Opening the door to better healthcare: Ensuring general practice is working for children and young people

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Introduction

This is a crucial time in the history of the health service. A new system has been brought in, intending to encourage more choice for patients, more involvement of patient and the public in health services, more competition on the basis of quality and a further developed focus on commissioning services based on the needs of local areas.¹ General Practitioner (GP) led Clinical Commissioning Groups have taken over the commissioning of the majority of health services. As part of these changes there will also be a new, single commissioner of the primary care that GPs provide - NHS England.

The role of general practice is crucial to the overall experience and outcomes of children using the health service. Its core functions² are to:

- Offer consultations as the first port of call for minor and non emergency health concerns
- Help to manage and coordinate care for pre-existing and long term conditions
- Refer patients to specialist attention in secondary care
- Issue prescriptions
- Carry out immunisation
- Provide treatments for minor ailments
- Provide health promotion advice and information

Article 24 of the UN Convention on the rights of the child, which enshrines children’s right to the enjoyment of the highest attainable standard of health, commits its signatories (including the UK government) to place emphasis of the development of primary health care in the provision of health services for children.³ The UK has the second highest mortality rate in Western Europe and as many as 5 deaths per day could be avoided if we equalled the lowest.⁴ It is vital that all opportunities to improve this situation are pursued.

NHS England and the Royal College of GPs have joined others in signing up to a pledge to improve child health outcomes.⁵ But to what extend are GP services in England being commissioned and delivered to make the best contribution they can to children and young people’s health? And what should be the priorities for its improvement within the new health system?

Evidence suggests that children may experience particular dissatisfactions with the service and that young people’s opinions about GP services are less positive than those of adults. Data shows dramatic increases in recent years of children being admitted to hospital for conditions that could normally be managed in the community and suggests great variation

¹ See The Government’s 2010 NHS White Paper: Equity and Excellence: Liberating the NHS
² The King’s Fund (2009) General Practice in England: An Overview
³ UN Convention on the Rights of the Child Article 24 (2)(b)
⁴ Ingrd Wolfe et al (2013), ”Health services for children in western Europe”, Lancet, 6 April 2013, pp1224–34
across the country in the extent to which these admissions are prevented. GPs themselves have identified a need for improvements, and many are at the forefront of innovation to better meet the needs of this group.

This report examines the available evidence on how well general practice is delivering for children and young people, including the evidence on their experiences of the services and the particular challenges they face in accessing them. Key challenge areas such as access, expertise, communication and incentives for service improvement are considered. It also examines some of the approaches to addressing those challenges, and in some areas pursued in practice.

It emerges that some of these challenges are related to major flaws in the framework in which GP services are commissioned and delivered. These flaws lie in the approach to commissioning primary care, the concept of out of hours services, and very limited mandatory training in paediatrics. As a result, the system is failing both children, young people and their families, and those GPs that want to provide them with the best care.

While the health secretary has recently announced that a chief inspector of GPs will be appointed to lead an overhauled system of assessment by CQC⁶, more positive and facilitative change is required to meet the needs of children and young people.

The report concludes that there are several areas where action will be needed to promote improvements in the way general practice meets the needs of children and young people. NCB calls on Government and national and local partners in the health system to:

- Ensure GPs have appropriate training to work with children, including **investment in extended initial training for GPs** and support and encouragement for existing GPs to develop their expertise
- **Take children and young people’s experiences into account** when measuring the performance general practice - not just those of adults.
- Ensure the **commissioning process** properly takes account of children and young people’s needs and facilitates improvement
- Make GPs services accessible to children, including **insisting on opening hours that are based on the needs of the community** and practice settings that are children and young people friendly
- Ensure children and young people are **empowered to exercise their rights** to provide feedback and to have complaints dealt with seriously as part of the making the NHS constitution work for them.
- **Support primary and secondary care to work in partnership** to promote coordination of care and access to expertise in the general practice setting

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⁶ Speech on 23 May 2013 “Primary Care and the modern family doctor” [Accessed 24/05/13]  
Why are we concerned about how GP services are performing for children?

This section looks at the evidence on children’s experience of using GP services and explores the real and wider potential impact on children’s health outcomes when these services are not performing as well as they could be.

Children’s experience of GP services

Children aged under 16 are excluded from national health surveys exploring NHS users’ satisfaction and the main survey of this kind on GP services only extends to those over the age of 18. The only evidence on children and young people’s experience of primary care services comes from smaller scale surveys and qualitative research. These sources suggest poorer experience and that particular vulnerable groups struggle to make the most of these services.

A study by the UK Youth Parliament into young people’s experiences of primary care services asked those being consulted to rate their experience of their last contact with a GP. Over a third of these young people rated it as average or poor. To put this in perspective, only 12% of the general population surveyed by the latest GP patient survey rated their overall experience of their GP surgery as neither good nor poor, fairly poor or very poor (figure 1).

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7 Cited from: Office of the Children’s Commissioner for England (2012), "It takes a lot of courage "- Children and young people’s experiences of complaints procedures for services for mental health and sexual health including those provided by GPs, pp84-85

8 GP Patient Survey – January to September 2012
In 2011, in collaboration with the young people’s website b-live, NCB conducted a poll of young people aged 11 to 19. Under half of those that responded said they would talk to their GP if they were worried about their health and over a quarter said that they were not comfortable talking to their GP.

A recent rapid review of the evidence on children’s views on health provision identified several studies which highlight some of the challenges that some vulnerable groups of children and young people face in accessing and using GP services:

Care leavers - A qualitative study of care leavers (aged 17-24) found that these young people were very critical of GPs, sometimes feeling that they were medically incompetent and lacked social skills. They also reported not been listened to by medical staff, who were said to be following their own agenda, and getting treatments they did not want or need. Some said they would not feel able to talk about mental health issues to the doctor because they did not trust them or thought they would not be interested. There were criticisms of receptionists who were perceived as hostile or over inquisitive and of delays before seeing a doctor or a practice nurse. Some experienced good relationships with doctors or practice nurses.

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9 NCB (2012), Teenagers’ views on their health and local health services

nurses, these tended to be young people who had a regular consultation with a single practitioner, but being able to do so was not a typical experience because of frequent housing moves.

*Young people seeking asylum* - A qualitative study of young people (aged 12-23) seeking asylum on their own found their experience of primary care to be mixed. Some young people reported difficulties in registering with doctor, and when they managed to see a doctor they were frustrated because they believed that GPs did not listen to them. Some were frightened to talk to GPs about their difficulties (e.g. sleeping problems in case they were prescribed drugs they might become addicted to), felt unable to talk to GPs about anxieties or other distressing feelings, or felt there was no point as they did not know what the GP could do to help. There were also positive experiences with GPs who had referred them to counselling, or respected their wishes not to take medication.

*Young people with mental health problems* - A research review of young people’s views on mental health services found that young people with mental health problems felt that many GPs lacked understanding, awareness, empathy and interest, and were reluctant to provide certain types of support. The study of care leavers cited above also highlighted the experience of some young people who found it difficult to talk to their GPs about mental health problems.

Looking at the youngest age group which the national GP patient survey does cover may also give some clues as to what the experience of older children may be. 2011 results from the survey show poorer satisfaction ratings for 18-24 year olds than older age groups, including (but not limited to):

- Overall experience of GP surgery
- Rating of GP involving you in decisions about your care
- Overall experience of making an appointment
- Helpfulness of receptionists at GP surgery

**The costs of a service that does not meet children’s needs**

It is important to remember that how GPs and their practices operate will also impact ultimately on health outcomes and mortality rates in children and young people. As highlighted above, 5 child deaths a day could be avoided if the UK performed as well as the best in Europe. The effectiveness of primary care, including that provided by GPs, must be considered as one of the factors contributing to this. GPs are normally the first health professionals to have the opportunity to identify serious sickness in a child when

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13 Note that positive ratings are still around 60-80% for 18-24s, but get higher for older groups
they present with symptoms and are, as the principal route to referral to secondary care, often the gatekeepers to more specialist attention. Practices also play a key role in ensuring children are immunised and providing children and their families with health promotion advice. They will normally lead on the coordination of care and managing a child’s medical records, so their communication with other health professionals is also crucial.

**Avoidable Deaths**

The Confidential Enquiry into Maternal and Child Health assessed the deaths of 230 children in 2006 for avoidability from a primary care perspective. Of the 82 cases where a GP had been involved in the care of the fatal condition 19 deaths were considered avoidable. Examples included:

- Failure to vaccinate a child (on the advice of a specialist or according to guidelines)
- Failure to recognise the severity of respiratory infection
- Failure to manage asthma according to guidelines
- Failure to closely follow up a child at risk of self harm.

21 cases were considered potentially avoidable, for example meningitis, congenital heart disease that was not detected at birth and drowning at home when the family’s vulnerability may have been picked up on.

Of the 62 cases where primary care was not involved but had seen the child in the last 12 months, 3 deaths were considered avoidable and 29 potentially avoidable.

**Avoidable A & E attendance and emergency admissions**

While the confidential enquiry highlights more extreme cases where individual practices or GPs did not meet expected standards, there are also costs to children and their families, and financial costs to commissioners, where the primary care service offer (or families’ perception of it) is not properly configured to meet need. The Kennedy Review identified that children, young people and their parents or carers are often either unwilling or unable to gain access to the care of a GP and they choose to go instead to the A&E department of a hospital. Nearly a quarter of all those attending A&E are aged under 16 and the number of attendances (figure 2) and emergency admissions are rising for this age group.

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15 Ian Kennedy (2010), *Getting it right for children and young people Overcoming cultural barriers in the nhs so as to meet their needs*, p19
16 In 2012 23% of A & E Attendences were for children under 16. The total number of attendees for this age group has risen 34.5% on 2008 figures. Health and Social Care Information Centre (2013,)  *Provisional Monthly Hospital Episode Statistics for Admitted Patient Care, Outpatients and Accident and Emergency Data - April 2012 to December 2012*
Avoidable attendance and admission to hospital is a problem primarily for three reasons:

- It can unnecessarily risk harm to the child involved, including from hospital acquired infections and the psychological trauma from experience of the hospital environment – as well as potentially making the experience more stressful for parents accompanying the child.

- It distracts the health professionals at the hospital from tending to more acutely ill children. The chairman of Care Quality Commission has said that emergency admissions through accident and emergency are out of control in large parts of the country and that as a result there was no cast-iron guarantee that there would not be a repeat of the situation at Stafford Hospital.\(^\text{18}\)

- It costs money that could be spent on more appropriate interventions– in terms of tariff payments from commissioners an emergency admission to hospital can cost around £1000 nearly 20 times as much as primary care at £53.\(^\text{19, 20}\)

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\(^{18}\) "A&E facing serious problem, health minister admits" BBC News 09/05/13 [Accessed 10/05/13] [http://www.bbc.co.uk/news/health-22460741](http://www.bbc.co.uk/news/health-22460741)

\(^{19}\) While it is generally accepted that admission to hospital can cost much more than primary care interventions in the community, here we have highlighted that this figure relates to the cost to commissioners. This is because In theory, being paid to admit children with minor illness could provide a useful subsidy for hospitals which can be used to provide better care for other children. Where subsidising effects are removed tariffs may have to be raised.

\(^{20}\) Based on 2010 figures from NHS West Sussex of £1,000 for an emergency admission and £53 for primary care cited from Andrews (2011), *Fundamentals of Commissioning health Services for Children*, Child Health and Maternity Partnership
The evidence also shows that while rates of A & E attendance are strongly influenced by deprivation, there is also significant variation between areas that cannot be explained in this way as demonstrated by figure 3.

Figure 2: Increase in A & E attendance of children aged 16 and under

A & E attendences fo children aged 16 and under - cumulative percentage increase on 2008 figures. Source: Health and Social Care Information Centre (2013) Hospital Episode Statistics
Following on from attendance at A & E, the decision to admit a child to hospital can be influenced by a range of factors. This can include changes in standard practice at the hospital, recommended pathways and availability of paediatric consultants in the acute setting who have the confidence to identify cases where admission is unnecessary. Figures for admission are worth considering, however, as further clues as to why increased numbers of children are attending A & E and to what extent this could be avoided. As with A & E attendance, the evidence shows that there is huge variability in the rate of admission of children to hospital which cannot be easily explained by levels of disadvantage.  

One very likely explanation is that, in many areas, children are being admitted for conditions that could be better managed in the community. Indeed a recent study of emergency admissions for children aged under 15 has found an increase of 18% for conditions where higher rates of admission are associated with poorer primary care. Admissions of less than one day for acute infections virtually account for the entirety of this increase.

In summary, what evidence we have suggests:

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Many children and young people have poor experiences of using GP services.

Increases and unexplained variations in A & E attendance rates appear to be linked to conditions amenable to primary care.

With this evidence in hand it is crucial to consider whether GP services may be making the contribution they should to better child health outcomes and what may be holding them back.
What’s not working?

This section explores some of the most common ways in which general practice can fall short of meeting the needs of children and young people in England and likely contributing factors as to why. It also highlights some of the solutions already proposed for improvement and innovative approaches being taken in some local areas.

Communication and relationship with the GP

A common theme in studies of children’s experience of health services is a perception that the child is not being involved in decisions about their care and that health professionals do not communicate in a way that is young person friendly.23 There is a sense that for vulnerable groups, such as children seeking asylum and care leavers, these can be particular challenges when accessing GP services.24 These groups in particular, as well as children and young people on the whole, find it difficult to talk about mental health issues with their GP. Over a third of those surveyed by the UK Youth Parliament said they would not consult their GP about particular issues such as sexual health, adolescent concerns, mental health, and weight. A significant proportion of young people appear to be generally uncomfortable talking to their GP. Some of young people’s explanations for this are set out in figure 4.

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23 Lavalle et al (2012), Listening to children’s views on health provision – A rapid review of the evidence, NCB
24 See Children’s Experience of GP services, above

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It is of course crucial that all children and young people feel able to approach their GP and can be honest about any health problems that they may be experiencing. Being able to check concerns at an early stage and refer to further investigation or treatment if necessary is a key purpose of general practice.

Good trust and communication is key to making sure children and young people are involved in decisions about their care in a way that is appropriate to their age, maturity and communication needs. Under Article 12 of the UN Convention on the Rights of the Child, Children and young people have a right to have their views heard on issues that affect them.25 Supporting children and young people to understand their health and be involved in decisions can also help improve outcomes. Studies have found that in the case of young people with asthma26 involvement can increase feelings of self control and

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reduce absenteeism from school and visits to A & E. There is also evidence that it supports the effective treatment of diabetes\textsuperscript{27} in children.

The finding of our survey that some young people do not understand what their doctor is saying to them is a cause for concern. There are obvious risks if a young person has not received the advice a GP thinks they have issued or a young person is not entirely confident in the process for any treatments they are supposed to self administer. This is likely a contributing factor to high rates of non-compliance with treatment amongst young people, such as those with asthma\textsuperscript{28} or diabetes\textsuperscript{29} or who have had a transplant\textsuperscript{30}. There is also evidence of great variations across the country in hospitalisation rates for conditions that require self care, such as the 4 to 6 fold variation in admissions to hospital for bronchiolitis or asthma\textsuperscript{31}, suggesting there is scope for some areas to achieve much better outcomes than they are currently.

If it is difficult to see the same GP for most appointments, which can mean that the GP that the child does see does not have an understanding how involved a child or young person is, could or should be in decisions about their own care and their preferred way of being involved. And it will be hard to build trust to help a young person have the confidence to discuss issues such as sexual or mental health. It can cause additional challenges for the care of children with more complex needs or disabilities\textsuperscript{32}. For example, families can find themselves explaining the child’s considerable medical history on each visit, and the lack repeated unfamiliarity of the professional can cause distress to children with neurological or learning disabilities, increasing occurrence of disruptive or challenging behaviour. It may increase the risk or ‘diagnostic overshadowing’ where a symptom is incorrectly identified as being a result of child’s primary diagnosis or disability rather than a new illness.

Some health professionals have reported that they feel only able to take an all-or-nothing approach to children’s participation in their care, as they do not have the confidence or tools to take more nuanced approach as the child matures\textsuperscript{33}. In many cases the default will be to only discuss things with the parent.


\textsuperscript{32}Contact A Family (2013), Making GP practices more welcoming for families with disabled children: Information for GP practice teams

\textsuperscript{33}Council for Disabled Children (2011), Managing My way, p22
If more time is needed for a child’s history or needs to be explained to a new doctor or for the child to be involved about discussions about their health this will often be obstructed by strict rules about the length of appointments (typically ten minutes) and to whom double appointments are made available. Having a follow up appointment with a practice nurse to support understanding of what has been agreed with the GP may be an option but young people and children’s families may not understand how to do this – or appointment booking systems may not facilitate it.

The extent of expertise available in the general practice setting

The UK has the shortest general practice training programme of 14 European countries, and the shortest of all UK medical specialities. And although care of children is part of the core curriculum objectives, and basic competencies are tested, training in hospital-based paediatrics is currently not a mandatory part of GP training. This is thought to result in less than half of GP trainees receiving in-hospital paediatric experience, and the majority who do not missing out on an important opportunity to learn how to identify and care for sick children. This will make effectively communicating with, diagnosing, treating and supporting children more of a challenge at some practices.

Dealing with relatively common mental health concerns among adolescents is a particular area where the right expertise may not exist amongst all GPs. A research review found that young people with mental health problems felt that many GPs lacked understanding, awareness, empathy and interest, and were reluctant to provide certain types of support. The Kennedy Review stressed that “there are significant shortages of professionals trained to care for young people with mental health problems at a time when an epidemic of such problems lies beneath the surface of society.”

A lot of the more specialist expertise in many areas of child health is based in secondary care providers. Families are often drawn to seeking help from these providers where primary care lead by a GP (supported by specialists and trained in child health) may be more appropriate. This is likely the result of a combination of the highlighted gaps in GP training and barriers to making advice from specialists available in community settings (outside of hospital).

Children who have a long term health condition and/or disability will often go straight to their consultant paediatrician for their health concerns. Some of these encounters with the hospital paediatrician will be for ailments such as coughs and colds that effect all children and young people and may not necessarily require such specialist attention. Three

34 RCGP (2012), Extended GP Training – Frequently Asked Questions, April 2012
35 Royal College of General Practitioners (2010), RCGP Child Health Strategy 2010-15, p6
37 Lavis, P. and L. Hewson (2010), "How many times do we have to tell you? "Young Minds Magazine 109: 30-31. Cited from Listening to children’s views on health provision, p34
38 Ian Kennedy (2010), Getting it right for children and young people Overcoming cultural barriers in the nhs so as to meet their needs, p13
quarters of parents of disabled children surveyed by Contact a Family in 2011 said that their child’s GP had no role in their care.\textsuperscript{39} This can mean such children and their families having to travel further than they should to receive support. In some cases, children will be taken to A&E, where they may have to wait hours to be treated and doctors do not have same ease of access to medical records- as these are held by GPs. It can also present challenges when a young person turns 18 no longer has access to paediatric care, as this role in coordination of care must then be passed to the GP, who, as a result of having little prior involvement, will have limited knowledge of the patient.

Community children’s nursing services, where they are available, are also vital for supporting children with long term conditions and those who have had an acute illness, outside of hospital. These are also often located in secondary providers. Should this division create a situation where there is no formal link up with primary care and the provision of such services, this may potentially place further distance between some sick children and their GP.

It is worth noting the observation made by the Child Health and Maternity Partnership in 2011 that some of the areas with the highest rates of emergency admissions are areas which have standalone children’s hospitals.\textsuperscript{40} This may be indicative of parents in such areas believing that these hospitals are the place to get the best care for their children. It may also be indicative of an over reliance in primary care on such services to care for acutely sick children and/or a ‘silod’ approach to provision which results in admission being the only way to access the expertise they host.

Box 1 briefly summarises some innovative solutions being pursued in three local areas to improve access to expertise in meeting children’s needs outside of hospital.\textsuperscript{41}

\textsuperscript{39} Contact A Family (2013), \textit{Making GP practices more welcoming for families with disabled children: Information for GP practice teams}

\textsuperscript{40} Andrews (2011), \textit{Fundamentals of Commissioning health Services for Children}, Child Health and Maternity Partnership, p8

\textsuperscript{41} Examples from South Gloucestershire and West Sussex are cited from: NHS Confederation (2012), \textit{Children and Young People’s Health in Changing Times}, pp22-23
NHS England has set out in its 2013-15 business plan its intention to “improve the skills of practitioners in primary care through the development of robust workforce planning” and to “develop and maintain mechanisms to enable revalidation of GPs, ensuring that skills are up to date and clinical standards remain high”. It is hard to tell whether this will include meaningful improvements to state of GP expertise in meeting children and young people’s needs.

Box 2 looks at the Royal College of GPs’ (RCGP) proposals for improving GP training. The Children and Young People’s Health Outcomes Forum, a group of

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43 RCGP (2012), *Enhanced GP training: the educational case*
44 RCGP (2012), *Extended GP Training – Frequently Asked Questions, April 2012*
Independent experts established by Secretary of State for Health to advise on achieving better health outcomes for children and young people, have also recommended that:

- all general practices that see children and young people to have a named medical and nursing lead
- all general practice staff, whether they are practice nurses or other members of the team, to be adequately trained to deal with children and young people.\(^\text{48}\)

RCGP’s Child Health Strategy and the Children and Young People’s Health Outcomes Forum also make recommendations ensuring that GPs get appropriate ongoing training and continuing professional development to meet the needs of children.

**Box 2: Improving GP training**

RCGP is proposing the extension of GP speciality training, initially from three to four years and that as part of this enhanced training all GP trainees undertake placements that provide them with appropriately supervised experience of paediatric problems. It is suggested that, for example, a trainee might gain valuable experience of paediatrics working in an acute paediatric hospital team, a children’s A&E department, or in a community-based child health centre, possibly as part of an integrated post. More broadly the enhancements are intended to focus on GPs roles as clinicians – effectively treating conditions where this can be done in primary care, Generalists – including better coordination of care for people with more complex conditions, and Leaders – including their increasing role in commissioning services. A minimum of 24 months spent in general practice placements is also recommended, as well as ensuring trainees get appropriately supervised experience of mental health problems.

The educational case for these improvements has been approved by Medical Education England. In response to the Children and Young People’s Health Outcomes Forum recommendation that the proposal be further supported, the Department of Health has stated it is supportive of the proposal and will carry out work on the economic and affordability cases with a range of key organisations. Health Education England has recently been tasked with working with the General Medical Council, RCGP and Department of Health to develop an approach to implementing this proposal.

\(^{46}\) Department of Health (2013) *Improving Children and Young People’s Health Outcomes: a system wide response*, p40

\(^{47}\) Department of Health (2013) *Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values: A mandate from the Government to Health Education England: April 2013 to March 2015*, p20

The experience of visiting the GP surgery

Young people have said that they dislike waiting for appointments and the waiting room environment. They are particularly sensitive to the perceived friendliness and lack of intrusiveness of reception staff, who could be very important as a barrier or encouragement to consulting a GP.\(^{49}\)

On their first visit to the GP on their own, young people may be feeling vulnerable and particularly sensitive to feelings of intimidation if reception staff are not friendly. Perceptions of time vary by age, and the lack of stimulation in the waiting room and uncertainty about when they will be called into the consulting room may be particularly difficult for children and young people.

Again, such quirks of accessing primary care can present more pronounced challenges for disabled children and their families. Having to wait for long periods surrounded by unfamiliar people can be a trigger for distress and challenging behaviour in some children. This can result in the child being less able to participate in the consultation, or the visit being abandoned altogether, either by request of the family or the practice. Parents can get frustrated having to explain why, for example, that would rather wait outside in their car until the doctor is free. Where families have had, in general, a poor experience of accessing GP services they will probably be more likely to resort to taking their child to A & E.

Some young people who are uncomfortable visiting their GP say this is because they do not know how to make an appointment. Young people may feel unable to ask their parents about the process if they want to discuss something with the doctor in confidence and variation in procedures between surgeries may present challenges in teaching about this in school.

Confidentiality is an important issue for young people accessing GP services. That some young people have described reception staff as over inquisitive and some practices have been known to refuse to allow younger teenagers to consult alone suggests that there is an issue of training and culture to be addressed.\(^{50,51}\) The location in which consultations take place can also have a bearing on confidentiality. If a practice is not easily accessible to the young person on foot or with public transport, they will be reliant on parents to take them their by car, making it hard to access the service without the knowledge of their parent. This will be a particular challenge for young people in rural areas.

Box 3 summarises some of the recommendations that have been made by RCGP\(^{52}\) and by the charity Contact a Family\(^{53}\) for improving children’s experience of visiting GP surgeries. Co-location with other children’s services and accessible venues can also be used to

\(^{49}\) Lavalle et al (2012), *Listening to children’s views on health provision*


\(^{51}\) Royal College of General Practitioners (2010), *RCGP Child Health Strategy 2010-15*, p10

\(^{52}\) Royal College of General Practitioners (2010), *RCGP Child Health Strategy 2010-15*

\(^{53}\) Contact A Family (2013), *Making GP practices more welcoming for families with disabled children: Information for GP practice teams*
improve access. In Herefordshire, for example, the GP Access Centre is located adjacent to a supermarket and provides consultations without the need for a pre-booked appointment. Providing access to GP consultations in school is has also been explored as a way to support easy and confidential access for young people in rural areas.

**Box 3: Making GP Surgeries more accessible and welcoming for children**

The RCGP Child Health Strategy recommends that practices ensure that they are young person friendly, including considering the You’re Welcome quality criteria - which are also supported by the Children and Young People’s Health Outcomes Forum for commissioning all services for teenagers. It also recommends ensuring consultations involve children and young people as much as possible according to their age and ability and makes recommendations regarding identifying and ensuring regular access to primary care for children with complex needs.

Contact A Family have produced a guide offering practical suggestions for GP surgeries to make it easier for disabled children to meet their GP. The suggestions include:

- Having an appointment system that allows patients to book an appointment with the same GP, to avoid children’s medical history and needs do not have to be explained repeatedly
- Asking receptionists to let parent-carers know if there is going to be a long wait and offering the option of waiting in the parents’ car outside or in a quiet room to avoid distress and challenging behaviour associated with sensory overload
- Talking to parents about how the child expresses themselves
- Using easy read information – to help parents familiarise the child with any medical procedures to be carried out, either in the GP practice or at hospital
- GPs asking the specialist in charge of the child’s care for guidance – regarding prescribing for minor illnesses or changing doses in their regular medication

**Accessing the service when it is needed**

A key barrier to access to primary care is the times at which a G.P practice makes their services available. Under a standard contract, GP practices are allowed to choose not to provide a 24 hour a day service. Outside of the usual hours of 8am to 6pm on weekdays and all weekends and bank holidays, practices can take part in alternative arrangements or leave it to the commissioner responsible to find another way of providing services at these times. This is known as ‘out of hours’ services, a concept which Ian Kennedy was particularly critical of:

“It is so utterly focused on the world, the needs and concerns of the professional. Children, young people and their parents/carers do not understand the notion of being ill or needing help ‘out of hours’. They recognise the idea of the routine and the unusual. And the unusual happens when it happens. And help is needed when it happens.”

While the majority of practices offer some extended hours, they are only paid for a minimal number of extra hours each week, determined by their practice population size. As a result, nearly all practices close at 6pm on most weekdays and many GPs have no involvement in the provision of ‘out of hours’ services. These arrangements mean that parents of younger children will be confused about where to go to when they have concerns about their child’s health, encouraging them to resort to A & E unnecessarily. There does indeed appear to be an increase in the rate of children attending A & E during evenings. As explained above, A & E is not likely to be the best setting for meeting these children’s needs and they may have to wait for several hours before being seen. Working parents may particularly struggle to take their child to surgery during its normal opening hours for less urgent appointments and default to A & E when they finish work or the child’s condition deteriorates.

Concerns about out of hours services continue to be raised with NHS England has launching a review into the sustainability of the new NHS 111 telephone service. 111 is intended to act as an out of hours urgent care service but in some area areas it has had to be suspended and previous and alternative providers, including GPs, have had to be called in to provide cover. Government have recently acknowledged challenges presented by the contract that created the concept of ‘out of hours services’ and that problems with access to GP services are contributing to increased pressures on A & E.

Getting services delivered at the times at which they are most needed may not be challenge unique to general practice – concerns have also been highlighted about the

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55 Ian Kennedy (2010), Getting it right for children and young people Overcoming cultural barriers in the nhs so as to meet their needs, p65
56 Department of Health (2009), GP Extended Opening Hours July 2009
57 NHS Employers, NHS England and British Medical Association (2013), 2013/14 extended hours directed enhanced service guidance
59 Royal College of General Practitioners (2010), RCGP Child Health Strategy 2010-15, p11
60 Ian Kennedy (2010), Getting it right for children and young people Overcoming cultural barriers in the nhs so as to meet their needs, p21
availability of consultant pediatricians at times of high demand in acute settings. A system which distinguishes ‘out of hours’ services using parameters that bear no relation to demand is, however, a particularly striking obstruction to delivering the best primary care for children and young people, and may serve to compound the challenge for other services in meeting demand.

For school aged children, the number of appointment slots available outside of school hours in the early evenings and at weekends is also reduced by these arrangements. This means that children are more likely to have to take time out of school even for routine or non-urgent appointments. A spell of illness or a long term condition requiring several such appointments could mean several missed lessons that a child may not be able to catch up on and, ultimately, avoidable harm to their educational outcomes.

RCGP have also highlighted the point that the number of children and young people presenting out of hours provides training opportunities for the assessment and recognition of the sick child, which suggests that GPs not involved in the provision of out of hours services are at a disadvantage when it comes to experience in the care of children.

NHS England has said that their aim is to promote a comprehensive health service, increasing access to the right treatment and coordinating care around the needs, convenience and choices of patients, their carers and families – rather than the interests of organisations that provide care. As part of a ‘seven day services review’, they plan to publish a report in autumn 2013 identifying how there might be better access to routine services seven days a week. As part of its current focus on urgent care, this will consider whether out-of-ours GP services arrangements should be changed. The Secretary of State has also suggested that GPs should, in the future, be responsible for their patients on a round the clock basis, with out of hours services provided on their behalf. This does not appear, however, to challenge the actual concept of out of hours services.

**Feedback and accountability**

It is vital that primary care services are given the opportunity to do the best they can for children and young people by knowing where there is poor satisfaction, being able to learn from complaints and having the same offer of financial reward as for other improvements.

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63 Royal College of Paediatrics and Child Health (2013), *Back to Facing the Future: An audit of acute paediatric service standards in the UK*, p24

64 Royal College of General Practitioners (2010), *RCGP Child Health Strategy 2010-15*, p11


Of a group of young people who were surveyed about their last visit to the GP and reported that they had been unhappy, only a minority of these said they had told anyone about this. They believe that nothing would be done, being worried about what the reaction to the complaint would be. Some also said they did not know how to complain. This survey fed into a report by the Children’s Commissioner for England on children and young people’s experiences of making complaints in mental and sexual health services, including those provided through GP practices. It found that complaints are not always treated in confidence, that young people are sometimes labeled as trouble makers and that staff in GP practices are among those not trained to be able to receive and act on complaints made by children and young people. This is concerning, not just by virtue of the feedback that practices are missing out on, but also as it suggests that the NHS constitution, and children and young people’s basic rights to have their views heard and to complain, are not being upheld.

The GP Patient Survey is a key measure of patients’ satisfaction with their primary care services. This survey is used as the basis for a number of measures in the NHS Outcomes Framework, which is used to hold the health service to account including the role of NHS England in their commissioning of GP services. As noted above, this survey only collects the views of those aged 18 and over. Furthermore it does not explicitly ask parents about their views on the services provided for their children, or report separately on this. This is crucial, as children under 5 visit the GP around 6 times every year on average – around twice as much as older children - and account for most of the increases in emergency admissions of children. The GP survey also concentrates on ‘satisfaction’ levels with various aspects of practice services. This may assume an understanding of the function of primary care and not account for deference or eroded expectations among the population – and therefore not be of much use to commissioners who have found other evidence that improvements may be needed.

The Children and Young Peoples Health Outcomes Forum has recommended that the NHS Outcomes Framework be improved to better reflect children’s views, including through extending the indicator on experience of GP services and other indicators measured by the GP Patient Survey to cover children. The Department of Health has committed to exploring the options and costs for doing this.

Many GP practices run a patient participation group which aims to act as a form of communication between the practice and its registered patients, including on feedback for

68 Office of the Children’s Commissioner for England (2012), “It takes a lot of courage “- Children and young people’s experiences of complaints procedures for services for mental health and sexual health including those provided by GPs, pp84-85
69 Health and Social Care Information Centre (2009), Trends in Consultation Rates in General Practice - 1995-2009
71 Report of the Children and Young People’s Health Outcomes Forum, pp29-30
72 Department of Health (2013), Improving Children and Young People’s Health Outcomes: a system wide response, p14
possible improvements. There are a number of barriers children and young people face in using these groups to influence GP services. Firstly some groups expressly forbid membership for those aged under 18 or 16. Secondly many run a membership system sometimes of limited numbers of patients which may be less amenable to children and young people’s often busy and fast changing lives or indeed those of working parents/parent-carers. These groups may also increasingly become focussed on GPs commissioning role, crowding out their original purpose. Lastly, as they are normally funded by the practice and membership normally limited to registered patients, the scope for independent challenge may be limited. On a more positive note, to receive additional funding for these groups in 2013/14, practices will need to demonstrate how they have engaged in a way that is representative of all registered patients. This could help improve the situation with respect to children and young people’s participation.

GP practices have been subject to CQC registration and inspection since April this year, and government have indicated that the chief inspector of general practice will lead a reformed, holistic, approach to inspection. This may be an opportunity to better hold GPs to account on the quality of service they offer. It is not clear to what extent this support and enable, as well as challenge, GPs to improve their services, and whether this will take account of children and young people’s needs and experiences.

**Commissioning primary care**

It is also important to consider how funding and commissioning arrangements facilitate the provision of good primary care for children and young people. The core funding of GPs services is determined on the basis of how many people are registered at a given practice, rather than the activities carried out to advise or treat patients. This is in contrast to secondary (e.g. hospital) care which is remunerated according to activity. This may create a risk that it is simpler, administratively speaking, to find funding for a referral to another professional in secondary care than for a GP to spend a bit more time getting to the bottom of a patient’s problem. This would impact particularly on children where they need more time to explain their symptoms or have treatment and advice explained to them.

There are arrangements for the funding of provision of extended services within GP practices and also for incentivising improvements in primary care. The Quality and Outcomes Framework (QOF) for primary care measures improvements in services and provides financial reward. Only 3% of its total scoring system relates to the care of children and young people.

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73 See the National Association for Patient Participation (NAPP) website: [www.napp.org.uk](http://www.napp.org.uk)

74 As demonstrated by example terms of reference/constitutions that can be found on the NAPP website [http://www.napp.org.uk/constitutions.html](http://www.napp.org.uk/constitutions.html) [Accessed 14/05/2013]

75 NHS Employers, NHS England and British Medical Association (2013) *2013/14 patient participation directed enhanced service guidance*

children. RCGP have recognised this as a challenge to be addressed.\textsuperscript{77} The Children and Young People’s Health Outcomes Forum has also described this representation as “unacceptably small” and recommended prioritisation the development of an appropriate range of incentives within the QOF for general practice to provide high quality care reflecting the needs of children and young people.\textsuperscript{78}

Through their new role in commissioning most hospital services GP’s might also be encouraged to use their primary care role to avoid the unnecessary use of these services.\textsuperscript{79} The absence or a more explicit and positive incentive to make improvements in meeting children and young people’s needs, however, is of concern.

The reforms to the health service have included an emphasis on renewing and building on the process of local health commissioning based on population need – through Joint Strategic Needs Assessment (JSNA) and the development of Joint health and Wellbeing Strategies (JHWS) being led by new Health and Wellbeing Boards. This is important for improving GP services. In the case of the challenge of ‘out of hours’ services for example in a densely populated area with a high proportion of working families, practices could be asked to stay open further into the evening and at weekends. Conversely a nationally negotiated contract would have to take into account the challenges that other areas, such as rural areas, would face in delivering such services, and potentially constrain service specifications to the lowest common denominator.

The commissioning agenda, however, appears to be less prominent in relation to GP services. The system for procuring primary care services is often referred to simply in terms of a contractual arrangement rather than an opportunity to configure services to meet population need and drive continuing improvements.\textsuperscript{80} Fewer than half of England’s GPs are contracted for their core services through a locally negotiated contract.\textsuperscript{81} And those contracts that are negotiated at a local level are subject to regulations which require opt-outs for ‘out of hours’ services and a right for the GP to move to the national contract (GMS).\textsuperscript{82} Furthermore, statutory guidance for health and wellbeing boards has suggested that NHS England could be represented by clinical commissioning groups in the JSNA and

\textsuperscript{77} It covers child health checks, child protection and the clinical care for asthma for those 8 years old and over. Royal College of General Practitioners (2010), \textit{RCGP Child Health Strategy 2010-15}, p7

\textsuperscript{78} Report of the Children and Young People’s Health Outcomes Forum, p67

\textsuperscript{79} The scale of this incentive could, in theory, not be limited to having this positive effect but also extend to discouraging GPs from making referrals when they are really needed

\textsuperscript{80} See for example Royal College of General Practitioners (2013), \textit{Commissioning a good child health service}: “GP practices will also have a contractual accountability to the National Commissioning Board (NCB).”

Pulse Today, 26/11/12, \textit{CCGs to influence GP contracts} : “Dame Barbara Hakin said that although the NHS CB will be responsible for holding the GMS and PMS contracts, CCGs will feed into that process.”

http://www.pulsetoday.co.uk/home/gp-contract-2013/14/ccgs-to-influence-gp-contracts/20000981.article#.UZD1UxqtxDxU [Accessed 13/05/13]

\textsuperscript{81} About 53% of primary medical services are provided under General Medical Services Contracts which are underpinned by a nationally agreed GMS contract. Personal Medical Services Agreements are negotiated locally but are underpinned by national regulations and account for just 44% of primary medical services. NHS Commissioning Board (2012), \textit{Securing excellence in commissioning primary care}

\textsuperscript{82} The National Health Service (Personal Medical Services Agreements) Regulations 2004
JHWS process. This could be seen as a potential conflict of interest as local GPs would likely take this role and be representing the body responsible for commissioning the services they themselves provide.

Local enhanced services (LESs) had been a way for the now defunct Primary Care Trusts to develop schemes in response to local needs (although the challenges highlighted above may suggest that they were not completely effective). NHS England said in 2012 that, as the new commissioner for primary care, it was unlikely to use this mechanism since its intention is that clinical commissioning groups (CCGs) should decide how best to use local resources to invest in community-based services that go beyond the scope of the GP contract. This may reflect the duty that is placed on CCGs to promote improvements in primary care. CCGs and their member practices may lack strong enough incentives, and, in some areas, inspiration as to what good services for children and young people look like, need to be able to take this forward.

NHS England have said, more recently, in their business plan, that “As a single commissioner of primary care services, we have the unique opportunity to redefine the role of primary care”. However, no commitments have been made about how this will be taken forward in way that promotes innovation to meet the needs of children and young people locally.

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Priorities for change

This report has considered children and young people’s experience of GP services, the challenges in providing good primary care for them in the GP practice and some of the solutions being proposed and implemented across the country. From all of this it is apparent that there is a need for national as well as local action to facilitate and encourage improvements of the services that GPs provide for children and to ensure accountability and consistent standards across the board.

It is vital that GPs have appropriate training to work with children - in identifying illnesses, coordinating their care, and supporting them to develop more involvement in managing their health as they grow. Even with extra training there may still be times where drawing on the expertise of a specialist may help a GP avoid unnecessary referrals to secondary care and maintain the confidence and good relationships with children and their families, particularly for those with complex needs. When children and young people need the support or input of GP services it is vital that they are able to access this at the time and in the setting that is most convenient and comfortable for them.

The system needs to allow children and young people to have the confidence to make the best use of GP services when they need them, and to play their role in looking after their health and helping services to improve. They need to be confident that they will be treated with respect when they access services and are taken seriously when they have feedback or a complaint. Children’s experiences must also be taken into account when measuring the performance of GP services as part of the NHS as whole. It is unacceptable that the GP patients survey is restricted to those aged over 18 and that this is then used as the sole basis for many measures in the NHS Outcomes Framework.

Many, including Ian Kennedy, the Children and Young People’s Outcomes Forum, RCGP and children and young people themselves have recognised similar sets of barriers. Such consensus is a good starting point for delivering change. The frameworks that shape services across the country such as the specification of mandatory training, approaches to commissioning and accountability mechanisms, however, appear to be serving to entrench these barriers. These systematic and structural determinants of care appear to take almost no account of children and young people’s need for high quality primary care. As a result, action is needed not just from individual GPs and their practices but right up to the highest levels of NHS leadership and Government.
Government must take forward the following actions with urgency:

- Confirm funding for the implementation of the Royal College of GPs’ proposal to extend GP training
- Make sure children’s experiences of primary care are reflected with at least equal weight to that of adults in the NHS Outcomes Framework, as per recommendations from the Children and Young People’s Health Outcomes Forum. To help monitor the quality of services heavily used by children under five the views of parents may also need to be sought.
- Deploy a strategy for primary care that can secure that GP services are built around the needs of children, young people and their families, paying particular attention to how commissioning and accountability mechanisms support families’ access to services when, where and how they want them.

Government policy on GP services, leadership and support from national agencies and professional organisations, and the actions of commissioners, providers and professionals must help achieve the following on an ongoing basis:

**Equipping GPs with the right expertise**

In addition to extending GP training, this means:

- Existing GPs must be offered adequate opportunities to develop their skills, expertise and experience in working with children and young people. Many organisations may have a part to play in this, including Local Education and Training Boards, Royal Colleges, Health Education England and the voluntary and community sector
- NHS England must use its role as commissioner of primary care to incentivise GPs to take up these opportunities and for trainee GPs to seek out opportunities to maximize their experience of working with children and young people
- Those CCGs and member practices that are rich in expertise in meeting children and young people’s needs and have been driving forward innovation in their local areas must come together to provide peer support for driving forward improvements in primary care across the country.

**Getting the commissioning process right reflect**

- Any forthcoming contract renegotiation between NHS England and GPs must put the needs of children, young people and families centre-stage and make clear progress on key issues such as practice opening hours
- There must be confidence that, whoever hold contracts with GPs, and however they are negotiated, that this promotes:
  - Consideration of local needs and opportunities for improvement in the provision of primary care for children and young people
  - Identification and rollout of good practice, particularly in reducing A & E attendances
  - A robust focus on the needs of the children, young people and the wider population rather than service providers
  - Partnership working with secondary care and primary care-oriented aspects of public health services
As long as the Quality and Outcomes Framework is used as key lever for improved services its scoring system must better reflect improvements to meet children and young people’s needs. Amendments to this end should be considered every time the Framework is reviewed.

NHS England should engage with Health and Wellbeing Boards to get the best out of their local GP practices for children and young people

Making services accessible

- The hours at which GP services can be accessed must be based on the needs of the local population including children, young people and their families. The NHS England ‘seven day services review’, to be published in Autumn 2013, should include plans to ensure that practice opening hours will be based on the needs of the communities they serve.
- Local commissioners of health and other services must work together to make GP services available in the most accessible settings for children, young people and their families, wherever that may be.
- Practices should be designed and run in children and young people friendly way and this should be monitored through inspections. This includes:
  - Supporting mechanisms that help children understand what is happening in an appointment such as appropriate printed information and taking extra time to explain advice and processes.
  - Ensuring continuity of care so that children’s involvement in their health can be developed.
  - Ensuring all staff are competent in working with children and respecting their rights.
  - Allowing flexibility to meet the needs of children and young people with particular access requirements or communication needs.

As identified by the Children and Young People’s Health Outcomes Forum and others, the You’re Welcome quality criteria remain an appropriate set of standards to work to.

Exploiting expertise based in other services

- Partnership between primary and secondary care must be fostered – this may entail adjustments to the configuration of secondary as well as primary care, with secondary care practitioners working in out of hospital settings to be more available to support GPs.
- Community children’s nurses, health visitors, school nurses and GPs should work together to ensure the care of individual children is well coordinated.
- Where administrative or structural barriers are identified, managers and commissioners should seek to address these.

Empowering children as service users

- Children and young people’s awareness and understanding of the NHS Constitution must be promoted and supported.
- GPs and practice staff must have an understanding of and commitment to children’s rights under the NHS Constitution. This should be addressed in training, appraisal, revalidation and inspection.
GP practices must have clear mechanisms for children and young people to provide feedback and for the practice to act on it. Healthwatch and NHS England should facilitate any support required to implement this. NHS England should look for evidence of such mechanisms in the monitoring of GP practices performance.

The risk presented to children and young people’s outcomes in ignoring these challenges is too great. The pivotal position of GP services in the wider system supporting children and young people’s health means that good outcomes are dependent on them performing their role effectively. Improvements in this area are key to catching up with the rest of Western Europe on child mortality, reducing avoidable admissions, and avoiding poor experiences of care and negative impacts on longer term outcomes. GPs must be properly equipped and supported to do their best by children and their families. We need to be confident that children and young people are properly taken into account and catered for in GP services. Children, young people and families need to see clearer evidence that this is the case in every area of the country. It is vital that improvements in how these services are commissioned and delivered are driven forward so that children’s needs are met.