

The Royal College of Paediatrics and Child Health (RCPCH) welcomes the opportunity to respond to the inquiry into patient centred care in the 21st Century. Please find below a short response to your key questions. We would be very happy to provide more detail and work with Mike Farrar and the panel on the Inquiry.

1. How do models of NHS care need to change to deliver better patient outcomes, as cost effectively as possible, for the growing number of people living with multiple long-term conditions?

Compared to other equivalent European countries, the UK fares worst for all cause childhood mortality for children between 0 and 14 years of age and the key areas where the UK rates appear to be relatively high are infant deaths and deaths among children and young people who have chronic conditions¹.

Within the UK the *NHS Atlas of Variation in Healthcare for Children and Young People*² shows wide regional variation across a range of indicators, including epilepsy admissions and asthma admissions. There are also marked social inequalities in death rates³.

One in seven 11-15 year olds in England have a long term illness or disability (Health Behaviour in School Aged Children Study, 2010) and urgent attention is needed to improve prevention and care for these children and young people.

The Children and Young People's Health Outcomes Forum's consultations with children, young people and their families highlighted the following problems, which are experienced by many children and young people with a long term condition or disability and their families:

- difficulty accessing the services they need, including obtaining diagnosis and accessing expert assessment
- inconsistency in the quality and quantity of services, fragmentation of services and particularly, a lack of 'join up' between health, social services and education services
- delays in provision of services, therapy and equipment
- boundary disputes over which organisation is responsible for provision of services
- the patchiness of good practice, such as the provision of a key worker approach to help with coordination and navigation of the health, education and social care

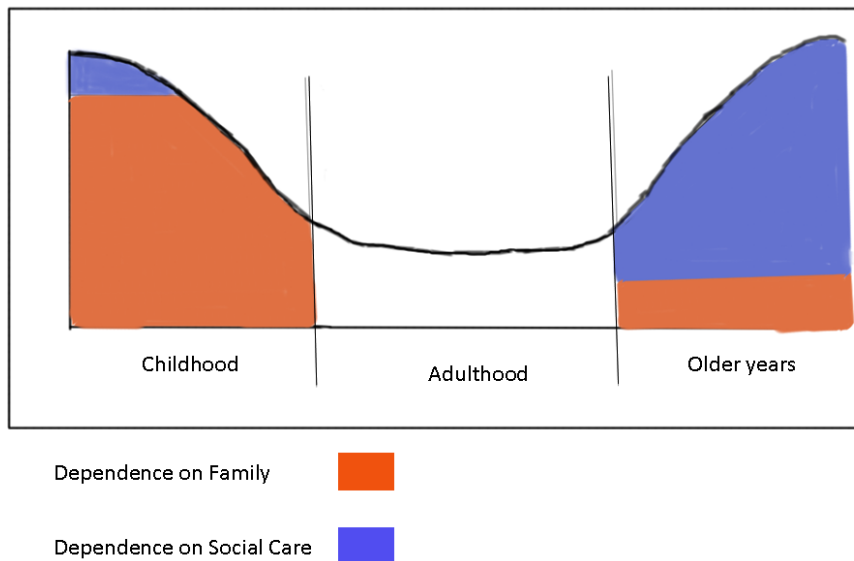
As with adults, integrated care is crucial for children and young people with long term conditions but, as shown by the diagram below, children are dependent on different care givers to the elderly so a different approach to integration of services is needed. This must focus on the integration of primary and secondary care and the integration of health and education.

¹ Wolfe, I et al (2014) Why children die: deaths in infants, children and young people in the UK

² Right Care (2012) NHS Atlas of Variation in Healthcare for Children and Young People.
<http://www.rightcare.nhs.uk/index.php/atlas/children-and-young-adults/>

³ Wolfe, I et al (2014) Why children die: deaths in infants, children and young people in the UK

Children and the elderly are dependent on different care givers, so they need different approaches to integration of services



Children and young people are heavily dependent on their families. We know that parents and children are frustrated by fragmentation and poor coordination between different services and across settings. This can lead to duplication and omission where families are forced into repeating information to different practitioners and services and consequently can be a very stressful experience of care for children and their families.

There should be an accessible and inclusive service in an appropriate setting (including appropriate provision for out of hours) for all health, education and social care needs as close as possible to the child and young person's home delivered by trained and competent professionals.

The service should be child and family centred so that families feel that they are listened to and that their specific needs are reflected in the single plan and the care that they receive. Across the range of settings, they want their care to be delivered in a coordinated way by professionals that are well trained and clinically effective. The RCPCH is calling for, just as is being proposed for the frail elderly, all children with long-term conditions to have a named doctor or health professional who coordinates their disease management. These children are vulnerable, often have complex needs and are frequently being seen by a plethora of healthcare professionals. For example 85% of children with epilepsy have developmental impairments, meaning they see a range of specialists, including paediatricians, health visitors, school nurses, geneticists and neurosurgeons. So it's crucial that there is one clinician coordinating the child's overall care so it is well planned and joined-up.

Transition to adult services is a particularly difficult time with inconsistencies in age of transfer, decisions made about transfer of clinical or care responsibility not related to need or in some cases no adult service available to transfer to. We want to highlight transition as a key area where there is a particular need for improved services. Adolescence can be a difficult transition for all young people, but there can be specific issues and challenges for young people with a long term condition or disability. Transition needs to promote the aspirations, independence and autonomy of the young person as they move to become a young adult.

The RCPCH has, and continues to develop further, strong links with the Royal College of General Practice to develop standards to improve care. The RCPCH is working with the Royal College of General Practice and the Royal College of Nursing on a new project, *Facing the Future Together for Child Health*, to ensure high quality care and diagnosis early in the pathway and to reduce unnecessary attendances at emergency departments and admissions to hospital.

The College is also building a portfolio of examples of good practice in primary/secondary care integration. For example, The Child Health General Practice Hub Model in the North West London: The hub model has been designed with patients to connect professionals from primary, secondary and tertiary care, to encourage shared learning and development, a whole person approach to caring for families, and patient, parent and professional confidence in the provision of child.

2. What does this mean for the way in which NHS resources are deployed across health economies in a financially constrained environment?

A succession of Medical Royal College reports^{4 5 6} have highlighted strong consensus amongst medical professionals and compelling evidence of the need to redesign services, concentrating specialist services into fewer centres. The RCPCH's *Facing the Future*⁷ publication makes the case for change in paediatrics. The model sees fewer, larger inpatient units which are better equipped to provide safe and sustainable care, supported by short stay paediatric assessment units (SSPAUs), networked services, and more care delivered closer to home through community children's nursing teams and better paediatric provision in primary care. To deliver the standards in care that children and their families can expect and deserve, some paediatric inpatient units must close, while increasing consultant numbers, expanding the number of nurses that work in paediatrics, expanding the number of GPs trainees undertaking posts in paediatric departments and decreasing the number of paediatric trainees.

To support healthcare organisations, the RCPCH has developed a robust, discreet and independent service review programme, using senior officers and specialist members of the College to visit services and provide feedback and advice on potential improvements. This includes addressing approaches to reconfiguration. More information is available at <http://www.rcpch.ac.uk/invitedreviews>.

The RCPCH is committed to the meaningful involvement of patients, families and the wider public in the NHS^{8 9}. The RCPCH believes patients and their families are not only beneficiaries of the NHS but also key stakeholders and therefore need to be involved in all areas of planning and service development. The RCPCH UK Youth Advisory panel and UK Parent and Carers Group actively advise

⁴ Royal College of Physicians (2012) Hospitals on the edge? The time for action. <http://www.rcplondon.ac.uk/sites/default/files/documents/hospitals-on-the-edge-report.pdf>

⁵ Royal College of Obstetricians and Gynaecologists (2011) High Quality Women's Health Care: A proposal for change <http://www.rcog.org.uk/files/rcog-corp/HighQualityWomensHealthcareProposalforChange.pdf>

⁶ Academy of Medical Royal Colleges, the NHS Confederation and National Voices (2013) Changing care, improving quality: reframing the debate on reconfiguration <http://www.nhsconfed.org/Publications/reports/Pages/Changing-care-improving-quality.aspx>

⁷ RCPCH (2011) *Facing the Future* <http://www.rcpch.ac.uk/facingthefuture>

⁸ RCPCH, NHS Confederation, Office for Public Management (2011) Involving children and young people in health services <http://www.rcpch.ac.uk/system/files/protected/page/Involving%20CAYP%20in%20Health%20Services.pdf>

⁹ RCPCH (2010) Not Just a Phase - a guide to the participation of children and young people in health services http://www.rcpch.ac.uk/system/files/protected/page/RCPCH_Not_Just_a_Phase_0.pdf

the RCPCH in its work to improve healthcare for children, young people and their families. The RCPCH also works closely with organisations representing patient and carer views and experiences of the NHS to develop standards for paediatric healthcare.

Commissioners need to engage with their Strategic Clinical Network (SCN) for Children and Young People. SCNs can advise CCGs on the best models of care for children and young people based on evidence where possible to do so.

The RCPCH has also been developing condition specific commissioning guidance, for example, for Downs Syndrome, to ensure that care is coordinated and joined up and that children and young people received the best clinical care in accordance with NICE guidance and other quality standards.

3. How can the role of general practice best be developed to support the new models of care required and what policy levers and financial mechanisms should be put in place to deliver these at the scale and pace needed?

The RCPCH is clear that closer working between child health professionals and general practice is required to ensure that children and young people are getting the right care, in the right place and at the right time.

Primary care practitioners have a crucial and unique role to play in safeguarding children as they are the most common point of contact for families. They 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, able to differentiate conditions and symptoms and have a public health and prevention (or safety-netting) approach. GP information systems also host a large amount of information about family members and GPs are well-placed to collate and disseminate this information.

There is strong demand for continuity of care from GPs¹⁰. The parents who are most satisfied with their GP/family doctors are those who receive continuity of care, and manage to build up a personal relationship over time. However, some say they see a different doctor each time they go to their local practice. It can cause additional challenges for the care of children with more complex needs or disabilities. For example, families can find themselves explaining the child's considerable medical history on each visit, and the repeated unfamiliarity of the professional can cause distress to children with neurological or learning disabilities, increasing occurrence of disruptive or challenging behaviour. It may increase the risk of 'diagnostic overshadowing' where a symptom is incorrectly identified as being a result of child's primary diagnosis or disability rather than a new illness.

The RCPCH has strongly supported the RCGP's case for the extension of GP training from three to four years, and recommend that increased numbers of GP trainees have paediatric experience as part of their rotation. Currently, a low percentage of GPs (estimated at between 40% and 50%) have specific targeted training in paediatrics rather than just experience gained during their GP registrar placement. Of those currently in GP training, 80% had less than 6 months experience in paediatrics¹¹,

¹⁰ Action for Sick Children (2013) First Contact Care Survey

¹¹ Walker V, Wall D and Goodyear H (2009) "Paediatric training for GP VTS trainees: are we meeting the requirement?" *Educ Prim Care* 20(1):28-33.

which is the time when they are best placed to become confident in the management of the acutely sick child.

Children and young people make up over a quarter of the typical GP's workload so we very much welcome that from September 2015 there will be a new course aimed at GPs to allow them to develop additional specialist skills to care for young people with long term conditions such as asthma, diabetes and epilepsy.

The RCPCH continues to work with the Children and Young People's Health Outcomes Forum on workforce and training issues.