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The future of child health services: new models of care

Briefing

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About this briefing

Different services and models of care for children and young people have been emerging around the UK, both within the Vanguard scheme and inspired by it. These models are emerging in response to a series of problems in current services for children and young people. This briefing describes the current state of child health and quality of care in the UK and how the emerging models are responding to these issues. The briefing is based on a 2015 Nuffield Trust workshop that brought together frontline clinicians, service users, commissioners, representatives from new care models and a range of other stakeholders. The briefing draws on presentations, discussions and materials submitted by delegates at the workshop, and other published literature.

'The future of...' series

Breaking down the traditional boundaries between primary care, community services and hospitals is vital if health and social care services are to be integrated around the needs of patients and service users. Doing so will require a move away from single institutions towards a systems-based approach organised around networks of care. This briefing is the first in a new series by the Nuffield Trust investigating the future of service delivery in various specialisms within the health service.

Acknowledgements

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We would also like to thank everyone who presented and attended the workshop.

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Key Points

- Child health has changed – over the last 45 years mortality data show an epidemiological transition away from acute infectious illness towards chronic long-term conditions. But the way health care services are provided is still heavily hospital focused and reactive. There are serious concerns about child health outcomes and the quality of care children and young people receive. Children and young people should receive at least the same level of attention and quality of care as adults.
- New models of care have tended to focus on adults. However, a variety of different models of children's health services have emerged over the last few years. These models offer different ways of managing the needs of children and young people with acute and chronic conditions. However, there is a lack of understanding of how they work and whether they could lead to an improvement in quality of care and health outcomes for children and young people.
- These new models of care have emerged in response to a series of problems in the current services for children and young people, in particular: the increasing use of hospitals to treat conditions that could be dealt with in other settings and related financial pressures; primary care being under severe pressure in terms of capacity, confidence, knowledge and skills; the often disjointed care provided between hospitals and the community, as well as other non-health services; and dissatisfaction amongst children, young people and their families.
- Common features of the new models of care that are emerging include: having a focus on understanding the needs of different sections of the child population and their families, and organising care to meet these needs; strengthening early and easy access to appropriate expert paediatric assessment in the community; understanding how children and their families use the health system, helping them use it more effectively, and actively working with them to design and improve the quality of services; making more of the range of community settings in which health care and wellbeing can be provided; encouraging early, proactive intervention; improving communication between primary and secondary care services; and addressing the wider needs of children and their families by working in multidisciplinary teams and joining up health records.
- An 'ideal' child health system is one: that understands children, young people and their families' specific needs (including the broader determinants of health) and is designed to address them; where there is access to high-quality paediatric and child health expertise and multidisciplinary teams in the community; that has linked-up timely information, communication, data and care (different forms of integration) to allow for continuous quality improvement; and where health literacy and education for children, young people and their families, as well as professionals, is prioritised.

1. Background

Despite significant improvements in child health in recent decades, children and young people (CYP) in the UK have poorer health outcomes than those in other comparable countries and large inequalities persist; there is also large variation in the quality of CYP health care services provided across the UK (Department of Health, 2013a). Over the last 45 years, mortality data show an epidemiological transition away from acute infectious illness towards chronic long-term conditions; however, the way services are provided is still heavily hospital focused and reactive.

Children have the right to the best health care possible (UNICEF, 1989), including good quality health services and the optimisation of determinants of health. The Marmot Review in 2010 highlighted the importance of giving children the best start in life to improve health and wellbeing, and reduce inequalities (Marmot, 2010). In this context health care services are only one of the many determinants of CYP's health outcomes. Also in 2010, Professor Sir Ian Kennedy undertook an independent review and highlighted: how services for CYP are currently a low priority in the NHS; that national and local policies around children's welfare need to be brought together; the need to reconfigure services, which would move away from the GP acting as a gatekeeper; the need to promote positive health; the gaps in good information and data; and how professionals could work differently to break down barriers (Kennedy, 2010). His review and a series of national clinical audits (Healthcare Quality Improvement Partnership, 2013; Royal College of Physicians, 2014) put the spotlight on problems in the quality of services delivered to CYP, including: the lack of paediatric expertise amongst GPs, leading to the use of accident and emergency (A&E) instead; lack of coordination between health services and education; and problems related to the transition of care to adult services (Kennedy, 2010).

In response to these challenges, in 2012 the Secretary of State for Health launched the Children and Young People's Health Outcomes Forum to inform a new strategy for improving health outcomes and health care for CYP. Through engagement with around 2,000 CYP, the forum identified poor outcomes and variation across the country, and made a number of recommendations for improvements (Lewis and Lenehan, 2012).[1] A system-wide response was put together which focused on early intervention and integration, safety and sustainability, and workforce training. Examples of this include: expanding the health visitor workforce; a focus on the wider determinants of health, wellbeing and resilience; improving diet and exercise through engagement in schools; the setting up of an integration board for CYP; and an integrated health and education review for 2–2½ year olds (Department of Health, 2013b). Highlighting the strong evidence for a life-course approach and the need to improve services for CYP, the 2012 Chief Medical Officer's report also provided a series of recommendations, reflecting those made by the Kennedy review (Department of Health, 2013a).

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[1] The recommendations were: putting CYP and their families at the heart of what happens; acting early and intervening at the right time; integration and partnership; safe and sustainable services; workforce, education and training; knowledge and evidence; leadership, accountability and assurance; and incentives.

Many of the key principles we set out in this briefing have already been called for previously (Aynsley-Green, 2008; Clements, 2013; Department of Health, 2013a; Kennedy, 2010; Lewis and Leheman, 2012; Marmot, 2010; NHS Confederation, 2011a; 2011b; 2012). For example, recently the Royal College of Paediatrics and Child Health, with the Royal College of General Practitioners and Royal College of Nursing, produced 'Facing the Future' standards that outline quality standards for mild to moderately unwell children. The 11 standards cover supporting primary care, safely reducing hospital stays and connecting the whole system (Royal College of Paediatrics and Child Health and others, 2015). Our research finds that most of the recommendations from these reports have not yet been implemented. And, it is important to note that some of the same issues were already being highlighted as long as 40 years ago (see Box 3 on page 9).

Box 1: Examples of why children's services need to be different to services for adults

- Children differ from adults in at least four important ways: 1) developmental change; 2) dependency on parents and other carers; 3) differential epidemiology (e.g. different health, illness and disabilities); and 4) demographic patterns (e.g. socio-economic determinants) (Forrest and others, 1997).
- Children's use of health services is different to other age groups, for example the rate of acute, short-stay hospital admissions in children is higher, and rising (Saxena and others, 2009).
- Children may need to be transitioned from paediatric to adult services, and have constantly changing needs in relation to their developmental stage and age (Wolfe and McKee, 2013).
- Education is especially important, rather than social care, and there is a greater dependence on the family than social care, compared to adults (Wolfe and others, 2016).
- There is an opportunity to prevent physical and mental ill health in adult life by improving the health of CYP (Marmot, 2010).

Consideration of children's services is limited in current national policy. NHS England's strategic plan has few explicit priorities for children and, other than mental health, child health is not explicitly incorporated into the most recent NHS Business Plan priorities (NHS England, 2013; 2015) – although CYP's needs can be addressed through all of its ten priorities. The NHS Five Year Forward View (NHS England, 2014) encouraged new models of care to be developed but, aside from some aspects of prevention, most do not focus on children. Policy-makers may prioritise other services, such as elderly care, before child health services, resulting in cuts in child health services and increases in child poverty (Taylor-Robinson and others, 2014). Given that reports such as the Five Year Forward View have encouraged the development of new models of care, there is a mandate for new models of care for CYP as well. Different services and models of care for CYP have in fact been emerging around the country, both within the 'Vanguard' scheme (NHS England, 2014) and inspired by it.

This briefing starts out by describing the current state of child health and quality of care in the UK, what continue to be the most pressing issues in child health services, and how the emerging new models of care are responding to these issues. The key principles of an ideal model/system for CYP are then presented. The briefing is largely based on a workshop run by the Nuffield Trust (see Box 2), as well as on presentations, discussions, materials submitted by representatives of the new models of care who attended the workshop, and published literature.

Box 2: Nuffield Trust workshop on new models of care for CYP

A Nuffield Trust roundtable workshop ('New models for delivering health services in the Five Year Forward View – what about the children?') held in September 2015 brought together frontline clinicians, researchers, service users, commissioners and policy-makers to better understand new models of health care services for CYP. The focus of the event was on primary care and the interface with secondary care, as evidence suggests that is where services are not currently managing to meet the needs and expectations of CYP and their families – there is a lack of capacity to provide rapid access to high-quality care in the appropriate setting.

A distinction was made between the clinical needs of CYP, and the broader needs of children and their families that would be addressed by other professionals. The main focus of the discussion was on the clinical needs, not because the broader social determinants are not important to address, but rather because participants felt that, at present, even the basic clinical needs of CYP are not being met appropriately.

Participants were asked to think about why new models of child services have emerged, what they are doing and why they may be better than the current service provision, as well as to consider the future direction of child health services. Overall, the aims of the workshop were to:

- understand what new models are emerging and why they have been developed
- understand their strengths and weaknesses, and how they measure their success
- share knowledge about these new models and decide how to move forward given the current context and national thinking on these issues.

The findings of this briefing are aimed at people working in local authorities, clinical commissioning groups (CCGs), non-health organisations that work with children, high-level policy-makers and other child service providers. It does not provide a comprehensive description of all the models of child health in the UK.

Box 3: What has changed since 1975?

Bridging in Health: Reports of studies on health services for children
(Brimblecombe and others, 1975)

This 1975 report considered changes to child health services in response to NHS reforms. Many aspects of child care have changed since then and some of the issues identified have been resolved, for example by the creation of community paediatricians who provide continued care for children with complex conditions, and the increased power of information systems to meet demands. However, 40 years on from the report, many of the same problems remain. The NHS reorganisation of 1974 in part focused on partnership building between child health specialists across sectors. It recommended 'health care planning teams', consisting of health professionals, education professionals and social workers who would plan services to meet the needs of patients and integrate health care in the community, hospital and at home. The report undertook surveys of health professionals and health care users to look at the gaps in hospital and community services, and ways to fill these.

The divide between hospital and general practice in health care provision was identified as the main problem. A lack of training in preventive care by all and an absence of hospital paediatricians in primary care were also identified. Consultant paediatricians were not perceived to be adequately considering all the emotional, educational, family and social problems that children may have.

Recommendations from the report:

- Improvements in training in preventive child care work, psychiatry and in community services.
- A primary health care team (including a GP and health visitor) to assume greater responsibility for the preventive aspects of child care and greater partnership working between child health and social services.
- Paediatric specialisation for preventive and curative work for children in general practice.
- Improved communication with community health services and the need to create data systems that work across sectors.

2. Case for change – health outcomes and quality of care

How have child health outcomes changed over time and relative to other countries?

While most CYP are healthy most of the time, an important proportion of them suffer from chronic conditions (Wolfe and others, 2016) – hence their needs and the models of care to address them are different. Mortality from all causes – injuries, communicable (infectious) and non-communicable diseases – has been declining over time and, today, mortality from non-communicable diseases rather than infectious diseases remains the largest cause of death for all children (Wolfe and others, 2014). So while the needs of children in the UK are not the same as they used to be in the 1970s, the health care services and the workforce providing for CYP are still largely tailored towards addressing their acute needs. Service organisation should be adapting to this epidemiological change (Wolfe and others, 2013). The increased long-term survival of children with complex disabilities also means that appropriate care needs to be in place to support them. While for adults and older people where multiple co-morbidities are common, it is the interplay between health and social care services that is more important; for CYP there is a greater reliance on the family and the education sector (Wolfe and others, 2016).

In the last 40 years the UK has fallen behind other comparable countries where mortality in CYP has declined more quickly (Viner and others, 2014). Despite large variation between regions, the UK has not managed to achieve the same reductions in infant mortality as similar[1] Organisation for Economic Co-operation and Development (OECD) countries and continues to be one of the worst performers (see Figure 1), as well as in under-five mortality (Institute for Health Metrics and Evaluation, 2013). Only recently, an announcement was made by the Secretary of State for Health, Jeremy Hunt, about working to reduce the rate of stillbirths, and neonatal and maternal deaths in England by 50 per cent by 2030 (Department of Health and The Right Honourable Jeremy Hunt MP, 2015). While this announcement is welcome, most preventable stillbirths in the UK are due to smoking, obesity, diabetes and alcohol, and are influenced by poverty, deprivation and income inequality, and there are serious concerns related to this about the recent cuts in public health funding (Tennant and others, 2015)

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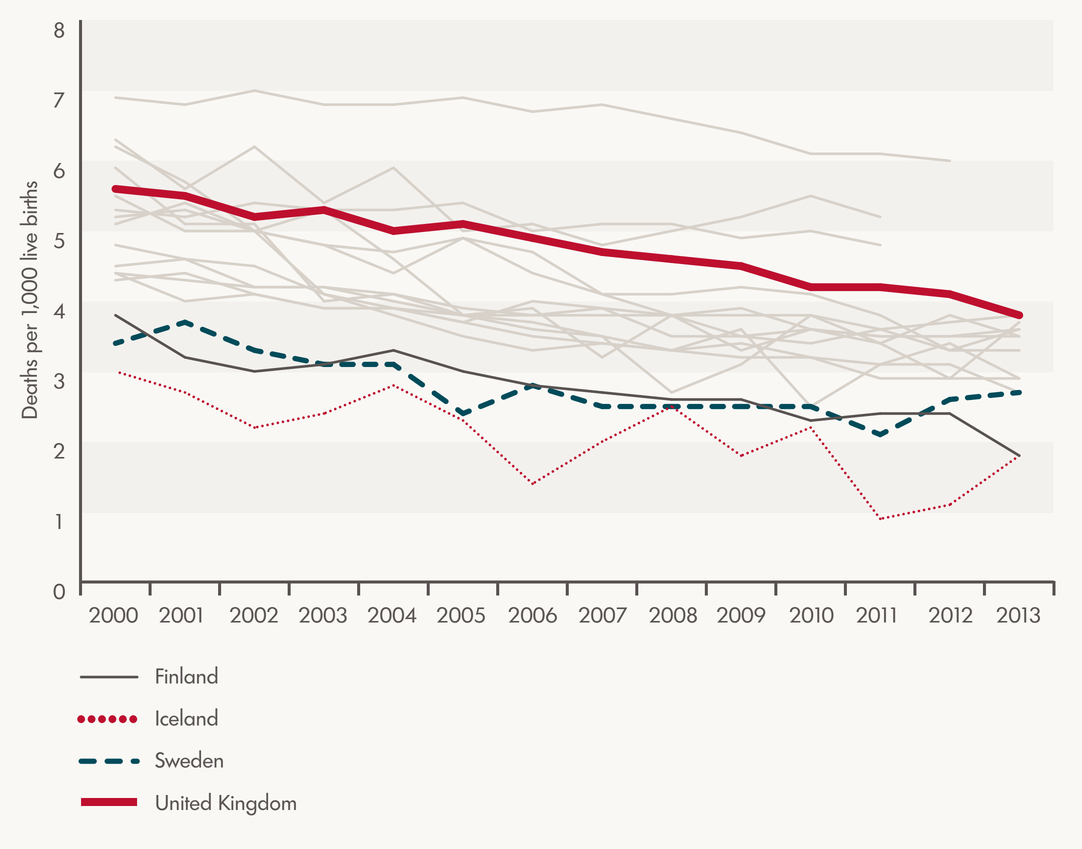
[1] Similar is defined as: i) similar Western European country or similar level of economic development; ii) minimum population of ten million people; iii) similar type of health system to the UK; iv) historically relevant or best performer. 'Similar' countries include: Australia, Belgium, Canada, Finland, France, Germany, Greece, Iceland, Ireland, Italy, the Netherlands, New Zealand, Portugal, Spain, Sweden and the US (Kossarova and others, 2015).

Figure 1: Infant mortality rates in comparable countries, highlighting the best performers and the UK



Source: Organisation for Economic Co-operation and Development, 2015

With respect to morbidity as measured by disability-adjusted life years (DALYs)[1] per 100,000, based on data from the Global Burden of Disease study (Institute for Health Metrics and Evaluation, 2013), for children under the age of five, the UK continues to perform poorly compared to similar countries (see Figure 2). However, in the older age groups, where there is also less variation between countries, the UK does well and has the lowest DALYs per 100,000. In 2013, in the UK, the largest burden of disease for children under the age of five was due to preterm birth complications (26 per cent) and congenital anomalies (22 per cent). For children aged 5–14 the largest burden of disease was due to mental health conditions (19 per cent) and nutritional deficiencies (19 per cent), and for the older children (aged 15–19) it was again due to mental health conditions (31 per cent), followed by back and neck pain (14 per cent).

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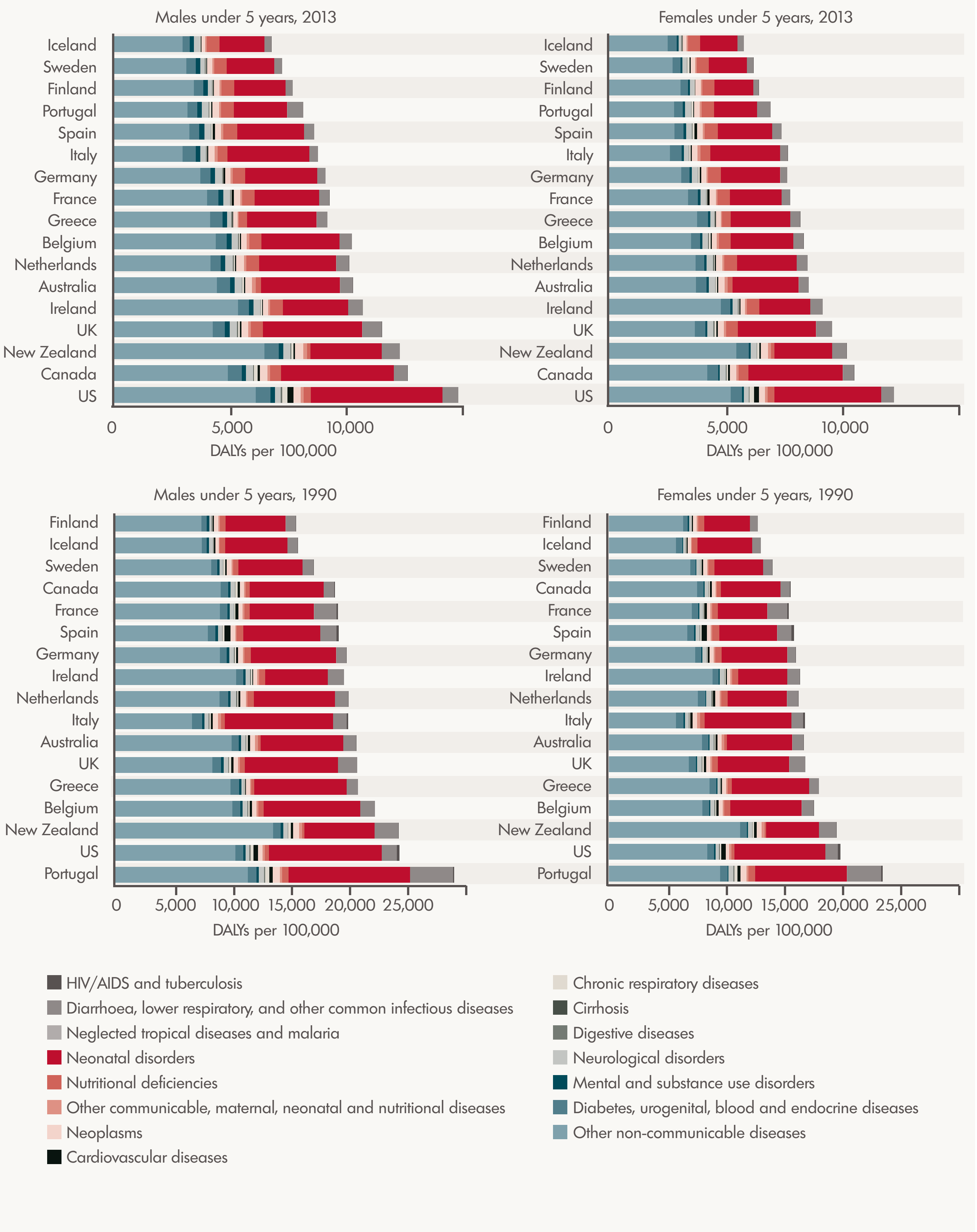
[1] DALYs are defined as the sum of years lost due to premature death and years lived with disability. DALYs are also defined as years of health life lost (Institute for Health Metrics and Evaluation, 2013).

Figure 2: Disability-adjusted life years (DALYs) per 100,000, children under five years, 1990 and 2013



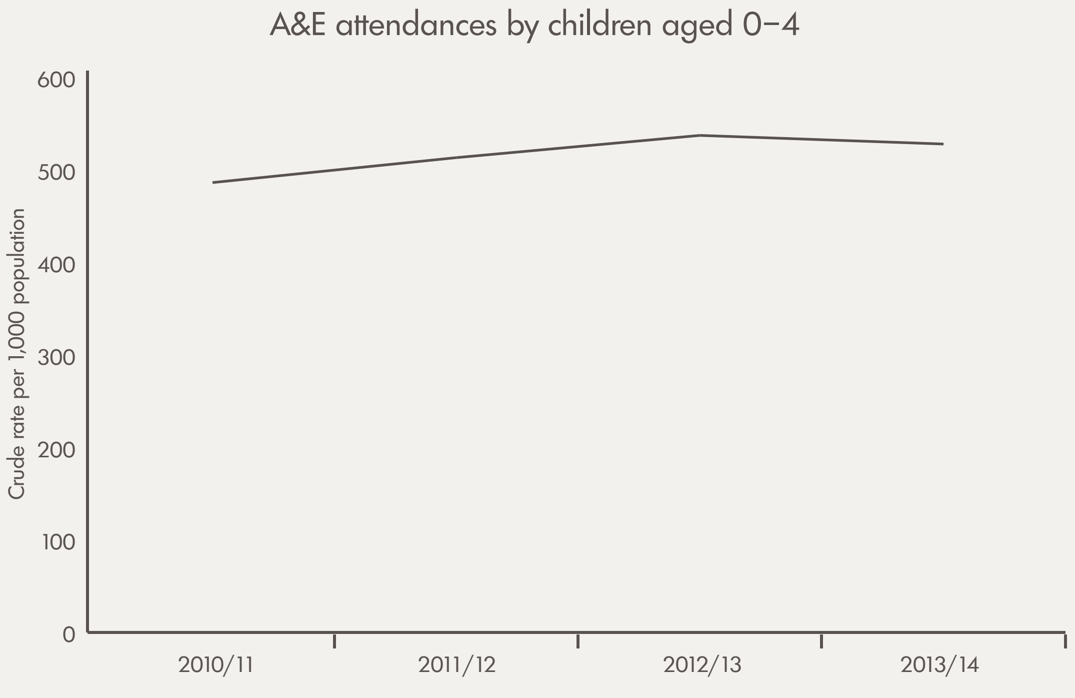
Source: Institute for Health Metrics and Evaluation, 2013

Quality of care for children and young people

The 2015 QualityWatch[1] Annual Statement (Health Foundation and Nuffield Trust, 2015) summarised the state of quality of care for children based on a number of indicators that can be monitored over time, including health promotion/prevention, and care for children with acute, chronic and mental health conditions. It found that there has been improvement in some areas that are affected by broader societal trends (for example the conception rate for under 18-year-olds or the proportion of women who smoke at birth). However, in 2014/15 nearly 22 per cent of children in reception class (aged 4–5 years) and one in three children in year 6 (aged 10–11 years) were overweight or obese. Between 2006/07 and 2014/15 the proportion of children in reception who were obese declined from 9.9 per cent to 9.1 per cent, but the proportion of children in year 6 who were obese increased by 1.6 per cent (Health and Social Care Information Centre, 2015a).

There has been an increase in A&E attendances for children under the age of five over time, which seems to have levelled off in the last year. Unplanned hospitalisations for long-term conditions (diabetes, asthma, epilepsy and convulsions) in people under 20 declined between 2003/04 and 2013/14, suggesting better management of these children in the community, as highlighted by epilepsy and diabetes audits (Royal College of Paediatrics and Child Health, 2014; 2015). However, the rise in emergency admissions for children under the age of 19 with lower respiratory tract infections, as well as unplanned hospital admissions for people under 20 due to ear, nose and throat infections, is of particular concern (see Figure 3). These trends suggest a need to better understand how acute conditions are managed in primary and secondary care.

Figure 3: Selection of indicators for the management of acute conditions in children and young people



Source: Health and Social Care Information Centre, 2015a

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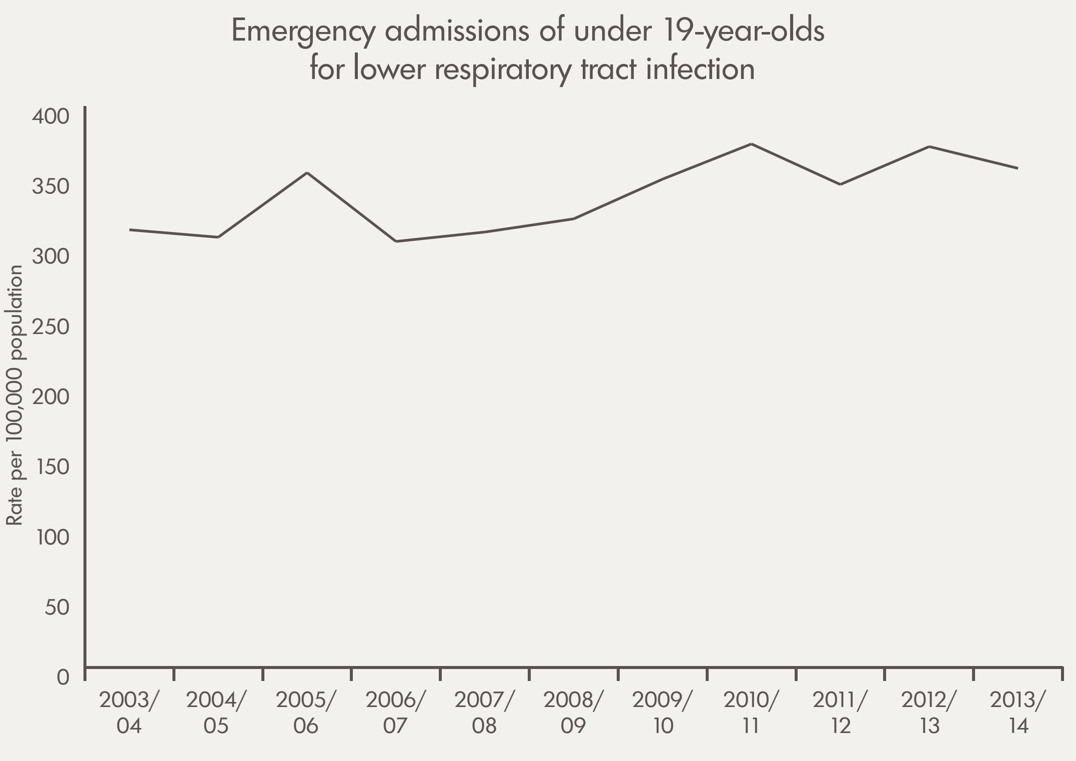
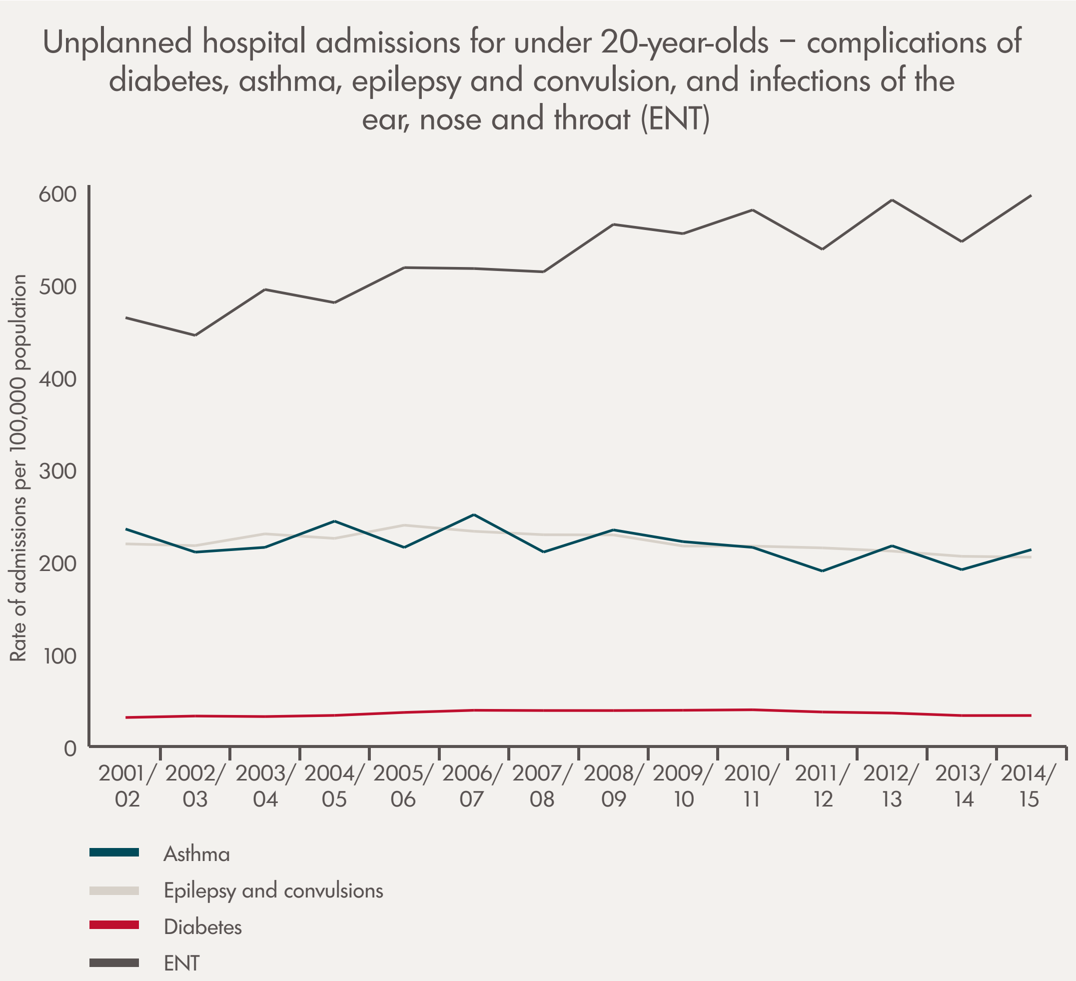
[1] QualityWatch is a joint research programme by the Nuffield Trust and the Health Foundation that monitors how the quality of health and social care is changing over time. It provides an authoritative resource on the overall quality of health and social care and highlights areas where improvement is possible.


Emergency admissions of under 19-year-olds for lower respiratory tract infection

Source: Public Health England, 2015


Unplanned hospital admissions for under 20-year-olds – complications of diabetes, asthma, epilepsy and convulsion, and infections of the ear, nose and throat (ENT)

Source: Health Foundation and Nuffield Trust, 2015

The QualityWatch Annual Statement also looked at the discrepancy in care between children and adults with diabetes and found that compared to adults a large proportion of children are not receiving the recommended care. It also highlighted concerns about the workforce for CYP in the community, for example the decline in the number of paediatric doctors working exclusively in the community, and there being no increase in the numbers of school nurses. Finally, quality of care in the primary care setting, where most care for CYP is provided, and mental health could not be assessed as data are not nationally available (Health Foundation and Nuffield Trust, 2014; 2015).

In addition to the need to better understand how acute conditions are managed in primary and secondary care, the 2015 QualityWatch Annual Statement highlights three problematic areas, with a particular focus on prevention across the board:

- **The need to provide a similar quality of service to CYP as for adults.** For example, an important aspect of providing similar quality of care is that the voice of CYP and their families should be taken as seriously as that of adult patients and their families. Historically, this hasn't happened. Children made up less than one per cent of respondents to NHS surveys between 2001 and 2011. Adolescents reported the poorest NHS experience of any age group (Hargreaves and Viner, 2012). Ensuring that all NHS surveys include CYP and their families was a key recommendation of the Children and Young People's Health Outcomes Forum report in 2012 (Lewis and Lenehan, 2012). Since then, things have improved slightly, with the launch of the CYP inpatient experience survey in 2014 (Care Quality Commission, 2014), which found that overall children reported good experience of care, but 41 per cent of parents and carers felt staff were not always aware of their child's medical history before treating them; one in three (35 per cent) said they were not definitely encouraged to be involved in decisions about their child's care and treatment; and for a similar proportion (32 per cent) staff were not always available when their child needed attention. But children are still routinely excluded from GP patient surveys and many others (Weil and others, 2015). There are also discrepancies between the proportion of budget allocated to CYP and the proportion of the CYP population needing services.
- **The need for more appropriate support for CYP with mental illness.** A focus on mental health in CYP is highlighted as priority in the NHS England Business Plan (NHS England, 2015). There is a need for service provision to be commensurate with physical illness and health care need.
- **The need to limit the trend for increasing obesity in childhood.** A coordinated approach to tackling obesity is especially important as public health functions are no longer part of the NHS and the risk of fragmentation is even higher.

In summary, while there have been impressive improvements in child health over the last decades, there is wide variation in the utilisation and quality of services (as highlighted in the Atlas of Variation; Cheung and others, 2012), as well as health outcomes historically and when compared to other countries; at the same time, there are crucial areas (primary care and mental health) where CYP receive care about which we have little information on quality due to a lack of data (Cheung and others, 2012; Department of Health, 2013a; Health Foundation and Nuffield Trust, 2015; Wolfe and McKee, 2013; Wolfe and others, 2013).

3. Case for change – other problems in child health services

Apart from the challenges in child health outcomes and quality of care identified in the previous section, there are other issues that persist in how services are provided to CYP that we have identified in the literature (Aynsley-Green, 2008; Brimblecombe and others, 1975; Clements, 2013; Department of Health, 2013a; Kennedy, 2010; Lewis and Lenehan, 2012; Marmot, 2010; NHS Confederation, 2011a; 2011b; 2012; Royal College of Paediatrics and Child Health and others, 2015), or that have been listed as the drivers by the new models of care and participants during the Nuffield Trust workshop:

a. Capacity in primary care

General practice is perceived to be where most paediatric services should be located, but there is a recognition that it often does not have the time, human and physical resources to adequately deal with the need. Currently there seems to be a capacity (for example availability of appointments) (BritainThinks, 2015) as well as in some cases a capability gap – perceived and real – between the services provided in primary care and secondary care in meeting the needs of CYP. This should be seen in the context that GPs in England are facing unprecedented demands and expectations from patients, as well as from policy-makers, politicians and regulators (Rosen, 2015). Overall, the current model of general practice is largely considered to be in need of reform and there have been different initiatives trying to transform the sector through scaled-up ways of working (for example federations or networks) or upskilling the workforce to learn about population health management, new ways of consulting with patients, new technologies and collaborative ways of working (Rosen, 2015).

b. Access to high-quality paediatric/child health expertise in the community

Participants at the Nuffield Trust workshop felt that a key challenge is that child health is not uniformly recognised as a problem and priority in primary care. Primary care is where most children are first and most frequently seen. However, there are concerns about the gap in paediatric expertise, knowledge and skills available in the community, specifically about the appropriate paediatric training of providers in primary care (Kennedy, 2010; Royal College of General Practitioners, 2010). At present, only 30–40 per cent of GPs have specialist paediatric training (NHS Confederation, 2012).[1] Participants also noted that there is no compulsory paediatric training for GPs, with most GPs having between none and six months of dedicated paediatric training, some of which may not be relevant to dealing with children in primary care (for example some of the neonatal work). Similarly, the expertise of hospital paediatricians is not sufficiently available in the community and hospital-based paediatricians are less well trained in minor illness management or health promotion. Workshop participants acknowledged, however, that GPs are only one aspect of primary care, so providing

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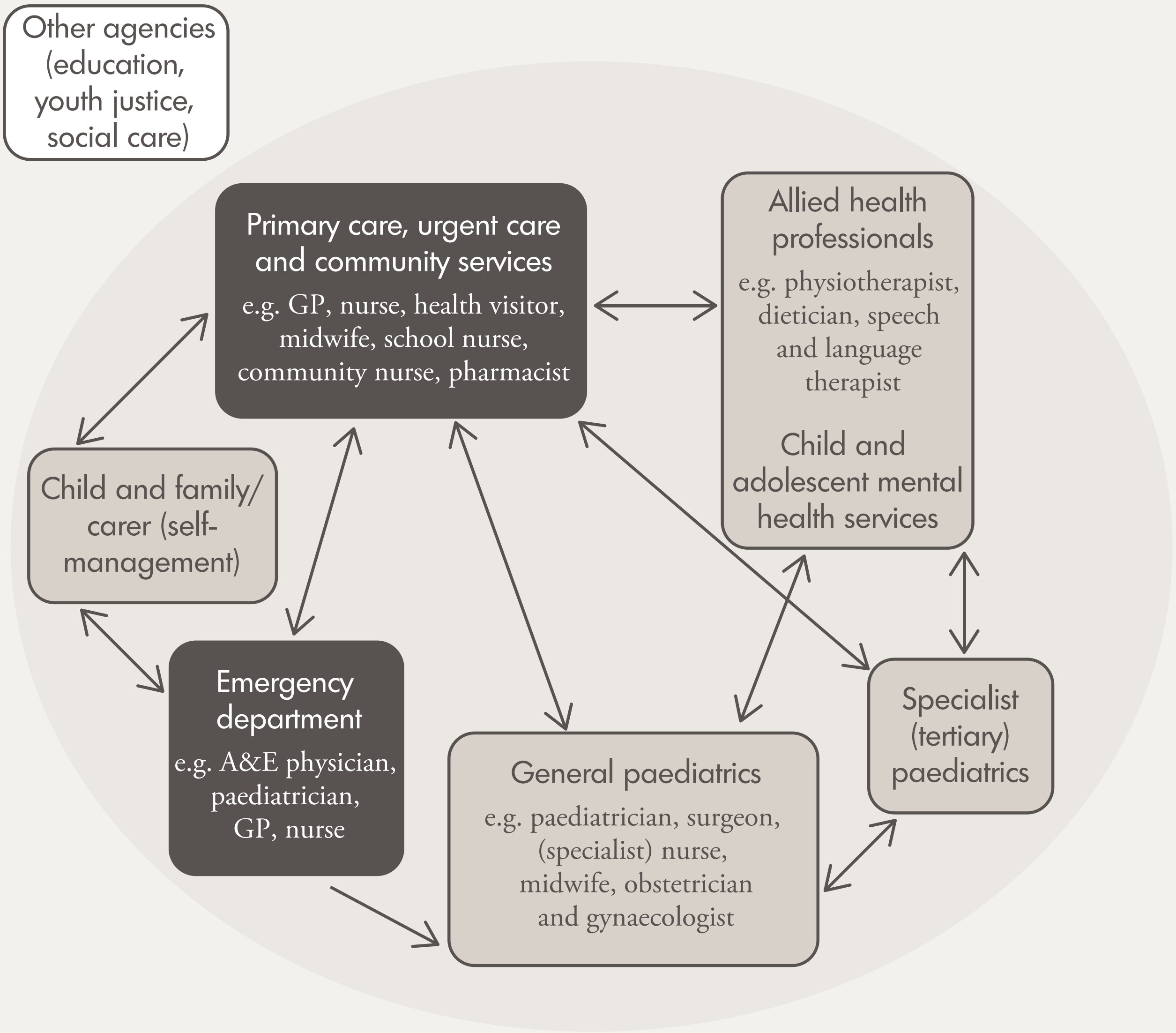
[1] Nationally children under 15 represent 10.9 per cent of GP workload (Gill and others, 2014). Other sources suggest that 25 per cent of GPs' patients are children, who together with their families may represent up to 40 per cent of GP consultations (Kennedy, 2010).

additional training to GPs in general paediatrics is only one way of improving access to high-quality expertise in the community. At the same time, GPs holding the gatekeeping role results in missed opportunities for early intervention and produces problems downstream in the health service, as well as suboptimal outcomes for the child or young person. Therefore, reaching an overall balance in access, knowledge and skills between care in the community and the hospital is essential.

Figure 4: How child health services are currently organised

Below is an overview of how paediatric/child health services are currently organised. This is a simplified model which does not cover all professionals, relationships and places involved in their care. However, it highlights what the current main route for CYP is into and through the system.



Note: Once CYP are under the care of a consultant, they may have direct access to secondary or tertiary specialist services.

c. Integrating and linking services, especially primary and secondary care (vertical integration)

The lack of integration between primary and secondary care services was a recurring theme at the Nuffield Trust workshop. Communication between GPs and hospital doctors was cited as problematic and ways to improve sharing of information, knowledge and care (going both ways) as being needed. GPs are not always able to get the support they need, both for individual patients and more generally for issues related to child health. At the same time, paediatricians are not always reaching out to primary care to augment family history, for example, or to arrange appropriate and coordinated follow-up care. For example, if hospital consultants do not know the child's GP, they are often hesitant to discharge them into the community, resulting in more hospital follow-up appointments and/or longer patient stays. There is also fragmentation of care for children with chronic illnesses (including mental health).

d. Financial pressures/inappropriate use of services

There is growing use of hospital emergency care in the management of acute illness, that could potentially be resolved outside the hospital (Gill and others, 2013). As well as being clinically inappropriate, high A&E use and increasing hospital admissions are expensive and diverting some patients, where clinically appropriate, to primary care could also be a cheaper option for commissioners. This is especially an issue at present when the NHS is under financial pressure and savings need to be made. The lack of capacity, paediatric expertise and communication between primary and secondary care, and perceived or real difficulties in accessing GP appointments, as well fragmentation of care, may be why parents seek care directly from A&E, or why care is often entirely offered in hospital.

e. Early intervention and broader determinants of health (horizontal, longitudinal and population integration)

There are also problems with coordination/integration between primary and secondary care, and the education sector, social care, the police and justice system, and, over time, transition to adult services (Wolfe and McKee, 2013). There is a need to reinforce the importance of intervening early in life on determinants of child health. This includes: healthy behaviour and lifestyle of the child and the parents (for example nutrition, smoking); the families' ability to care for the child; education; the broader socio-economic conditions (i.e. social protection, poverty and inequity); and the environment. Child health (both physical and mental) is largely influenced by these broader determinants rather than the health care system, so there is a need to work with a range of professionals across the different sectors and organisations with a focus on children's health and wellbeing. Health services tend to be reactive, rather than focused on the needs of different child health populations and working to improve their health outcomes in childhood and later on as adults. For example, unmet health care need in adolescence is an important, independent predictor of poor physical and mental health outcomes in adulthood (Hargreaves and others, 2015). Similarly, early intervention for young people with mental health disorders can prevent a range of short- and long-term lifetime costs (Chowdry and Oppenheim, 2015; Department of Health, 2013a; House of Commons Health Committee, 2014).

Greater emphasis on health promotion and disease prevention, and proactive early intervention where every contact with a child and the family is used as an opportunity, are essential. Schools are only weakly connected to health and wellbeing services in the

NHS – there are many opportunities for collaborative innovation in prevention, health and wellbeing promotion, and early intervention. In the long-term, the benefits of intervening early and investing in the broader determinants of child health will lead to a reduction in the disease burden and therefore benefit adult health and social care services.

f. Patient experience and expectations, and health literacy

There is a mismatch between health care delivery and the expectations of CYP and their families (Department of Health, 2013a). Some of the key areas identified from literature reviews and focus groups with CYP and their families include: the need for better transition to adult services; improving the role of GPs; better access to services, especially mental health; improving the role of schools in CYP's health and wellbeing; making services more CYP-friendly; better coordination and integration of health care; and more information about health services, including rights and responsibilities (Department of Health, 2013a). Organisations need to actively listen to, and take account of, the views of CYP. Lack of health literacy in the population, both in terms of medical conditions and the system, may mean that children may not be able to be looked after at home and parents may not know which services are available and how to access them.

4. How are new models of care addressing the problems?

In this section we provide examples of how the new services or models of care are trying to address the problems identified in CYP's health care. We identified new services and models of care for CYP from the literature and through expert advice. Here we look at a sample of 12 of these new models, representatives of which participated in the Nuffield Trust workshop.

Table 1: Overview of 12 new models of care for CYP

Detailed descriptions of each of these and many other models can be found on the Royal College of Paediatrics and Child Health website.[1]

Acutely Sick Kid Safety Netting Interventions For Families (ASK SNIFF) University College London, University of Northampton, University of Oxford, University of Leicester	A tool to provide parents with information to help them determine when to seek help for an acutely sick child under five years of age and to facilitate effective safety-netting when used in consultations between parents and health care professionals. A number of evidence-based tools were developed in collaboration with parents. These will be tested and clinically evaluated following implementation.
Imperial Child Health General Practice Hubs – Connecting Care for Children (CC4C) St Mary's Hospital, Imperial College Healthcare NHS Trust	CC4C involves groups of two to six general practices within inner North West London working with paediatric consultants to provide care to practice populations of approximately 4,000 children. The hubs were established in response to high outpatient and emergency department attendances by children. Multidisciplinary meetings are held with primary care and paediatric consultants, where they discuss cases, share ideas and learn together. GPs in the hub practices might also have telephone or email conversations with a consultant to discuss the most appropriate approach for a particular patient.

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[1] Royal College of Paediatrics and Child Health (2015) Facing the Future Together for Child Health: Practice examples. www.rcpch.ac.uk/improving-child-health/better-nhs-children/service-standards-and-planning/facing-future-together-chi .

Children and Young People's Health Partnership (CYPHP) Evelina Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	CYPHP (formerly called Evelina London Child Health Programme) focuses on everyday health and care for a population of 120,000 children and young people in the London boroughs of Southwark and Lambeth. It is a coalition of CCGs, local authorities, acute providers, third sector, and family and patient representatives. The programme is combined into four components: a whole-system approach for long-term conditions, with specialist nurses delivering prevention, early intervention and treatment; improving everyday health care, including joint clinics and training between GPs and paediatricians, paediatric hotlines and decision-support tools; improving access, including user engagement and youth-friendly services; and sustainable cross-system training, including emotional resilience training in schools and training for school nurses, social workers and youth workers.
Electronic Personal Child Health Record (ePCHR) Royal College of Paediatrics and Child Health	The Personal Health Care Record (PCHR) is the main record of a child's health and development. The parent or carer owns and retains the PCHR, in which they enter their child's health information, access and use information contributed by health care professionals, and share this record with any organisation or individual they choose to. The ePCHR is an electronic version of the PCHR which has been piloted at two sites in Liverpool and South Warwickshire, and is being further piloted in parts of London. The ePCHR supports the government's Healthy Child Programme, recording details of screening tests, immunisations and reviews, as well as signposting to relevant information.
Hospital@Home Islington Community Children's Nursing Team (CCNT)	The Islington CCNT provides a safe and comprehensive service with the aim of facilitating early discharge from hospital, and preventing and reducing unnecessary attendances and admissions to hospital. Its Hospital@Home service began in August 2014 and runs from 8am to 10pm. It provides care for acutely sick children in the community. The primary care clinics aim to educate and improve the self-care skills of families, as well as increase the clinical competence of practice nurses.
Liverpool Family Health and Wellbeing model	This new model aims to establish a multi-agency culture of shared care and seamless service delivery across essential child and family services. Organised around key service themes such as Giving Children the Best Start in Life, Keeping Children Healthy and Safe, and Supporting Sick Children at Home, this initiative is improving ways of working across providers and services. Clinicians from primary and secondary care are working closely to improve the health of CYP through delivery of excellent clinical services, but at the same time closer working with local authority colleagues is helping to sustain a focus on the child's learning and development needs, and whole-family approaches.
Luton care pathways Luton and Dunstable University Hospital NHS Foundation Trust, Luton CCG and Cambridge Community Services	In Luton there were high volumes of children presenting to A&E and secondary care paediatric services with common conditions. This initiative involves the development of clinical pathways for the highest volume conditions (fever, diarrhoea, vomiting, seizure, asthma, bronchiolitis, abdominal pain and head injuries). Developing these pathways further enhances an ethos of collaboration between acute and community services and children's commissioners.

Salford Children's Community Partnership Kids' Health Matters and Salford Health Matters	The Salford Children's Community Partnership is a project that aims to reduce paediatric short-stay hospital admissions by providing enhanced illness assessment and management within general practice. Assessment and treatment for acutely unwell children (e.g. fever management, treatment of wheezy episodes and mild dehydration) can be initiated by the advanced paediatric nurse practitioner (APNP) as an alternative to hospital-based care (when safe and reasonable to do so). The APNP team also has strong links with the local acute children's community nursing team and paediatricians from the local district general hospitals. Children are referred from any of five local GP practices if they meet the 'acutely unwell child' inclusion criteria.
Smithdown children's walk-in centre	Smithdown children's walk-in centre is a nurse-led service for the assessment, diagnosis and management of children's unplanned minor illness and injury (from birth to 15 years). The programme was set up to address the increasing number of children attending A&E with primary care problems. It aims to reduce inappropriate A&E attendances, improve the experience of children and their families, and reduce pressure on GP services.
Up-skilling GPs in the clinical management of children with acute health problems. Partners in Paediatrics (PiP) and local NHS partner organisations	In North Staffordshire the number of children with acute health problems admitted to paediatric wards was about twice the admission rate of other hospitals in similar communities. An interactive up-skilling programme for primary care was developed for the top ten conditions. Ten master-class sessions, run by paediatric consultants, were held to increase competence and confidence in managing acute paediatric conditions in primary care. Paediatric pre-referral guidelines and urgent care referral guidelines were produced and made readily available to all clinicians in primary care.[1]
Paediatric Unscheduled Care Pilot (PuC) North of Scotland Planning Group	To enable safe, sustainable paediatric care in rural Scotland, this programme trialled a dedicated on-call paediatric consultant model, providing 14 rural general and community hospitals with single point of contact access to paediatric consultants, 24 hours a day, seven days a week, via video-conference. Within individual rural hospitals, following initial nurse triage, two models were put in place: assessment by a trainee (foundation year/GP trainee), which often resulted in referral onto regional paediatric services, without further evaluation if needed; or evaluation by experienced rural practitioners, who may carry out investigation or initiate active management, prior to referral for advice/transfer. Consultant input via video-conference resulted in significant improvements in both care delivered and need for transfer.
Reducing avoidable presentations and admissions, and improving the quality of care for CYP (Wessex Healthier Together) Wessex Strategic Clinical Network	This programme is designed to reduce the number of unplanned hospital presentations and improve the quality of care for CYP across Wessex by strengthening the primary and secondary care interface. This should help CYP to access the 'right care' at the 'right time' in the 'right place' and from the 'right person'.

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[1] For more information: www.partnersinpaediatrics.org

Table 2 provides an overview of what problems the new services or models are trying to address. The different categories in the table are not entirely exclusive and we are also aware that no categorisation will perfectly capture the attributes of the different models. The 12 models all cover aspects of integration which are thought to improve patient experience and clinical care. Most models emerged to address the availability of paediatric expertise in primary care, to improve patient experience and health literacy, but especially to increase vertical integration, i.e. linking primary and secondary care. The second most common form of integration is horizontal, where services are linked with other sectors such as education, social care, youth justice and population (disease prevention and population health promotion). Longitudinal integration (across the life course) is addressed by four of the models.

Table 2. What the 12 models of care are trying to address

Model	Capacity in primary care	Access to high-quality paediatric/ child health expertise in the community	Integrating and linking services (vertical integration)*	Financial pressure/ inappropriate use of services	Early intervention and broader determinants of health*			Patient experience and expectations, and health literacy
					Horizontal integration	Longitudinal integration	Population integration	
ASK SNIFF							✓	✓
CC4C		✓	✓	✓	✓	✓		✓
CYPHP	✓	✓	✓	✓	✓	✓	✓	✓
ePCHR			✓		✓			✓
Hospital@Home		✓	✓					
Liverpool Family Health and Wellbeing model			✓		✓	✓	✓	✓
Luton care pathways	✓	✓	✓	✓		✓		
Salford Children's Community Partnership	✓	✓	✓	✓				
Smithdown children's walk-in centre	✓	✓	✓					
PiP		✓	✓		✓		✓	✓
PuC		✓						
Wessex Healthier Together		✓					✓	✓

*Using the integration framework by Wolfe and others, 2016

The following boxes highlight how the different models are addressing the problems identified in the previous section.

1. Capacity in primary care

For example CYPHP, Luton care pathways, Salford Children's Community Partnership and Smithdown children's walk-in centre

Despite being mentioned as a driver by many, few models seek to address the problem of capacity in primary care. In the example of Smithdown, the community nurses run a parallel service that can be accessed directly by parents, from the GP or from hospital. Similarly, the Salford Children's Community Partnership have emergency clinics run by paediatric nurse practitioners. CYPHP (rapid access clinics and hotlines) and Luton care pathways (rapid response team) both have additional services for acutely unwell children that could reduce GPs' workload. This also has the effect of moving care closer to the patient in an attempt to reduce problems with access and improve efficiency.

2. Access to high-quality paediatric/child health expertise in the community

For example CC4C, CYPHP, PiP, PuC, Salford Children's Community Partnership and Wessex Healthier Together

Most programmes tried to improve access to high-quality paediatric/child health expertise in the community. CC4C, CYPHP and PuC are models that aim to improve two-way learning between GPs and paediatricians. Paediatricians can help GPs to manage children with chronic or complex illnesses, including mental health, and GPs can help paediatricians to look after children with everyday health and social problems. This can take the form of: multidisciplinary meetings involving other health care professionals, social care, education and voluntary sector professionals; joint clinics or telephone/teleconference support; or teaching and clinical guidance.

PuC uses video-conferencing for more remote parts of the country to access specialist assessment. This may also improve the referral process as the decision is made via a joint assessment. The Salford Children's Community Partnership provides a general practice-based alternative to A&E through advanced paediatric nurse practitioners providing high-quality care for children with common acute conditions in the community. Evidence from their evaluation showed that satisfaction scores on a nationally validated assessment tool (GPAQ survey) were almost double the national benchmark scores for service quality in general practice (unpublished data from Salford Children's Community Partnership). CC4C uses multidisciplinary case discussion meetings, joint GP–paediatrician outreach clinics, telephone and email hotlines, and both face-to-face and webinar case-based teaching to build capability within general practice, and to strengthen the connections with hospital services. This means that GPs can use their time more effectively and, through working with paediatricians and other child health professionals, begin to take more preventive approaches to managing their population of CYP.

Wessex Healthier Together uses a number of different channels to educate parents/carers, children, young people and health professionals, and signpost and improve the quality of services. PiP carried out up-skilling programmes and master-class sessions for GPs and nurses in the clinical management of common acute (primary care) conditions for which children were usually referred to hospital. A high percentage of participants found the programmes extremely useful or very useful (Hawkes, 2011).

3. Integrating and linking services, especially primary and secondary care (vertical integration)

For example CC4C, CYPHP, ePCHR, Hospital@Home, Salford Children's Community Partnership and PuC

Most programmes sought to link primary care with hospital services. A number of models considered new ways to design health systems to provide easy and flexible access to care. The programmes mentioned above that aim to improve clinical expertise in the community (CC4C, CYPHP and PuC) also improve the links between GPs and paediatricians by providing regular contact to help break down professional barriers. Others sought to introduce a new cadre of workers that can provide this link, for example Salford Children's Community Partnership. Community-based nursing, such as by Islington CCNT (Hospital@Home), is an extension of secondary care into the community, providing care closer to home and a connection between general practice and specialist paediatric care. ePCHR is trying to improve communication between health care providers by producing electronic joint personal records that help information flow.

4. Financial pressures/inappropriate use of services

For example CC4C, Luton care pathways and Salford Children's Community Partnership

Only some programmes were created directly in response to financial pressures. The Luton care pathway model involved developing a number of urgent care pathways for children, for example fever, abdominal pain and head injuries. These were designed to streamline care and reduce the reliance on A&E. The Salford Children's Community Partnership programme, which introduced a community-run specialist nurse clinic, resulted in a 38 per cent reduction in the total spend on paediatric acute admissions in the participating practices (compared to control practices; unpublished data from Salford Children's Community Partnership), and broke even in net costs. CC4C, which introduced multidisciplinary meetings in GP practices, managed to shift care from hospitals to primary care settings and resulted in a reduction in secondary care usage and increased patient satisfaction (Montgomery-Taylor and others, 2015).

5. Early intervention and broader determinants of health (horizontal, longitudinal and population integration)

For example CC4C, CYPHP, Liverpool Family Health and Wellbeing model, and PiP

A few programmes, such as CYPHP, Liverpool Family Health and Wellbeing model, and PiP, took a public health perspective, i.e. starting from assessments of population need rather than clinical demand in established services. These programmes work across sectors to improve the determinants of health. The Liverpool Family Health and Wellbeing model, for example, uses a family-based approach located in children's centres and primary care centres, and links education, social care, maternity and child health to improve the health of mothers and young children, and reduce inequalities. In addressing services required for CYP with paediatric gastroenterological and rheumatological conditions, and health assessment and care in cases of child sexual abuse, for example, PiP seeks to integrate health/social care, education and third-sector organisations using multidisciplinary team approaches. CYPHP has a number of population-oriented components to its model, for example teaching mental health resilience to children and teachers in schools. CC4C runs multidisciplinary team meetings with doctors, nurses, health visitors, child and adolescent mental health services (CAMHS) professionals, therapists, social care workers and dental trainees, who then work together to address the needs of children and their families.

6. Patient experience and expectations, and health literacy

For example ASK SNIFF, CC4C, CYPHP, PiP and Wessex Healthier Together

Most programmes tried to improve patient experience with active engagement, and listening to the views of the CYP and their carers/families. This helps to meet patient expectations and makes sure the programmes are appropriate. PiP's rheumatology group worked with parents to produce a DVD for commissioners explaining how small gaps in services have disproportionate effects on quality of care and life for their children.

Some models explicitly sought to support parents in caring for their children, mainly focusing on understanding how children and their parents access and use information, and helping them understand the system and how to access it. ASK SNIFF sought to improve health literacy by producing a tool that helps parents to identify acutely sick children. Dudley CCG and Metropolitan Borough Council, one of the PiP members, developed an 'Early Help Hub' that signposts users to services that are available. The interventions are prevention focused and work across mental and physical health. The Evelina Academy (CYPHP) has two components – one for CYP and families to support and enhance health literacy (especially for long-term conditions) and the other for health professionals and schools to boost knowledge, skills and confidence.

PiP have published ten top tips that young people produced from an event that would make a difference to the quality of experience of their interactions with health professionals (Partners in Paediatrics, 2014). Wessex Healthier Together uses a number of different channels to educate parents/carers, CYP and health professionals, and to signpost and improve the quality of services. The CC4C programme has service users who are 'Practice Champions'. They become active members of the local health care team, sharing knowledge and insights to, from and within the community.

The effectiveness of most of these models is yet to be determined even though there is evidence of improved patient satisfaction and reduced hospital activity. While evidence-based/value-based commissioning is called for, there aren't sufficient incentives in the system to take part in the research and provide the necessary evidence. However, it is still important to understand what has been driving the development of these models, their goals and what makes them different from how services are currently delivered, so that they can guide the design of child health services in the future.

None of the models sought to explicitly change priorities at a local or national level, though each team would advocate and seek funding for their own programme. Based on a SWOT (strengths, weaknesses, opportunities and threats) analysis (see Appendix) of the 12 models, the most often cited strengths of these models were: taking a population focus when addressing the needs in the community; and building on existing services through developing connections and relationships. This may have allowed the release of capacity and expenditure in secondary care (for example reduced admissions, outpatient usage, length of stay and non-attendances), and some workshop participants noted that the service was 'cheap'. Most models considered the involvement of patients and their families in the design of the service as a core strength, and essential for service development. The enthusiasm of those involved and the (personal and professional) relationships built were considered to be essential for the success of many of the services and new models.

Weaknesses mentioned were related to concerns about the cost of the service and its sustainability, a need for economies of scale, and related financial constraints. These include the broader financially constrained environment, but also the payment mechanisms in place that do not encourage proactive co-working between primary and secondary care, as well as the need to show impact to obtain funding, but the need for funding to show impact. Other weaknesses relate to IT, especially how essential it is to join up information about users with technological innovations (i.e. electronic health record) and avoid developing silo solutions. Finally, issues around the complexity of some of the services/models and problems with accountability and governance were also raised, in particular, the lack of accountability for children's services commissioning and provision overall – at present it is very widely spread across agencies, sectors and professional groups. Some of the core strengths were also considered to be some of the main weaknesses or threats, for example the relationships established by enthusiastic leaders.

5. Key principles of the ideal model/system

Participants at the Nuffield Trust workshop were asked to identify the principles of an ideal system or model for CYP health services, or in other words: what should be different in how the NHS provides care to children and young people in 5–10 years' time to improve their health outcomes?

The key principles set out in Figure 5, and explained below, were identified:

Figure 5: Principles of an ideal child health model/system

Understand children, young people and their families' specific needs (including broader determinants)	Health outcomes
Enable access to high-quality paediatric/child health expertise in the community	
Link up information, data, communication and care (horizontal and vertical)	
Health literacy and education	

1. Understand children, young people and their families' specific needs (including broader determinants)

As highlighted earlier, most children are healthy, but a large proportion of them also suffer from chronic conditions. Also, children's needs change continuously with their age and their health can quickly deteriorate, so the system needs to be flexible enough to respond rapidly in the appropriate setting. Segmenting the population allows us to understand CYP's general and specific needs, including the broader determinants of their health, so that these together with their expectations can be met, and resources targeted more efficiently.

The Imperial (CC4C) and Evelina (CYPHP) programmes (see Figure 6) are using this approach to determine the needs of different groups of CYP in their projects. For example, a child with a single chronic physical condition requires some specific physical and mental health services that will be different from the services required by a child with complex needs. At the same time, all children should be able to access high-quality paediatric urgent care in the community. Evidence from focus groups with CYP and their families in Lambeth and Southwark on their experience of the health service identified issues around: seeking and accessing care from their GP (and how these may differ if a child has a chronic/complex condition); experiences of hospital care and coordination of care; self-management of acute and chronic conditions; inadequate school support; and the need to support families and provide information (Action for Sick Children, 2013; Children and Young People's Health Partnership, 2014). These reflections from CYP and their families should be taken into consideration when re-designing services.

Figure 6: Examples of population segmentation models from Imperial (CC4C) and Evelina (CYPHP)

Broad patient 'segments':

Healthy child
Advice and prevention e.g. Immunisation / Mental wellbeing / Healthy eating / Exercise / Dental health

Vulnerable child with social needs
e.g. Safeguarding issues / Self-harm / Substance misuse / Complex family and schooling issues / Looked-after children

Child with complex health needs
e.g. Severe neurodisability / Down's syndrome / Multiple food allergies / Child on long-term ventilation/ Type 1 diabetes

Child with a single long-term condition
e.g. Depression / Constipation / Type 2 diabetes/ Coeliac disease / Asthma / Eczema / Nephrotic syndrome

Acutely mild-to-moderately unwell child
e.g. Upper respiratory tract infection / Viral croup / Otitis media (middle ear infection) / Tonsillitis / Uncomplicated pneumonia

Acutely severely unwell child
e.g. Trauma / Head injury / Surgical emergency / Meningitis / Sepsis / Drug overdose

Cross-cutting themes found within many or all of the patient segments are: safeguarding, mental health, school issues, transition and inequalities. This segmentation model also allows the activity and spend on a population of CYP within a defined locality, split into age groups, to be assessed and analysed. This presents the opportunity for utilising different payment and contracting mechanisms for child health.

Social adversity and vulnerability
Aim: to build resilience and emotional wellbeing

Well child/youth
Aim: to ensure that CYP are kept healthy and minor illnesses are managed in the most appropriate place.
Initial outcomes: improved knowledge and use of health care.

Acute mild
Aim: to improve health care use by providing a better balance between access and expertise in the community and preventing unnecessary trips to hospital.
Initial outcomes: fewer visits to hospital, fewer avoidable hospital admissions.

Acute severe
Aim: to improve care of CYP to ensure that the right professionals with the right skills. work in the right place to detect serious illness promptly and provide safe, effective care.
Initial outcomes: less time to diagnosis, reduced length of stay, improved patient experience.

Single long-term
Aim: to improve the outcomes of CYP with chronic conditions.
Initial outcomes: fewer visits to A&E, fewer hospital admissions, more care that meets quality standards, improved patient experience.

Complex long-term
Aim: to improve quality and experience of care and to maximise health and wellbeing.
Initial outcomes: improved integration between services, better patient experience supported by documented multi-professional care plans held by families.

Mental health
Aim: to improve quality and experience of care and to maximise mental health.
Initial outcomes: improved access to mental health services, better coordination between physical and mental health, better patient experience.

Public health and health education
Aim: to bring prevention and health education into all frontline care.

Source: Watson, 2015; Children and Young People's Health Partnership, 2014.

Regardless of the exact segmentation approach used, taking a population view allows the service to determine whether the general and specific needs of CYP are being met, but also to be proactive about the care required for a group of children (or adults), whether that is early intervention to prevent deterioration or proactive management of a group with a certain illness/es, as seen internationally in examples of 'population health systems' (Alderwick and others, 2015). The use of a segmentation approach that links population groups coherently to forms of service would be a major improvement on much current practice. Overall, understanding the population needs in an area, and creating a widely supported plan that identifies priorities for change and improvement efforts, is the first crucial step for accountability.

National Voices have identified how 'good, coordinated, integrated care' should look from the perspective of children with complex needs and the people who are important to them (National Voices and Think Local Act Personal, 2015). The main areas identified are: respect and being listened to; choice and control; supporting my dreams and goals; friends, relationships, people and things around me; support that is personal to me; support for the people who are important to me; and making changes and growing up.

The areas identified go beyond what CYP would want from a specific service they receive, to specify what they would like from their lives and how different professionals should support them, especially as CYP have different clinical, developmental and social requirements to adults (National Voices and Think Local Act Personal, 2015). A similar approach could be used for other groups of children or patients (for example healthy children with acute care needs and their families), which could then be used to identify a selection of measurable and meaningful patient-centred process and outcome measures[1] to allow us to monitor and evaluate whether the needs of these children are being addressed. Workshop participants were also particularly concerned about inequities in service provision and outcomes, as well as broader determinants of health.

> *"Ease of access is very important. Parents don't care about the theory, they just want the best care for their children then and there. The pathway/route chosen depends on the needs of the child and also the parent – parents of children with long-term conditions have a much greater knowledge of the system and the treatment their child needs."*
>
> Quote from attendee at the Royal College of Paediatrics and Child Health (RCPCH) Parents and Carers Group focus session[2]

2. Enable access to high-quality paediatric/child health expertise in the community

Regardless of the population segment of children, easy access to high-quality paediatric and child health expertise in the community needs to be significantly improved to provide care that is effective, safe and responsive, as well as equitable, coordinated and continuous (Cecile and others, 2016). As one Nuffield Trust workshop participant noted: "get the quality right and the rest will follow". In one form or another, most of the new models of care featured in this briefing are focusing on moving or strengthening the quality of paediatric care in the community, trying to build on current resources and workforce. Depending on local circumstances, some of the solutions – or combination of – could be implemented immediately, while others are more systemic and expensive, and will take longer to implement. Solutions include:

- **Direct (phone/email) access for the GP to a named paediatrician/specialist nurse.** To discuss individual CYP cases when needed.
- **Multidisciplinary case discussion meetings.** These provide the opportunity for a broad group of professionals (including GPs, health visitors, paediatricians, school nurses, practice nurses, children's community nurses, CAMHS workers, therapists, dentists and social workers) to come together to discuss children and families who would benefit from broad input. These sessions can cover a number of patients and allow all professionals to share concerns and insights. They also provide an important opportunity to learn and to build connections and relationships that strengthen other aspects of the service.

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[1] These measures should also be aligned with the five key areas of the NHS Outcomes Framework: i) preventing people from dying prematurely; ii) helping people recover from ill health and injury; iii) ensuring a positive experience of care; iv) enhancing quality of life for people with long-term conditions; v) treating and caring for people in a safe environment and protecting them from avoidable harm (Department of Health, 2014).

[2] These quotes are from a focus session with the RCPCH Parents and Carers Group that was held in March 2014, involving six parents and carers from across the UK.

- **Primary care paediatric clinics.** These include paediatric nurse-led walk-in clinics where routine needs can be addressed or seriously ill children be spotted, or paediatricians doing outreach clinics alongside GPs in primary care. Some models involve a standard approach where a GP practice (or a group of them) offers a regular paediatrician-led children's clinic (in a child-friendly space) where children can be seen and cases discussed. Other professionals (multidisciplinary workforce) involved in the care of the child/young person (for example school nurses, health visitors) would also participate in these clinics. Similar approaches have been used for geriatric patients.

- **Actively engaged senior care lead with appropriate paediatric/child health training.** Depending on the specific needs of the child (and those will change over time depending on the condition, duration of illness, age and so on), every child or young person in the community should be in the care of a senior professional with appropriate paediatric training from birth onwards, who would: be responsible for, and have an excellent understanding of, the child's care needs (social, emotional, physical) and his or her family circumstances; be proactively engaged in the care of the child; and ensure that he or she is receiving high-quality, continuous and coordinated care that is child-/family-centred. This could be the GP, consultant paediatrician, clinical psychologist or specialist nurse.

- **Community care under one roof (physical or virtual).** There are multiple specialists within a hospital who can discuss complex cases. Primary care would benefit from a similar child-centred approach. This 'one-stop shop' in the community, whether the GP practice or a child health centre, is where all the needs of the future mother, family, baby and child, as well as young person could be met by the community multidisciplinary workforce (i.e. GP, physiotherapist, speech therapist, school nurse, clinical psychologist, social worker, paediatric/specialist consultant), including basic diagnostics services (for example x-ray, phlebotomy). Children and their carers would have easy access to these hubs and their needs would be quickly assessed and addressed by the appropriate professional(s), who could then direct them to the most appropriate service. Scaled-up primary care (i.e. federations and networks of practices) could provide the means to making a multidisciplinary workforce available to CYP. Accountable Care Organisations (ACO) in the US provide coordinated care to a patient through a network of doctors and hospitals that share financial and medical responsibility. How this works can be explained through an example of a broken-down car and a team of car engineers looking at it together, rather than assessing the wheels separately from the engine (Gold, 2015).

- **Workforce and training.** Increasing capacity in primary care depends on the availability of trained staff. Moving staff from one location to another would not necessarily improve services. Longer-term training systems need to be put in place to develop adequately trained staff. Staff working with CYP need to have the appropriate knowledge, skills and experience to be able to provide high-quality, safe advice and care. Professionals need to have the training that is appropriate to the level and intensity of contact they have with CYP (Ewing and Smith, 2015), continuously develop their knowledge and skills, and share their skills with other professionals, patients and their families. There was agreement amongst the Nuffield Trust workshop participants that the lack of trust of patients in primary care can only be addressed if staff have the appropriate skills to meet the expectations of patients and their families. There was doubt about the extent to which training can be standardised across the country. However, the need to strengthen the paediatric skills of GPs has been recently called for (Royal College of Paediatrics and Child Health and others, 2015). Workshop participants agreed that GPs are essential to the provision of paediatric care in the community and that their paediatric training could be strengthened. Alternatively, paediatricians could receive more general, community-focused training and work in the community, while maintaining close links with specialist paediatricians in the hospital.

> *"We need to create new ways for children and young people to access primary care support, such as better paediatrics in GP surgeries which could stop children being sent to A&E, which increases workload and is scary for the child. More out-of-hours pharmacies/knowledge of out-of-hours pharmacies, child pharmacies, GP drop-in sessions with child-specific/only appointments and access to more paediatric specialists. What happens if we can't get to see the GP, what do we do then? There should be a GP/paramedic hotline to a paediatric consultant so they can ask questions when not sure as they have the most experience in dealing with CYP, especially those with long-term conditions."*
>
> Quote from attendee at the RCPCH Parents and Carers Group focus session

3. Link up information, data, communication and care

It is essential to have up-to-date communication and good information/data flow with the child/young person and their family, not only across the different health professionals (for example GPs, school nurses) and professionals in other sectors (for example education, social care, justice) in the community, but also with secondary and tertiary care, so that services can be tailored to the needs of the child and the family. Relationships need to be established in order to break down professional barriers and comfortably move the child between the different professionals and sectors. While services can be physically connected, high-quality virtual connection is also a viable option. Technology and linked data should be key enablers for this:

- **Technology.** There is a need to make better use of very simple technology (email, phone) to improve communication and exchange information, as well as to provide services (for example, phone consultation, email consultation, long personal consultation, short follow-up phone consultation) tailored to the needs of the patient. Technology should be used by providers as a tool to reach out to other providers, or by patients for them to obtain quick access to advice, rather than having to wait unnecessarily for a face-to-face appointment.

- **Common child health record and integrated data (patient, registries, system) to allow for continuous quality improvement, accessible by all through a single point.** Ideally, the common record, including the NHS number as a unique identifier and patient data, would be across the different systems of care (for example including education), but this joining up is proving to be difficult, even within the NHS. While national implementation of this may take a long time, workshop participants suggested the use of the GP record in the short term. Allowing patients to hold their own information (for example an expanded red book or the paper record held by pregnant women) is currently being explored. It is essential to also have nationally linked data in order to be able to understand changes in the quality of care provided over time. At present there is very little understanding of the quality of community services and services provided in general practice at a national level (Dixon and others, 2015; Foot and others, 2014). Without these data, it is difficult to know whether services provided to CYP are of high quality, safe, equitable and responsive to the needs and expectations of patients. Issues around clinical governance and data sharing at the individual and population level will also need to be addressed.

> *"Communicate with young people directly via the channels that they use – apps, online chat, where it is easier to communicate online than on the phone – and less intimidating."*
>
> *"There needs to be data sharing, including for out-of-hours GPs, with a single point of contact, reinforced by experts on the end of the phone."*
>
> Quotes from attendees at the RCPCH Parents and Carers Group focus session

4. Health literacy and education

Workshop participants agreed that it is essential that CYP and their families, as well as professionals, know where to get information and advice from and to have a 'shared language'. Integration with other sectors, such as youth justice or voluntary organisations, is also important, but has not been specifically covered in this briefing. Important aspects of health literacy and education are:

- **Educate and engage parents** so they understand the health care system and how to navigate it, as well as how to manage their child's acute and chronic illness where appropriate and actively listen to their needs. The family cares for the child 365 days a year, while the health professionals only have a few appointments a year with them. Hence, there is a need to proactively and continuously work with the families, listen to their needs and views, and support them so they can build trust in their providers as well as the confidence to raise their concerns and self-care when appropriate. For example, a child with a chronic condition and his or her family should get to know their team of professionals (in person or virtually) who will be/may be involved in their care, so depending on the needs, they understand who can help them, when, how and how to quickly access them. *Every encounter with the family should be used as an opportunity to improve the child's health.*
- **Educate staff about the roles and responsibilities of other staff in the system.** Staff that are likely to work together in the system should also be trained together. Different professionals need to understand each other's perspectives, roles and responsibilities, and create a partnership; the goal of which is to improve the health of the child/young person.
- **Use the currently under-used and under-supported school system.** This would work through multiple channels for different groups of children (for example healthy children, children with complex needs) and would involve:
    - educating all children about the multiple aspects of their physical and emotional health and how to stay healthy, as well about the health care system and what it can do for them
    - actively working with and educating teachers to help improve the health and education outcomes of all children, as well as of children with specific health needs
    - through the children, reaching out to parents to educate them and involve them in improving care for their children.

> *"Include self-care in the national curriculum. Schools should teach parents and children about health issues and give information. This should also include community clubs so there is community child first aid; a chance to gain more knowledge. School nurses could increase training, knowledge, prescriptions – more services available through them. Create packs for parents when entering the UK containing advice on where to access health care for their children and workshops for parents run by pharmacists on how to give medication."*
>
> Quote from attendee at the RCPCH Parents and Carers Group focus session

These principles are aligned with the emerging recommendations of others on how primary care should look in the future so it can meet the needs of all citizens, not only CYP (Primary Care Workforce Commission, 2015; Rosen, 2015; Smith and others, 2013). For example, the recently published Primary Care Workforce Commission report also recommends that GP practices should have access to a named paediatrician and named children's nurse (Primary Care Workforce Commission, 2015).

While at present there is limited published evidence internationally about the different health care models for children and their effectiveness (Wolfe and McKee, 2013), the principles identified here are broadly consistent with some of the best practices in other European countries, which have started to respond to the epidemiological transition by adjusting their chronic and first-contact services in primary care, as well as moving towards integrating systems, as seen in Sweden and the Netherlands. While direct comparisons with these countries is complicated, the main principles that emerge focus on the organisation of flexible first-contact models, appropriate professional training, organisation of out-of-hours services, and task-sharing between doctors and nurses (Wolfe and others, 2013). At present there is a new EU project, MOCHA, which will be describing and comparing models of primary care and the interface with secondary care across 30 EU countries (Clinical Informatics and Health Outcomes Research Group, 2015), findings of which should also inform us in the future.

Conclusion

Although much has improved over the last few decades, many problems around the health of CYP remain unaddressed and, if not tackled, could eventually cause additional pressures on adult health and social care services. There is a need to obtain support for child health at a national level (with a national CYP strategy) and achieve a change in the culture of how CYP are viewed and the services they receive (Aynsley-Green, 2007; Kennedy, 2010). As Sir Aynsley-Green, President of the British Medical Association, put it: "nothing will fundamentally change without a revolution in the way we think about children" (Aynsley-Green, 2007, p. 60).

The new models of care discussed in this briefing provide an opportunity to improve the quality of services for CYP and increase efficiency; for professionals to develop and learn from each other, and break down barriers; and to link up not only services, but information across disciplines, professionals, patients and their families. But there are of course challenges, for example, the financially constrained environment, complex funding arrangements and inequalities in provision. Resistance to change can also be a problem, as well as maintaining the long-term motivation and engagement that is essential to bringing about systemic change. It can often be difficult for new models to demonstrate cost savings or quality improvement in the short term and a significant amount of patience is required. Having a formal vehicle through which new models can advocate for change may also be important. Finally, timely and meaningful data are essential to drive continuous quality improvement at all levels of the system.

The impact on children's health outcomes of wider social and economic problems (for example families in poverty) and government policies to address these should not be under-estimated, particularly in light of cuts to health services, especially in preventive public health, which are likely to lead to greater inequalities and harm children (Bhatia, 2015; Tennant and others, 2015). While many of the new models discussed here are medically focused, there is widespread agreement that solutions should include the wider health workforce and other sectors. There should be a system-wide framework for accountability, not just at the micro and meso level.

Local system leaders are needed who can lead across organisations for CYP – the governance needs to be right, with proper leadership at both the clinical and system-wide level. At present, care for CYP is organised through a set of systems that are not aligned, resulting in sub-optimal care and outcomes. The new models of care provide an opportunity that should not be missed.

Appendix: Summary of SWOT analysis of the 12 new models of care

STRENGTHS

- Addressing the needs of the community:
  - population focus
  - improving/providing rapid access to paediatric expertise and/or care in the community
  - improving the experience of patients and their families
  - focusing on prevention and early intervention
  - providing an appropriate service in the appropriate setting
  - multidisciplinary, multi-agency approach
  - strengthening the skills of professionals
- Building on the current service:
  - placing GPs at the heart
  - building on the current workforce
- Untapping hidden resources/reducing expenditure in secondary care:
  - reduced A&E attendance
  - reduced length of stay
  - reduced unplanned admissions
  - better use of beds
- Involving patients and their families in the design of the service
- Strong relationships and enthusiasm
- Addressing an area of national concern

WEAKNESSES

- Financial constraints
- Economies of scale
- Sustainability
- Staffing capacity
- Commissioning
- IT
- Relationships and complexity
- Governance and accountability

OPPORTUNITIES

- Improve outcomes
- Transferability to other areas/groups
- Use of federated models
- GP-led solutions can appeal to GP-led commissioners in CCGs
- Empowering and engaging patients, their families and the community
- NHS funding gap to make savings
- Linking up information and services across professionals, users and disciplines (integration through multidisciplinary teams, links with adult services, and across primary and secondary care etc)
- Technology
- Professional development
- Data and evidence to drive change

THREATS

- Financially constrained environment
- Conflict of interest (primary and secondary care divide)
- Future training and educational needs of the workforce
- System/political changes
- Sustainability
- Fragmentation
- Information governance
- Information sharing
- Broader socio-economic environment (for example families in poverty)
- Inequities
- Resistance to change
- Requires continued engagement/relationships/motivation
- Low priority

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