Commissioning a good child health service

CIRC – Clinical Innovation and Research Centre, 2013

Joint publication with:
Royal College of Paediatrics and Child Health
Royal College of Nursing

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The Royal College of General Practitioners was founded in 1952 with this object:

'To encourage, foster and maintain the highest possible standards in general practice and for that purpose to take or join with others in taking steps consistent with the charitable nature of that object which may assist towards the same.'

Among its responsibilities under its Royal Charter the College is entitled to:

'Diffuse information on all matters affecting general practice and issue such publications as may assist the object of the College.'
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Commissioning a good child health service
Executive summary

Regardless of one’s view on its merits or otherwise, the Health and Social Care Act is now law and the changes that will come into place from 2013 will, unquestionably, radically alter the health and social care landscape – indeed in some areas this is already happening.

There is no doubt that all health and social care professionals want the best for their patients. Whether they are a hard-pressed GP in a busy urban practice, a paediatrician working on the front line of a large hospital or a commissioner based in one of the new Clinical Commissioning Groups putting together their initial plan, each one wants to do the same thing – to guarantee a high-quality service for every patient coming into the NHS.

In creating this document, the Royal College of General Practitioners (RCGP) and Royal College of Paediatrics and Child Health (RCPCH), with the support of both the Royal College of Nursing (RCN) and Department of Health (DH), have attempted to answer the question ‘How do you commission the best possible service for children?’ We have intended it to help light a path for commissioners, to support them in ensuring that, in both primary and secondary care, there is a set of key principles by which they can abide and develop and build upon. We hope that these will not only enhance and strengthen the relationship between GPs and specialist paediatricians as well as nurses and other practitioners who are responsible for providing care for children, but will also contribute to narrowing any potential variations in care: a template from which commissioners can draw so that the treatment a child receives is as high quality in Newcastle or Newquay – and everywhere else in between.

So, what conclusions did we reach?

First, without a clear set of principles and a vision for how health care can be best delivered within the individual health economy of each local commissioning area, it will be hard to deliver the standard of service that children need. This is dependent on a relationship of collaboration, not competition. Children’s services have always ‘leaked’ across Local Authority boundaries, be they Statutory Health Authorities, Primary Care Trusts or now Clinical Commissioning areas. There is much evidence that a multi-professional approach working across well-defined clinical networks will provide the best guarantee of success and, critical in the current financial environment, offer value for money. This means ensuring that not only people but also systems, including IT, work more efficiently to integrate across all aspects of a child’s journey.

Second, to this end, the importance of good communication between schools, health visitors and doctors should be seen as having almost equal parity as that between primary and secondary care clinicians. This multidisciplinary ‘conversation’ needs to be encouraged and supported by commissioners so that it is more structured, resulting in children’s health problems being detected and acted on quickly. Equally, while ‘systematising’ more of a child’s’ journey through the health sphere will reap greater benefits, the advantage of acting opportunistically should not be lost. This can apply in primary and secondary care – for example, in the area of immunisation checks through the early and proactive engagement of parents of young people who are indulging in risky behaviours such as substance or alcohol misuse and indeed with those who are obese. Making ‘every contact count’ is a worthy aspiration but to do it well requires a creative and truly joined-up approach – acting across boundaries, specialities and practice areas.

Third, in an environment of rapid and wide-ranging change it is more important than ever that commissioners and practitioners must be aware of their responsibilities so that children who are vulnerable or at risk do not fall through the gaps. This applies in areas such as safeguarding, where commissioners need to ensure practitioners are given the appropriate level of training for their organisational role and have incorporated relevant educational programmes into their professional development plans. This will enable practitioners to recognise, assess, plan and provide for children as well as parents who need extra support in bringing up their children. It will also help them to carry out wider professional duties such as participating in child protection conferences and contributing to serious case reviews. The same applies in the area of mental health, where appropriate awareness amongst the two groups of the Four-Tier Strategic Framework is the basis of providing better care for children with mental health problems.
Of course, health services do not exist in a vacuum. The Marmot Review provided ample evidence of the huge disparities in health inequalities across different social groups – the report should be required reading for all those working with children. However, while it is important to understand the bigger picture, it is frankly more important that it is addressed. The recent publication of the *NHS Atlas of Variation in Healthcare for Children and Young People* offers an excellent databank. It is an opportunity to act on the unacceptable variations in child care across given constituencies. This is an example where the well-worn phrase of the advantages of a ‘holistic’ approach genuinely applies. Being able to identify where the best exists and how it is achieved means commissioners can develop services that will have the maximum benefit because they are being delivered where they are needed most. Local Joint Strategic Needs Assessments will help commissioners know their ‘patch’ and which services to target at which areas to best reduce those inequalities. Plainly, care is also likely to be worst for those patients who are not registered with the system, and we believe that Clinical Commissioning Groups (CCGs) and the National Commissioning Board (NCB) have a shared responsibility to tackle this entrenched problem regardless of whether it happens because individuals feel they cannot or because they will not engage with healthcare services. Flexibility is required in these situations particularly when children, who are directly affected by their parents’ decisions, do eventually find their way into the system.

Last, the accepted definition of children and young people (CYP) in the UK covers those aged 0–19 and we have consciously maintained a wide-lens view of this, given that transition into adult services is a highly risky time for some children. It should become standard that a re-registration process takes place for children around their sixteenth birthday. This will enable professionals to work with the adolescent, alone, to undertake an appraisal of what services are available and might be required over the ages of 16–19. This could also provide the platform from which adolescents can take ownership of their own health care. As long as CYP have rights to health care, their involvement in shaping decisions about themselves will be valuable in, and of, itself. However, as they progress through childhood, it is this meaningful participation that can often be the source of innovative solutions for both practitioners and commissioners.

This is, unquestionably, an important moment in the way the NHS and wider health and social care disciplines deliver for children. This document attempts to help those involved in making decisions – commissioners, health professionals and children themselves – shape services, so they can do the maximum good for all children. Health, despite the huge challenges it faces, should always be a race to the top, not the bottom. In a system that is facing fundamental changes, understanding the difference between acceptable and excellent has, arguably, never been more important.
Foreword

The majority of care for CYP within the NHS is delivered by GPs within the wider context of family care. Children aged four years and under typically visit their GP six times a year, with school-age children seeing their GP two to three times a year. Around a quarter of a GP’s patients are under 19 years of age.

The experiences of CYP in early life – and even before birth – have a crucial impact on their life chances. GPs have immense influence on their health and are instrumental in helping them develop into healthy adults. But there is an increasing perception that GPs are spending less time on looking after children. Significant numbers of children are also living in poverty and experience poor access to good health care.

The continuing trend to shift health care ‘closer to home’ will require GPs, alongside paediatric and nursing specialists, to play an even greater role.

As well as providing clinical care, this will involve development of Advance Care Plans for children with life-limiting conditions and targeting the most vulnerable and socially excluded.

It is a role we are ready to take on. Indeed, providing trainee GPs with more experience of paediatric and child health is one of the tenets on which the RCGP’s current case for extended and enhanced GP training is built.

Only 40–50% of GP trainees currently undertake a paediatric placement during their training. Enhanced GP training will ensure that all doctors entering general practice have the time and opportunity to develop the skills and experience required to adequately recognise and care for sick children. The RCPCH’s Facing the Future document sets out the mutually beneficial role that placements for GP trainees in acute paediatric services can provide.

The commissioning agenda presents many challenges for GPs, paediatricians and all those working with CYP – but also many opportunities.

We need to be able to work effectively and together to deliver high-quality services so that our young patients receive the best care possible, at whichever point they access the NHS and for however long.

Integration with adult mental health, drug and alcohol misuse services, youth offending teams and adult medicine services will also be essential, and the promotion of good health should be included in all contacts with a child, a young person and their family.

Good commissioning – or planning – is the key and this guide will help you commission the right services for your patients. It will help you meet their current and future needs in the most effective and cost-effective way possible.

We are delighted to be working in partnership with our colleagues at the RCPCH, the RCN and the DH in England. It is so important that we get this right so that we can deliver the best possible health outcomes for every child we see.

Prof. Clare Gerada MBE FRCP FRCPsych FRCGP
Chair, RCGP
Foreword

There are better starters than me, but I’m a strong finisher.
(Usain Bolt)

There is much that is good about the health care we provide for our children – but we have considerable room for improvement. Within this document, concerns are presented that cross every domain, from the quality of unscheduled care to the services we provide for young people with long-term conditions, as well as Child and Adolescent Mental Health Services (CAMHS), transition to adult care, safeguarding and preventive health care. There are, of course, areas of excellent practice; but that very excellence throws into sharp focus the huge variation between the best and the worst of services. Many would argue that variability is our greatest challenge, with up to seven-fold differences in some aspects of care around the country.

If we can get things right for today’s CYP, we will reap our reward in the longer-term health and wealth of the nation. We all recognise that achieving this is going to be a long game, and yet we know that politics is a short game. No government is able to see through the consequences of its policies to their full conclusion.

The importance of this document lies in the fact that, while politicians and administrations come and go, GPs remain. They have always been expected to understand the needs of their local population so as to provide high-calibre primary care services, but they now need to take bold commissioning decisions that will transform care delivery systems and outcomes.

Health care has traditionally been designed around the needs of adults, and the demographic and economic justification for this is self-evident. By contrast, the majority of children enjoy good health and they have therefore been seen as a ‘minority’ stakeholder. Following the success of the London Olympics the consequences of poor lifestyle choices, rising obesity and diseases that have their determinants in childhood have started to capture the attention of all those involved in health care. Locally determined initiatives and innovation will be needed if we are to ‘inspire a generation’ to improve its health.

We know there is a balance to be struck between providing care closer to home and providing specialist services that offer children and families cutting-edge technologies and drug treatments. However, highly specialist services for children with the most complex care needs will be dependent on consistency and nationally defined service specifications. By contrast, it is creative local commissioning that has the potential to generate the greatest economic and healthcare impact, and this in turn will be dependent on the interaction between CCGs, Health and Wellbeing Boards and a broad range of local stakeholders.

Success is always a team effort. We have had many starting guns through the reforms to the NHS, the economic climate, and most recently the Children’s Outcome Strategy. The real test of the new systems and of this guidance will not be in the starting, but in the finishing.

Dr Hilary Cass
President, RCPCH
Preface

In the late summer of 2011 following a discussion between the RCGP and RCPCH, a report was commissioned to define what a good child health service looked like from both the primary and secondary care perspectives. It was hoped that such a report would not only act as a useful resource for service providers and other stakeholders but would also serve as a guide to ‘commissioning a good child health service’. This report is the product of this initiative and is the result of a series of joint meetings during the past year. It encompasses not only the contributions of the RCGP and the RCPCH but also those of the RCN with some additional commentary from the DH. It is not intended to be a detailed guide for commissioners but one that introduces the key principles of a good child health service that need to be considered when developing and improving child health services. The joint Working Group has tried to produce a ‘reader friendly’ document based on sound evidence for the members of our three Colleges who may be involved in commissioning child health services.

The challenges for us as GPs at the centre of current health service changes are many and the report highlights the importance and value that additional training and professional development can contribute. We strongly support the current proposals for the extension and enhancement of GP training, particularly in safeguarding, and professional knowledge exchange between GPs and specialist paediatricians.

We also endorse the important role of nurses in the current NHS changes through their input to specialist services in clinics and their strong support in the community and schools, where the educational and advisory elements of practice are crucial.

Finally, from the outset it was envisaged that this document would be the first of a series as we embark on a journey for commissioning services that are still being defined and refined. The next in the series will address the services provided by the Local Authorities and Health and Wellbeing Boards and we look forward to your engagement of our members in this continuing process.

We hope that you find this document useful in developing services to improve the care of our children.

Prof. Nigel Mathers MD PhD FRCGP
Chair of the Working Party, Vice Chair of RCGP Council

Roger Hammond
Interim Director of Research and Policy, RCPCH
Acknowledgements

A small Working Group drawing upon the expertise of the four collaborating partner organisations developed this document. Membership of the group comprised:

- Prof. Nigel Mathers – RCGP, Vice Chair of Council and Chair of the Working Group
- Roger Hammond – RCPCH, Interim Director of Research and Policy
- Dr Janice Allister – RCGP, Clinical Champion for Child Health
- Dr Vimal Tiwari – RCGP, Clinical Champion for Commissioning
- Dr David Paynton – RCGP, Clinical Champion for Commissioning
- Dr Edward Wozniak – Department of Health Professional Adviser, Paediatrics
- Dr Carol Ewing – RCPCH, Officer for Workforce
- Peder Clark – RCPCH, Health Policy Lead
- Fiona Smith – RCN, Adviser in Children and Young People’s Nursing.

Thank you to the many others who have contributed to this document with commentary and feedback.
Chapter 1

Principles and vision

The commissioning of health services through GPs places them at the heart of multi-professional service provision and this is particularly so in considering children and young people’s (CYP) health care. Maintaining and improving the health and wellbeing of CYP need integrated services utilising collective expertise and resources efficiently. This requires all those in contact with children to have a clear, comprehensive understanding of the context and content of local services and access to all relevant information.

GPs will play a part at all levels of the new commissioning structures, working in Federations or Associations, independently and with other clinicians and allied healthcare professionals. However, this report specifically sets out the challenges faced in dealing with the 0–19 age group who represent more than 20% of the UK population. As the only group who will form the next generation of adults, there is good evidence that their health care will definitively influence the future health of the nation and deserves special consideration not only because of the impact on health services and the cost of providing them but also the skills and abilities of the workforce who will care for them.

The first point of contact for a child or young person with health services is usually the GP practice. GPs are also leading commissioning of local healthcare services in England from April 2013. This guide sets out for these important stakeholders a shared vision developed with GPs, paediatricians and children’s nurses of what a good children’s health service looks like from a primary care perspective.

Example of integration – flexibility and learning new skills

In Walsall the involvement of a school nurse in giving a diabetic child his insulin saved the child having to be taken by the head teacher every lunchtime to his grandmother’s house just so she could administer it.

The RCGP, the RCPCH and the RCN believe that:

- the GP practice is currently the appropriate locus for a ‘knowledge hub’ for all information about a child or young person, but increasingly children and families should be provided with information about themselves and their condition to enable self-management
- the GP/primary care team is best equipped to help a family navigate the system, contextualise commissioning decisions and be responsible for holding and maintaining all health-related information about a child or young person, often within the wider context of knowing the family and its background
- GPs need to be clear about their child health knowledge and gaps, and regularly take up opportunities for continuing professional development (CPD) in this area
- participation of young people in planning and refining the service, formally or informally, individually and collectively, is crucial to ensuring good care
- children’s health care is usually best delivered through a multidisciplinary team, with the GP at the centre collaborating with stakeholders, including local voluntary and authority partners, community care and acute care
- we should continue to evaluate and improve the standard of care provided to children and their families.

A practice must be supported in this central role for families by all other health-related teams in contact with the child or young person as well as being accessible (perhaps through the school nursing team) to education and other commissioned children’s services.
Commissioning a good child health service

Delivery of high-quality care in England is increasingly focused on measurable outcomes, such as the Public Health Outcomes Framework\(^1\) and the Children and Young People's Health Outcomes Framework.\(^2\)

The NHS, Public Health and Children’s Outcome Framework have set high-level standards for certain conditions and processes, but these initiatives should not be combined when focusing on child health. While these indicators provide a sound structure for design and delivery of services, there are many more determinants of quality. When looking at the planning and provision of services alongside these formal criteria, the following principles of good care within primary care settings should be considered.

**Multidisciplinary teams need to address the following**

- Consider changes that could and should be made to encourage young people to use the GP services more.
- Giving information about continuing access to clinical, social, physical and financial support (for example personal budgets), appropriate access and information.

**What should good information sharing mean for the team?**

- Information systems that cross different health systems both locally and beyond (for example outside of health as well).
- Consideration is given to IT systems and their other relationships.
- All professionals need to be clear about their roles, responsibilities and boundaries.
- Giving case reviews, including CYP with complicated and complex needs, by the team at a practice meeting.
- What information should the child, young person and family be given to ensure they are safe?
- What information can be given regarding medicines?
- Can older CYP access their results online?

Information sharing with children, young people and family as well as professionals is key. The team also needs to address, for example, the following questions when developing information-sharing systems.

All health and social care professionals who need access to the record of the child and young person should have this as well as the ability to update them.
Chapter 2

Governance and accountability

Governance

The heart of good governance is to achieve legitimacy by agreeing the key strategic outcomes with partners within available and identified resources. Improving life chances for children as an overarching objective focuses as much on the social and educational outcomes as health indicators. This means the Local Authority taking the lead in many aspects of children’s commissioning but working in partnership with CCGs as joint commissioners.

Doing the right things becomes the first priority with ‘doing things right’ as a necessary subsequent prerequisite. This also implies having an agreed strategic plan for children’s services that focuses on improving their life chances.

Good governance for commissioning of children’s services requires the joint commissioning for children’s services with the Local Authority. The system should agree:

• the overarching objectives and the underpinning strategic aims
• on sharing of resources on an ‘open book’ basis with the potential to recycle savings back into children’s services to support the overarching objectives
• the key milestones over a three- to five-year period but with an annual joint operational plan
• a process for monitoring progress over time as well as the mutual operational responsibilities including data sharing and safeguarding
• to hold each other to account for delivery and key ‘Gateway’ points.

The Health and Wellbeing Board (HWB) holds the ultimate governance key to the local system on behalf of the community. The HWB holds the CCG and Local Authority to account for delivery of the local system.

The HWB will play a key role in promoting a culture of joint working but will also have to find a way of working with other governance groups such as education.
Accountability

Primary Care Trusts were accountable upwards to their Board but CCGs will now have a more complex system of accountabilities (see Figure 2).

Accountability should be seen as working both ways, especially with GP member practices having a key role as providers of care as well as being commissioners. GP practices will also have a contractual accountability to the National Commissioning Board (NCB). The HWB may also have a relationship with the NCB, although without formal accountability. The key to accountability will be having an agreed annual delivery plan with key deliverables.

Different lines of accountability will have slightly different drivers:

- the NCB will want to see delivery of the government’s mandate within available resources. This will be translated into a number of key outcomes that the CCG will need to ensure are delivered
- the HWB will want to be accountable in meeting the local population aspirations especially in terms of improving life chances for children. This will be in addition to the NCB set outcomes
- the member practices have yet to determine what their drivers will be for children’s services but it would probably be in terms of better integrated teams supporting groups of practices.

The challenge for the CCG will be to enmesh these different strands in a single commissioning strategy and hold providers to account for delivery.
Commissioning

Overall, within a health and Local Authority system, the strategic needs of the population are determined by the Joint Strategic Needs Assessment (JSNA) and responsibility for the JSNA sits with public health. It is the HWB who then takes accountable responsibility for macro-commissioning through the Joint Health and Wellbeing Strategy (JHWS). The HWB is a sub-committee of the Local Authority.

Ideally the overall aim of the JHWS for CYP should focus on ‘Improving Life Chances for Children’. This overarching theme would then be subdivided into a number of key components, some of which will focus on education, safeguarding, children with complex disabilities, inequalities, etc., as well as the commissioning of more traditional acute children’s services.

The JHWS will need to consider its own local population outcome measures alongside those coming down from the NCB.

The money to commission children’s services for the CCG comes from the NCB but there is the potential to share budgets with Local Authorities with an agreed legal framework. The CCG will of course be expected to work with the HWB around them and the NCB specialist commissioning group in those clinical areas that are determined.

The CCG and Local Authority are responsible for their own commissioning decisions but will need to demonstrate how they integrate their approach to commissioning in order to improve overall children’s life chances. In addition the CCG, being a membership organisation, is also accountable to its practices.

The Local Authority Health Scrutiny function will hold the HWB to account with scrutiny decisions being made by the whole council rather than as a sub-committee.

Local Authorities may also consult, with Healthwatch acting as the patients’ advocates. Primary care itself is contractually accountable to the NCB but it is expected that the CCG will have a strong influencing role on the way primary care responds to the needs of children.

All those involved with commissioning will be expected to declare any potential conflict of interest. All providers will be expected to work within local agreements, especially with respect to information sharing, quality, safeguarding, data collection, transparency and confidential enquiries. The HWB will want to promote integration, shared objectives and mutual incentives if the population outcomes identified in the JHWS are to be achieved.
Chapter 3

Context

Health in the UK is related to educational attainment and financial status. There is a difference in life expectancy in England of up to 16 years between the wealthiest and poorest members of society. This is reflected in the health of our children. The UK has the second highest child death rate among the 24 richest countries in the world, with deaths 35% higher in poorer households. Despite falling rates, neonatal mortality and stillbirths are currently averaging 7.5 per 1000 births, varying widely across regions. These rates are linked to poverty and social exclusion, and equate to a loss of around 6500 babies each year.3,4

Recent reports by Marmot (2010),5 Kennedy (2010)6 and Allen (2011)7 make important recommendations to improve children’s health, reduce health inequalities and increase life expectancy. These reports are based on emerging evidence and new information on neurological and physiological development of the foetus and infant. They suggest that addressing parental poverty, deprivation, nutrition, emotional and health issues during pregnancy and in the early years contributes to reducing health inequalities and improving health outcomes for the child in later life.

Child health issues of greatest concern to commissioners in 2013

- Increase in unscheduled attendances.
- Neonatal feeding problems.
- Inappropriate A&E attendances.
- Prenatal and adolescent mental health issues.
- School issues – exclusion of very young children with troublesome behaviour.
- Children with chronic and long-term illness.
- Transition issues.
- Safeguarding and looked-after children.

General practice offers a comprehensive service free at the point of delivery, taking into account physical, psychological and social factors. GPs are often very familiar with their most troubled patients. These patients often suffer from recurrent depression or other long-term and chronic conditions, and have limited resources with which to improve their lives. Although Local Authorities may have an in-depth understanding of the public health needs of their populations, they have historically not had the appropriate systems in place to work with the local NHS to obtain the best care to improve the health and wellbeing of the community.

The impending changes in health structure in England will include clinically led commissioning, an unprecedented opportunity to develop and implement a whole-system approach. This will bring together multiple service strands to ensure that all children are born with the best possible life chances, and to reduce health inequalities while increasing life expectancy.
Our current situation

In 2011 England was home to 12 million children and the health of these children will profoundly impact the future health of the nation. Approximately 1 million CYP may have mental health problems, which given their proportion of the population is a serious concern for the future.

In addition, mental health problems have a significant impact on the costs related to the management of long-term conditions. For example, the total cost to the health service of each person with diabetes and co-morbid depression is 4.5 times greater than the cost for a person with diabetes alone.

In a typical year, a pre-school child will see their GP six times, a school-aged child 2–3 times, one in 10–15 will be admitted to hospital and one in a thousand to intensive care. GP interactions will clearly be influential in determining the impact on health service resources and in particular cost of provision. Urgent or unplanned care lead to 100 million calls or visits to the NHS each year. This represents about one-third of activity in the NHS and over half of the cost.

Five common conditions in children account for 50% of urgent care in A&E. A 25% reduction in these events would save the NHS £179 million. The stark contrast in cost between NHS Direct online contact (typical 2008/9 cost of £0.12) and the cost of A&E attendance (typical 2008/9 cost of £75) indicates the potential cost benefit of reducing emergency care. Despite the scale of urgent health care, historically more attention has been paid to the way we manage planned activity, especially in hospitals. Too often this has resulted in unintentional conflict. There is now an opportunity for the whole network to think afresh about how to get the best possible urgent care system across a local community. Good commissioning practices that are based on effective pathways of care that include multi-professional working will be valuable.

To put these issues into perspective, the King’s Fund has cited a simulation exercise of real-time commissioning issues undertaken by Lincolnshire NHS Trust to assess the potential impact of commissioning pressures. The stresses and strains of dealing with the pressures involved were soon apparent and the need for GPs to ensure good communication with a range of professionals (both clinical and administrative) to provide support and assurance was clear. This emphasised that a ‘whole systems approach’ is essential to delivering effective commissioning of CYP’s services.

What is your local child health profile?

The Child and Maternal Health Observatory (ChiMat) offers a wide range of analytical tools and data about health inequalities and variation in service provision to support analysis and planning of maternity and child health services including Child and Adolescent Mental Health Services (CAMHS). Specifically, the NHS Atlas of Variation in Healthcare for Children and Young People includes interactive data on up to seven-fold difference in levels of service received, and the ‘Child Health Profiles’ provide a detailed comparison and data for services in Local Authority and PCT catchment areas.

Child health provision needs to include:

- an awareness of the rights of the child
- primary prevention
- early identification and intervention when problems detected
- statutory obligations including early safeguarding and child protection
- partnership working with children, young people, parents and carers.

There should also be a determination that all care should be high-quality care delivered at the appropriate time and place.
Areas requiring improvement

• Infant immunisation rates.
• Parenting education and support.
• CAMHS services.
• Transition, particularly to adulthood.
• Looked-after children.
• Too many children in care far from home.
• Information sharing – many community and acute child health services do not have access to effective electronic records.

A further contextual issue for GPs to consider in relation to the four notional ages (0–4; 5–9; 10–14; 15–19) of a ‘healthy child’ is location.

In addition to the service and cost issues mentioned above, the geographical issues that, in combination with the size of population for which local authorities are commissioning services, will present logistical challenges. Averaged incidences of child illnesses based on national statistics are likely to be misleading. We already know that each area has its own profile of health issues to deal with (see Tables 1 and 2) and the establishment of networks across similar authorities to enable sharing of good practices will prove essential to effectiveness.

Local Authority comparisons of children’s health from ChiMat Child Health Profiles, 2010

Table 1: Larger than average population authorities

<table>
<thead>
<tr>
<th>Factor</th>
<th>Kent</th>
<th>Birmingham</th>
<th>England average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant mortality</td>
<td>3.6</td>
<td>7.3</td>
<td>4.6</td>
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<tr>
<td>Child mortality</td>
<td>14.3</td>
<td>19.4</td>
<td>16.5</td>
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<td>Children under 16 in poverty</td>
<td>18.8</td>
<td>34.9</td>
<td>21.9</td>
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<tr>
<td>Children in care</td>
<td>54.0</td>
<td>75.0</td>
<td>59.0</td>
</tr>
<tr>
<td>Hospital admission for substance misuse (15–24 yrs)</td>
<td>54.5</td>
<td>56.7</td>
<td>63.5</td>
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<td>Children using alcohol</td>
<td>20.0</td>
<td>6.0</td>
<td>15.0</td>
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<tr>
<td>Hospital admission due to injury</td>
<td>1315.4</td>
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<td>Not in education or training</td>
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<td>7.4</td>
<td>6.0</td>
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<td>First-time entrants to youth justice system</td>
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<td>1130</td>
<td>1160</td>
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<td>Children 0–19 population</td>
<td>350,500</td>
<td>288,800</td>
<td></td>
</tr>
</tbody>
</table>

Notes: There are 212 authorities listed. The population of 0–19 CYP in 2011 was 12 million. The average population of CYP per authority in UK is 56,604.
Table 2: Smaller than average population authorities

<table>
<thead>
<tr>
<th>Factor</th>
<th>Blackburn</th>
<th>Southend-on-Sea</th>
<th>England average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant mortality</td>
<td>8.0</td>
<td>3.7</td>
<td>4.6</td>
</tr>
<tr>
<td>Child mortality</td>
<td>27.6</td>
<td>15.8</td>
<td>16.5</td>
</tr>
<tr>
<td>Children under 16 in poverty</td>
<td>28.4</td>
<td>24.4</td>
<td>21.9</td>
</tr>
<tr>
<td>Children in care</td>
<td>96.0</td>
<td>76.0</td>
<td>59.0</td>
</tr>
<tr>
<td>Hospital admission for substance misuse (15–24 yrs)</td>
<td>108.6</td>
<td>49.1</td>
<td>63.5</td>
</tr>
<tr>
<td>Children using alcohol</td>
<td>14.0</td>
<td>14.0</td>
<td>15.0</td>
</tr>
<tr>
<td>Hospital admission due to injury</td>
<td>2164.8</td>
<td>1395.8</td>
<td>1466.0</td>
</tr>
<tr>
<td>Not in education or training</td>
<td>7.3</td>
<td>5.1</td>
<td>6.0</td>
</tr>
<tr>
<td>First-time entrants to youth justice system</td>
<td>870</td>
<td>500</td>
<td>1160</td>
</tr>
<tr>
<td>Children 0–19 population</td>
<td>42,500</td>
<td>39,300</td>
<td>56,604</td>
</tr>
</tbody>
</table>

Your Child Health Profile

There is a seven-fold difference in services received in different areas of the country, allowing for deprivation. The NHS Atlas of Variation comprises a series of maps of England showing this variation for different conditions. ChiMat also offers a wide range of analytical tools and data about health inequalities and variation in service provision to support analysis and planning of maternity and child health services including CAMHS.

Joint Strategic Needs Assessment

The JSNA\textsuperscript{15} is a statutory, area-based annual summary of the health and care needs of a Local Authority population. Developed in partnership with health, voluntary and statutory partners and involving local service users, the JSNA provides local service planners with core data on population health needs and links to the strategic planning for how those needs should be met. More about your local JSNA and what a good one looks like can be found through the NHS Confederation.\textsuperscript{16}

Health outcomes for CYP in the UK still need to be improved\textsuperscript{17} and significant challenges face children’s services over the next few years.\textsuperscript{18} The Children and Young People’s Health Outcomes strategy for England in 2012 focuses on how health care can be improved in measurable ways.\textsuperscript{19}

The Children’s Outcomes Forum report

The Children’s Outcomes Forum is the climax of six months’ intensive work and consultation, emphasising the importance of listening to CYP’s perspectives.\textsuperscript{20} It highlights the need for continuing GP training and CPD in CYP’s health and wellbeing. The proposed outcomes will be the basis for further discussions and plans to improve what we do with and for CYP, and their parents and carers.
The RCPCH vision Modelling the Future 1, 2 and 3 fully supports an integrated care model that is underpinned by high-quality communication. The vision sets out a generic pathway that can be delivered by a networked approach to the provision of care. The care pathway consists of the steps to make the initial diagnosis, the review stage for an established condition, and the transition stage (back to normal, on to adult services or into palliative care). Within each step, there are component parts such as prevention, recognition, assessment and interventions. At all stages clinicians must consider the impact on the child and the consequences for the family. There are many established networks for CYP already, and one key network function is to share and benchmark information and clinical practice against quality assurance criteria.

An example of where integrated care is currently lacking is with respect to the vulnerable child. Prof. Sir Ian Kennedy and Lord Laming have set out the clinical and managerial challenges, and described the lack of a ‘joined up’ approach to paediatric care in England as demonstrated by poor communication, lack of connected thinking and inadequate quality improvement processes. Joint guidance issued by the NHS Confederation, RCPCH and Office for Public Management describes the biggest risk to the quality of care for CYP as occurring when a patient transfers from one organisation to another. There has to be quality of care across care pathways by different providers who work in a collaborative ‘integrated care’ system with access to information and data.
Chapter 4

Collaborating in care

GPs always need to see their patients in context – their family, social, living conditions and the particular needs and difficulties of their local community.

Parents and carers, as well as CYP themselves, are anxious to take responsibility and share decisions as much as they can. This will work best within a relationship of mutual trust, which needs to be nurtured.28

Programmes and ways forward

Programmes that are implemented usually reflect policy changes resulting from evidence and research as well as financial management.

Healthy Child Programme, 0–5 years and 5–19 years (2009)

The present government has committed to providing 4200 more health visitors by 2015, to lead in the 0–5 years implementation of this programme.29 School nursing, too, is undergoing a ‘makeover’. Health visitors’ and school nurses’ new service model clarifies roles and responsibilities.

Levels of involvement

The Healthy Child Programme is universal, but has four levels of involvement for different children and families:

- your community – working with local communities and services to provide a range of services, including services provided by communities themselves, such as breast-feeding support
- universal service for all families – antenatal and postnatal support and early years work, including the one- and two-year reviews and school readiness
- universal plus some families, some of the time – particular help such as assessment and support for women with postnatal depression, addressing specific issues that arise
- universal partnership plus some families all of the time – children or parents with ongoing difficulties (this includes parental issues, such as mental health problems and addiction, and health issues, such as a child with a disability or illness), and for some families will include intensive multi-agency support.

Targeted interventions

The programme involves health ‘promotion and prevention’ at critical life stages:

- pre-conception – with health promotion including nutrition, tackling obesity, smoking reduction, decrease in alcohol and substance misuse, and an increase in age of first conception
- antenatal – early booking and screening, attention to maternal psychological and physical health, parenting guidance and support for breast-feeding
- postnatal – encouraging interaction between parents and child, performing screening checks, promoting timely immunisation and giving general safety guidance
- pre-school – ongoing support through parenting groups, appropriate socialisation in children’s centres and nurseries or other facilities
- school age – involving health, education and social care services in emotional and physical resilience
- adolescence – transition through different life stages, enabling adequate preparation.

All child health provisions include an intrinsic awareness of the rights of the child, and statutory obligations such as early recognition of safeguarding and child protection issues. This means that, in partnership working with children, young people, parents and carers, all care should be the right care at the right time in the right place, first time.
Chapter 5
Multidisciplinary teams

Families expect that all health professionals, particularly health visitors and midwives, work closely with their GP and communicate with each other to ensure that they receive the appropriate care from the right person at the right time. General Medical Council (GMC) guidance for doctors emphasises that information sharing among health professionals is integral to safe and effective care, and that the GP is the key person who needs to be informed of all health interventions. Other health professionals have similar practice guidance. There is also a wealth of advice on information governance as to what can and cannot be shared between members of a team and with families, on CYP, and how IT systems can be used safely and effectively.

Care for children closer to home has always been the ideal, but has been increasingly challenging with advances in paediatric medicine, technologies, pharmaceuticals and palliative/end-of-life care. Continuity of care and responsibility for individual families (for example with the conscientious follow-up of immunisations, repeat prescriptions and the support for parents and siblings) will always be important.

First-class community and primary care for CYP encompassing acute, long-term care, palliative and end-of-life care, health promotion and child health screening will increasingly be delivered by a multidisciplinary team of generalists and specialists including, for example, children’s diabetes nurse specialists, children’s respiratory nurse specialists and children’s epilepsy nurse specialists. This can work effectively through the network model of care. The generally accepted definition of a clinical network was first published by the Scottish Office in 1999 and has been re-launched within the RCPCH initiative ‘Bringing Networks to Life’. Working alongside GPs and paediatricians, a range of allied healthcare professionals, including therapists, specialist children’s nurses based within primary care and a comprehensive community children’s nursing team, will provide cost-effective models of service provision integrating primary and secondary care. This will enable children to be cared for cost-effectively at home whenever possible. This improves family cohesion and involvement, can prevent hospital admission and enables early discharge and reduced length of stay.

Children’s Outreach Assessment and Support Team (COAST), Portsmouth PCT

This community children’s nursing service project was established by commissioners to reduce admissions and facilitate early discharge. The timeline was as follows:

- 2008 – facilitate early discharge
- 2010 – out-of-hours GP
- June–August 2010 – GP pilot
- September 2010 – all GP practices, Portsmouth City.

Of the admissions 76% had a zero length of stay (and 52% were less than four hours).

Over the 6-month period the number of children:

- referred by GP = 130
- GP would have sent to hospital if COAST did not exist = 55
- GP would review in surgery if COAST did not exist = 72.

Over a 6-month period the savings were £49,335.

Further information is available from Angela Anderson, Service Manager, NHS Portsmouth PCT, 023 9282 2444, ext. 4004.
Specialist children’s nurses can support and manage CYP with long-term conditions such as diabetes in the community from the time of diagnosis, improving blood glucose control, enabling access to education, preventing admission and reducing the necessity for review in secondary care settings. Cost-effective models of provision include clinical nurse specialists based within primary care, providing in-reach to specialist inpatient provision as required.

Community children’s nurses enable CYP with complex healthcare needs and disabilities to be cared for at home and to access mainstream education where possible. Where such teams provide 24/7 services they can support families and GPs to provide palliative and end-of-life care, enabling CYP to die at home.

Rainbow Trust children’s charity case study: support from a voluntary sector organisation

Family support workers provide social care support to families who have a child with a life-threatening or terminal illness. The support given can be available 24 hours a day at times of crisis and encompasses emotional and practical support from diagnosis to throughout the child’s illness. It includes the provision of bereavement support as necessary. Working together with other health and social care agencies, Rainbow Trust aims to offer a holistic package of care.

Referral to Rainbow Trust can come from any source. The workers will support families in making contact with other agencies and can signpost to other sources of help as needed. Should the child require home-based end-of-life care, Rainbow Trust can work with other agencies to become a part of a package of care offering 24-hour care and support or it can be contacted via its 24-hour helpline to supply emergency care as necessary. The workers will support families at the time of death, dealing with practical arrangements and the funeral. Rainbow Trust will then offer ongoing bereavement support to all family members for as long as is required.

Further information is available from Anne Harris, Director of Care Services, Rainbow Trust Children’s Charity, anne.harris@rainbowtrust.org.uk, 01372 363438.

Experienced children’s nurses working as advanced nurse practitioners in GP practices and some walk-in centres could effectively assess, treat and discharge many children with minor injuries and illnesses. These nurses should be commissioned to provide health promotion, support and advice to young people, parents and families as part of the wider team. Community pharmacists also have an invaluable role in the provision of advice to families, with many having completed additional training and able to prescribe medication according to agreed protocols and guidelines.
Children’s Acute Nursing Initiative: Children’s Community Nursing Service, Children’s Directorate of Newcastle Hospitals NHS Foundation Trust

The Children’s Acute Nursing Initiative (CANI) team was created to facilitate much earlier hospital discharge for CYP with acute illnesses and exacerbations of chronic conditions. Nursing care by the CANI team includes:

- clinical monitoring, assessment and continued treatment
- intravenous medication for a large number of conditions up to three times a day
- support and advice to reduce parental anxiety
- further education and information to empower parents to care for their child during the period of illness and recovery.

In the first year the service has facilitated the early discharge of 335 children and freed up to 2318 acute bed days (1372 days in cubicles).

An evaluation of the services provided by the CANI team, managed by Newcastle Hospitals NHS Foundation Trust, showed that during the fiscal year 2008–9 274 patients were referred from the hospital to care within the home. This resulted in 1996 potential bed/cubicle days saved, which is equivalent to £1.1 million in hospital costs. After accounting for CANI staffing and equipment costs, the potential saving to the trust amounted to £923,768.

Further information is available from Jocelyn Thompson, Community Matron, Children’s Community Nursing Services, jocelyn.thompson@nuth.nhs.uk, 0191 2823450/1.

Health visitors and midwives have a key role in supporting women and their partners during pregnancy and in the early years of life. Recent evidence highlights the importance of a seamless approach throughout the antenatal, birth and early years with midwives, health visitors and GPs working closely to address issues such as smoking, maternal mental health, breast-feeding, nutrition and obesity. Health-visiting interventions, when well planned and coordinated, reduce problems in later childhood, promote self-care and resilience, and prevent ill health. Health visitors also have key responsibilities for the Healthy Child Programme, 0–5 years.

Hello Baby, NHS Blackpool

NHS Blackpool created the ‘Hello Baby’ course to help new mothers who have postnatal depression. It helps mothers to understand the unique needs of a baby and increases attachment and bonding.

Ensuring school readiness and working in partnership with school nurses is vital, enabling CYP themselves to make healthy life choices. It also allows those with long-term conditions or complex healthcare needs play a key role in enabling access to education and ensuring staff have the right knowledge, skills and support needed.37–39

Good communication is crucial to ensure that right care is delivered to the right person in the right place with the right outcomes – principles of good practice with respect to handover and communication in delivering integrated care wherever children, young people and their families may access care or require support.

In order to implement these principles, particularly where a number of organisations are involved in the child’s healthcare journey, clinical and other information must be:

- clearly understood by and acceptable to the child and young person and his or her family
- clearly understood and agreed by all professionals involved.

Most of all, the pathway needs to be explicit to the child or young person, family and all professionals involved as to who is accountable and responsible for what type of care provided, particularly if accountability or responsibility moves on to another professional or between agencies. Effective, high-quality communication and handover mechanisms within the care pathway for the child or young person should be an integral part of:

- service-level agreements between the organisations providing care
- clinical governance systems and quality assurance processes to measure outcomes in the organisations providing care
- all training, CPD and revalidation processes for professionals involved in the care of the child or young person.

In recent years, information governance frameworks have been developed to support the NHS40 and other partner organisations so that information sharing, within a confidential framework, can become core to clinical practice. Some progress has been made. The electronic discharge summary, for example, provides information from a child’s hospital stay for the GP optimally within 24 hours.41 Standards of communication and information sharing can potentially be evaluated through the use of quality indicators for emergency departments, in particular whether CYP have a safe discharge and close senior doctor involvement.42,43 There is still a long way to go before good communication and information sharing within teams becomes integral to everyday care44,45 so that integrated care becomes the standard.46,47
Chapter 6

Mental health

One in ten children between the ages of five and 16 has a clinically diagnosed mental health disorder. Further, more than half of all adults with mental health problems were diagnosed in childhood, and subsequently fewer than half of them were treated appropriately at the time. There is therefore an urgent need for commissioners to design integrated care pathways. Health professionals in primary care must be sensitive to CYP’s mental health needs and general wellbeing. This is particularly important when children become young adults because the prevalence of mental health problems increases in adolescence. Mental disorders affect 10.4% of boys aged 5–10, rising to 12.8% of boys aged 11–15, and 5.9% of girls aged 5–10, rising to 9.65% of girls aged 11–15.

Particular mental health issues relevant to CYP are conduct disorders, emotional disorders, neurodevelopmental disorders such as autism spectrum disorder or attention deficit hyperactivity disorder (ADHD), attachment disorders, problems with substance misuse and eating disorders. CYP may suffer from more than one mental health condition. For example, autism and ADHD may coexist in the same child, and care pathways work best if aligned as much as possible. Indeed, the term ‘children with troublesome behaviour’ is a good catchall.

Over the next three years, there will be considerable investment in a CAMHS service transformation project, Increased Access to Psychological Therapies (IAPT). The changes involve improved access, more precise categorisation of the nature and severity of the difficulties on presentation, a recognition of complexity (such as being subject to a care order or protection plan) and the effect on the child’s or young person’s education, employment or training (EET). There will be a greater emphasis on recording measures of recovery, change and satisfaction with treatment.

The present services for more severe and complex problems are still being commissioned. In some areas there is already joint CAMHS commissioning with the Local Authority, with joint social care/health/educational placements, bearing in mind the need to care for children nearer to their homes and families, and with greater attention to outcomes. The complexity and variety of these problems requires an integrated response. The role of CAMHS is integral to planning and coordinating care for vulnerable CYP, but collaboration with the voluntary sector and other public services such as schools and the criminal justice system is also critically important to protect young people’s mental health and emotional resilience across the life course. As a father who responded to the DH’s review of CAMHS said, ‘If you do one thing, just get people who know what they are doing to work together better.’ This should be the guiding principle for CCGs as they plan services for the children in their locality.

Mental health services for CYP are organised around the principle of a Four-Tier Strategic Framework, dependent on the severity and complexity of the patient’s case. Tier 1 services are non-specialist mental health professionals, for example GPs or associated health professionals such as school nurses and health visitors who may work with, for instance, common problems of childhood such as sleeping difficulties or feeding problems. Tier 2 consists of specialised primary mental health workers (PMHWs) who can offer support around assessment (which may result in further referral within their team) and treatment of problems in primary care, such as family work, bereavement and parenting groups. This tier of services also includes substance misuse and counselling services. Tier 3 services consist of specialist multidisciplinary teams based in a local clinic. The cases that Tier 3 deal with would be more complex than those dealt with at Tier 2, for example assessment of development problems, autism, hyperactivity, depression or early-onset psychosis. Tier 4 services are inpatient, highly specialised outpatient and day units. They may include secure forensic adolescent units, eating disorders units or specialist neuro-psychiatric teams. It should be noted that these definitions are not inflexible, and practitioners may be working across tiers.
The Royal College of Psychiatrists (RCPsych) has, through the auspices of its Quality Network for Inpatient CAMHS (QNIC) and Quality Network for Community CAMHS (QNCC), led the way in setting service standards for both community CAMHS and inpatient services. These standards provide an essential guide for commissioners, as they underline the importance of involving young people in the planning of these services, providing age-appropriate settings, information sharing and integration with other local services.

**Example: mental health**

Corina, age 15, has been told to come to the GP because she feels very low. Her mother has chronic depression with several hospital admissions. Corina is also being harassed by a former girlfriend with whom she had a sexual relationship. Her attendance at school is becoming problematic. On further questioning there is a history of domestic violence and Corina has taken several small overdoses. She has several complexity factors and her drop in school attendance is concerning. The GP approached social care and the school with the intention of arranging a more detailed assessment and a multi-agency meeting to find the best way forward. The police became involved too because the bullying escalated.

Recommendation: consider the right person, for the right place, at the right time (sometimes this is difficult and needs a joint decision!).
Chapter 7

Safeguarding children and young people in the NHS

In 2012 in England alone there were 12 million CYP. Looked after are 89,000 children, either in residential placements or foster/kinship care. On average, one child dies every week at the hands of another person. The need for safeguarding children has increased in recent years and shows little sign of abating.

Table 3: Child protection and looked-after children statistics for England, 2007–11

<table>
<thead>
<tr>
<th></th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>% increase (2007 to 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referrals</td>
<td>545,000</td>
<td>538,500</td>
<td>547,000</td>
<td>607,500</td>
<td>612,600</td>
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<tr>
<td>Initial assessments</td>
<td>305,000</td>
<td>319,900</td>
<td>349,000</td>
<td>390,600</td>
<td>440,800</td>
<td>44.5</td>
</tr>
<tr>
<td>Core assessments</td>
<td>93,400</td>
<td>105,100</td>
<td>120,600</td>
<td>141,500</td>
<td>184,800</td>
<td>85.4</td>
</tr>
<tr>
<td>Children in need</td>
<td></td>
<td></td>
<td>339.0 per 10,000 children</td>
<td>343.4 per 10,000 children</td>
<td></td>
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</tr>
<tr>
<td>Child protection plan</td>
<td>33,300</td>
<td>34,000</td>
<td>37,900</td>
<td>35,700</td>
<td>42,330</td>
<td>27.1</td>
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<tr>
<td>Looked-after children</td>
<td>60,000</td>
<td>59,500</td>
<td>60,900</td>
<td>64,400</td>
<td>65,520</td>
<td>9.2</td>
</tr>
</tbody>
</table>

Whose responsibility is it to safeguard children?

All children have a right to be protected from ‘physical or mental violence, injury or abuse, neglect, maltreatment or exploitation including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child’.  

All agencies coming into contact with children have a safeguarding responsibility – it is a shared responsibility.

Safeguarding requires fine judgement and rigorously applied systems (such as registering new children or using appropriate Read coding). It flourishes when professionals and agencies work together, and this applies particularly to working with health visitors and midwives. When assessing the harm or risk status of a child, it is important to focus on parental vulnerabilities (such as substance or alcohol misuse, mental health and domestic abuse) as well as environmental, societal and socioeconomic factors.
Safeguarding children across services: messages from research for health professionals working with children

- Emotional abuse and neglect (like all forms of child maltreatment) have an extremely damaging and corrosive impact on children’s long-term life chances but sometimes they only come to light through a ‘crisis’ incident or injury.
- The impact of maltreatment on babies in utero and in the first two years of life is particularly damaging.
- Early help following identification of harm and/or unmet developmental needs is essential to protect children. This is much more effective than reactive help to a crisis situation or injury.
- Coexisting parental problems such as poor mental health, alcohol and substance misuse, domestic abuse (intimate partner violence) and learning disability increase the likelihood of children suffering significant harm.
- ‘Witnessing’ domestic abuse is a damaging form of emotional abuse and harms babies as young as nine months. Pregnancy is a high-risk period for the onset of domestic abuse.
- Adolescent neglect is the most common form of abuse in 10–15-year-olds but is difficult to identify and often goes unnoticed.
- Maltreated children placed away from home, through adoption, special guardianship or long-term foster care, do better than those who remain with abusive or neglectful parents and continue to suffer harm.

GPs are well positioned in the community and may have unique knowledge of all family members. They offer continuing care, are experienced in making quick judgements and predicting risk, are able to differentiate conditions and symptoms, and have a public health and prevention (or safety-netting) approach. GP information systems host a large amount of information about family members and GPs are well placed to collate and judge which information should be shared.

Although well placed to discharge this responsibility, GPs are not responsible for making a specialist diagnosis of child abuse and neglect. Rather, they are required to share concerns appropriately and, when indicated, refer on to the relevant statutory agency responsible for carrying out an assessment and arranging medical examinations, as appropriate, to help determine whether or not child abuse has occurred.

Lord Laming sought to ensure that primary care professionals were proactive in doing all they could to keep children safe and to have suitably rigorous training to support this. The Kennedy Review in 2010 supported the need for comprehensive training. The competencies expected of GPs and their staff are set out in Intercollegiate Guidance.60 The Children’s Outcomes Forum 2012 showed that there is unacceptable variation in the amount of safeguarding education and training that GPs receive (see Chapter 8 and below for practice points).2 GPs and their staff will also be expected to have updated Criminal Records Bureau checks as before.

Responsibility for coordinating the activity in regards to safeguarding and protecting children currently rests with the Local Safeguarding Children’s Board (LSCB) – there is one in each Local Authority area. They have a particular role in developing policies and guidance, in providing training, and in undertaking Serious Case Reviews. The local Children’s Social Care department has the responsibility for responding to concerns about a particular child, and if necessary commencing child protection proceedings. This may lead to the child being made subject to a child protection plan (previously they were placed on the Child Protection Register) if they are thought to be at risk of significant harm.
The involvement of health professionals is important at all stages of work with children and families in:

- recognising children in need of support and/or safeguarding, and parents who may need extra help in bringing up their children
- contributing to enquiries about a child and family
- assessing the needs of children and the capacity of parents to meet their children’s needs
- planning and providing support to vulnerable children and families
- participating in child protection conferences
- planning support for children at risk of significant harm
- providing therapeutic help to abused children and parents under stress, including those with mental health needs
- playing a part, through the child protection plan, in safeguarding children from significant harm
- contributing to serious case reviews (where a child has died or has been seriously harmed as a result of abuse or neglect), including advice on the disclosure of medical records
- contributing to Child Death Reviews.

The Health and Social Care Act 2012 transfers the responsibilities for safeguarding children from PCTs and Strategic Health Authorities to CCGs and the NHS Commissioning Board (Health and Social Care Act 2012 s129 and s131 of Schedule 5, Part 1).

All NHS workers are expected to demonstrate skills and competencies as described in Safeguarding Children and Young People: roles and competences for health care staff (2010), as appropriate for their individual roles.60

The new CCGs have specific responsibilities for assuring the safeguarding for CYP, including those responsible for looked-after children. The specific responsibilities of the new NHS commissioning organisations for safeguarding children are currently under discussion.

It is expected that the accountability framework will be published at the same time as the final version of Working Together. Each CCG will be expected to have a designated doctor (usually a paediatrician) and nurse, and a named GP and nurse.

**Good practice in safeguarding**

Good practice in safeguarding at the primary care level requires:

- a practice safeguarding lead for CYP
- a practice safeguarding plan with local phone numbers and contacts such as school nurses (mail addresses), midwives, health visitors, the police and social care
- reliable practice systems
- regular meetings with the primary care team about CYP of concern
- significant event monitoring of safeguarding events and case reflection on an individual and practice level (see audit tool in RCGP toolkit)61
- keeping a record of learning for Care Quality Commission and Ofsted inspections
- a matrix of Criminal Records Bureau clearance and accreditation of training of all staff to the level required by intercollegiate agreement.

An example of good practice in safeguarding comes from a recent audit using the RCGP/NSPCC audit tool in Hertfordshire, which showed that 98% of practices have a GP safeguarding lead.61
GMC guidance

From September 2012 the GMC places a duty on all medical practitioners, even those who treat only adults, to identify CYP at risk of abuse and neglect. This new guidance helps define the boundary between parental freedoms and child protection concerns. It emphasises the importance of good communication with children, parents and families when there are child protection concerns. It also gives direction on respecting confidentiality and when to share information, good record-keeping practice, seeking consent for examination investigation, access to notes, understanding how other professionals involved in child protection work consider and act on child protection concerns, and training and skills development.

For those involved in specialist child protection work there is advice on giving evidence in court as a witness of fact and as an expert witness. In addition there is advice about recording family and other close relationships (section 58).

A companion guide is 0–18 Years: guidance for all doctors, which develops the duties and principles set out in Good Medical Practice but focuses on CYP from birth until the eighteenth birthday.
Chapter 8

GP/team competencies and training issues

The overwhelming majority of NHS care for CYP is delivered in general practice within a context of their parents and their family. Children of four years and under visit their GP on average six times each year and school-age children visit their GP between two and three times each year. All GPs therefore need high-quality training in leading, coordinating and delivering care for CYP. To ensure the best quality of care GPs need to be able to recognise and treat sick children, help them to keep healthy and prevent illness. GPs also need to respond effectively to child protection issues and help children and their parents cope with chronic illness and disabilities.

Recognition and treatment of sick children

All doctors working in primary care need greater opportunities for exposure to sick children to develop and maintain the skills to recognise adequately the sick child, and to assess, diagnose and manage them safely and effectively. This will include improved training on the implementation of national guidelines and providing patient information including safety-netting advice. See www.spottingthesickchild.com.

Improving care for children with complex and long-term conditions

GPs need to adopt increased responsibility for coordination and signposting to services as well as developing the skills to actively coordinate the transition period when a young person with a long-term condition or disability is transferred to adult services. This will require GPs to develop strong professional relationships with schools, social care and other healthcare providers.

Supporting healthy childhood development

GPs need enhanced skills to provide more high-quality early-life care for at-risk infants and children, including being able to care for premature babies following early neonatal discharge. They also need to support parents and develop more effective pathways for effective family interventions in the prevention or management of lifestyle-associated health conditions such as obesity.

These activities not only require well-developed clinical skills but are also closely bound up with the generalist and leadership roles of the GP, who needs to become increasingly skilled in:

- organising child-friendly services
- diagnosing and managing childhood illnesses
- communicating effectively and balancing risks
- dealing safely with uncertainty and knowing when and to whom to refer.
Strengthening and developing training

Strengthening and developing the training for doctors in general practice is critical in delivering improved care and outcomes for CYP.

Approximately 60% of GP registrars do not currently have an opportunity to experience acute childhood illness in a specialist setting during their three-year specialist training programme. To improve the urgent care of children, it is essential that GP registrars have the opportunity to gain experience of caring for acutely sick children in an appropriate safe environment. Although specialist-based placements can also provide opportunities to learn about the role of secondary care in, for example, the management of serious long-term conditions, it is insufficient for comprehensive training because primary and secondary care working environments are fundamentally different. Increased specialisation in hospital paediatrics makes a broad generalist paediatrics experience more difficult to achieve in hospital.

GP training as currently delivered is not meeting the outcomes required by the RCGP curriculum and the RCPCH. Discussions between the two Colleges are in progress to introduce a system to exchange professional expertise between GPs and specialist paediatricians leading to joint opportunities for CPD and accreditation.

An integrated training curriculum and the current proposal by the RCGP for an extended period of training from three to four years would ensure that GPs have the required skills and confidence to be proficient in dealing with sick CYP.
Chapter 9

Health inequalities

Most health professionals will be familiar with Julian Tudor Hart’s inverse care law, which states ‘the availability of good medical care tends to vary inversely with the need for it in the population served’. Tudor Hart was a pioneering GP who understood that his responsibility was to his population, and not just to the patients that presented to him. While Tudor Hart’s work in a Welsh mining village is a model for a community-based approach to reducing health inequalities, today’s GPs and nurses face greater barriers to achieving that kind of personal engagement with their populations. However, modern GPs have more tools at their disposal to address health needs. The RCGP’s guide Addressing Health Inequalities still rings true: ‘Primary care is innovative in its ways of working and has unique access to the heart of communities.’

Many conditions and health problems continue to disproportionately affect more deprived communities, a fact made explicit by Sir Michael Marmot’s review of health inequalities in England, published in 2010. This is particularly apparent with children. At Reception year, 12.6% of children in the poorest decile are obese, compared with 6.8% in the most affluent decile. This is starker still at Year 6, where 23.6% of the poorest and just 12.8% of the richest are obese. The Marmot Review offers both an excellent grounding in the evidence but also includes recommendations pertinent to clinicians and commissioners, with the intention of achieving two of the review’s objectives: to ‘give every child the best start in life’ and ‘enable all children, young people and adults to maximise their capabilities and have control over their lives’.

HWBs offer an excellent forum to coordinate a multi-agency response to population health needs, with a targeted approach to vulnerable communities where necessary. The importance and long-term cost-effectiveness of early intervention has been highlighted by MP Graham Allen’s review, and primary care is well placed to deliver this in collaboration with other agencies, working in multidisciplinary teams, drawing on the knowledge and expertise of health visitors and school nurses (see Chapter 5).

In 2010 the King’s Fund produced a report as part of its independent inquiry into the quality of general practice, which looked at the steps that GPs could take in addressing inequalities. This highlighted the shift in culture needed in primary care towards greater awareness of the need to address inequalities, both in terms of the inverse care law and everyday clinical practice. The report recommended using GPs’ demographic data and community knowledge to intervene opportunistically to address inequalities in their local area.

Any approach to addressing health inequalities must be based upon good-quality data. Public Health Observatories are being integrated into Public Health England, where they will continue to be an excellent source of detailed intelligence about the health profiles of local populations. Similarly, the expertise of public health colleagues will be important to harness, both through their involvement with HWBs and as commissioning support and advice. This data profiling and their detailed knowledge will help to provide a base for an evidence-based strategy that is able to provide care and health promotion advice for those that most need it.

The health workforce and health inequalities

The Institute of Health Equity at University College London, set up following the Marmot Review, is at the time of writing currently producing guides for different medical specialities on addressing health inequalities. Their initial report on The Role of the Health Workforce in Tackling Health Inequalities highlights good practice across the UK, with their primary care examples including multidisciplinary primary care teams in deprived areas of London. This includes Great Chapel Street in Westminster, which provides comprehensive health services including psychiatric and dental care to homeless people (see www.greatchapelst.org.uk). The following chapter outlines the challenges of providing care for children who are unregistered with GP practices, including the young homeless.
Chapter 10

Non-registered families

Children in families who are not registered with primary care may present a particular problem to GPs. How to assess, commission and deliver for members of the local population who do not present or are transient requires considerable skill and knowledge. Nonetheless, it is not an insurmountable challenge for the primary care clinician who knows his or her community and the issues that may fall outside the usual caseload. In terms of children, three groups that may fall into this category are asylum seekers, Gypsy Travellers and the homeless young.

The health needs of asylum seekers are complex and intertwined with a system that is difficult for users to navigate, alongside a number of language and cultural barriers. As a result of their experiences in their home countries, they may be particularly vulnerable to mental distress. The underlying principle is that refugees and asylum seekers are entitled to all NHS services. While DH guidance says that failed asylum seekers should not be registered in primary care, GP practices currently have the discretion to accept applicants as registered NHS patients. A best-practice principle may be to register all groups. More information is available to clinicians and commissioners with concerns from the Refugee Council and other voluntary organisations. Primary Care Commissioning also provides guidance for GPs on the entitlements of overseas visitors to primary health care.

Gypsy Traveller groups are a second group that typically have poor access to primary care. The size of this population group is difficult to accurately gauge, with estimates varying between 180,000 and 300,000 in the UK. The Department for Communities and Local Government (DCLG) reports that there are 5100 Gypsy and Traveller caravans in England as of January 2012. Although there are sites across the country, they are particularly concentrated in the east and southeast. Figure 3 gives some indication of the distribution of these communities throughout England.
On basic indicators of mental and physical health as life expectancy and anxiety or depression, Travellers have worse outcomes than less transitory communities. From a child health perspective, studies suggest high infant mortality and perinatal death rates, low birth weight, low immunisation uptake and high child accident rate. This general poor health is attributed to a combination of three factors: poor accommodation, poor access to education and health, and discrimination.

In terms of access to both of these groups, health visitors and school nurses, as a universal service, are essential in ensuring that these hard-to-reach groups are engaged in primary care and their health needs are met. GPs need to be sensitive to the health issues of these vulnerable communities and work with their associated health professional colleagues to plan appropriately.

Homeless CYP are another vulnerable group who have complex, heterogeneous health problems. Homelessness is unlikely to be an one-off or isolated incident; studies show that it is frequently linked to family breakdown, violence, unemployment and poverty. The homeless young are also highly likely to have mental health problems, including anxiety and depression. The voluntary sector often plays a key role in providing basic care to homeless people and supporting them to access health services. CCGs will need to work closely with Local Authorities when planning innovative approaches to address the needs of homeless children, through the work of outreach programmes and targeted interventions.

The DH produced a useful guide to provision of primary care services to excluded groups in 2010, called *Inclusion Health: improving primary care for socially excluded people*, which, while mostly directed at adult populations, contains guidance on how effective commissioning can help hard-to-reach groups.
Chapter 11

Adolescence

Adolescence has been described as ‘one of the greatest challenges facing paediatrics – and indeed the health services’ – this century.78

We know that there are high rates of young people consulting their GP.79 Around half of Year 10 pupils (14–15-year-olds) had visited their GP in the three months preceding a recent survey but 25% of the girls reported feeling uneasy.80

Patterns of health-seeking behaviour begin early in adolescence and the seeds are often sown for subsequent health-seeking behaviour. It is important that young people know what they can consult their GP and practice nurse about and that practices are welcoming.81

Our understanding has increased of the importance of respect and confidentiality, and of CYP feeling listened to and heard in the privacy of the consultation. The ‘You’re Welcome’ campaign has set us standards of access, confidentiality, appropriate giving of information and ways of communicating.

Adolescence is a time of profound change from childhood to adult life, characterised by physical, psychological and social changes in preparation for adult life. A prevailing theory of adolescent development is that the brain and psychological development that continues through puberty into early adulthood results in a highly adaptable but exquisitely sensitive human being. The adolescent is perfectly suited to the transition to adulthood but also vulnerable to disorders of mood and emotional wellbeing (for example eating disorders, depression, anxiety, self-harm, fatigue and somatoform disorders), and prone to risks in the physical and social environment (injury, weapons, sexually transmitted infection, alcohol, drugs and teenage pregnancy). Although 80% of young people show remarkable resilience in ‘weathering the storms’ of adolescence, 20% do not do so well.

We face specific challenges in the UK with regard to high rates of sexually transmitted disease, self-harm and suicide, alcohol use and obesity amongst young people. Rates of underage conception remain high when compared with other countries of similar income, although teenage pregnancy on average fell to the lowest level in 2009 (although there is local variation). Stress-related and mental health issues have increased. Health inequalities and experiences of racism remain real obstacles for many young people.

Case history

A 13-year-old presented with a four-month history of recurrent headaches. There were no features to suggest an underlying cause and the consultation also identified that he was severely obese and that he had not been in school for almost nine months after the sudden, unexpected death of his mother. He had moved to live with his father and had fallen into a pattern of low mood, low self-esteem, emotional overeating and poor diet, lack of exercise and excessive screen use. He frequently argued with his father about school attendances and his father was unable to cope and left him to his own devices. After screening for medical complications of obesity the young man was referred to a youth worker who used a local youth group to establish regular peer socialisation along with working individually on issues of bereavement, self-esteem and motivation. The youth worker established liaison with the father, the school and the educational welfare officer. The young person returned to school, his headaches have resolved, he is eating healthily and exercising. He has lost a significant amount of weight and established a memory book to celebrate his mother’s life and their relationship. His relationship with his father is re-established and he is now acting as a peer mentor for new members of the youth group. He wishes to pursue a career as a chef and is receiving support from school to realise his ambition.
Commissioning a good child health service

Commissioning services for young people that address the physical, psychological and social needs within a multidisciplinary framework and close integration with education and the voluntary sector are most likely to address the health needs of young people. They will have long-term effects on the development and deployment of social and economic capital.

Transition for children and young people

The transition from childhood to adulthood involves a transfer of health responsibility from the parents/carers to the young person and is a time of particular vulnerability for young people with long-term conditions. All young people will transfer to adult-oriented services whether they have a long-term condition or not. As a universal service for all ages, the GP is a key partner in the process of transition.

However, parents report a ‘postcode lottery’. Those with high levels of need will require more specific arrangements through multi-agency panels, case conferences and care planning, reviewed yearly as a minimum. There also needs to be regular monitoring and review of the systems involved. An obvious target for improvement is the ‘alignment’ of services across transitions – for example integrated teams ‘without walls’ in adult neurology and metabolic services to make them accessible by young adults, or adult mental health and learning disability services ensuring young people are not ‘lost’ at a crucial stage of their lives. Another is that in the past families and patients have looked only to secondary care for support; they need to feel that GPs are on their side too, seeking them out and working with them and other professionals and agencies. This could include advocacy for innovative services.

As a key partner in the process of transition the GP has a responsibility to:

- advocate for young people to establish their independence within the healthcare system – the young person could ‘re-register’ with the practice as they move to adulthood
- provide continuity and consistency for the young person, i.e. seeing the same GP rather than lots of different ones
- pay attention to health promotion such as sexual health, mood, eating and exercise, smoking, alcohol and substance use
- see the young person without their parents/carers and being explicit about the confidential nature of services
- undertake a role in enhancing motivation and self-management, for example through brief interventions or suggestions regarding practical aspects of care collection of repeat prescriptions
- act as an informational hub as the locus of care moves within the wider health system.
Chapter 12

Recommendations

This report is timely through its delivery of recommendations at the birth of new commissioning structures and with the launch of the report of the Children and Young People's Health Outcomes Forum. One of the key questions the report asks is ‘How will children, young people and their families have the confidence that the system will deliver for them?’

In recognition of this paper being the first in a series addressing the steps needed to assure confidence in the system, it is a fundamental requirement that the voice of the patient is acknowledged and is a common thread throughout the document.

Context

Recommendations for commissioners

Children will become the future adult population and not attending adequately to their health, particularly prenatally and in the early years, will prove vastly resource intensive in the future and will increase health inequalities. To ensure such systemic failure does not happen, we recommend that the many measures required on the commissioning of services for CYP, set out in the report of the Children and Young People's Health Outcomes Forum, are addressed.

Child healthcare service requirements are not synchronous with geography or size of health authority. They will not only require multi-professional working but also a network of services throughout a region in order to tackle prevalent issues and provide value for money. Commissioning of services should not therefore be addressed in isolation but rather as part of a national and regional strategy.

Recommendations for practitioners

Review whether all practice staff (including GPs) have the required knowledge, skills and competencies to fulfil their roles and carry out their responsibilities. Monitor and evaluate the service provided.
Collaborating in care

Recommendations for commissioners
Collaboration is key to providing child-centred care. A useful question to ask is ‘How could having a more collaborative attitude help us provide better care for CYP?’

Recommendations for practitioners
We need IT systems and processes that more efficiently link all aspects of GP responsibilities with the child’s or young person’s journey. Useful questions for a practice to ask include ‘Does the practice provide both information and a strictly confidential service for young people?’ ‘How well do we fulfil the “You’re welcome” criteria?’

We need to ensure that our communication systems with health visitors and school nurses are efficient and effective. Checks on immunisations and development demand a lot of time and effort, but can be done opportunistically. Other useful questions include ‘Who in the practice team takes responsibility for catching up with immunisations and the 6–8 week baby checks?’ ‘Can we offer space for school nurses to consult after school or other innovative services for our CYP?’ ‘Are practice nurses aware of the Healthy Child Programme and their role?’

We need to be able to recognise parents with problems of their own, such as drug or alcohol use, mental health problems or domestic abuse, and respond to those needs, knowing that the children and teenagers might be affected by their parents’ difficulties.

Mental health

Recommendations for commissioners
Commissioners should be aware of the Four-Tier Strategic Framework for mental health services and commission services correspondingly.

Recommendations for practitioners
Practitioners should be familiar with the Tier 1 framework that guides practitioners.

Safeguarding

Recommendations for practitioners
Ensure that all GPs and nurses in the practice are aware of their safeguarding responsibilities and are trained to the levels specified in the Intercollegiate Guidance as appropriate to their organisational roles.  

Ensure practitioners are aware of their responsibilities towards all CYP, including looked-after children, and incorporate relevant education into their professional development plans.

Place emphasis on practitioner teams working towards improving outcomes for all children, including looked-after children:

- recognise, assess, plan and provide for children in need of support and/or safeguarding and parents who may need extra help in bringing up their children
- contribute to serious case reviews, Child Death Reviews and to enquiries about a child and family
- participate in child protection conferences.
GP/team competencies and training issues

Recommendations for practitioners
Informal training opportunities should be commissioned. Staff should maintain their skills and have the opportunity to do so. Multi-professional staff engaged in all aspects of children’s health care should receive safeguarding awareness and training at levels 1–6.

Health inequalities

Recommendations for commissioners
All CCGs should work with their local HWBs and use the JSNA to identify and commission appropriate interventions with particular at-risk communities. GPs and CCGs should take an opportunistic and holistic approach to health inequalities, using this information and these partnerships to address the inverse care law and provide and commission services where need is greatest.

Recommendations for practitioners
All GPs should familiarise themselves with the Marmot Review, the RCGP’s publication Addressing Health Inequalities, and their local data about their population’s CYP from ChiMat, to establish the particular health issues prevalent in their constituency.

GPs need to be flexible in appointment booking for members of at-risk and deprived communities.

Non-registered families

Recommendations for commissioners
GPs and CCGs should liaise with the local HWBs to coordinate appropriate health and social care support for non-registered families in their area.

CCGs and the NCB have a dual responsibility to ensure patients are registered and those who are not registered have primary care service available to them.

Recommendations for practitioners
GPs need to familiarise themselves with DH and British Medical Association guidance on treating asylum seekers where appropriate. With all non-registered patients, GPs should take an opportunistic approach to their health care, with flexibility in the appointment system and a particular emphasis on the rights and health of the child or young person.

Adolescence

Recommendations for practitioners
Meet with young people around birthday times for review. Re-registration with the practice around their sixteenth birthday would provide an opportunity to see the young person alone, reiterate the range and confidential nature of services provided by the practice, undertake a reappraisal of the transition process and undertake health promotion with particular regard to young people’s health issues.
Appendix 1

Embedding the principles of good communication, collaboration and information sharing into the integrated care model

These principles should apply to each and every step of a child’s or young person’s journey along the pathway. Practitioners and commissioners should ask:

- is there an overall lead professional for the coordination of the care of the child or young person?
- who is supporting and leading each step of the child or young person’s journey?
- has the child or young person and his or her family been involved in the design of the pathway?
- have all methods of communication met the cultural needs of children or young people and families?
- have the needs of vulnerable groups of children or young people and their families been addressed including travellers or asylum-seeking families who may not be registered with a GP?
- which professionals are involved and at what stage in the pathway, for example GP, paediatrician (general, community, specialist), emergency clinician, obstetrician CAMHS, health visitor, GP practice nurse, community children’s nurse, specialist children’s nurse, school nurse, allied health professionals, partner agencies?
- how is information shared between respective professionals and are other professionals, if required, aware of this shared information, for example face to face, written reports, hand-held records, telephone consultation, email, teledicine, links to websites, evidence-based information complying with ‘You’re Welcome’ or web links to ‘self help’ groups?
- how is this information shared with the young person and family by the respective professionals? Are all of the professionals aware that this information has been shared with the young person and family?
- do IT systems across organisational boundaries permit information sharing between professionals and with children or young people and their families where required?
- is confidentiality for the young person concerned addressed in all processes of communication?
- does the child or young person and his or her family know whom to contact during the normal working day and out of hours during the weekday and at weekends?
- do professionals in training get the opportunity to learn best practice from communication processes?
- is information and data shared with national registers and databases as appropriate?

It is important throughout to be aware of what constitutes maltreatment. There is new GMC guidance and recommended codes (see www.clininf.eu/maltreatment).

Information sharing

Is there an overall lead professional for the care of the child or young person and on the handover systems to other professionals?

- Is it clear to the child or young person and his or her family when responsibility and accountability is transferred on the child’s or young person’s journey at each stage in the pathway from one professional to another? And is this made explicit to all of the professionals involved?
- Where and when is information shared?
- Are these resultant actions shared in a timely way with the child or young person and professionals involved, and documented in the child’s or young person’s care plans?
- Is information sharing conducted, for example, in a face-to-face way, by telephone, by letter, by email or by teledicine?
• Who is present during information sharing and what are their roles and responsibilities?
• Is the child or young person and family, where required, involved in the sharing of information, for example at a multidisciplinary team meeting?
• Does the child or young person receive clear information about who is in charge if a change of professional or organisation is made?
• Are the IT systems robust enough to have effective information sharing?
• Are information-sharing systems effective out of hours on weekdays and at weekends?
• Do information-sharing processes respect patient confidentiality?
• Are the cultural needs of the child or young person and his or her family met through all information-sharing systems?
• Do professionals in training get the opportunity to learn best practice from information-sharing processes?
• Are information-sharing processes evaluated against standards with feedback mechanisms for service improvement?
Appendix 2

Examples of pathways for complex needs, the vulnerable child and transition to adult services

A young person with severe persistent eczema is referred to the paediatrician by GP. He or she is given a treatment that is licensed for prescription by a paediatrician who has the appropriate knowledge and competencies (via appraisal process). The paediatrician wants to share care with the GP and so he or she clarifies in the letter how long each treatment is given for, and if the GP is happy to continue monitoring the patient on the specialist treatment. In order for the GP to monitor this treatment, the specialist provides evidence-based guidelines and includes information on what to look for with respect to side effects. The specialist provides advice on mechanisms to refer back if required and why a referral has been made to someone else. There is also a request to the GP or family to let the specialist know if they not happy with the plan, or if any further questions need to be addressed. The young person and family are copied into all correspondence and provided with the necessary information sheets. If other professionals such as the community children’s nurse, school nurse or health visitor are copied in to correspondence, the specialist makes it clear what he or she is asking them to do.

Transition from paediatric to adult secondary care

Transition for those with a long-term condition is a complicated psychosocial process as the young person moves to taking responsibility for care while facing the usual challenges associated with adolescence. Long-term conditions may impact upon educational and vocational achievement, establishing relationships and having a family, economic wellbeing, self-esteem, emotional wellbeing, mental health and life expectancy. CYP with long-term conditions will have developed a close and trusting relationship with paediatric medical and nursing specialist teams; careful preparation and support is required to ensure that they and their families are enabled to cope with the expectation of self-management and care usual in adult services. There are some paediatric services where no equivalent adult service exists and there are some long-term conditions that are so rare they fall outside adult service configurations.

‘Transition and continuity’ and ‘concern for family and friends’ are two of the eight important markers of patient-centred care identified by the Picker Institute.84 Others include:

- continuing support for friends and family members as caregivers and ‘advocates’
- involving the patient (child or young person) in decisions about his or her care, and enabling self-care through developmentally appropriate information about medicines, diet and physical needs
- planning and coordination of ongoing treatment, equipment supply and social care across different departments, agencies and professions, and ensuring the patient and his or her family understand
- ensuring that social as well as physical and psychological transitions are addressed. Successful transition services pay attention to social transitions such as:
  - peer education and support and socialisation
  - liaison with education
  - vocational opportunities and careers advice
  - participation and involvement in service design and delivery
  - modelling good self-care and healthy lifestyles
  - money management, budgeting and benefits support
  - giving information about continuing access to clinical, social, physical and financial support (for example personal budgets).
Ensure adult services are commissioned and prepared to receive young people. Services should provide an appropriate environment and information for young people and their families, with providers skilled in young people’s health as well as the long-term condition. Commissioning should incorporate the views of children, young people and their families who have travelled the pathway through paediatric to adult services.
Appendix 3

Principles of good care

- Swift and accurate diagnosis (including paediatric expertise as required).
- Consistency of approach to meet professional standards and concerns dealt with effectively.
- A focus on the right quality of care as close to home as possible, with attention to physical and environmental needs.
- Surveyed experience reports of families being satisfied.
- Clarity of costs, resources and benefits.
- Involvement of and continuing support for friends and family members as caregivers and ‘advocates’.
- Involving the patient (child or young person) in decisions about the future as much as possible, respect for preferences, and enabling self-care through comprehensible information about medicines, diet and physical needs.
- Emotional support, empathy and respect.
- Continuity of care and smooth transitions.
Appendix 4

Key definitions and terminology

Integrated services

There are a number of definitions of integrated care. For example, the RCGP defines integration as ‘patient-centred, primary care-led care with multi-professional teams where each profession retains their professional autonomy but works across professional boundaries, ideally with a shared electronic clinical record’.

When applied specifically to the care of children, it refers to a framework of CYP’s services across service and professional boundaries, through which a child or young person and his or her parents or carers can move ‘seamlessly’. This involves:

- agreed ‘pathways’ of care with separate expert teams fulfilling different roles along the pathway
- no rigid separation between primary and secondary care
- sharing between GPs and other agencies (and vice versa) of children’s services
- an active CYP section of the HWB.

The child’s journey

The ‘journey’ is a child’s experience from needing help to receiving it. This is not only in early intervention for child protection, but also includes all of a child’s contact with professionals, as described by Eileen Munro’s interim report The Child’s Journey (2010).85

Pathways of care

A pathway is an algorithm of care, where different contributors work flexibly with the child or young person at the centre. Examples include:

- Children’s and Young People’s Urgent and Emergency Care pathway
- ACT’s care pathway for CYP with life-limiting conditions.

Communication

This is one of the most important aspects of the practice’s relationship with the child or young person, most especially in the consultation itself. The GP and practice team should be accessible, competent, involve the child or young person in decisions about his or her care, keep confidentiality, respect needs and preferences, show continuity and help negotiate transitions. All of these aspects require good communication skills. See the GMC’s 0–18 Years: guidance for all doctors.28

Consent and capacity

These are linked and will determine how involved and to what degree the child or young person can be responsible for decisions about their care. The child or young person’s opinions should always be sought, even if it is difficult because of communication or learning disorders (see sections 24–32 of the GMC’s 0–18 Years: guidance for all doctors).28
Health and Wellbeing Boards

These are statutory boards with a collaborative function. They are well placed between the Local Authority and CCGs to have a coordinating role, particularly services for CYP. We recommend active participation and engagement with the HWB, and for the director of children’s services to have a place on the board.

Informatics

These provide essential tools for collaboration in care, including in:

- sharing decisions with a patient – information given to and held by the child or young person and his or her parent or carer
- recording, and coding of concerns that can be viewed by others with access, including the patient
- reflection and learning, including audit and quality improvement.

*Examples of informatics tools*

*Summary Care Record*

In participating practices, annotations and, particularly, medication, can be viewed in other health contexts. This has not yet been implemented in all areas. The promise is for patients to be able to view their records by 2015.

*Digital information for parents*

The Department of Health created a new initiative in May 2012 designed to inform and remind parents and carers of babies’ and young children’s needs through the ‘Foundation Years’.86

*Digital discharge summary*

A GP will receive an agreed summary on the child’s discharge from hospital.
References


43 Royal College of General Practitioners, Royal College of Nursing, Royal College of Paediatrics and Child Health, College of Emergency Medicine. *Right Care, Right Place, First time?* London: RCPCH. 2011.


70 Refugee Council, www.refugeecouncil.org.uk/.


