma. http://www.sign.ac.uk/guidelines/fulltext/101/index.html
- NICE clinical guideline 69 (2008). Prescribing of antibiotics for self-limiting respiratory tract infections in adults and children in primary care. http://www.nice.org.uk/CG069
- NICE clinical guidelines 47 (2007). Feverish illness in children - Assessment and initial management in children younger than 5 years. http://www.nice.org.uk/CG047
- RCGP 2010. RCGP Child Health Strategy 2010-2015. http://www.rcgp.org.uk/pdf/CIRC_RCGP_Child_Health_Strategy_2010_2015_FINAL.pdf
- RCGP 2007. Curriculum Statement 8 - Care of Children and Young People. http://www.gmc-uk.org/8_Care_of_Children_and_Young_People_01.pdf_30449178.pdf

[9] RCGP Child Health Strategy 2010-2015.

General practice management indicator 1 (#46)

Indicator	Percentage of children and young people admitted to hospital for acute asthma exacerbation.
Rationale	Most patients with asthma should be well managed in the community by primary care. Acute asthma admissions highlight where community management could be improved.
Definitions	**Indicator description:** Percentage of children and young people admitted to hospital for acute asthma exacerbation. Similar to three indicators developed (see below for references): ▪ *NHS Outcomes Framework 2012/13*: Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s ▪ *NHS IC Compendium of population health indicators*: Emergency hospital admissions: children with asthma, <16 years ▪ *GMC Quality and Outcomes Framework 2012/13*: Practice meets internally (QP9) and externally (QP10) to review data on emergency admissions and develops three care pathways (QP11) Both NHS indicators are constructed to measure asthma hospital admissions at the population level rather than at the individual practice level. The detailed information is collected needs to be utilised and made available to individual general practices to determine their specific rate. The new QOF indicators are not specific to children. **Indicator construction:** *Numerator* Number of children and young people (5 – 18 years) admitted to hospital for acute asthma exacerbation. Asthma is defined in terms of the following ICD-10 codes: J45-J46. *Denominator* All children and young people (5 – 18 years) registered with a general practice. **Note*: Denominator refers to all children in a practice. **Indicator format** Raw numbers; percentage; asthma admission rate per 1000
Data source	Hospital Episode Statistics (HES); Population statistics (ONS); QMAS
Technical issues	Linking data collected with individual practice; adjusted for prevalence
Type	Outcome
Level	Regional
GRADE	1 = expert consensus
Source guideline	SIGN guideline 101 audit criterion 8.2 GMC QOF 2012/13 quality indicators QP9, QP10, and QP11
Other source information	▪ Department of Health NHS Outcomes Framework 2012-13 indicator 2.3.ii ▪ NHS IC. Compendium of Population Health Indicators. Unique ID=P00957.
Other issues / note	-

General practice management indicator 2 (#62)

Indicators	Children on long-term prescriptions should have an annual review in primary care.
Rationale	All children on long-term prescriptions should be monitored to maximise compliance, and to ensure their symptoms are well controlled and they are not experiencing unwarranted side effects.
Definitions	**Indicator description:** Proportion of children on long-term prescriptions that have an annual review in primary care. **Indicator construction:** *Numerator* Number of children (0 – 18 years) on long-term prescriptions that have an annual review in primary care. Prescriptions will be identified by the appropriate READ Codes. Long term prescriptions will be defined as any prescription on repeat. As defined in QOF guidance: "The underlying principles of any medication review, whether using the patient's full notes or face to face are: 1. All patients should have the chance to raise questions and highlight problems about their medicines. 2. Medication review seeks to improve or optimise impact of treatment for an individual patient. 3. The review is undertaken in a systematic way by a competent person. 4. Any changes resulting from the review are agreed with the patient. 5. The review is documented in the patient's notes. 6. The impact of any change is monitored."(QOF 2012/13) *Denominator* All children (0 – 18 years) registered with a general practice taking a long-term prescription. **Indicator format** Raw numbers; percentage
Data source	QMAS; Local data collection
Technical issues	Defining long term prescriptions
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	GMC Quality and Outcomes Framework for 2012/13 indicator Medicine 12: ▪ "A medication review is recorded in the notes in the preceding 15 months for all patients being prescribed repeat medicines."
Other source information	-
Other issues / note	6300 medication related safety incidents reported in children in 2008 (Children and Young People's Health Outcomes Forum)

General practice management indicator 3 (#12a)

Indicator	Antibiotic prescriptions in children should be accompanied by clearly documented rationale for this decision.
Rationale	Routinely prescribed oral antibiotics in children with feverish illness without a clear diagnosis are not indicated, and may lead to increased rates of antimicrobial resistance and increased susceptibility to infections.
Definitions	**Indicator description:** Proportion of antibiotic prescriptions in children that are accompanied by clearly documented rationale for this decision. **Indicator construction:** *Numerator* Number of antibiotic prescriptions in children (0 – 18 years) that are accompanied by clearly documented rationale for this decision. Antibiotic prescriptions will be identified by the appropriate READ or BNF Codes. Clearly documented rational for prescribing will be identified by looking at the primary care records. *Denominator* All children (0 – 18 years) registered with a general practice with an antibiotic prescription. **Indicator format** Raw number; percentage
Data source	QMAS; local data collection as per NICE audit criteria 2a, 2b and 3 (NICE CG69)
Technical issues	-
Type	Process
Level	Practice
GRADE	2 = low
Source guideline	NICE clinical guideline 69 recommendations 1.1.3 and 1.1.7 (2008, reviewed June 2012) NICE clinical guideline 47 recommendation 1.4.2.3 (2007, review decision date January 2011, update in progress)
Other source information	▪ Arroll B et al. *Cochrane Database Syst Rev* 2005;(3):CD000247 ▪ Spurling GK et al. *Cochrane Database Syst Rev* 2007;(3):CD004417
Other issues / note	25% of general practice consultations and 60% of antibiotic prescribing due to respiratory tract infections (NICE CG69)

General practice management indicator 4 (#66)

Indicator	General practitioners should document written reflection of their paediatric continuing professional development (CPD) activities undertaken within each 5 year re-validation cycle.
Rationale	General practice is continually changing and it is important for general practitioners to regularly update their knowledge base. Continuing professional development helps facilitate this process and should include regular paediatric courses.
Definitions	**Indicator description:** Proportion of general practitioners who document written reflection of their paediatric continuing professional development (CPD) activities undertaken within each 5 year re-validation cycle. **Indicator construction:** *Numerator* Number of general practitioners who document written reflection of their paediatric continuing professional development (CPD) activities undertaken within each 5 year re-validation cycle. *Denominator* All general practitioners. **Indicator format** Raw number; percentage
Data source	Local data collection; annual re-validation and appraisal
Technical issues	Ideal data sources
Type	Process
Level	Practice
GRADE	1 = expert consensus
Source guideline	▪ Derived from the expert group ▪ Royal College of General Practitioners. Curriculum statement 8 - Care of Children and Young People. London: Royal College of General Practitioners, 2007. ▪ General Medical Council (GMC). Protecting children and young people: The responsibilities of all doctors. 2012-Jul-10 ▪ Royal College of General Practitioners (RCGP). RCGP Child Health Strategy 2010-2015. 2010
Other source information	-
Other issues / note	-

Appendix F: List of published papers

Gill PJ, Hislop J, Mant D, Harnden A. General practitioners' views on quality markers for children in UK primary care: a qualitative study. *BMC Family Practice*. 2012 Sep;13:92.

Gill PJ, Goldacre MJ, Mant D, Heneghan C, Thomson A, Seagroatt V, et al. Increase in emergency admissions to hospital for children aged under 15 in England, 1999–2010: national database analysis. *Archives of Disease in Childhood*. 2013;98:328-34.

Gill PJ, Hewitson P, Peile E, Harnden A. Prioritizing areas for quality marker development in children in UK general practice: extending the use of the nominal group technique. *Family Practice*. 2012 Feb 3;29(5):567-75.

Gill PJ, Wang KY, Mant D, Hartling L, Heneghan C, Perera R, et al. The evidence base for interventions delivered to children in primary care: an overview of Cochrane systematic reviews. *PLoS ONE*. 2011;6(8):e23051.