Commissioning
Comprehensive Children’s Community Nursing services

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## Contents

**VOLUME 1  Commissioning Guidance**  
3

- Foreword  
4
- Executive Summary  
6

1. Introduction  
14

2. Policy Guidance  
17

3. The local picture in the South East  
33

4. Current National Workforce Issues  
47

5. The Vision for Comprehensive Children's Community Nursing Services  
54

6. The Nursing Workforce, Roles and Skills Mix to deliver the Vision  
57

7. Service Provision for the 4 Groups of Children and Young people  
64

8. Implications for Commissioning  
87

**VOLUME 2  Service Specification**  
95

**VOLUME 3  References and resources**  
119
In April 2013, the Strategic Clinical Networks were established to bring together clinicians, commissioners, children, young people, families and other stakeholders to develop new models of services. Our task was to address challenging issues that conspire to mean that the UK languishes at the bottom of EU league tables for a range of health outcomes for children and young people (CYP). We all want to make things better.

The network has led on a programme of work that has included a number of projects that have all aimed to improve services available to children and young people at home, school, in primary care and community settings.

Our goal has been to support the design and function of services that can provide prompt care to children and young people in a safe and effective way, keep them out of hospital whenever possible and enable their early discharge when hospital is unavoidable. We have focussed particularly on those with acute and short-term conditions, long-term conditions, complex needs and disabilities, and CYP who require palliative and end-of-life care. We are aiming to support CYP to manage their condition, improve their disease control and overall quality of life, now and in the future.

We see children’s nursing as the engine of service improvement and therefore we present a vision for modern children’s nursing as part of a cultural shift and a locality ‘Team within Teams’ model of nursing provision. We believe the future lies in the extension of nurse-led acute care in the community, alongside GPs and primary care. We believe that the future lies in well-developed community nursing for children and young people with long-term and complex conditions and disability, including those who need end-of-life care. We believe that the future lies in the close integration of these services with local authority, third sector and other organisations to ensure comprehensive, robust and sustainable care.

I hope our advice will inspire all of us to realise the potential of children’s nursing to make a real difference. I hope it will inspire us to work alongside children, their families and others to realise this vision for ourselves.

Dr Ryan Watkins
Joint Clinical Director South East Maternity, Children and Young People’s Strategic Clinical Network
Acknowledgements

The development of this document has been led by the South East (SE) Maternity Children and Young People's (MCYP) Strategic Clinical Network (SCN).

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- South East Children and Young People’s Commissioners

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- Expert Working Group – 6c CCN led by Wendy Nicholson - Professional Advisor, Department of Health
Executive Summary

Our children deserve better

Our children have the right to the enjoyment of the highest attainable standard of health and facilities for the treatment of illness and rehabilitation of health (UN 1989). Yet we know from the UK position in the child mortality rates across Europe that it is imperative that the NHS reviews and improves our approach to meeting the health and emotional wellbeing needs of children and young people, because they deserve better (DH 2012; CYP Outcomes Forum 2015).

The South East (SE) Maternity and Children and Young People (MCYP) Strategic Clinical Network (SCN) has worked to support commissioners across Kent Surrey and Sussex, in their decision-making and strategic planning for programmes of work related to out of hospital care for children and young people.

The commissioning of equitable, safe, comprehensive and sustainable children’s community nursing (CCN) is critical to realising a whole-system approach to reducing avoidable hospital attendances, delivering care closer to home and improving patient experience and clinical effectiveness 24 hours, seven days a week.

Despite innovative service models of children’s community nursing (CCN) being in existence in the UK since the late 1980s, the position in 2015 is that although there are some examples of highly successful CCN services delivering equitable, comprehensive and sustainable provision across all four groups of children, many areas are not. The SE MCYP SCN CCN audit across Kent, Surrey and Sussex identified comprehensively where we are now and what commissioners need to consider to make the case for change in developing a strategic shared vision for modern children’s nursing across all settings, and that assures improved health outcomes for children and young people.

This commissioning guidance for CCN services is made up of three volumes:

- **Volume 1** Commissioning Guidance
- **Volume 2** Service specification
- **Volume 3** References and resources

All three volumes are interrelated.
The purpose of the commissioning guidance is to:

- Support commissioners across the South East to drive forward a strategic shared vision for modern children’s nursing and whole system planning
- Support providers to clarify the current challenges within the system and deliver a safe, sustainable and comprehensive children’s nursing service across a range of settings
- Identify the benefits of building community nursing services that form an integrated part of a co-located wider network of multiagency child and family services

The commissioning guidance is divided into eight Chapters with recommendations and critical considerations set out within each chapter. The summary of these is as follows:

Chapter 1 sets the context and introduces the five SCN MCYP project work streams, which captured the extensive stakeholder evidence:

1. Acute and short-term conditions
2. Long-term conditions
3. Disabilities and complex conditions work
4. Life-limiting and life-threatening illness
5. Children’s Workforce Development

The purpose within each of the project groups was to:

- understand the current picture of services through a CCN audit
- work closely with the clinicians, children and their families to make the diagnosis of what is working and what is not, while gaining insight into current appetite for change towards forecasting a clear future for children’s nursing in line with NHS England’s Five Year Forward View
- support commissioners to develop, explore and evaluate strategic ideas and options for change

Chapter 1 – Recommendation

- Clinical Commissioning Groups (CCGs) to review the advice and take forward as appropriate the SCN programme recommendations in future planning from 2015/16 and beyond.

Chapter 2 sets out the international and national policy drivers, the professional and regulatory evidence, together with children and young people’s voices and experience. The wide ranging evidence makes clear the imperative for change.

Chapter 2 – Recommendations

- Providers should ensure that there is a named CCN team for each local GP practice or cluster of GP practices. This named CCN team should provide advice and support to GPs and Practice Nurses and act as a conduit to the CCN service.
- CCGs should move quickly to commission equitable services and ensure that each acute general children’s service is supported by a community children’s nursing service that operates 24 hours a day, seven days a week for advice and support for unscheduled and end-of-life care, with visits as required depending on the needs of the children using the service (minimum 8am to 8pm).
- CCGs should review current and future Care Quality Commission (CQC) reports across children’s services providers and specifically explore further the recommendations for community nursing services.
**Chapter 2 – Critical Considerations**

- CCGs and providers should work together to review current Royal College of Nursing (RCN) guidance and prioritise the development of a good CCN services.
- CCGs explore further how this work has a wider impact on the configuration of future services.
- CCGs and providers should act on the recommendations of the ‘Facing the Future: together for child health standards’ Royal College of Paediatrics and Child Health/Royal College of Nursing/Royal College of General Practitioners – (RCPCH/RCN/RCGP).
- Providers and CCGs should review their position against the Department of Health ‘NHS at Home’ recommendations.
- Providers should explore further the forthcoming publication of 6C for Children’s Community Nursing.
- CCGs plans should be supported by the latest ‘CYP Outcomes Forum Annual Report’ published in 2015.
- Providers should work together to share best practice.
- CCGs should consider the ‘Five Year Forward View’ in relation to CYP outcomes and changes ahead with regard to the vanguard sites to develop local models.
- NHS England will work towards using national outcome measures that join up NHS, Public Health, social care and education, and are more specific for CYP to support CCGs.
- CCGs must review current international data available to explore variations to learn from the best performers.

- CCGs and providers should develop a strategy to work towards the recommendations made in the CYP Outcomes Forum second annual report and accompanying reports.
- CCGs and providers should review national and local CYP feedback and accelerate the development of the Friends and Family test agreed by NHS England.
- Providers should move quickly to involve CYP fully in their own health and wellbeing, and in improving the services they use, involving commissioners in this process.

**Chapter 3** sets out the South East position following the comprehensive CCN audit, identification of the South East Commissioning Plans and feedback from a range of stakeholders through the project groups, engagement events and the CQC. The local evidence is complemented by insight into the local workforce issues.
The Project Working Group Key Messages

<table>
<thead>
<tr>
<th>PAST</th>
<th>CURRENT</th>
<th>FUTURE</th>
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<tbody>
<tr>
<td>No Clarity or Cohort of CYP</td>
<td>Some direction from NHS AT HOME</td>
<td>Clarity of Cohorts of CYP Acute, LTC, Disabilities, E of L</td>
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<tr>
<td>Care only in hospital</td>
<td>Care is hospital focused</td>
<td>Care Closer to Home</td>
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<td>Child only focus</td>
<td>Family Centered Care</td>
<td>Co production with CYP families</td>
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<td>Silo Working</td>
<td>Building relationships across Boundaries</td>
<td>Seamless Boundaries One Team</td>
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<td>24/7 HOSPITAL Care and GP</td>
<td>Monday to Friday Access Community</td>
<td>Seven Day Access Community</td>
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<tr>
<td>Lack of Strategy for CYP</td>
<td>Individual area Ad Hoc Plans</td>
<td>Joint Planning - Clusters</td>
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Chapter 3 – Recommendations

- Secondary, primary and community providers should prioritise a system-wide development of safety netting advice given to children and young people and their families, regardless of where and how they access care, to support self-care and effective discharge.
- CCGs and providers should involve CYP and their families in their care and support local processes to gain feedback and encourage involvement for all ages.
- CCGs should review current and future CQC reports across children’s services providers and specifically explore further the recommendations for community nursing services.
- Secondary and community providers should work with Health Education England (HEE) Kent, Surrey and Sussex (KSS) to support the development of a SE acuity tool to determine nurse workforce requirement.

Chapter 3 – Critical Considerations

- CCGs and providers should review the current SE audit findings and develop a strategy to build on the gaps in conjunction with this guidance.
- Commissioners should support the commissioners’ forum in order to maintain a consistent approach and learn from each other when prioritising the development of a comprehensive nursing community service.
- CCGs and providers must develop a joint strategy to deliver and sustain good quality services to the four groups of children.
- Providers and HEE should act now to plan for the workforce challenges ahead.
- HEE KSS should explore further how the change in the health visiting and school nursing workforce has an impact on children’s nursing.
- HEE KSS should support providers to enter the correct occupational code for the CCN workforce to allow a clear picture of current and future workforce.
Chapter 4 considers the current national workforce issues and how this informs strategic workforce planning as part of a whole-system vision of CCN commissioning.

Commissioned training places for children’s nurses have risen from 2,151 in 2013/14 to the planned 2,182 for 2014/15. However, the number commissioned for West Sussex, Thames Valley, and North Central and East Sussex have declined.

“There is no shortage of people wanting to train in the specialty, but previous cutbacks seriously restricted the numbers coming into the profession. I am concerned that there are not enough neonatal, children’s intensive care and community children’s nurses to provide the specialist care required.”

Fiona Smith, The Royal College of Nursing’s Children and Young People’s Nursing professional lead.

Currently workforce planning is not aligned to strategic plans. In March 2015 HEE published Raising the Bar following the Willis Review and although this is not a definite agreed plan at this stage, it will raise the debate of how children’s nurses are trained in the future.

Staff shortages are common across all levels of children and young people’s health services in the South East, which means there are significant challenges to providing safe and sustainable, 24-hour services across the current configuration. Registered children's nurses are critical to the delivery of skilled, child-focussed healthcare.

In addition, overseas children’s nursing training is not recognised in the UK, thus requiring nurses from overseas to be supervised. This makes recruiting nurses from other nursing disciplines and from overseas more difficult and potentially less cost-effective.

There are also limited training opportunities for nurses to develop as either specialists or advanced nurse practitioners. Children’s nurses working at specialist, advanced and consultant level can make a significant contribution to the redesign, development and delivery of children and young people services (RCN 2014).

Chapter 4 – Recommendations

• HEE KSS should support providers through the CYP Programme Board to support the outcomes of the Shape of Caring Review in relation to children’s nursing.

Chapter 4 – Critical considerations

• Providers should explore further the use of new technology to collect data to reflect workforce practices and activity data.

• CCGs, HEE and providers should review the current ‘Consider the Workforce Education and Training Theme Group’ report from the CYP Outcomes Forum.
Chapter 5 sets out the vision for comprehensive, needs-led children’s community positioned nursing services, encompassing considerations for clinical care, workforce and positive child and family experience. The locality arranged ‘Teams within Teams’ service model is proposed. Local and national evidence suggests that the components of an equitable, safe, comprehensive and sustainable CCN service include the following:

**Components of a comprehensive needs-led CCN service**

<table>
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<tr>
<th><strong>Access scope</strong></th>
<th><strong>Integrated delivery</strong></th>
<th><strong>Sustainable service</strong></th>
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<tr>
<td>for CYP groups (0-24yrs) seven days 8-8 visits 24hr end-of-life care</td>
<td>that is locality and community positioned</td>
<td>models and skilled workforce</td>
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<tr>
<th><strong>Collaborative relationships</strong></th>
<th><strong>Supported by technology</strong></th>
<th><strong>Clinical nursing leadership</strong></th>
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<td>Agreed care pathways</td>
<td>innovations and performance data review</td>
<td>Robust clinical governance, supervision and education frameworks</td>
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**Chapter 5 – Recommendation**
- Community and secondary care providers should support CCGs to explore further the concept of ‘Teams within Teams’ across localities to facilitate a sustainable model that is productive and equipped for multiagency integration.

**Chapter 6** provides detail on the role of the children's community nurse, and specialist and advanced children's nursing practice in contemporary health care. Guidance on skill-blended options is also presented to inform an effective service model.

**Chapter 6 – Recommendations**
- Secondary and community providers need to reassure CCGs and HEE KSS that their services are needs-led and skill-blended with a competent workforce.
- HEE KSS should accelerate the need for clearly defined education and training programmes to support the additional nurses, assistant practitioners and health care assistants, who will be required to work within the CCN teams.

**Which children does a CCN service provide for?**

The Department of Health NHS at Home (2011) report identified the four groups of children and young people a comprehensive CCN service should provide for:
- Children with acute short-term conditions – part of the urgent/unscheduled care pathway
- Children with long-term conditions
- Children with complex needs and disability, including continuing care
- Children with life-limiting and life-threatening conditions.
Chapter 7 details who the children are, the nursing interventions required and what good provision looks like for each group.

Chapter 7 – Recommendations

- CCGs should accelerate the development of a sustainable and preventative model of home and school-based nursing provision, reflecting principles of admission avoidance and effective and safe discharges.
- Secondary, primary and community providers should prioritise the system-wide development of safety netting advice given to children and young people and their families, regardless of where and how they access care to support self-care and effective discharge.
- Secondary and community providers should work together to form an agreed approach to discuss clinical effectiveness, audit, critical incidents and complaints to assure CCGs on quality improvement for children’s nursing.
- CCGs and NHS England should accelerate the development of the PACE Setter Award using the Step by Step Guide to support pathways and primary care quality standards.
- Local authorities and universal services providers need to work with NHS England to review current health visiting and school health nursing specifications, considering this guidance to ensure there is no duplication and that it promotes joined up working across professionals.
- Community and secondary care providers should support CCGs to explore further the concept of ‘Teams within Teams’ across localities to facilitate a sustainable model that is productive and equipped for multiagency integration.
- CCGs should work with local authorities to ensure there is an agreed understanding for health providers to have a named special school nurse with a clinical and public health skill set for each Special School and access to a pharmacist advisor.
- CCGs should move quickly to commission equitable services and ensure that each acute hospital has access to a CCN service that operates 24 hours, seven days a week for end-of-life care.
- Kent Surrey, Sussex collaborative agree a three tier model of commissioning for CYP palliative and end-of-life care.

Chapter 7 – Critical Considerations

- Care pathways for long-term conditions should clarify roles and outcomes using clinical nurse specialists and CCN specialist practitioners to ensure business continuity across primary, secondary and community providers.
- CCGs and providers should work with Together For Short Lives.
- Providers should build on current strategies to increase good practice in advance care planning for CYP.
- CCGs and providers have to accelerate discussions on the implications of the 2015 NHS England report “Developing a New Approach to Palliative Care Funding.”
Chapter 8 outlines the implications for commissioning. A comprehensive CCN service that forms an integrated part of a co-located wider network of multiagency child and family services presents particular challenges for commissioning for sustainability. This perhaps suggests in part why the current CCN service commissioning profile across the South East is so vastly inconsistent.

There are at least 30 funding streams necessary for a comprehensive CCN service with sub-specifications. For example, continence and continuing care, and the critical inter-relationships with commissioning for other CYP services.

To ensure the vision becomes a reality, there would need to be changes in how providers are incentivised and contracted to deliver integrated care pathways and joint outcomes for the child and family. Examples of what different contractual models of commissioning might look like are presented.

Chapter 8 – Recommendations

- CCGs should develop a strategy for children’s nursing services across primary, secondary and community services for CYP aged 0 to 25 years population, with an action plan for each year.
- Community and secondary care providers should support CCGs to explore further the concept of ‘Teams within Teams’ across localities to facilitate a sustainable model that is productive and equipped for multiagency integration.
- Local authorities and universal services providers need to work with NHS England to review current health visiting and school nursing specifications, considering this guidance to ensure there is no duplication and that it promotes joined up working across professionals.
- CCGs should move quickly to commission equitable services and ensure that each acute hospital has access to a community children’s nursing service that operates 24 hours, seven days a week for unscheduled and end-of-life care.
- CCGs, secondary and community providers should prioritise the development of a data management system (such as a dashboard) to reflect the baseline KPIs suggested in the specification.
- Providers to develop a single plan for health conditions shared across the system.

Chapter 8 – Critical Considerations

- CCGs should ensure that financial incentives in the health system are evolved to encourage innovation and development that delivers the types of services CYP want.
- CCGs and providers should review the outputs from an expert Payment By Results (PBR) group.
- CCGs and providers should review Commissioning for Quality and Innovation (CQUIN) payments for CYP and collectively work towards improvements in quality.

Volume 2 sets out the service specification using the national commissioning service specification template and should be read alongside the NHS Standard Contract Technical Guidance and the Commissioning Guidance.
Strategic Clinical Networks (SCNs) locally and nationally have brought together clinicians and patients to provide strategic advice on what good looks like in areas of particular healthcare challenge. The South East (SE) Maternity and Children and Young People’s (MCYP) SCN has worked to support local commissioners in their decision-making and strategic planning for programmes of work related to Children and Young People’s (CYP) out of hospital care.

The purpose of this guidance is to:

- Support commissioners across the South East to drive forward a strategic shared vision for modern children’s nursing and whole-systems planning, underpinned by quality, training and education, applying commissioning levers to ensure effectiveness of CCN services.
- Support providers to clarify the current challenges within the system and to deliver a safe, sustainable and comprehensive children’s nursing service across a range of settings.
- Identify the benefits of building community nursing services that form an integrated part of a co-located wider network of multiagency child and family services.

Over a period of 23 months, the MCYP SCN has developed a network of engaged stakeholders for our children and young people’s programme of work. The clinical leads were appointed in February 2013.

The Clinical Advisory Group has been established since November 2013. This group has been invaluable to this programme in driving the improvements required. Working group webinars and meetings have been running since June 2014. In addition to the programme the SCN has been sharing best practice and endorsing the development and implementation of acute care high volume pathways to encourage timely and effective care out of hospital.

This SCN programme, originally referred to as ‘Moving the Clinical Care of Children and Young People from Secondary Care to Community and Primary Care Settings,’ has supported further CCN development with an agreed joint approach to commissioning care closer to home for children and young people across the SE and will enhance, develop and define a way forward to:

- Improve the experiences of children, young people and their families
- Deliver care across integrated services including primary, secondary and in some cases tertiary care, transition into adult services and children's social care, education and housing services

The programme has brought together for the first time clinical experts and commissioners across the South East to determine what it would mean to implement a model of care building on the 2011 NHS at Home Department of Health publication. This guidance is based on the current landscape and information available at the time of writing. It is envisaged that this work will require on-going large scale transformational change, resulting in shifting the balance of care from acute to primary and community settings.
The outputs of this programme have been documented in the SCN two year business plan programme and projects 2014-2016. The programme’s overall aim is to support a reduction of inappropriate paediatric attendances and admissions to secondary care. There were two phases to this work. Phase 1 included the baseline review of services from March to May 2014 by scoping existing NHS at Home models (using a Sussex audit as the basis).

Phase 2 was working with the five project groups listed below to agree a CCN service model and associated service specification.

1. Acute and short-term conditions
2. Long-term conditions
3. Disabilities and complex conditions
4. Life-limiting and life-threatening illness
5. Children’s Workforce Development

The MCYP SCN has taken the following approach:

1. Understand the current picture of services through a CCN audit
2. Work closely with the clinicians, children and their families to make the diagnosis of what is working and what is not, while gaining insight into the current appetite for change
3. Work towards forecasting a clear future for children’s nursing in line with NHS England’s Five Year Forward View
4. Support commissioners to develop, explore and evaluate strategic ideas and options for change

Our Project Working Groups, Clinical Advisory Group insight and soft intelligence have told us that:

- Children and young people who experience ill-health and disability are faced with significant variability of service provision across the SE (for example, some 24/7 services, some Monday-Friday 9-5, some not in existence) and this contributes to less positive outcomes and experiences.

- There is a long-standing and continuing lack of understanding of providing care closer to home, which includes the early year’s settings and school for CYP with nursing needs. In the past this was driven by a lack of investment in community services with the pathway focused on acute care delivery.

- Different types of contracts and out of date specifications exist. There is inequitable access and evidence of a variable workforce. For further information see Chapter 5 Volume 1 and Appendix 1.

- There has been some attempt to commission NHS at Home or make plans to build comprehensive services but this is on an ad hoc basis and not all CCGs have identified CCN services as a priority in their commissioning plans.

- Children’s nursing services have been unable to progress for many reasons such as; lack of integration across sectors, inequitable and fragmented services and no children’s nursing workforce plan aligned to a wider nursing strategy.
Stakeholders would like to see the following in place:

- Further Integration across health, education and social care
- Equitable delivery of service to all families
- An agreed children’s nursing strategy with a workforce and education plan for the next five years and beyond
- A jointly produced CCN NHS specification that builds on a shared vision for modern children’s nursing across primary, secondary and community care

Following publication of this commissioning guidance, there is an expectation that commissioners will continue to:

- Engage with local stakeholders to set the direction for children’s nursing locally and build a coherent children’s nursing strategy focused around other children’s services.
- Work with providers to support the proposed recommendations to take CCN services forward into the modern NHS.
- Review locally the rights, pledges and commitments for children and young people when using the NHS in England. Children and Young People expect equitable access to services, safe clinical care, advice on wellbeing and prevention, excellent communication, involvement in their care, collective involvement in wider services, integration and transition, with a complaints procedure that meets their needs.
- Review on-going national and local policy and guidance, and adapt to local needs. The current guidance is referred to in Chapter 2.

Recommendations

CCGs to review the advice and take forward as appropriate the SCN programme recommendations in future planning from 15/16 and beyond
Policy Guidance

International

The Royal College of Paediatrics and Child Heath has published a vision for 2015 called Making the UK’s child health outcomes comparable to the best in the world. It states that the Government needs to commit to action in the following five areas:

1. Prevent children and young people from becoming unwell, act early and intervene at the right time
2. Tackle child health inequalities
3. Reduce the number of child deaths
4. Make the NHS a better place for children and young people
5. Involve children and young people in decision-making on health and wellbeing issues

The 2015 Report of the Children and Young People’s Health Outcomes Forum states that if we compare ourselves with Sweden, the country with the lowest mortality rate for children and young people (after allowing for population size among other variables), we find that in the UK five children under the age of 14 die every day who would not die in Sweden. This equates to the alarming figure of 132,874 years of life being lost each year in the UK, the majority of which would be as healthy adults contributing to the country’s social and economic strength.

Our Children Deserve Better, published in 2012 by Dame Professor Sally Davies (Chief Medical Officer), clearly and compellingly articulated the need for all parts of the NHS to review and improve our approach to meeting the health and emotional well-being needs of CYP. This again highlights the difference between other countries and the UK showing morbidity and inequality (when compared with similar countries).
The CYP Outcomes Forum Second Annual Report explains that emergency hospital admissions from all causes in CYP (aged 0 to 19 years) have continued to rise. The rate has fluctuated in recent years with no clear trend. Preschool and late teenage groups remain the most likely to be admitted. However, specific subgroups of hospital admissions are rising, for example, admissions for respiratory infections in those aged under the age of five.

Although this is due to a combination of public health factors and community care, the mean duration of hospital admission within a region seems to inversely correlate with regional admission rates. This supports the role of health care factors rather than other determinants of health as an explanation. The “deprivation gap” for overall hospital admissions widens during adolescence: the most deprived quintile of adolescents is twice as likely to be admitted than the least deprived, which is a much larger deprivation gap than for any other age group.

This second annual report states that emergency department attendance rates among CYP in England have risen year-on-year and were 40 per cent higher in 2011/12 than in 2007/8. The deprivation gap in attendances is preserved over the past five years, reflecting a universal increase in the use of A&E services.

The CYP Outcomes Forum Second Annual Report concludes that:

- Progress on child and adolescent mortality has been on a downward trajectory in the past 40 years relative to comparable countries, including those in the European Union.
- Other indicators of child health and healthcare have shown progress in some areas since the inception of the CYP Outcomes Forum, but these are accompanied by worrying negative trends in others.
- Geographical variation and disparities among different socioeconomic groups persist, and in some areas are worsening.
- Key priority areas must be: mortality from non-communicable diseases, geographical variation, health inequalities among socioeconomic groups and the rising use of urgent/emergency healthcare among all age groups, in particular those with long-term conditions.
### CYP

There are over 15 million under 20s in England accounting for nearly 25 per cent of the population and of these

- 6 per cent have a disability
- 14 per cent have a long standing illness
- Over 10 per cent have asthma
- 66,000 have autism
- 60,000 have epilepsy
- 23,000 have diabetes
- 68,840 are looked after (31 March 2014)
- 48,300 are subject to a child protection plan (31 March 2014)

*Source: Children and Young People’s Outcomes Forum (2015)*

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### PRIMARY CARE

CYP are 25 per cent of a GP population but 40 per cent of its workload, young children being particularly frequent users

- 80 per cent of all illnesses in childhood are managed by families at home
- children under the age of five will see a GP approximately six times a year
- children over the age of five will see a GP two to three times a year
- 25 per cent of calls to NHS Direct involved children - *Source: British Journal of Medicine, Young people's use of NHS Direct: a national study of symptoms and outcome of calls for children aged 0–15 (2013)*

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### A&E

- Under 20s account for over 4.9 million (26.5 per cent) of A&E attendances each year compared to 3.6 million (19.4 per cent) A&E attendances by those aged over 65 (HES 2012/13). Attendances have risen over 40 per cent from 2007/8 to 2010/11.
- Up to 50 per cent of children under the age of one and 25 per cent of older children attend an A&E each year.
- 75 per cent seen in A&E are fit enough to be discharged home.
- 1 in 20 children with head injury are admitted, meaning 19 in 20 are sent home.

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### HOSPITAL ADMISSIONS

- 5 per cent of the NHS budget is allocated to children’s healthcare.
- 1 in 11 children will be referred to a hospital Out Patient Department
- 1 in 10 to 15 will be admitted to hospital.
- more than one third of short-stay admissions in infants are for minor illness that could have been managed in the community.
- the majority of children’s admissions to hospital, including a significant amount of surgery in childhood, are unplanned.
Royal College of Nursing (RCN)

The Royal College of Nursing provides a contemporary perspective of children and young people’s nursing in primary and community settings, emphasising the crucial role of CCN (RCN 2014).

To deliver good CCN services, the RCN believes that:

- Every child and young person has the right to expect care to be provided at home and supports the care of ill and disabled children being delivered closer to home, where it is clinically appropriate and safe to do so;
- CCN services that provide for all ill and disabled children will deliver meaningful health outcomes;
- Children, young people and their families, as experts of experience, should be consulted throughout service planning and development and be at the heart of decision-making about their own/their child’s health;
- Children’s nurses play a pivotal role in the delivery of clinically appropriate and safe care across the health and social care continuum;
- Learning disability nurses with specific child health knowledge and skills also play a central role in the lives of children and young people with learning disabilities, within a needs-led skill-blended CCN service;
- Providers and commissioners of health care services must undertake robust children’s services workforce planning to reduce the likelihood of a diluted children’s nursing workforce and inappropriate skill mix;
- A whole-system approach is needed to shift care out of hospitals and re-provide services in the community;
- Integration and co-ordinated care improves continuity, reduces fragmentation within the health and social care systems and delivers good patient outcomes; and
- Collaboration between local authorities, commissioners, service providers and frontline staff has been instrumental in delivering successful integrated care models.

Aligned to the drive to nurse children at home, the shift of care from acute hospitals to community settings is both a global trend and an international priority (RCN, 2013b). The importance and value of nursing children at home has been recognised nationally and internationally for more than 50 years in a variety of channels; government policy, professional bodies, voluntary sector organisations and research evidence (see Table 1).
<table>
<thead>
<tr>
<th>AUTHOR</th>
<th>TITLE/COUNTRY</th>
<th>DATE</th>
<th>KEY MESSAGES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ministry of Health</td>
<td>The welfare of children in hospital: the Platt report</td>
<td>1959</td>
<td>Children should not be admitted to hospital if it can be avoided.</td>
</tr>
</tbody>
</table>
| House of Commons Health Select Committee | Health services for children and young people England | 1997   | All children requiring nursing should have access to a CCN service staffed by qualified children’s nurses wherever they live.  
  - This service should be available 24 hours a day, seven days a week.  
  - Every GP should have access to a named community children’s nurse. |
| Department of Health/Department of Education and Skills | National service framework standard 6: children and young people who are ill England | 2004   | Children and young people who are ill should receive timely, high quality and effective care as close to home as possible.                                    |
| Welsh Assembly Government  | National service framework for children, young people and maternity services in Wales | 2005   | A CCN service supports the child’s right to care at home and reduces avoidable hospital admissions.                                                                                                           |
| Royal College of Nursing   | A child’s right to care at home | All four countries | 2009 | Every child has a right to expect care to be provided at home unless they need to be admitted to a hospital environment.  
  - Appropriate help and support from a CCN team should be available for parents/families to enable them to care for their child at home. |
| Royal College of Nursing/Well Child | Better at home campaign | All four countries | 2009 |  
  - Timely, high quality and effective care to be delivered in the home where possible.  
  - Packages of care should be provided that co-ordinate health, social care and education in a way that meets the individual and on-going needs of the children and their families.  
  - Greater financial investment in children’s nurses to work specifically with this group of vulnerable children and bridge the gap between hospital and community services. |
| Department of Health       | NHS at home: children’s community nursing services Country? | 2011   | Currently, few local community children’s nursing services are able to meet the needs of all ill and disabled children and young people. CCN services are the bedrock of the pathways of care Identification of what safe and sustainable CCN services look like. |
| Department of Health       | Recommendations to improve children and young people’s health results: independent report | All four countries | 2012 | The NHS and social care have been designed around the system rather than the individual; the system feels fragmented to children and young people and their families who have to tell their story repeatedly, striving to be heard and get the joined up care they need.  
  Designing and planning health and health care round the needs of the individual child or young person, taking account of their changing needs over time, will improve their experience of the service and their health outcomes – not just at a point at time, but for the longer term – and improve their lives enormously.  
  Since this publication there have been two further Annual Reports in 2014 and 2015 |
| Royal College of Nursing   | Moving care to the community: an international perspective | All four countries | 2013 | A whole system approach is needed to effectively shift care out of hospitals and provide these services in the community. Nurses play a pivotal role in supporting and promoting better co-ordinated care.  
  - Where integrated care models have been successful, there is evidence to show that close collaboration between local authorities, commissioners, service providers and frontline staff have been instrumental in that success.  
  - Investments must be made to strengthen the community nursing workforce and priority must be placed on enabling and supporting nurses through education, training and developing leadership skills to ensure the right nurses with the right skills are leading the way. |
Critical considerations

CCGs and providers should work together to review current RCN guidance and prioritise the development of a good community children’s nursing (CCN) services

Royal College of Paediatrics and Child Health

Teams across SE with others across the UK completed a Royal College of Paediatrics and Child Health (RCPCH) Survey on Community Children’s Nursing Teams during May 2014 and there were 70 responses received. These results below are a reflection of all teams being set up differently. This is why across the SE we need to have consistency in teams and commission for outcomes and have an agreed specification. Survey feedback is outlined within Table 2.
Table 2: Survey feedback

<table>
<thead>
<tr>
<th>SURVEY FEEDBACK</th>
<th>WHAT DO WE NEED TO DO?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only 35.3 per cent of respondents stated that they work office hours on weekdays only.</td>
<td>CCGs need to be aiming for seven-day services</td>
</tr>
<tr>
<td>All respondents stated that they provide services for all categories listed; acute, long-term conditions, disabilities and complex conditions but the highest majority (87.5 per cent) was children with life-limiting and life-threatening illness, while 46.9 per cent of respondents said that they spent 25 per cent of their time on care for children with acute and short-term conditions.</td>
<td>CCGs need to ensure all four categories have equitable access</td>
</tr>
<tr>
<td>74.6 per cent of respondents said they provide services enabling early discharge for children with acute and short-term conditions.</td>
<td>CCGs need to ensure 100 per cent access to early discharge services and 100 per cent provision of education to parents with acute short-term conditions</td>
</tr>
<tr>
<td>73 per cent of respondents said they provide education and training for children and parents for children with acute and short-term conditions.</td>
<td>CCGs need referrals to be widened from other professionals and services</td>
</tr>
<tr>
<td>96.8 per cent of referrals are made via children’s unit/hospital, whereas only 6.3 per cent of respondents say referrals are made via NHS 111/24/Direct.</td>
<td>CCGs need 100 per cent access to early discharge services and 100 per cent provision of education to parents with acute short-term conditions</td>
</tr>
<tr>
<td>50 per cent of CCNTs surveyed were located within children's unit/hospitals. This means that the other 50 per cent were located in community.</td>
<td>CCGs need to consider current team provision and collaborative approaches between providers</td>
</tr>
<tr>
<td>85.7 per cent of respondents said they get emergency advice via the on-call registrar/consultant.</td>
<td>CCGs should aim for access to on call advice</td>
</tr>
<tr>
<td>In terms of urgent (non-emergency) advice, 77.8 per cent of respondents said they get advice via telephone and 58.7 per cent via email. The majority of this advice is given by either a paediatric consultant or a senior trainee. 47.5 per cent of respondents stated that this advice was available 24 hours, seven days a week.</td>
<td>CCGs need to ensure that CCNs get access to advice 24 hours, seven days a week</td>
</tr>
<tr>
<td>22.2 per cent of respondents have a named CCNT for each GP surgery in their area, with only 1.6 per cent of respondents having a named children’s nurse specialist for each GP surgery in their area. The role involves accepting referrals, assessment of care, home visits, intervention of care, discharge and documentation, family support, respite care, joint liaison with partner agencies, information and research, educational competencies and training.</td>
<td>CCGs need to ensure that each GP surgery has a link CCN team</td>
</tr>
<tr>
<td>CCNTs support local preventative measures and education by engaging with local school nurses and health visitors (68.3 per cent) as well as developing and providing information leaflets about conditions and self-care (54 per cent). Only 11.1 per cent of respondents mentioned engaging with local pharmacies.</td>
<td>CCGs need CCNs to support universal services and other professions</td>
</tr>
<tr>
<td>Open access policy that allows the child to return to the unit for further assessment and treatment if the family think that the child's condition has deteriorated since returning home.</td>
<td>CCGs need to ensure safety netting advice is given to parents</td>
</tr>
<tr>
<td>Hospice at home service provides 24/7 on call access to families for telephone advice and support and visits.</td>
<td>CCGs need to commission 24/7 end-of-life care</td>
</tr>
</tbody>
</table>
This work will require discussions around the wider configuration of children’s services and cannot be done in isolation. The Royal Collage of Paediatrics and Child Heath have published a position statement on reconfiguration. Their key principles for reconfiguration must be considered; think differently, unite the clinical community, demonstrate partnership between primary and secondary care, unite the political community, engage early, use appropriate language and communication depending on the audience, safe and high quality services that are accessible must be a priority, consider the wider impact of reconfiguration, establish and maintain relationships, and honesty is imperative.

In May 2015 the Royal College of Paediatrics and Child Health/Royal College of Nursing/Royal College of General Practitioners (RCPCH/RCN/RCGP) launched Facing the Future: Together for child health, which sets out new standards that apply across the unscheduled care pathway to improve healthcare and outcomes for children, focusing on the acutely mild to moderately unwell child. The 11 standards are themed around:

- Supporting primary care to care safely for the child in the community, preventing unnecessary attendance at an emergency department or unnecessary admission to hospital.
- Reducing length of stay where children are admitted to hospital and enabling these children to go home again as safely and as quickly as appropriate (whilst preventing unnecessary re-attendances and readmissions).
- Connecting the whole system, streamlining the patient journey and improving patient experience.
Commissioning a 24/7 service

There has been much debate and emerging evidence around a 24/7 CCN service, which started at the House of Commons Select Committee in 1997 (see table 1) and has been reviewed within the latest RCPCH/RCN/RCGP unscheduled care standards mentioned above.

The determinants of 24/7 as they are advised in 2015 are as follows:

- There needs to be 24 hours a day, 365 days a year access to end-of-life nursing care for children and young people at home if that is the families choice (DH/NHS England).

- There needs to be 24 hours a day, 365 days a year access to children's community nursing advice and support for unscheduled care, with as a minimum visits from 8am to 8pm, seven days a week (RCPCH/RCN/RCGP).

- There needs to be 24 hours a day, 365 days a year access to children's community nursing advice and support for children with long-term conditions, complex needs and disability, with, as a minimum, visits from 8am to 8pm, seven days a week (NHS at Home DH).

Recommendations:

- Providers should ensure that there is a named Children’s Community Nursing team for each local GP practice or cluster of GP practices. This named CCN team should provide advice and support to GPs and Practice Nurses and act as a conduit to the Children’s Community Nursing service.

- CCGs should move quickly to commission equitable services and ensure that each acute general children’s service is supported by a community children’s nursing service which operates 24 hours a day, seven days a week for advice and support for unscheduled and end-of-life care, with visits as required depending on the needs of the children using the service (minimum 8am to 8pm).

Critical Considerations

- CCGs should explore further how this work may have a wider impact on the configuration of future services

- CCGs and providers should act on the recommendations of the Facing the Future: together for child health standards (RCPCH/RCN/RCGP).
In 2011, The Department of Health set out the following recommendations in the publication of NHS at Home. These still apply today.

- Families can rely on services that are accessible, equitable, comprehensive, sustainable and flexible for all children and young people with a nursing need regardless of geography or diagnosis.
- Families are able to put being parents first and healthcare providers second and are confident they have the skills to care for their child through a genuine partnership with health professionals.
- Implicit in this is that parents are kept fully informed about their child’s diagnosis, complications and what to look for.
- Advocacy is offered where the views of children and young people and their families are different or where they need someone else to speak to on their behalf or represent them.
- Families experience a co-ordinated seamless service that is centred on parental choice and decision-making, personalised to the individual child and family, and promoting independence and quality of life.
- Children and young people are admitted to hospital or stay in hospital only when it is clinically unsafe to care for them in the community.
- Children in need of a comprehensive care package will experience fewer hospital admissions and fewer visits to accident and emergency departments for crisis management.
- Children with complex needs who are vulnerable to infection are protected from healthcare acquired infection.
- Families have reliable, simple and easy access to the resources required to provide optimal care for their child, allowing them to focus on caring for their child and spending more time being a family (for example, information and equipment).
- Families have a genuine choice about end-of-life care, acknowledging the preferences of the child/young person and of the families.

**Critical Considerations**

- Providers and CCGs should review their position against the 2011 Department of Health NHS at Home recommendations.
- Providers should explore further the forthcoming publication of 6C for Children’s Community Nursing.
- CCGs’ plans should be supported by the latest CYP Outcomes Forum Annual Report published in March 2015.
In 2014 Dr Shribman’s final report, *Getting it right for children & young people* (including those transitioning into adult services): a report on CQC’s new approach to inspection, resulted in 73 recommendations, a number of which formed the basis of two successful pilot inspections of specialist children’s hospitals (Sheffield and Alder Hey) that took place in May-June 2014. This includes examples of what good looks like for CYP services, what you would expect from an outstanding service and what would indicate that a service needs improvement. This report recommends that the CYP inspection sub team should always speak to a community children’s nurse even if they are employed by another Trust. The community inspection programme needs to comprehensively capture children’s services across secondary and community care and this should reflect the importance of pathways of care.

To get to the heart of how CYP use services and experience care, *The Care Quality Commission (CQC)* always asks the following questions of every service provider or service: and gives an overall rating:

1. Overall rating for Community health services for children, young people and families.
2. Are Community health services for children young people and families safe?
3. Are Community health services for children, young people and families effective?
4. Are Community health services for children, young people and families caring?
5. Are Community health services for children, young people and families responsive?
6. Are Community health services for children, young people and families well-led?

**Recommendations**

- CCGs should review current and future CQC reports across children’s services providers and specifically explore further the recommendations regarding community nursing services

**Critical Considerations**

- Providers should work together to share best practice.
NHS England - Five Year Forward View

Within NHS England, not all policy is directly related to CYP. However, if we are aspiring to achieve the models in the Five Year Forward View and make it a reality we must be horizon scanning and networking to review the outcomes and changes ahead with regard to the phase one vanguard sites.

The outcomes from the Five Year Forward view will only set the current challenges, but as more evidence becomes available to support commissioners and providers we need to ensure that plans are in place to improve care for the CYP of today and tomorrow.

Currently, the NHS England Business Plan focuses on the CYP pledge:

1. Best practice guidance to support the implementation of the suite of recommendations from reviews across maternity and children and young people services produced by April 2015.
2. Develop guidance for CCGs to ensure children with Special Educational Needs (SCN) have access to services in their care plan based on a single assessment across health, social care and education by March 2015.
4. Develop an implementation plan for the Children and Young People Pledge and implement key aspects of the pledge on behalf of the organisation by March 2015.
5. Create a safety net of care by coordinating within and across systems with identified professions to deliver a safe effective response to care that follows the child or young person on their journey in their communities.

National Frameworks

The Children's Community Nursing Service within a vision for Modern Children’s Nursing will support delivery against the NHS and PHE Outcomes Frameworks and the 2013/14 indicators as described in the service specification. Further information is available in the 2015/16 NHS Outcomes Framework. The latest data on the Public Health Outcomes Framework is useful in terms of accident and emergency for 0 to 4 year old attendances. All of the Public Health Outcomes can be viewed within the SCN Profile for 2014. For further Information and benchmarking use the CYP Health Benchmarking Tool.
CYP Outcome Forum

The work of the Children and Young People Health Outcomes Forum has championed the need to focus on children and young people’s outcomes. The second annual report for 2015 was published on 10 March 2015 and looks at the forum’s impact since it was established in January 2012, as well as looking ahead to what the forum thinks the next Government should do to improve children and young people’s health outcomes. Accompanying the Annual Report are six theme group reports and two separate papers that set out key questions and challenges with examples of good practice.

Patient-Centered Outcome Measures

NHS England has announced that there will be seven sites across the country chosen to develop Patient-Centered Outcome Measures (PCOMs) for children and young people with a range of health conditions, including, asthma, complex respiratory conditions, palliative care and for the users of wheelchair and posture services. The outcomes of this work must be reviewed and adapted for local use.

Critical Considerations

- CCGs should consider the Five Year Forward View in relation to CYP outcomes and changes ahead with regard to the vanguard sites to develop local models.
- NHS England will work towards using national outcome measures that join up NHS, public health, social care and education and be more specific for CYP to support CCGs.
- CCGs must review current international data available to explore variations to learn from the best performers.
- CCGs and providers should develop a strategy to work towards the recommendations made in the CYP Outcomes Forum second annual report and accompanying reports.
National CYP Voice

The Royal College of Paediatrics and Child Health in 2011 reported that only 64 per cent of commissioners engaged with children and young people in reviewing their experiences.

The Patient Experience Network (PEN) concluded that even though many NHS organisations had grasped the importance of patient experience and planted this within their cultures, there is still variation, even within particular organisations, and work is still required to implement this within cultures. A PEN survey showed that less than half the respondents had a precise strategy to improve patient experience to include engaging directly with children and young people.

Significant work is being done at a national level to engage with children and young people. For example, roll out of the Friends and Family Test this year, Care Quality Commission feedback from CYP and their families and the launch of the NHS England Youth Form in March 2014. However, there are still improvements to be made. The following key questions and challenges have been raised within the Children and Young People’s Health Outcomes Forum 2014/15 theme group report on Culture and Engagement and Voice.

1. The needs of children and young people need to be reflected in services
2. Children and young people’s engagement in their own care must be supported
3. There must be leadership and accountability, nationally and locally for children and young people’s participation
4. Equality must work in the participation agenda
5. There will be a review/refresh of the You’re Welcome standards to create a youth health offer
6. Local Authorities Education, Young People’s Councils, Youth Parliaments and Young People’s champions need to interface and work with health and wellbeing boards
7. Creating a children and young people friendly culture
8. Ensuring the rights of CYP articulated in the United Nations Convention is realised
Children and Young People nationally have expressed the following:

- I want nurses and doctors who listen and act skilfully
- I want a nursing service that meets my needs
- I want to tell my story once
- I want nurses to help me to feel safe to help manage my health condition
- I want nurses who do what they say they will do
- I need to feel confidence in a trusted nursing service
- I want a nursing service that is responsive to my family needs
- I want quick access to nurses and doctors who are knowledgeable

The Association of Young People’s Heath carried out an online national survey in October 2014 in which ninety-eight young people responded. This evidence concluded that young people are keen to provide input into the design and commissioning of health services intended for them. They were generally positive of the health services they used but saw room for improvement and wanted a chance to input their views. This survey highlighted the importance of improving our accountability systems and complaints procedures in relation to young people.
What children and young people and their families and carers expect from CCN Services

In April 2009 Professor Bernie Carter and Dr Jane Coad carried out an appreciation review of Children’s Community Nursing (CCN) services in England involving professionals, families and CYP, looking at what works well now, what could work better and the visions for the future.

**Review of CCN Services - Families Feedback**

### User Centred Service
- Attributes of a CCN and good will
- Current delivery of CCN

### Could be better
- Under pressure and lacking options
- Diversity, deficits/discrepancies and lack of definition
- Commissioning and lack of funding

### Visions for future
- Genuine partnerships with families
- CCN to have a strong corporate identity
- More CCN to deliver accessible, equitable, comprehensive, sustainable and flexible service

Whilst commissioners and providers need to consider the national picture and evidence, to apply this locally they must also reflect on the local context in which they are working.

**Critical Considerations**

- CCGs and providers should review national and local CYP feedback and accelerate the development of the Friends and Family Test agreed by NHS England.
- Providers should move quickly to involve children and young people fully in their own health and wellbeing and in improving the services they use, and involve commissioners in this process.
Local Picture in the South East (SE)

CCN audit

The CCN audit has highlighted that there are varying degrees of delivery in place for all four NHS at Home categories. The majority of SE caseloads are for children with complex and life-limiting conditions. As services are under resourced it is understandable that the opportunity to deliver urgent care and discharge from urgent care is lost.

Children’s nursing roles have the potential to carry out an assessment of the presenting child, produce child-centred personalised health plans, educate the child or young person, their family and wider children’s workforce, case manage as Key Worker, deliver bespoke nursing services and most importantly be accessible when families need care.

Across SE, there is a need to have appropriate specialist nursing roles and advanced practice in community children and young people’s nursing to provide good quality health care services.

- Current nursing services in the community are not integrated for CYP with long-term conditions, continuing healthcare needs or end-of-life care. This highlights fragmented and fragile service provision with limited accessibility for families.
- There is no formal partnership working or joint plans from the different provider organisations that currently deliver the services. In addition to this there are other issues to consider:
  » There are historical gaps in service access for all CYP across SE, as highlighted through the CCN audit. This shows disparity and inequity in service provision.
  » The current community workforce is below the recommended staff whole time equivalent per population ratio, without including other community nursing.
  » Nursing services across community and acute settings are working in silos with a lack of strategic vision and leadership.
- There has been no completed commissioning review of all of these nursing services and therefore there are no updated and agreed service specifications within contracts. This is due to unreliable funding streams and significant lack of data.
- Despite widespread recognition of the benefits and improved outcomes for children and young
people, the development of community children’s nursing (CCN) teams across Kent, Surrey and Sussex remains fragmented and inequitable.

- Although some CCN services are successfully delivering quality services, very few of the existing CCN services are able to offer a 24/7 service that is especially critical for end-of-life care.
- The Children and Families Act 2014 has a significant impact on how services are provided for and will test the interface between the practice of children’s nursing and adult nursing.
- We have not embraced the workforce challenges for future registered children’s nurse challenges. The changes to undergraduate nurse education standards (NMC, 2010) mean that in the future all nurses will receive pre-registration preparation to enable them to deliver both primary and community-based care.
- We have not embraced the post-qualified workforce challenges for postgraduate children’s nurses. There has been a lack of investment in education to allow for delivery of both primary and community-based care advances roles.
- We have not embraced the non-qualified workforce challenges. There has to be a skill mix approach with teams working together to provide nursing care across all sectors.
- Shifting towards more out-of-hospital care provides opportunities to extend current services and develop different and exciting ways in which children and young people receive or access care.

Critical Considerations

- CCGs and providers should review the current SE Audit findings and develop a strategy to build on the gaps in conjunction with this guidance

South East Commissioning Plans

Commissioners across SE are working with differing timescales and plans for effective community children’s nursing. Table 3 shows the current position and plans.
Table 3: South East Commissioning Plans

<table>
<thead>
<tr>
<th>AREA</th>
<th>FEEDBACK FROM COMMISSIONER’S RE CURRENT AND FUTURE PLANS</th>
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</table>
| Medway | • Medway and Swale CCG have set up a steering group and sub groups  
• Dartford, Gravesham and Swanley CCG is carrying out a community paediatrics service review. |
| Kent | • West Kent CCG is discussing the findings of the two workshops with commissioners and providers to seek clarity on which elements of the new model should be prioritised in phase 1.  
• West Kent CCG is ensuring that the new community children’s nursing service is fully aligned with its five year strategic plan, new primary care model and projects linked to urgent and planned care.  
• KCC Public Health and KCC Education are seeking resolution with the CCGs as to the provision of children’s health care in special schools.  
• West Kent CCG is planning to write a business case and service specification to consider, linked to the proposed community children’s nursing service. |
| Sussex | East Sussex Joint Commissioners and CCGs are reviewing services post Better Beginnings – including reviewing short stay paediatric assessment units.  
West Sussex Joint Commissioners and CCGs are reviewing CCN services across the following areas:  
• Special School Nursing  
• GAPS and complex commissioning for Mid Sussex  
• Urgent Treatment Centre (SASH and Crawley) in relation to CYP  
• Pilot of Advanced Paediatric Nurse Practitioner with IC24 (Compass)  
• CCN stage 2 focusing on extended hours and links with urgent care teams. |
| Brighton and Hove CCG is supporting a programme of work to strengthen and support primary and community care in working with children and young people. This supports the following parallel strands:  
• Roll out of urgent care pathways with workshops and discussion in practice cluster groups, working with children’s centres to develop parent education events.  
• Longer term development of an outcomes based children and young people’s locally commissioned service in line with primary care transformation programme.  
• Development of a community children’s nursing model to fit with the above. |
| Surrey | Guildford and Waverley Children’s Commissioning Team have undertaken a baseline review of the range and scope of CCN services in Surrey during 2014-15. This included:  
• Visiting CCN services across the county, discussing with nurses what works well in their teams and what challenges they face.  
• Collection of staffing data including WTEs and skill mix.  
• Mapping different service levels within the county.  
• Mapping specialist nursing roles, who they are employed by and their level of integration across the care spectrum.  
• Working to ascertain the spend on CCN services across the three providers; this is complex due to being rolled into block contracts with two providers.  
Guildford and Waverley Children’s Commissioning Team developed and presented a paper in May 2015. This included an overview of the SCN paper. In the short to medium term the plan is to develop a local service specification, whilst developing a longer term plan of re-commissioning the Surrey CCN service, ensuring that it provides a modern, flexible, equitable and high quality to families across the county. |
Critical Considerations

- Commissioners should support the commissioners’ forum in order to maintain a consistent approach and learn from each other when prioritising the development of a comprehensive nursing community service.

Figure 1

As part of engaging with CYP and seeking their feedback on the children’s community nursing service in West Sussex, the following picture was drawn by a 7 year old child who previously experienced needle phobia. This child demonstrates her value of nursing at home on her sofa.
Feedback from Annual Survey: Source Sussex Community NHS Trust West Sussex Teams

“For a parent to feel included in their child’s care. My son was older so he was able to talk about his own treatment/pain. The team did this well, I felt able to be part of his treatment but also giving him space. I could easily have been missed. Thank you for all you did for us.”

“We didn’t know about the community nurse service - the hospital told us. This is a great service for us, so we don’t have to take our baby boy to the hospital for his wound dressing change. The nurses were very professional and helpful.”

“That the nurses are up to date with latest clinical evidence and skills i.e. that they can give me specialist and thereby more effective care than the GPs (for eczema) When ** has seen my boy I have certainly valued her specialist expertise.”

“It saved me from countless trips to the hospital which was amazing. It’s great having people who understand the medical parts to ask questions via text and phone call. It’s been really important that they knew the medicines and side effects as I had questions about that.”

“Just to know that there is someone else on the other end of the phone who I can contact for advice and support other than hospital staff, especially in between admissions to hospital as it is very worrying especially when your child is first diagnosed and everything seems quite daunting. Having spent over a year trying to get help from my GP in treating my son’s eczema, the community nurses have come to the rescue. They have given us lots of alternative treatments until we have found some that work well. My son used to wake several times a night scratching. He can now sleep through. Very very grateful for the help.”
**Feedback from Annual Survey** Source Sussex Community NHS Trust West Sussex Teams

“The most valuable thing to our family is the knowledge that we have the support from the nursing team on the end of the phone if we need it. I have NO complaints at all, just praise for their wonderful work and dedication – THANK YOU for doing it right. Thank you.”

“Having Snowdrop is a lifeline. You have personal care with a familiar face every week. No problem is too big or small. They are all excellent.”

“We have been very pleased with the care that ** has received over the last few years…the community nurse is an invaluable member of my daughter’s and our support team – thank you.”

**Things that could be improved:**

“Maybe making appointments for children at high/secondary school later in the afternoon/early evenings so they do not miss out on school (exam years).”

“Perhaps a once a month, open clinic to discuss small issues and see other patients who are local, and collect supplies at the same time?”

“Possible emergency weekend contact.”

**Recommendations**

- Secondary, primary and community providers should prioritise the system wide development of safety netting advice given to children and young people and their families regardless of where and how they access care to support self-care and effective discharge.

- CCGs and providers should involve CYP and their families in their care and support local processes to gain feedback and encourage involvement for all ages.
**Feedback from Project Working Groups:** Source: South East Strategic Clinical Network 2014

### Table 4

<table>
<thead>
<tr>
<th>AREA OF WORK</th>
<th>KEY FEEDBACK</th>
</tr>
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</table>
| **Project 1** - Acute and short-term conditions | 1. Need for [High Volume pathways](#) to be implemented across SE  
2. Need for consistent and planned GP Education and work closely with Public Health agenda re injuries and A&E Attendances for children under 4 years  
3. Need for new roles such as Advanced Paediatric Nurse Practitioner working in primary care or front of hospitals |
| **Project 2** - Long-term conditions | 1. Need for specialist nurses to work more closely with community teams  
2. Need for tariff clarification in community for LTC |
| **Project 3** - Disabilities and complex conditions | 1. Need to clarify role of special school nurses and funding streams  
2. Need to support packages of care with personal health budgets |
| **Project 4** - Life-limiting and life-threatening illness | 1. Need for NHS providers to have formal partnerships with hospice teams to provide 24/7 services  
2. Need to share practice on Advance Care Planning and use of Electronic Palliative Care Coordination Systems (EPaCCS) and Intelligence Based Information System (IBIS) for CYP across SE  
3. Need for clarification on specialised commissioning and local provision needed. |
| **Project 5** - Children’s Workforce Development | 1. Need for workforce planning and education commissioning for children’s nurses acute and community |

The Project Working Groups Key Messages are outlined below to show what they were like in the past, what the current state of play is and what is required in the future.

<table>
<thead>
<tr>
<th>PAST</th>
<th>CURRENT</th>
<th>FUTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Clarity or Cohort of CYP</td>
<td>Some direction from NHS AT HOME</td>
<td>Clarity of Cohorts of CYP Acute, LTC, Disabilities, E of L</td>
</tr>
<tr>
<td>Care only in hospital</td>
<td>Care is hospital focused</td>
<td>Care Closer to Home</td>
</tr>
<tr>
<td>Child only focus</td>
<td>Family Centered Care</td>
<td>Co production with CYP families</td>
</tr>
<tr>
<td>Silo Working</td>
<td>Building relationships across Boundaries</td>
<td>Seamless Boundaries One Team</td>
</tr>
<tr>
<td>24/7 HOSPITAL Care and GP</td>
<td>Monday to Friday Access Community</td>
<td>Seven Day Access Community</td>
</tr>
<tr>
<td>Lack of Strategy for CYP</td>
<td>Individual area Ad Hoc Plans</td>
<td>Joint Planning - Clusters</td>
</tr>
</tbody>
</table>
Critical Considerations

- CCGs and providers must develop a joint strategy to deliver and sustain good quality services to the four groups of children
- Providers and Health Education England should act now to plan for the workforce challenges ahead

Local CQC Key Messages

Table 5

<table>
<thead>
<tr>
<th>ORGANISATION</th>
<th>LINK TO REPORT</th>
<th>IMPROVEMENTS OR COMMENTS TO NOTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brighton and Sussex University Hospitals</td>
<td>Community Health Services Children Report</td>
<td>Actions the provider must or should take to improve:</td>
</tr>
<tr>
<td>CCN Team</td>
<td>Date Inspection 20 May 2014 Report 8 Aug 2014</td>
<td>• Review of the nursing establishment in light of the concerns raised by staff over current caseload</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Ensure that staff are supported to attend external training courses and are provided with time and resources that are fair and equitable to the individual staff member department or trust</td>
</tr>
<tr>
<td>Kent Community Health for all children's services</td>
<td>Community Health Services Children's Report</td>
<td>• The CCN team was also reported as being red RAG rated, with a staff turnover of 20.1 per cent as of April 2014 reported as being “Adverse.” The CCN team, were each RAG rated Green for staff sickness levels, and each service was in line with the expected trust benchmark rate of 3.75 per cent.</td>
</tr>
<tr>
<td></td>
<td>Date of inspection visit: 9 to13 June 2014 Date of publication: 2 September 2014</td>
<td>• The CCN Team attended multi-agency safeguarding meetings that were attended by representatives from Social Services and Kent Police.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The CCN team and continuing health care team had developed strong links with the local children’s hospice in order that they could provide timely, flexible and consistent care to the children and families they supported.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The CCN team provided support to children out-of-hours and they also operated a weekend rota system. Kent Community Healthcare NHS Trust provided services to children and young people across 12 different localities. The services were commissioned by eight different CCGs.</td>
</tr>
<tr>
<td>Sussex Community Trust</td>
<td>Reports</td>
<td>Actions to be improved across children's services. The specialities most affected by vacancies were, school nurses, paediatricians, speech and language therapy, physiotherapy, administrative staff and children’s community nurses.</td>
</tr>
<tr>
<td></td>
<td>Date of inspection visit: 8 to 11 of Dec 2014 Date of publication: 19 March 2015</td>
<td>Good Practice related to CCN in CYP</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The CCN team operated a “checking in” system whereby staff texted or rang the office-based nurse to notify them of their location. There was a process for escalating any issues if a staff member failed to check in.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• One area we visited told us that that nursing teams had recently identified an unexplained increase in demand to care for teenagers needing a surgical procedure to treat a pilonidal sinus. A member of staff then worked with the team to produce a pathway and guidance for staff to follow that reflected national guidance to meet this group’s particular needs.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• We were also told that a member of staff had identified a theme and trend with inappropriate or poorly planned discharge packages for children discharged from a local trust for children. This staff member contacted the trust and is working with them to develop a robust discharge pathway that bridged the gap between acute and community care.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• We were also informed about a member of staff who identified the lack of a home oxygen protocol for children who are discharged from an acute hospital setting with home oxygen. This staff member is currently assisting the trust to design a home oxygen protocol.</td>
</tr>
</tbody>
</table>
Recommendations

- CCGs should review current and future CQC reports across children’s services providers and specifically explore further the recommendations re community nursing services.

Current local workforce issues - What does the children’s workforce look like in South East?

Health Education Kent, Surrey, Susses (HEE KSS) state in their workforce plan for 15/16 that there is 105.42 WTE Paediatric Nurses with a head count of 1244. Graph 1 below looks at children’s nursing across areas

Graph 1: Children’s nursing whole time equivalent- June 2014

Source: Health and Social Care Information Centre (2015)
What does HEE KSS Draft workforce plan for health education 15/16 say regarding paediatric nursing?
Supply and demand forecast KSS paediatric nursing

Graph 4

Paediatric nursing is made up of many specialist areas of children's nursing, making it at times difficult to code. Despite the apparent shift towards seemingly an oversupply, we believe the demand forecast to be too conservative and will also be increasing over the next five years. This is supported by the birth rate forecast increases across KSS in the coming years. This workforce is also a feeder for community specialist nurses, supporting children with long term conditions and closer to home.
How do we work out the numbers?

The Royal College of Nursing *Defining staffing levels for children’s and young people’s services* (2013) guidance was first produced in 2003 as a result of a Delphi study. This guidance has been revised to encompass additional areas of children's and young people's services. The guidance and standards apply to all areas in which infants, children and young people receive care, as well as across all types of services commissioned by the NHS, including acute and community, as well as third sector and independent sector providers. The standards are the minimum essential requirements for all providers of services for babies, children and young people.
Table 6: South East Population and Workforce Modelling Related to Each CCG

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Ashford</td>
<td>31240</td>
<td>12.50</td>
</tr>
<tr>
<td>NHS Brighton and Hove</td>
<td>59009</td>
<td>23.60</td>
</tr>
<tr>
<td>NHS Canterbury and Coastal</td>
<td>46688</td>
<td>18.67</td>
</tr>
<tr>
<td>NHS Coastal West Sussex</td>
<td>100726</td>
<td>40.29</td>
</tr>
<tr>
<td>NHS Crawley</td>
<td>27866</td>
<td>11.15</td>
</tr>
<tr>
<td>NHS Dartford, Gravesham and Swanley</td>
<td>62659</td>
<td>25.06</td>
</tr>
<tr>
<td>NHS East Surrey</td>
<td>43638</td>
<td>17.46</td>
</tr>
<tr>
<td>NHS Eastbourne, Hailsham and Seaford</td>
<td>38905</td>
<td>15.56</td>
</tr>
<tr>
<td>NHS Guildford and Waverley</td>
<td>50103</td>
<td>20.04</td>
</tr>
<tr>
<td>NHS Hastings and Rother</td>
<td>39463</td>
<td>15.79</td>
</tr>
<tr>
<td>NHS High Weald Lewes Havens</td>
<td>38669</td>
<td>15.47</td>
</tr>
<tr>
<td>NHS Horsham and Mid Sussex</td>
<td>54698</td>
<td>21.88</td>
</tr>
<tr>
<td>NHS Medway</td>
<td>69031</td>
<td>27.61</td>
</tr>
<tr>
<td>NHS North West Surrey</td>
<td>81034</td>
<td>32.41</td>
</tr>
<tr>
<td>NHS South Kent Coast</td>
<td>45801</td>
<td>18.32</td>
</tr>
<tr>
<td>NHS Surrey Downs</td>
<td>69540</td>
<td>27.82</td>
</tr>
<tr>
<td>NHS Surrey Heath</td>
<td>22342</td>
<td>8.94</td>
</tr>
<tr>
<td>NHS Swale</td>
<td>27965</td>
<td>11.19</td>
</tr>
<tr>
<td>NHS Thanet</td>
<td>32879</td>
<td>13.15</td>
</tr>
<tr>
<td>NHS West Kent</td>
<td>116836</td>
<td>46.73</td>
</tr>
<tr>
<td>South East Coast</td>
<td>1059072</td>
<td>423.63</td>
</tr>
</tbody>
</table>

Please note 423.63 whole time equivalent for community nursing alone. The current gap is unknown due to the recent changes in coding and counting for CCN occupational codes. The RCN modelling must be used alongside the professional judgement tool for working out staffing numbers and rotas.

To support providers, commissioners and partners such as HEE in the local workforce issues, there must be recognition of the national challenges we currently face with the nursing workforce. This will be discussed in Chapter 4.
Recommendations

• Secondary and community providers should work with Health Education England (HEE) Kent Surrey and Sussex (KSS) to support the development of a SE acuity tool to determine nurse workforce requirement

Critical Considerations

• HEE KSS should explore further how the change in the health visiting and School Nursing workforce has an impact on children’s nursing
• HEE KSS should support providers to enter the correct occupational code for the CCN workforce to allow a clear picture of current and future workforce
Current national workforce issues

What does a good children’s nursing workforce look like?

Stated in Nursing Children and Young People (2014) Volume 26 No 8

“Commissioned training places for children’s nurses have risen from 2,151 in 2013/14 to the planned 2,182 for 2014/15. However, the number commissioned for West Sussex, Thames Valley, and North Central and East Sussex has declined.

RCN children and young people’s nursing adviser Fiona Smith said: “There is no shortage of people wanting to train in the specialty, but previous cutbacks seriously restricted the numbers coming into the profession. I am concerned that there are not enough neonatal, children’s intensive care and community children’s nurses to provide the specialist care required.”

Key statements related to the children’s nursing workforce

Working with children and young people requires a workforce that is skilled in the developing child, including understanding and responding to their evolving capabilities, integrated into the profession specific knowledge and skills. For example, childhood physiology, pharmacology, health conditions and impact.

The big question is whether the increase in training places proposed will be enough to ease the pressure on hospitals and community. Currently workforce planning is not aligned to strategic plans. In March 2015 HEE published Raising the Bar. Although this is not a definite agreed plan at this stage, it will raise the debate of how children’s nurses are trained in the future to consider a whole-person approach to training and the role of the future nurse with children’s nursing and/or community nursing as a chosen specialist field.

Staff shortages are common across all levels of children and young people’s health services in SE, which means there are significant challenges to providing safe and sustainable, 24-hour services across the current configuration. Trained children’s nurses are critical to the delivery of skilled, child-focussed healthcare. Insufficient numbers of nurses are training to be children’s nurses. This is likely to lead, in time, to nursing personnel across SE unlikely to understand the needs of all children and their families. There is also an issue of inconsistency in relation to children’s training in nursing. For example, for registered nurses not specialising in children’s care, there is no ability to access even an abridged version of a children’s training module. In addition, children’s training overseas is not recognised in the UK, thus requiring nurses from overseas to be supervised, even though they may
be hugely experienced children’s nurses in their own countries. This makes recruiting nurses from other nursing disciplines and from overseas more difficult and potentially less cost-effective.

There are also limited training opportunities for nurses to develop as either specialists or advanced nurse practitioners. Children’s nurses working at specialist, advanced and consultant level can make a significant contribution to the redesign, development and delivery of children and young people services (RCN 2014).

Health Education England should commission education to ensure that the workforce is trained to deliver care that is appropriate for children and young people, in the same manner as is being currently carried out for age-appropriate care for older people.

The workforce plan Investing in People for Health and Healthcare published by Health Education England (HEE) in Dec 2014 states that they will increase children’s nurse commissions in 2015/16 by 161 (7.4 per cent), which should provide more than enough to meet anticipated patient need in acute settings. They do say that they need to do more work with NHS England and others to understand the extent to which these services are expected to shift to the community and revisit the supply forecasts accordingly. They also need to understand why many graduating staff do not appear to be working in children’s services.

Providers have told HEE that there is a shortage of senior specialist children’s nursing roles (which is currently an employer responsibility) and so they will work with NHS employers and other partners to undertake a review of children’s nursing and proposals for how the system might address this going forward.

HEE are continuing to deliver on a 15 year ambition to build a workforce shaped around the needs of patients, as set out in our Strategic Framework. They will progress this work through their Shape of Care and Shape of Training Programmes, and through piloting a ‘life cycle’ approach to workforce planning, starting with children and young people services.

The children’s nursing workforce represents a key workforce trained to address the very specific and unique challenges of caring for sick children. Operating in all settings from community team through to major tertiary centres for our sickest and neediest children, they are a scarce and valuable resource.

HEE analysis below indicates that some of this specifically trained resource may be being employed in general adult services. While the care they provide is clearly necessary, it is concerning that the system may not be fully utilising their specialist skills and knowledge.
Forecast supply by Health Education England (HEE)

Proposed training levels are forecast to deliver 5,876 FTE growth in available supply by 2019. This would represent an increase of 36.5 per cent over this five-year period. However the recent pattern of growth in the children’s nursing workforce strongly indicates that newly qualified children’s nurse graduates are not being employed in paediatric nursing services. Low growth between 2010 and 2012 could be due to the number of funded posts available. However in 2013/14 employers grew their establishments but the number of staff employed failed to grow in line with these new opportunities, despite the very large volume of newly qualifying children’s nursing graduates.

HEE needs to understand what is happening with this graduate workforce as the volume of training undertaken should be resulting in significantly higher growth to this workforce. Both the drive for significant growth in the nursing workforce for adult acute services and the rapid expansion of the health visiting workforce may be components of the answer and if so we may see greater growth in paediatric nursing as these two areas return to a degree of more normal growth. The proposed increase in school nursing training across England is an extra 142 places but, to put this into context, there are only 340 places on offer and there are over 20,000 schools across England. Currently there is a vacancy rate of 25 per cent.

Provider demand forecasts

As at 1 April 2014, NHS Trusts indicated that they have 1,012 full time equivalent (FTE) vacancies (5.9 per cent) in the paediatric nursing workforce.

Trusts indicate that they expect to increase their requirements by 988 FTE (5.8 per cent) by 2019. This is comprised of an increase of 523 FTE (3.1 per cent) in 2014/15 and further smaller increases between 2015 and 2019 of 465 FTE (2.7 per cent). This means that trusts would require an increase of 679 FTE in 2014/15 if they were, on average, to achieve NICE guidance in respect of maximum acceptable vacancy levels.
Table 7: Children’s Nursing Forecasts

<table>
<thead>
<tr>
<th>CHILDREN’S NURSING</th>
<th>FTE</th>
<th>PER CENT INCREASE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current vacancies</td>
<td>1,012</td>
<td>Inc 5.9 per cent</td>
</tr>
<tr>
<td>Supply required to achieve 95 per cent</td>
<td>155</td>
<td>1 per cent</td>
</tr>
<tr>
<td>2014/15 Increased demand</td>
<td>523</td>
<td>3.2 per cent</td>
</tr>
<tr>
<td>Immediate supply requirements</td>
<td>679</td>
<td>4.2 per cent</td>
</tr>
<tr>
<td>2015-2019 Demand 4642.9</td>
<td>464</td>
<td>2.9 per cent</td>
</tr>
<tr>
<td>Total additional supply needed 2014-2019</td>
<td>1143</td>
<td>7.1 per cent</td>
</tr>
</tbody>
</table>

Source: Health Education England

Across England where were children’s nurses working?

Table 8: Whole Time Equivalent (WTE) WTE Across Children’s Nursing Areas

<table>
<thead>
<tr>
<th>MONTH YEAR WHOLE TIME EQUIVALENT (WTE)</th>
<th>NOV 2014 WTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children’s nurse working in acute CYP services</td>
<td>12768</td>
</tr>
<tr>
<td>Children’s nurse in acute, elderly and general</td>
<td>333</td>
</tr>
<tr>
<td>Nurse consultant children’s</td>
<td>34</td>
</tr>
<tr>
<td>Modern matron children’s</td>
<td>217</td>
</tr>
<tr>
<td>Managers who are children’s nurses</td>
<td>334</td>
</tr>
<tr>
<td>Paediatric nursing (different from children’s nurse)</td>
<td>10742</td>
</tr>
<tr>
<td>Other 1st level children’s</td>
<td>5133</td>
</tr>
<tr>
<td>Other 2nd level children’s</td>
<td>91</td>
</tr>
<tr>
<td>Children’s nurses working in maternity</td>
<td>104</td>
</tr>
<tr>
<td>Children’s nurses working in community</td>
<td>397</td>
</tr>
<tr>
<td>Children’s nurses working in education</td>
<td>44</td>
</tr>
<tr>
<td>Children’s nurse working in neonates</td>
<td>1150</td>
</tr>
<tr>
<td>Total children’s nursing workforce</td>
<td>31347 WTE</td>
</tr>
</tbody>
</table>

Source Health and Social Care Information Centre (2015)
These statistics relate to the contracted positions within English NHS organisations and may include those where the person assigned to the position is temporarily absent, for example on maternity leave.

**National data indicates the following key challenges for this professional group:**

- An ageing workforce
- Disparity and lack of consistency in preparation for training for the role across England
- Reduced number of Health Education Institutions offering the training
- Lack of clearly defined career pathways and progression

Further challenges identified nationally and locally include:

- The workforce is static and there is limited workforce succession planning
- The role is far ranging and evolving as individual, family and population health needs change
- There is lack of clarity regarding the role of community Children’s Nurses and no consistent approach to service delivery
- There is lack of profile nationally for the role
- The role not being promoted as a career option
- There is a lack of opportunities for CPD and career progression
- There is often lack of confidence and competence to work outside of hospital settings

**HEE’s call for evidence and other perspectives**

The work of the children and young people’s programme continues to indicate a number of areas of unmet need for children, including where they have to access generalist/adult services rather than people trained in the particular needs of our young people.

The fact that NHS trusts are indicating continuing growth after 2015 is a clear signal that staffing in this area is likely to continue increasing.

In this context, the wide consensus that further growth in this workforce remains a priority seems clear. In addition to the evidence of the RCN above HEE also received evidence from the Royal College of Paediatrics and Child Health (RCPCH) in relation to children’s service workforce in its wider sense.

**Demand and supply summary**

- The volume of training proposed by HEE’s Local Education and Training Boards should be more than adequate to ensure the needs of children and young people can be met by registered nurses specifically trained to meet their unique needs.
- The volume of supply forecast may also create opportunities for the role of children’s nurses in community teams to be explored as a component of the drive to expand this workforce.
- HEE’s investment plan shows their intention to increase children’s nurse commissions in 2015/16 by 161 (7.4 per cent). HEE will have increased children’s nurse commissions by 192 over the past two years.
Further actions for Health Education England and their partners:

1. They will work with their partners to understand why the large volumes of graduating staff do not appear to be ending up employed in children’s services. There are no indications of widespread under-employment and as such it would appear graduates are finding opportunities elsewhere or otherwise children’s services are suffering exceptional levels of turnover, which again is not supported by available evidence.

2. HEE is also aware that the general shortage of specialist nurses is particularly acute within specialist paediatric services and indeed has resulted in threats of bed closures.

3. NHS trusts report high levels of vacancy and unmet need for specialist nursing roles, but responsibility for developing current staff formally lies with employers themselves. A combination of tight budgetary positions and the fact that training your own nurses does not guarantee that they will stay and work in your unit means there is little incentive for individual trusts to make this investment. HEE will lead a conversation with the service and employers on whether we should take a greater role in developing the specialist nursing workforce on behalf of the system.

The challenge of mobilising the profession of children’s nursing requires due attention by all providers. It is expected that providers will develop a robust workforce development plan. This should be jointly led in collaboration with HEE demonstrating service transformation, service monitoring and workforce growth including supervision arrangements.

In planning the workforce for future care models we must consider the expectations of staff, the demographics, use information and technology to our advantage and take into account the social, political, economic and environmental context.

It takes three years to train a children’s nurse. If as a collective we make wrong decisions about how many children’s nurses we require we risk locking the service into outdated models of care. The strategic framework 15 should be the guide used to get our investments in the future nursing workforce in place. Framework 15 | Health Education England Strategic Framework 2014 -2019

The following high-level recommendation areas in the recent Workforce Education and Training Theme Group report from the CYP Outcomes Forum second annual report need to be addressed at national level:

- Encouraging ownership and oversight
- Developing standards and training
- Monitoring performance
- Supporting integrated working and effective pathways of care
- Encouraging cultural change

The forum’s work-stream will continue to support the system in identifying and responding to these challenges, working closely with the Chief Medical Officer’s Children and Young People’s Health Outcomes Board to hold Health Education England and other partners to account for delivering an integrated workforce for children, young people and families.

In order to realise the workforce numbers that are required there must be an alignment to the vision that is being created to meet the needs for the population of CYP. Chapter 6 discusses the vision for comprehensive children community nursing services.
Recommendations

- HEE KSS should support providers through the CYP programme board to support the outcomes of the HEE Shape of Caring Review (2015) in relation to children nursing.

Critical Considerations

- Providers should explore further the use of new technology to collect data to reflect workforce practices and activity data
- CCGs, HEE and providers should review the current Consider the Workforce Education and Training Theme Group report from the CYP Outcomes Forum.
The vision for comprehensive children’s nursing services

The increased emphasis in health policy nationally and internationally on integrated care, responsive access and care closer to home, for all children with acute short-term and long-term conditions, complex health needs and life-limiting and life-threatening conditions necessitates robust commissioning arrangements. Effective commissioning arrangements for Children’s Community Nursing (CCN) services will enable innovative solutions to transpire across Kent, Surrey and Sussex, assuring improved health outcomes for children and young people.

The overall vision for a modern children’s nursing service is to enable children, young people and their families to have good physical and emotional health and wellbeing, through providing a joined up, high quality, community positioned model of care, which effectively reduces the need for hospital attendances and admissions.

The term modern children’s nursing is derived from reviewing the scope, advancement and innovations of modern day children’s nursing, to deliver advanced and specialist practice, across a range of settings. Modern children’s nursing acknowledges the need for nursing that is primary and community positioned, in addition to nursing those children who need to receive treatment and nursing in hospital.

Children’s community nursing was established as a specialism by environment of care in the 1990s as part of ensuring high quality and safe nursing out of hospital.

The current need to respond to the increasing acuity and complexity of nursing in the community, together with the need to include a broader scope of nursing access for children presenting with acute, short-term conditions out of hospital, calls for a fresh approach to the nursing of children and young people. This new approach needs to maintain the excellence in the children’s community nursing specialism that has existed for those children with long-term conditions, complex needs, disability and life-limiting conditions together with integrating new advanced children’s nurse practitioner roles to diagnose and treat children with acute short-term conditions.

The other essential dimension of modern children’s nursing relates to maximising the critical available resource of the registered children’s nurse across Kent, Surrey and Sussex and the evidential skill mix of registered and unregistered staff required to deliver a comprehensive nursing service to all four groups of children.

Modern children’s nursing is about identifying the unique contribution of the role of the children’s nurse to deliver advanced and specialist nursing (condition specific and by environment of care) supported by the evidential skill mix to deliver care closer to home, reduce preventable and avoidable attendances and/or admissions to hospital, and improve health outcomes for children and young people as part of a multi-professional and multiagency team around the child and family.

A comprehensive CCN service forms an integrated part of a co-located wider network of multiagency child and family services. It can provide for the existing and
future needs of children, ensuring consistent, high quality transition between services such as hospital and home or between health, social care, education or children’s and adult services (RCN, Parker et al 2012 2014).

The Royal College of Nursing (RCN) 2014 identifies that a good CCN service has the following attributes:

- **A safe service** with consistency of care across environments and professionals; there is clarity of level of autonomy, accountability and responsibility within the teams and professionals with robust community accorded clinical governance.

- **A comprehensive service** with integrated and coordinated locality care that caters for all four groups of CYP; the service is responsive and flexible to local population needs and accessible seven days a week, with 24-hour provision and an on-call service.

- **A sustainable service** with robust workforce planning and development and the innovative use of critical mass of workforce within a locality; the right people with the right skills will be available in the right place at the right time.

Local and national evidence suggests that the components of an equitable, safe, comprehensive and sustainable CCN service include the following:

### Components of a comprehensive needs-led CCN service

<table>
<thead>
<tr>
<th>Access scope</th>
<th>Integrated delivery</th>
<th>Sustainable service</th>
</tr>
</thead>
<tbody>
<tr>
<td>for CYP groups (0-24yrs)</td>
<td>that is locality and community positioned</td>
<td>models and skilled workforce</td>
</tr>
<tr>
<td>seven days 8-8 visits</td>
<td>24hr end-of-life care</td>
<td></td>
</tr>
<tr>
<td>24hr end-of-life care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th>Collaborative relationships</th>
<th>Supported by technology</th>
<th>Clinical nursing leadership</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agreed care pathways</td>
<td>innovations and performance data review</td>
<td>Robust clinical governance, supervision and education frameworks</td>
</tr>
</tbody>
</table>

The locality arranged ‘teams within teams’ service model

A locality arranged ‘teams within teams’ approach to provision should be commissioned to facilitate a sustainable model that is productive and equipped for multiagency integration. CCGs must move to integrated teams around these children to reflect locality and school cluster arrangements and realise efficiencies. The ‘team within teams’ service model maximises productivity of the available workforce to rotate across teams as the need arises. An evidential skill mix supports the fluidity of this delivery.
Figure 2 below - A ‘teams within a teams’ locality arranged service model sets out how the four groups of children would be cared for with different teams interconnected. The commissioner will need to understand what this means in relation to other children’s services commissioned and how nursing services transform to provide value for money.

**Figure 2**

A whole system strategic approach to workforce planning and professional development is required to implement a modern approach to children’s nursing. Chapter 6 will support an agreed understanding of nursing roles and skill mix required for comprehensive services delivering teams within team’s model.

**Recommendations**

- Community and secondary care providers should support CCGs to explore further the concept of ‘Teams within Teams’ across localities to facilitate a sustainable model that is productive and equipped for multiagency integration.

*Source: SE SCN Working Groups and Clinical Advisory Group.*
The nursing workforce, roles and skills mix to deliver the vision

The role of the children’s community nurse

There are a number of health professional roles that contribute to a comprehensive community nursing service. The focus of this chapter is to set out the nursing and assistant roles that are necessary to deliver a safe, comprehensive and sustainable service.

A children’s community nursing service will need:

- Advanced children’s/paediatric nurse practitioners (APNPs) in both acute assessment of the presenting child unknown to the caseload as well as advanced children’s community nurse practitioners (ACCNPs), who case manage a defined caseload of children usually with long-term conditions, complex needs and/or life-limiting, life-threatening conditions. The APNP case manages all presenting children referred, for example as part of an urgent care pathway. Both of the above roles have undergone accredited mentorship and clinical assessment, recorded with the Nursing and Midwifery Council (NMC). Advanced practice is a level of practice rather than a specific role and is a particular stage on a continuum between novice and expert (Figure 3, page 59). The advanced nurse practitioner working with CYP is a highly experienced and knowledgeable nurse, educated to Masters level and able to use clinical judgement and autonomous decision making in relation to the assessment, diagnosis, management and evaluation of care.

- Children’s community nurse specialist practitioners (CCNSP) are specialists (by environment of care) in community nursing. CCNSPs have undergone accredited mentorship and clinical assessment recorded with the NMC and are case managers of a designated caseload of children.

- Clinical nurse specialists (CNS) For example, Diabetes Nurse Specialists, are specialists by condition or continence as specialists by interrelated health conditions. CNS roles are usually aligned to specialist service specifications and specific tariff funded services. An exception is continence, which is interrelated across a number of funding streams.

The KSS CCN Audit and stakeholder event showed there to be some overlap between these roles, particularly between CCNSPs and CNS roles. Clear local care pathways should to be developed to avoid inequalities or duplication in provision.
Children’s and learning disability nurses, assistant practitioners (Band 4) and nursery nurses/health care assistants (Band 3) are other professionals who make up a nursing care team. A number of CCN services across Kent, Surrey and Sussex have established the Health Care Assistant role. Sussex Community NHS Trust has developed the CCN assistant role, which combines supporting community nursing, special school nursing and continuing care/short breaks nursing and care activity.

**Table 9**: Roles and titles in children’s nursing – Professional qualifications and nursing practice experience specifications.

<table>
<thead>
<tr>
<th>ROLE TITLE AND SUMMARY DESCRIPTION</th>
<th>ABBREVIATION AGENDA FOR CHANGE BAND RANGE</th>
<th>EXPECTED PROFESSIONAL QUALIFICATIONS</th>
<th>EXPECTED CLINICAL PORTFOLIO OF EXPERIENCE</th>
</tr>
</thead>
</table>
| Consultant Nurse                   | r/va  
8a- 8c                                 | Registered nurse- children Masters or doctoral level with **Accredited educator and clinical assessor** Portfolio dependent on specialty. History and clinical examination; clinical decision making/diagnosis Recorded with the Nursing and Midwifery Council (NMC). | Evidence of a clinical and professional portfolio that demonstrates expert level nursing practice within: • Leadership and management • clinical practice • education and • research The advanced role profile is characterised by high levels of clinical skill, competence and autonomous decision-making. |
<table>
<thead>
<tr>
<th>ROLE TITLE AND SUMMARY DESCRIPTION</th>
<th>ABBREVIATION AGENDA FOR CHANGE BAND RANGE</th>
<th>EXPECTED PROFESSIONAL QUALIFICATIONS</th>
<th>EXPECTED CLINICAL PORTFOLIO OF EXPERIENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced Paediatric/Children's Nurse Practitioner</td>
<td>APNP 7-8a Competent 7 Proficient 7/8a Expert 8a</td>
<td>Registered nurse- children Masters with Accredited mentorship and clinical assessment Mandatory modules: History and clinical examination; clinical decision making/diagnosis; Non-medical prescribing. Recorded with the Nursing and Midwifery Council (NMC).</td>
<td>Evidence of a clinical and professional portfolio that demonstrates competence to expert level of nursing practice experience within: • Leadership and management • clinical practice • education and • research The advanced role profile is characterised by high levels of clinical skill, competence and autonomous decision making.</td>
</tr>
<tr>
<td>Advanced Children's Community Nurse Practitioner</td>
<td>ACCN 7-8a Competent 7 Proficient 7/8a Expert 8a</td>
<td>Registered Nurse- children Masters with <strong>Accredited mentorship and clinical assessment</strong> Mandatory modules: Primary and community care policy; History and clinical examination; clinical decision making/diagnosis; leadership and innovation. Suggested additional: Non-medical prescribing Recorded with the Nursing and Midwifery Council (NMC).</td>
<td>Evidence of a clinical and professional portfolio that demonstrates competence to expert level of nursing practice experience within: • Leadership and management • clinical practice • education and • research The advanced role profile is characterised by high levels of clinical skill, competence and autonomous decision making.</td>
</tr>
<tr>
<td>Children's Community nurse specialist practitioner</td>
<td>CCNSP 6-8a Competent 6 Proficient 7/8a Expert 8a</td>
<td>Registered Nurse- children Degree or Masters in Specialist Community and public health Practice. <strong>Accredited mentorship and clinical assessment</strong> Mandatory modules: Primary and community care policy; History and clinical examination; clinical decision making/diagnosis; leadership and innovation. Recorded with the Nursing and Midwifery Council (NMC).</td>
<td>Evidence of a clinical and professional portfolio that demonstrates significant nursing experience mapped to specialist field and includes: • Leadership and clinical management • clinical practice • education and • research The higher banding relates to higher level of proficiency/expertise expected and breadth of role.</td>
</tr>
</tbody>
</table>
**Clinical Nurse Specialist**
Role focus is as nurse specialists by condition, for example, Diabetes, Epilepsy, Asthma, Continence. Nurse Specialists who are specialists by condition.
CNS roles are usually aligned to specialist service specifications and specific Tariff funded services.
Nurse specialist by health or medical condition, for example continence or diabetes.

**ABBREVIATION** CNS
**AGENDA FOR CHANGE BAND RANGE** 6 to 8a
**EXPECTED PROFESSIONAL QUALIFICATIONS**
Registered Nurse- children Degree with
Additional clinically based educational preparation within the speciality.
**EXPECTED CLINICAL PORTFOLIO OF EXPERIENCE**
Evidence of a clinical and professional portfolio that demonstrates significant nursing experience mapped to specialist field and includes:
- Leadership and clinical management
- clinical practice
- education and
- research
The higher banding relates to higher level of proficiency/expertise expected and breadth of role.

**Special school Nurse**
Role focus is Public Health school nursing, including child protection and safeguarding responsibilities, and children’s nursing specialist in childhood neuro-disability nursing in the school setting.

**ABBREVIATION** SSN
**AGENDA FOR CHANGE BAND RANGE** 5 to 6
**EXPECTED PROFESSIONAL QUALIFICATIONS**
Registered nurse- children
*with some schools a mental health nurse may be required.*
Degree or Masters in Specialist Community and public health Practice- either schooling nursing or community nursing (Band 6).
**Accredited mentorship and clinical assessment**
For Band 5: diploma or degree level children’s nurse.
**EXPECTED CLINICAL PORTFOLIO OF EXPERIENCE**
Evidence of a clinical and professional portfolio that demonstrates significant nursing experience mapped to specialist field i.e. nursing in special schools and includes:
- Leadership and clinical management
- clinical practice
- education and
- research
The higher banding relates to higher level of proficiency/expertise expected and breadth of role.

**Children’s Community Nurse**

**ABBREVIATION** CCN
**AGENDA FOR CHANGE BAND RANGE** 5- 6
**EXPECTED PROFESSIONAL QUALIFICATIONS**
Registered Nurse- children
Degree or diploma level.
**EXPECTED CLINICAL PORTFOLIO OF EXPERIENCE**
From newly registered to experienced children’s nurse in any setting.

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**The role of the children’s community nurse –advanced and/or specialist**

The children’s community nursing team support all children and families closer to home. The following picture (figure 4) sets out the encompassing nature of the role such that a CCNSP can provide for all four groups of children.
The unique role of the children’s community nurse

- Providing leadership and case management
- Delivering nursing care and support across the life course
- Assessing, planning, implementing and evaluating evidence based care interventions within the community setting and autonomously/independently (without back up), assessing and managing risk
- Contributing to the assessment of health needs of children and monitoring the effectiveness of safe care packages
- Working in partnership with parents/carers and families to provide nursing care and support
- Delivering nursing care to the defined delegated cases under the supervision of the case manager (named nurse)
- Liaising with GPs and secondary care to reduce hospital admission and support early discharge
- Advocating for the child/young person to ensure their rights and needs are safeguarded at all times
- Encouraging integration of the child/young person into a normal family, school and community life and supporting transition across the life course (0 to 19 years)
- Empowering children and families to manage care closer to home
- Nursing specialist in the environment
- Acting as a lead professional and key worker role
What does the skill mix look like?

The modern children’s nursing workforce delivering a community orientated service needs to have a mix of ACCNPs and APNPs. To assure robust clinical governance, advanced nurse practitioners will need formal access to appropriate medical practitioners and/or nurse consultants with a definitive clinical supervision framework.

Registered advanced and specialist nurses should have competencies to a high level in assessment, treatment planning, communication, risk assessment, specific interventions such as prescribing of dressings, initiating diagnostics (X-ray, bloods), action sample taking (bloods) and have case management responsibilities assigned to their roles and specific areas of interest.

There should be additional education and professional development opportunities in the full range of clinical and public health nursing practice to enable staff to deliver according to their registration, roles and the specification.

Professional related education and training should be undertaken to expand the core competencies of staff and to ensure expert knowledge in these specific fields. This should be based upon current evidence-based practice and NMC guidelines. Consideration should be given for a compliment of non-medical prescribers, community nursing prescribers and Patient Group Directives (PGD), which allow a greater scope of medicine management in the community.

Junior nurse practitioners should work under the management of senior nurse practitioners and be expected to build their nursing portfolio, skills and knowledge. Unregistered team members deliver care supervised by a registrant and support the work of registered members in their daily work tasks carried out within the community. They should support further expansion of home-based care for children following discharge or as a result of a health assessment, provide practical help/care for children who are considered palliative and offer a range of hours to meet individual needs. Unqualified staff should attain/work towards core competencies to NVQ level 3/4 and/or Foundation degree standards and be trained in specific areas of care according to the individual needs of the child or young person.

All staff should be expected to attend the relevant statutory and mandatory training programmes and comply with trust policies. All CCN staff should participate in annual personal development planning.

The staffing requirements of the teams will be decided by the provider organisation to deliver the specified standard of care within the financial envelope.

The staffing establishment will depend on the child population, the weekly hours of access and the demand (activity) across all four groups of children within a given locality. Supervisory time for team leaders needs to be factored into any establishment calculations. Each team will need an administrator as part of provision of a productive service that maximises clinical staff direct patient delivery.

In 2013 the RCN recommended that for an average sized district, with a child population of 50,000, a minimum of twenty whole time equivalent community children’s nurses are required to provide a holistic CCN service in addition to any child specific continuing care investment.

The staffing skill mix needs to reflect the child population needs profile and the scope of delivery.
Within the specification (that is, all four groups of children) to assure the most effective mix of advanced, specialist, generic and unregistered staff.

The professional lead for the service should be a registered children’s nurse who has completed an accredited advanced and/or community education and development programme.

A mandatory requirement for productive community service delivery is the use of hand-held devices for staff to access and record patient data timely and responsively, in addition to reducing avoidable travel time to and from base.

Allied health professional roles that are co-dependent features of a comprehensive children’s community nursing service should be considered alongside a CCN service specification. For example, specialist community respiratory physiotherapy and occupational therapy.

In order to support providers in planning the competencies and skills required for the nursing workforce, Chapter 7 examines the four groups of children at which this vision and model is aimed.

Recommendations

- Secondary and community providers need to ensure CCGs and HEE KSS that their services are needs-led and skill-blended with a competent workforce.
- HEE KSS should accelerate the need for clearly defined education and training programmes and preceptorship to support the additional nurses, assistant practitioners and health care assistants, who will be required to work within the CCN teams.
Service provision for children and young people

Acute and short-term conditions – key statements

- The number of children admitted to hospital and presenting at A&E is rising. Evidence suggests that many of these cases could be managed outside an acute setting (Department of Health 2010; Hockey et al 2013).
- Around a quarter of those presenting at A&E in 2012/13 were children (The King's Fund analysis of 2012/13 HES data).

Admissions to hospital with zero days length of stay for under 5s 2013/14

- Activity = 46,358
- Total cost= £55,559,884
- Cost per child on average = £1,198.49

A&E attendances with no investigation or treatment for under 5s 2013/14

- Activity = 39,193
- Total cost = £1,980,527
- Cost per child on average = £50.53
Who is this nursing care for?

For most children, the GP is their main point of contact with the health service. While children make up nearly one-fifth of the population in England, they are estimated to account for two-fifths of a typical GP’s workload. Despite this, the Royal College of Paediatrics and Child Health estimate that in many parts of the country, between 40 and 50 per cent of GPs have had little or no formal paediatric training. This leaves many GPs without the skills and confidence to assess and treat children in their surgery, leading many to refer children to hospital for conditions such as fever, asthma or constipation that could be managed in primary care. Department of Health, Getting it right for children, young people and families: Maximising the contribution of the school nursing team: Vision and Call to Action (2010).

Presentation to A&E or admittance to hospital for children and young people with problems that could easily be treated within the community is becoming an all too common experience. On the other hand, outpatient appointments are provided, more often than not, in a hospital setting when they could be provided closer to home in most instances.

A 2008 study found that only 25 per cent of children and young people admitted to A&E with non-major conditions should have been treated by an A&E clinician, and that 87 per cent of the same category of patients could have presented at a different entry point. Another study found that 36 per cent of referrals to paediatricians were potentially preventable in most circumstances. They are children with minor problems and thought to be due to a lack of knowledge or confidence by some GPs.

Supporting high volume pathways

In 2012 West Sussex highlighted that high volume admissions account for 48 per cent of all admissions. There is a similar picture nationally (50 per cent). In Luton they had 85 per cent high volume conditions (HVC) often bypassing primary care with no dedicated children’s Emergency Department. High volume admissions include those for fever, diarrhoea and vomiting, bronchiolitis, head injury and asthma, wheeze. Further data for South East can be found in appendix 2.

High volume condition pathways are helpful in terms of sharing messages, educating/upskilling staff and reducing variation in care by promoting consistent assessment and management as set out in the pathway. This vision for modern children’s nursing in relation to acute and short-term conditions supports the implementation of HVC pathways. Here is an example of the fever Acute Setting Pathway, the Advice Sheet for Families and the Primary and Community Care Pathway. Other pathways have been developed. To view the pathways go to the SCN website.

Children’s nurses, working along a range of pathways and in both community and acute care, will increasingly undertake clinical assessments, diagnose, interpret X-rays and diagnostic imaging, plan, prescribe and evaluate treatment, make referrals, discharge and provide follow-up care, often without reference to medical practitioners.
What does good provision look like?

Table 10 shows how the Five Year Forward View relates to a modern children’s nursing vision in relation to acute care.

Table 10

<table>
<thead>
<tr>
<th>FORWARD VIEW</th>
<th>MODERN CHILDREN’S NURSING</th>
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<tbody>
<tr>
<td>Increased access to a simplified urgent and emergency care system, through strengthened clinical triage</td>
<td>Families will have clear consistent pathways and advice first time, encouraging self-care and empowerment. Modern children’s nursing will use these pathways.</td>
</tr>
<tr>
<td>Better integration between urgent and emergency care services</td>
<td>Agreed care pathways for APNP and CCN roles and delivery. Rotational and shared training opportunities.</td>
</tr>
<tr>
<td>24/7 access to community and primary-care based services, with robust arrangements for referral to hospital-based care, if necessary</td>
<td>Innovative partnerships for the four groups of children.</td>
</tr>
<tr>
<td>Emergency care provided in specialist centres, linked with each other and with smaller hospitals, through new partnership options</td>
<td>Modern children’s nurses can be included in the winter planning and system resilience discussions. Modern children’s nursing must be part of Urgent and Emergency Care Networks discussions.</td>
</tr>
<tr>
<td>Skilled workforce with right skills in right place</td>
<td>Children’s nurses will work with advanced and specialist paramedic and primary care roles to support care closer to home.</td>
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</tbody>
</table>

Ultimately, parents of children who are faced with the option with seeing an on-call GP they don’t know or going to an A&E department often choose the latter, even though many of these cases can be dealt with in the community. Provision of primary and community care is changing within SE, through practice networks, unifications and alliances in an attempt to improve care.

If we are aspiring to make the Five Year Forward View a reality we must be horizon scanning and networking to review the outcomes and changes ahead with regard to the phase one vanguard sites.
Examples of national case studies and further information

Table 11 shows successful teams and innovations for acute short-term conditions that will be a resource for commissioners. Further case studies are included in the Facing the Future Together for Child Health Standards (RCPCH), launched in April 2014.

### Table 11

<table>
<thead>
<tr>
<th>EXAMPLE</th>
<th>LINK TO FIND OUT MORE</th>
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<tbody>
<tr>
<td><strong>CANI – Newcastle (acute led)</strong> Winner of HSJ Award</td>
<td><a href="#">CANI Hospital Website</a></td>
</tr>
</tbody>
</table>
| **Making it Better Manchester and Healthier Together Manchester (CCN Models)** The outcome of the CCN review will be available soon. | • [Making it Better Evaluation](#)  
• [Healthier Together](#) |
| **CRAFT- Leicester (A and E Focus)** | • [Team Info](#)  
• [CCG Survey](#) |
| In early 2013, a review of this service was undertaken by Leicester City CCG. The review found that out of 64 practices in the city, only five were referring children. | |
| **NHS Stoke** Acute Led Community Provision and GP Training | • [Hospital at Home Team](#)  
• [Partners in Paediatrics](#) |
| **COAST – Portsmouth** On its 5th anniversary this year the team has successfully prevented the unnecessary hospital admission of over 3,600 children in the city since 2008. | [Provider Solent Website](#)  
Commissioned by Portsmouth Clinical Commissioning Group |
| **Salford** Embedding advanced paediatric nurse practitioners (APNPs) upstream and at source has reduced the paediatric non-elective admission spend by 40 per cent within Salford Health Matters’ general practice site in Little Hulton (Greater Manchester). The Salford Children's Community Partnership better manages acute childhood illness with a redesigned pathway within general practice. In the words of one mother: “they made it good, they made it safe, they made it local. I don’t need to go to A and E.” | [Salford Health Matters CCG](#)  
[www.salfordhealthmatters.co.uk](http://www.salfordhealthmatters.co.uk)  
Contact details: Katie Barnes, Project Development Lead, and Salford Children's Community Partnership.  
katie@kidshealthmatters.org.uk |
| **Imperial College General Practice Hub** The Imperial child health general practice hubs comprise groups of two or three general practices within Inner North West London, which work with paediatric consultants from St Mary's Hospital to provide care to practice populations of approximately 4,000 children. The hubs have three core components | This includes using specialist community nurses  
For more info visit [here](#) |
| **CAKES Course Luton** Children's Assessment knowledge and Examination Skills  
Course offered in primary and secondary care for the last three years (seven courses). All lectures taught by a paediatric consultant to an audience of 140 NP, GP, paramedics, A&E staff nurses and CCN. | [Trust Website Luton and Dunstable University Hospital](#)  
Health Education England Presentation |
| **Children's Rapid Response Team Phase 2**: 4 Community APNP roles, Extension to out of hours and extend referral from GP practices. Jan 2014. Developed as a sustainable model of integrated working between acute and community services within Luton. Supports GPs A and E and Paediatric Assessment Unit. They have received referral as follows: 23 per cent Fever, 39 per cent bronchiolitis, 1 per cent Head injury, Asthma and Wheeze 24 per cent D and V 11 per cent Abdominal Pain 2 per cent | [Hospital website](#) |
| **Islington CCN Team** Children's Hospital at home Project  
Commissioned by Islington CCG to reduce hospital admissions and stays by at least 10 per cent  
Workforce includes nurses admin and a paediatrician. Offering 8am to 10pm | |
Local case study example from nursing workshop

Figure 5 outlines as local case study example from a nursing workshop. A two year old with severe eczema, viral wheeze and food allergy. Key messages for future care:

1. Requires key coordinator role supported by improved IT systems
2. Care closer to home seven days – using all workforce to support this change
3. Education is a large part of care – being clear on each other’s roles and joining up

Figure 5

- Requires clinical care key coordinator clarity of CCN roles and CNS roles
- Open access to advice
- Prescribing
- Like salford model

- Requires one stop assessment
- Think waiting times clinics
- Diagnosis when?

- What about HV role in contact for advice and emotional support
- Are they clinical? Is it part of HCP Minor illness

- Primary care
- Improve repeat prescription
- Could be first port of call or joint clinics
- What is the role of practice nurse?

- Team skill mix
- Specialist
- Nurse paediatrician and dietician

- Two year old severe eczema viral wheeze food allergy

- Requires IT systems to join up with communication flows
- Admin support

- Training
- Family
- Education setting
- Care close to home could be done in Childrens Centres
A local example of innovation: Children’s Out of Hours Minor Illness PATC2H Assessment and Support Service (COMPAS)

This programme will support the implementation of a new children’s nursing team in West Sussex called COMPASS, which stands for: Children’s Out of Hours Minor Illness PATC2H Assessment and Support Service.

It is all about building resilience to families as the added value to an A&E attendance. The award will allow the Paediatric Acute Care Team Closer to Home (PATC2H) Steering Group (umbrella) to set up and evaluate the COMPASS service.

(Phase 1) of the move to bringing care closer to home for CYP. COMPASS aims to reduce A&E attendances and short stay ward attenders (CAU activity) and maximise outcomes for CYP and families.

The richest outcome will be the increase in confidence and ability/resilience for parents/ families when their child is ill the next time round. COMPASS is to be run by APNPs / NPs and started on 20 January 2015, being tested on three evenings a week (as the workforce is “grown”). It is based in the adjoining out of hour’s service at St Richard’s Hospital. The award is being used to fund an APNP post for four months to ensure strategic implementation of the project through engagement with stakeholders, building networks and trust, and providing clinical leadership. The NHS At Home Agenda is a key national and MCYP SCN priority and learning from this new service will be shared across SE networks.

What could be the impact for children and young people?

- Avoids unnecessary hospital stays offering a safe alternative to short stay
- Reduces separation anxiety for both CYP and their siblings
- Continuity of care and treatment at home – care closer to home
- Reduces disruption to family life
- Increases opportunity for health education
- Positively reinforces self-care abilities/builds resilience and confidence
- Empowers parents/carers to make effective healthcare decisions in the future within a relationship of mutual trust and respect
What to commission for a good acute and short-term conditions nursing service

- High quality unplanned care including on-going assessment, children’s nursing and support.
- Reduction in number of unscheduled and avoidable child and young person attendances and admissions to secondary care that could be safely managed in the community.
- Collaboration between of emergency/unplanned care for children including the following: GPs (in and out of hours), CCNs, Primary Care Teams, local pharmacists, children’s A&E and Children’s Assessment Unit.
- Improved access for early clinical assessment and/ or follow up of a child within their own home.
- Prevention of re-admission of children to hospital as appropriate.
- Promoting the health and wellbeing of the sick child and their families through health education and support.
- Improving the urgent care of children: it is essential that GP registrars have the opportunity to gain experience of caring for acutely sick children in an appropriate safe environment.

This will require:

- Seven days working with a new model of care that reflects the five year plan models
- Advanced children’s nursing roles that include assessment and diagnosis of the presenting child
- Increased CCN workforce to include acute short-term conditions follow-up care and interventions.
- Incentives for the whole system to work together for children and young people to drive reconfiguration of services commissioned and provided going forward.
- Implementation of acute care high volume pathways
- Continued investment in training including clinical suites
- Adopting PACE Setter – Quality standards for primary care (See link on SCN Website for One Page Summary, video and Step by Step Guide)
- Completion of intravenous antibiotic treatment for identified infection (cellulitis, respiratory infection)
- Follow up nursing care – referrals from GPs, acute paediatricians and Advanced Paediatric Nurse Practitioners
Recommendations

• CCGs should accelerate the development of a sustainable and preventative model of home and school-based nursing provision reflecting principles of admission avoidance, and effective and safe discharges.

• Secondary and primary and community providers should prioritise the system-wide development of safety netting advice given to children and young people and their families, regardless of where and how they access care to support self-care and effective discharge.

• Secondary and community providers should work together to form an agreed approach to discuss clinical effectiveness, audit, critical incidents and complaints, to assure CCGs on quality improvement for children’s nursing.

• CCGs and NHS England Direct Commissioning should accelerate the development of PACE Setter Award using the Step by Step Guide to support pathways and primary care quality standards.

Long-term conditions – key statements

Asthma

• Over 10 per cent of children and young people in England have asthma (CYP Outcomes Forum, 2013)

Epilepsy

• The 2013 CYP outcome forum states that there are 60,000 children and young people with epilepsy in England

• More than one in five people with epilepsy have learning or intellectual disabilities

Who is this nursing care for?

• All children and young people with long-term health conditions

The CYP Outcomes Forum states that there are now 23,000 children and young people with diabetes. Please note that diabetes has been out of scope for this programme due to national tariff work and the National Diabetes Audit.

Long-term conditions

• The 2013 CYP Outcomes Forum states that 14 per cent of children and young people in England have a long standing illness (including mental health and physical health)
What does good provision look like?

- Consistent high quality safe care seven days a week
- Joint working between primary, secondary, tertiary and community care
- Skilled workforce with right skills in right place outside of hospital
- Interventions, care and training (parents/carers and wider children’s workforce) in the home and school throughout childhood and particularly during transitions
- Families having clear consistent advice first time, encouraging self-care and empowerment
- Implemented transition pathways
- Specialists by condition (Clinical Nurse Specialists) and specialists by environment of care (Children’s Community Nurse Specialist Practitioners), working to agreed and evidenced based care pathways
- Fair funding across acute and community
- Closer working with pharmacists regarding medications

Respiratory

- Clinical assessment, care planning and evaluation
- Provision of consumables and medical equipment
- Support with tracheostomy or nasal prong changes
- Cough/sputum sampling and implementation of treatment
- Training parents/carers including basic life support with tracheostomy and/or assisted ventilation
- Monitoring of lung function
- Administration of Intravenous antibiotics or other prescribed medication
- Education/training to staff within school and social environments
- Palivizumab is administered to infants who are perceived at being at high risk of suffering significant harm if respiratory syncytial virus (RSV) was acquired. Community positioned clinics to be decided locally.

Epilepsy

- Sourcing and provision of Joint Epilepsy Care plans for children/young people with newly diagnosed epilepsy who require emergency rescue medications
- Review of seizure profiles, emergency protocols and school health care plans
- Epilepsy awareness training and one-to-one assessment of competency in all day care and pre-school facilities.
- Education and training for child and parents/carers
- Competency based training of healthcare skills to the wider children’s workforce
- Medicines review and blood sampling to identify therapeutic drug levels
- Information giving and self-management interventions
- On-going emotional support to child and family throughout childhood and particularly during transitions.

Neurological conditions

Neurological disorders affect a significant proportion of all referrals to CCN teams. See under complex needs and/or disability.
Dermatology

- Skilled nursing assessment of skin conditions in childhood
- Delivery of education, training and support in the management of eczema including the application of wet wrapping to families and carers. In accordance with the care need identified by the local dermatology consultant
- Provision of post-operative wound management
- Tissue viability assessment and pressure care – support with maintaining skin integrity, provision of pressure relieving aids

Renal

- Blood pressure monitoring for steroid monitoring
- Support with home dialysis
- Blood sampling
- Catheterisation
- Stoma management
- Training/education to families and carers to achieve independent management of the child or young person’s condition

Allergies

Allergies are increasing within the population. With more individuals requiring emergency medication for anaphylaxis the service shall provide the following interventions

- Skin prick testing (with resus facilities in place)
- Nationally recognised anaphylaxis training to families and carers to achieve independent management of the child or young person’s condition
- Education to families and carers on the daily management of allergy and provision of care within the agreed health care plan to achieve independent management of the child or young person’s condition

Orthopaedics

Post-operative care interventions:

- External fixator and traction care
- Provision and organisation of adoptions/mobility aids
- Plaster cast after care management
- Pressure care to ensure skin integrity

What to commission for a good long-term conditions nursing service

Key messages for future care:

1. Gaps in provision and access to specialists not consistent
2. Who else needs to be involved for care planning?
3. CNS roles need to be clarified and how other roles can work together – continuity planning
4. Seven day working – out of hospital
**Recommendations**

- Local authorities and universal services providers need to work with NHS England to review current health visiting and school health nursing specifications and consider this guidance to ensure there is no duplication and that it promotes joined up working across professionals.

**Critical considerations**

- Care pathways for LTCs should clarify roles and outcomes using clinical nurse specialists and CCN specialist practitioners to ensure business continuity across primary, secondary and community providers.
Key statements

- There are 770,000 disabled children under the age of 16 in the UK. This equates to one child in 20 in the review of Health care for disabled children and young people (CQC 2012).
- The 2013 CYP Outcomes Forum states that 6 per cent of CYP in England have a disability.
- Community nurse specialist roles, which include on-going complex case management, often highly complex discharge co-ordination and key working/lead professionals, are known to improve health outcomes, including positive child and family experiences throughout childhood and at transition to adult services.

Who is this nursing care for?

- Children with complex health conditions and/or neurodisability
- Children who meet continuing care criteria with nursing needs
- Technology dependent children and young people, including. Total Parental Nutrition, , Assisted ventilation and oxygen dependent
- Children with more than one condition

Neonatal

The CCNs work with neonatal outreach specialists to facilitate early discharge for neonates with a health need, empowering families through training, education and support to care for their infant and forging a positive family environment as early as possible.

Interventions Include:

- Education and training for families and carers to undertake nursing interventions and care
- Implementation of home oxygen therapy and oxygen weaning programme
- Oxygen saturation monitoring
- Enteral feeding management
- Promotion and support with breast feeding while establishing complete oral feeding
- Weight monitoring in partnership with health visiting during period of significant health need.
- The service shall work in partnership with the NICU in secondary care, midwives and health visitors.

Complex needs

Children/young people with long-term and/or complex health needs that impact on their everyday lives most often require coordination of support from a variety of professionals and agencies.

Interventions include:

- Key working/case management/team around the child
- Complex discharge co-ordination (local and tertiary)
- Transition co-ordination, planning and support
- Assessment, care planning and evaluation of presenting diverse range of symptom and pain management
- Responsive community nursing such as stoma care and management/skin integrity review
• Education and training for child and parents/carers
• Competency based training of healthcare skills to the wider children’s workforce
• Blood pressure monitoring during steroid therapy
• Signposting to services and support, information giving and self-management interventions
• On-going emotional support to child and family throughout childhood and particularly during transitions.
• Continuing care assessments
• Referral to: therapies, social care, education, voluntary agencies
• Supporting enteral feeding care management
• Provision of consumables and training of medical devices
• Sleep studies – for children suspected of having sleep obstructive apnoea’s, impaired lung function (muscular dystrophy, cerebral palsy).

The SEN Code of Practice offers guidance on the health services for children and young people with Special Educational Needs (SEN) and disabilities and their families. These services provide early identification, assessment and diagnosis, intervention and review for children and young people with long-term conditions and disabilities. For example, chronic fatigue syndrome, or life-threatening conditions such as inoperable heart disease.

The multi-disciplinary child health team, including paediatricians, therapists, clinical psychologists, dieticians and specialist nurses such as health visitors, special school nurses, school nurses and community children's nursing teams, provide intervention and review for children and young people with SEN and disabilities and should contribute to supporting key transition points, including to adulthood. They aim to provide optimum health care for the children, addressing the impact of their conditions, managing consequences for the families and preventing further complications.

Supporting children with medical/health needs in special schools – special school nursing

Special school nurses who are children’s nurses and responsible for both clinical and public health nursing should form part of a comprehensive CCN service. Some schools may also require a mental health nurse to support children with specific emotional and behavioural needs and those CYP with diagnosed mental health conditions.

Special school nurses should be aligned to each locality CCN team. The RCN recommend that every special school that educates children with complex medical/health needs and disabilities should have a designated school nurse who supports education with the clinical and public health needs of students.

In West Sussex a joint commissioning task and finish group is currently reviewing special school nursing. A commissioning matrix, healthcare assessment tool and specification are being developed as part of reviewing the current provision and agreeing a sustainable service model. This project is linking up with the British Academy of Childhood Disability and Royal College of Nursing, who are planning to publish a position statement on supporting children with every day health needs in school.

There is a key transition when children move across CCG boundaries that presents a critical risk for children with complex needs. A mechanism by which this transition can be assisted needs to be in place.
Continence promotion

Constipation is a common problem for children under five years of age. This can become a chronic and complex problem when not managed in a timely and appropriate manner. The constipation care pathway clearly identifies timescales and definitions for the identification and treatment of conditions. A comprehensive children’s community nursing service should integrate with Level 1 service provision and deliver Level 2 service provision. Children’s continence nurse specialists (community positioned) work in an integrated way with CCNs.

The service shall provide the following interventions

- Assessment and management of bladder and bowel continence problems in childhood
- On-going care and management for complex continence referrals
- Administration of enemas
- Dietary and toileting advice, including supervision of nursery nurse/assistant practitioner/early support worker roles providing toilet training programmes
- Monitoring of compliance and medication needs
- Stoma management (Antegrade colonic enema, ileostomy and colostomy)
- Support with bowel washout

What does good provision look like?

Children’s community nurses and community specialist roles form part of the wider co-located multiagency child and family services.

Specialist community nursing teams regularly carry out case management, complex discharge co-ordination and key working as a member of the team around the child.

Multi-professional health care enablement teams (includes therapies) provide timely and responsive transition to home rehabilitation and care support for the following:

- Post-surgery rehabilitation and care support
- Responsive continuing care support where the child’s needs are deteriorating but not end-of-life
- Children with assisted technology needs post discharge, for example Long Term Ventilation where the team provide a transition before handing over to a long-term care provider
- This service could also include social care need for short-term emergency care support, for example when a parent goes into hospital
- Specialist nursing support and training for short break services.

What to commission for a good complex disabilities nursing service

- Support in schools to allow for educational progress and outcomes – all nursing services joined up. That is, Special schools, CCN and specialist nurses. Jointly commissioned with education.
- Local offer – this will include how children’s nursing services will meet the local offer set by the joint commissioning arrangements. Must include nursing, continence specialist equipment, emergency healthcare provision and continuing healthcare funding.
• Specialist CCNs for children with complex needs: key working; discharge co-ordination; case management, training and emotional support to children and families.

• CCGs are failing to drive improvements in children’s continence care, according to the Paediatric Continence Forum (PCF). Information from 203 of 211 CCGs reveals that only 32 per cent commission all four main continence services: bedwetting, daytime wetting, toilet training and constipation/soiling. It also shows that more than one third plan to commission new paediatric continence services or review existing provision. PCF has published a paediatric continence commissioning guide which recommends that the four main continence services are joined and run by dedicated children’s continence professionals.

• Supporting pupils with medical conditions in school (special school nursing)

The joint commissioning duty in the Children and families Act 2014 (CAF) specifies that the local authority, its partner CCGs and NHS England must establish local governance arrangements that ensure clear ownership and accountability for provision and strategy.

• Joint commissioning arrangements around CAF, continuing healthcare, and supporting medicines in schools are clear accountabilities for children's nursing services.

• Clear responsibilities of priority – health and wellbeing strategies or Better Care Fund

• Clear outline of what education health and care plans for children mean within nursing services

• Some examples from the pilots can be found here Information packs

• Agreed and clear accountabilities and responsibilities for local offer
Figure 7: Local case study example from workshop – 10 year old with complex needs

Recommendations

- Community and secondary care providers should support CCGs to explore further the concept of ‘Teams within Teams’ across localities to facilitate a sustainable model that is productive and equipped for multiagency integration.

- CCGs should work with local authorities to ensure there is an agreed understanding for health providers to have a named special school nurse with a clinical and public health skill set for each special school and access to pharmacist advisor.
Life-limiting or life-threatening illness – key statements

• It is estimated that there are at least 49,000 children under 19 years across the UK living with a life-limiting or life-threatening condition who may require palliative care services (Fraser, L. K, Rising national prevalence of life-limiting conditions in children in England. 2012). There are over 300 conditions that fall into the life-limiting and life-threatening category.

• The End-of-Life Parliamentary Inquiry/Review 2015 states that “Palliative care needs of children and young people are often protracted, frequently occurring prior to their last year and sometimes extending over several years. It is common for children and young people’s conditions to fluctuate and, as such, it is often much more difficult to identify when they are moving into their end-of-life phase.”

• Together for Short Lives explain that geography has a significant impact on the extent to which children and families are able to access 24/7 palliative care. Some families living in remote rural areas do not have access to the CCN teams or paediatric services they need. Whether or not children are able to die at home or in their place of usual residence largely depends on whether they can access a sustainable local CCN service. The lack of availability of CCN teams has a detrimental impact on 24/7 children’s palliative care support.

• Hospice care is not restricted to caring for people in a hospice building. As witnesses told us, it is also about providing specialist palliative care services to people in their own homes and providing respite support to the families and carers of terminally ill adults and children.

• Together for Short Lives said “Families tell us that just using the local hospice for 15 hours to get a night’s sleep so that they can keep going is totally imperative to their daily lives. Families will break down and local authorities will find themselves in the position of having to take these children into care, and there are not the resources available. It makes good economic sense to enable funding for short breaks.”

Who is this nursing care for?

Palliative care

The service shall facilitate preferred place of care and ensure services are delivered in line with recommendations from ACT (now Together for Short Lives)

Interventions include:

• Delivery of pain, symptom and medication management
• Administration of medication
• Advice and support regarding end-of-life care choices
• Referral to support services (hospice, other nursing agencies, social care)
• Facilitation of the provision of equipment
• Provision of a 24 hour on-call service
• Specialist emotional support and bereavement
• Nurse prescribing
What does this mean?

Table 12: Together for Short lives (categories)

| CATEGORY 1 | Life limiting conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis. Irrespective of the duration of threat to life on reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failures of heart, liver and kidney. |
| CATEGORY 2 | Conditions were premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy. |
| CATEGORY 3 | Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years Examples: Battens Disease, Mucopolysaccharidoses. |
| CATEGORY 4 | Irreversible but no progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex healthcare needs, high risk of an unpredictable life threatening event or episode. |

- **Life-limiting.** A life-limiting illness is an illness which may not be immediately life threatening but which imposes limits on a person's quality and/or quantity of life.

- **Life-threatening.** A life-threatening disease is a disease that is potentially fatal, likely to result in imminent death. It includes conditions caused by both natural (for example, infective) and unnatural (for example, trauma) factors. Children with life-limiting illnesses may also develop life-threatening complications that are mostly responsible for their death.

- **End-of-life care.** This is the care of a person during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline.
What does good provision look like?

**Figure 8:** A three-tier system of palliative care services

Adapted from *Craft and Killen (2007)* sourced from and Together for Short Lives Website

The Core Care Pathway for Children with Life-limiting and Life-threatening Conditions is a revision of the world’s first care pathway for children with palliative care needs, Integrated Multi-agency Care Pathways for Children with Life-limiting and Life-threatening Conditions, which was published by ACT (now Together for Short Lives) in 2004 and re-issued in 2007.

We encourage you to use this Core Care Pathway alongside the suite of Together for Short Lives pathways, which are designed for more specific circumstances:

- The Transition Care Pathway for young people (2007)
- A Neonatal Pathway for Babies with Palliative Care Needs (2009)
- A Care Pathway to Support Extubation within a Children’s Palliative Care Framework (2011)

More information on all these resources is available at togetherforshortlives

There are six standards advocated by together for short lives relating to different stages in care. These highlight the need for collaboration with professionals and planning of care with families.
Stage 1 Diagnosis or recognition

1. The prognosis sharing significant news
2. Transfer and liaison between hospital and community services

Stage 2 On-going Care

3. Multidisciplinary assessment of needs
4. A child and family care plan

Stage 3 End-of-life

5. An end-of-life plan
6. Bereavement support

NHS England has recently published a palliative care development currency. The currency is a first attempt to group specialist palliative care into packages of care that are similar in terms of resource need and clinical input. The currency is not mandatory and will be further tested and refined during 2015/16. The aim is that it will provide a meaningful tool to support service planning and commissioning.

To be able to consider this moving forward, CCGs must review the palliative care development currency, which is a first attempt to create a set of currency units that are suitable for use across all organisations providing palliative care in England, whether to adults or children. Children's age was a key driver of variations in direct costs. ‘Phase of illness’ was also associated with direct costs, as was ‘physical severity’ (grouped into high, medium and low). Diagnosis had a complex relationship with cost variations but has not been included as a variable in the development currency for children at this stage. Services provided to a twenty-five year old person who was continuing to receive care in children's services would be recorded in the children's currency. The children's pilot involved thirty-nine organisations, including hospitals, voluntary sector providers, commissioners, community health trusts, a university and children's palliative care networks.

A total twenty-eight units of cost for children has been developed. Currencies are grouped into three ‘provider categories’: acute inpatients, hospice inpatients and non-inpatient/community settings. The acute inpatients currency applies to phases of care for admitted patients in an acute setting.
**Oncology**

Managing children/young people with oncological disorders requires the children’s community nurse specialist to undertake the link practitioner role in order to effectively co-ordinate the delivery of prescribed therapy. Care pathways are established nationally. This is a specialist role which requires the nurses to be trained in the administration of chemotherapy.

Interventions include:
- Case management
- Blood sampling with adjustment and monitoring of treatment/medication
- Organisation of admission for therapy
- Administration of prescribed medication (chemotherapy, antibiotics, EPO, blood products)
- Co-ordination of oncology clinic
- Education/training within nursery/school

Local case study example from workshop – Sixteen and a half year old with cancer

**Key messages for future care:**

1. Clear pathways for transition required and nursing roles clarified and funded appropriately – should go up to 0 to 24 years. Also needs a medical pathway/psychological services/specialist social worker.
2. Wider Use of Adult Charities for 16 to 18 years as another option.
3. Requires further think around provision of care for SE approach to young facilities – not just cancer.
4. Requires seven day working with cover for 24/7 end-of-life
6. Future nursing workforce should include expertise in young people’s care.
Figure 9: Local case study example from workshop

Table 13: Local case study example from workshop

<table>
<thead>
<tr>
<th>IF UNDER CYP SERVICES</th>
<th>IF UNDER ADULT SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staffing numbers in team’s struggle to meet need.</td>
<td>CCN services still not adults</td>
</tr>
<tr>
<td>West Sussex End of Life for 12 weeks East Sussex CCN</td>
<td>CNS/CCN Brighton</td>
</tr>
<tr>
<td></td>
<td>Eastbourne- haematologist sharing care in adults. No bed capacity in Hastings</td>
</tr>
<tr>
<td>Surrey have specification saying two weeks</td>
<td>CCN team</td>
</tr>
<tr>
<td>East Kent – case by case basis</td>
<td>CCN Team</td>
</tr>
<tr>
<td>West Kent able to provide End of Life</td>
<td>Referrals not often made to CYP service</td>
</tr>
<tr>
<td>Medway – via outreach team</td>
<td>Half patch covered by children’s workforce and half patch covered by Macmillan</td>
</tr>
</tbody>
</table>
What to commission for a good nursing service for life-limiting and life-threatening conditions

- A Kent, Surrey and Sussex agreed collaborative three-tier model of CYP palliative and End of Life Care
- Requires across systems networks of care to provide person-centred coordinated care for families
- Formal partnerships between NHS and charitable organisations to deliver 24/7 holistic case management
- Agreed pathways and payment systems across providers
- Access to short breaks including nurse-led

Recommendations

- CCGs should move quickly to commission equitable services and ensure that each acute hospital has access to a community children’s nursing service which operates 24 hours, seven days a week for end-of-life care.
- KSS collaborative agree a three-tier model of commissioning for CYP palliative and End of Life Care.

Critical considerations

- CCGs and providers should work with Together for Short Lives
- Providers should develop strategies to build on good practice in advance care planning for CYP
- CCGs and providers have to accelerate discussions on implications of the recent NHS England report developing a new approach to palliative care funding

Read more about the End-of-life Parliamentary Review for Children and Young People
Implications for commissioning

What would this vision mean for commissioning?

A comprehensive CCN service that forms an integrated part of a co-located wider network presents a particular commissioning challenge and perhaps suggests in part why the current CCN service commissioning profile across the South East is so vastly inconsistent.

Figure 10 shows the complexity of the funding streams. It identifies the sub specifications and types of funding streams across other services showing the need for interrelationships with commissioning in other CYP services.

To ensure the vision becomes a reality there would need to be changes in how providers are incentivised and contracted to ensure delivery of integrated care pathways and joint outcomes for the child and family.
In order to contract this vision, work is required to deliver clear, concise and readily communicated outcomes. For example, CYP experience, early intervention, increasing families to self-care, survival rates, reducing secondary care attendances and admissions, coordinated, patient centred care, effective information sharing and use of technology. Intervening early in life affects health and wellbeing in later life. This is underpinned by sound science and finance. Our Children Deserve Better 2012 states that there is a six to ten per cent annual rate of return on investment for spends on intervention in the early years.

Contracting for service integration needs to be in place across primary, secondary, community care and the third sector. Many CCGs are starting to consider how they might use their commissioning and contracting tools to encourage providers to work together in different ways. There is a lot of interest and activity in new contractual forms and a number of models are developing in different ways, with different terminology. The commissioning and contracting for integrated care chapter focuses on three contractual vehicles being used by commissioners to deliver integrated services. These frameworks are:

1. Prime contractor model
2. Prime provider model
3. Alliance contract model
The SCN would advise that commissioners consider forming a CYP Leadership Board to build trust and relationships across statutory and non-statutory providers, then to explore alliance contracting further for CYP nursing. There would need to be an agreed membership with terms of reference covering the legal and governance support. Commissioners must consider if each CCG would access the same board or we would have one for each area across Kent, Surrey and Sussex. There must be sharing of intelligence across SE and consideration of non-statutory contracts.

**Figure 11:** What would it look like as a Prime Contractor Model?

CCG and Joint Commissioners across the SE or Split by Area KSS in a joint venture

<table>
<thead>
<tr>
<th>PRIME CONTRACTOR HOLDS SUB CYP CONTRACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>The CYP Nursing Contract could be within a larger contract or separate as part of a wider CYP contract</td>
</tr>
<tr>
<td>Sussex Sub Contractor</td>
</tr>
<tr>
<td>Acute CYP Providers Nursing Contract</td>
</tr>
<tr>
<td>Community CYP Provider Nursing contract</td>
</tr>
<tr>
<td>Personal budgets</td>
</tr>
<tr>
<td>CYP Charities SLA</td>
</tr>
</tbody>
</table>

The SCN would advise that this should be explored one to two years after reviewing the alliance contracting option via the CYP leadership board. This is due to the financial risks and relational risks. It would enhance pathways, be simple for commissioners to manage and enhance accountability onto statutory and non-statutory providers. There would need to be further work done to decide if it is an option to have one single nursing contract or sub contracts across Kent, Surrey and Sussex.
**Figure 12:** What would it look like as a Prime Provider Model?

CYP Nursing Providers may wish to have a joint venture. They may wish to have this as part of other CYP services.
The SCN would advise that this model would be considered three to five years from now. It would improve control over provision across a pathway including being able to move money within the pathway. However, with current provider configurations it could be a possible provider monopoly with perverse incentives that could limit patient choice. Providers (statutory and non-statutory) may be in a position to have a joint venture in each area of Kent, Surrey and Sussex. Commissioners would need to consider if the nursing contracts would sit in a wider CYP services contract.

The CYP Outcomes Forum states that CYP needs are not being met by the financial incentives currently being used across health and social care. They want to do further work on this with clinicians, commissioners and the regulatory bodies to develop appropriate methodologies. Two important points have been raised which are relevant to this work:

- The Better Care Fund should review the approaches taken in older people to take similar approaches to CYP care, particularly with complex and long-term conditions.
- Currently, in the Quality Outcomes Framework for primary care only three per cent relates to CYP whilst the thirty per cent of primary cares work is CYP. This needs to be reviewed.

Reference costs

The Health and Social Care Act 2012 gives Monitor and NHS England joint responsibility for the pricing of NHS services in England. Although different costing purposes may require different approaches, Monitor has developed six universal principles that should be applied to all NHS costing exercises. These are: stakeholder engagement, consistency, data accuracy, materiality, causality and objectivity, and transparency.

In order to fully cost a CCN service, the following stakeholders would need to be involved:

- clinical staff (including consultants, other health professionals, nursing staff, clinical support services)
- non-clinical staff involved in service delivery (including operational managers, education and training colleagues, research and development colleagues)
- staff from the informatics department and clinical coding department
- finance staff (including management accountants and those involved in contracting or commissioning)
- End users (including senior management of providers, regulators, commissioners)
- Consider the costs to families (parents not working and burden of care on family)

A local example in Kent

The Specialist Community Children’s Nursing and Short Breaks Services provided by Kent Community Health NHS Trust have demonstrated in their team booklet the use of tariff data to describe the value of the team with regards to efficiencies. They have used National Intelligence data broken down by CCG to allow them to demonstrate where they are successfully managing specific children’s condition in the community and preventing their admission to hospital. They have based their contact price as £109 per visit. They have used the following 2012/13 tariffs (£3,100) for complex needs and (£227) for outpatients.

An estimated explaining a total of 9,481 contacts with (£109) cost minus the acute tariff total cost
(£3,719,586) will provide a total saving of £2,686,157. This could be done on scale across the SCN if there was a database and local business intelligence support to support commissioners, but can be difficult as tariffs change and community data is lacking.

The Department of Health is looking into the possibility of a pilot collection in community services using the Community Healthcare Groups (CHGs), which are currently being developed by HSCIC. The CHGs will be based on the Children and Young People’s Health Services Data Set (CYPHS).

In order to support commissioners until further information is available, the SCN supports the use of the following resource. Unit Costs of Health and Social Care 2014. This resource includes information on what is required to work out costs (such as wages/salary costs, salary on costs, qualifications costs per year, overheads, non-staff costs, capital overheads, travel, working time, training Time, unit costs and ratio of direct to indirect time).

Table 14 provides cost comparisons to inform validity of further business cases that need to be built on locally. It also informs the need for critical skill mix and planning of community budgets.

**Table 14**

<table>
<thead>
<tr>
<th>STAFF GROUP</th>
<th>SALARY</th>
<th>COSTS</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital nurse</td>
<td>Based on the median full-time equivalent basic salary for Agenda for Change Band 6</td>
<td>£42 (£49) per hour; £104 (£120) per hour of patient contact.</td>
<td>Band 6 Community Comparison</td>
</tr>
<tr>
<td>Community nurse (adult)</td>
<td>Based on the median full-time equivalent basic salary for Agenda for Change Band 6</td>
<td>£43 (£50) per hour; per hours home visiting (including travel) £57 (£66) per hour of patient-related work.</td>
<td>Hosp Band 6 Comparison</td>
</tr>
<tr>
<td>Health visitor</td>
<td>Based on the median full-time equivalent basic salary for Agenda for Change Band 6</td>
<td>£43 (£50) per hour; £61 (£71) per hour of home visiting; £65 (£76) per hour of patient-related work.</td>
<td>For info</td>
</tr>
<tr>
<td>Clinical support worker (community)</td>
<td>Based on the median full-time equivalent basic salary for Agenda for Change Band 2</td>
<td>£21 per hour; £30 per hour of home visiting; £25 per hour of patient-related work. £20 per hour</td>
<td>For Skill mix (Community use Band 3 and 4)</td>
</tr>
<tr>
<td>GP</td>
<td>Based on per patient contact lasting 11.7 minutes</td>
<td>Including direct care with qualification £45 Without £37 excluding direct care with qualification £41 without £34</td>
<td>GP cost has many other unit costs to consider.</td>
</tr>
<tr>
<td>Community pharmacist</td>
<td>Based on the average salary</td>
<td>£51 (£57) per £128 (£142) for direct clinical contact £64 (£71) patient related care</td>
<td>Role to play in self-care</td>
</tr>
</tbody>
</table>
### Table 15: Examples of Costing for Specific Cohorts of Children

<table>
<thead>
<tr>
<th>AREA OF SERVICE</th>
<th>UNIT COSTS 2013/14 FOR COMMUNITY NURSE</th>
<th>UNIT COSTS 2013/14 TOTAL PACKAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>End-of-life Care at Home Child</td>
<td>Per Week £ 7,827, per hour £46.60 (if working 24/7)</td>
<td>No other costs included</td>
</tr>
<tr>
<td>Longer life Illness – Child with multiple disabilities</td>
<td>Costs Community Nurse 1 Home Visit a Fortnight Total per annum £4,047</td>
<td>Total Cost £96,668</td>
</tr>
<tr>
<td>Longer life Illness Trajectories – Cystic Fibrosis</td>
<td>Costs Community Nurse 1 Home Visit a Fortnight Total per annum £4,047 Community Nurse 1 Home Visit a Fortnight Total per annum £4,384</td>
<td>Total Cost £84,738</td>
</tr>
</tbody>
</table>

Source: Unit Costs of Health and Social Care 2014
Recommendations

- CCGs should develop a strategy for children’s nursing services across primary, secondary and community services for the 0 to 25 year old population, with an action plan for each year.
- Community and secondary care providers should support CCGs to explore further the concept of ‘Teams within Teams’ across localities to facilitate a sustainable model that is productive and equipped for multiagency integration.
- Local authorities and universal services providers need to work with NHS England to review current health visiting and school health nursing specifications and consider this guidance to ensure there is no duplication and that it promotes joined up working across professionals.
- CCGs should move quickly to commission equitable services and ensure that each acute hospital has access to a community children’s nursing service which operates 24 hours, seven days a week for unscheduled and end-of-life care.
- CCGs and secondary and community providers should prioritise the development of data management system such as a dashboard to reflect the baseline Key Performance Indicators suggested in the specification.
- Providers to develop a single plan for health conditions shared across the system.

Critical considerations

- CCGs should ensure that financial incentives in the health system are evolved to encourage innovation and development that delivers the types of services CYP want.
- CCGs and providers should review the outputs from an expert PBR group.
- CCGs and providers should review CQUIN payments for CYP and collectively work towards improvements in quality.
- CCGs and provider business intelligence could design an agreed way of costing efficiencies for prevention of admission.
VOLUME 2
SERVICE SPECIFICATION
The service specification document should be read in conjunction with:

2. Volume 1 (Commissioning Guidance) and Volume 3 (References and Resources) when adapting this specification for local use.

This specification is to support the provision of high-quality nursing care that is responsive to the health needs of children, young people, their families and carers in the four groups of children and young people specified below:

- Children with acute and short-term conditions
- Children with long-term conditions
- Children with disabilities and complex conditions, including those requiring continuing care and neonates (in conjunction with neonatal care)
- Children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care

Commissioning arrangements supporting the specification should be framed by the following principles:

- Children’s Community Nursing (CCN) forms part of an integrated, co-located wider network of multiagency child and family services.
- Children and Young People (CYP) should be treated and cared for as far as possible within their own community and close to home.
- Commissioners should ensure that appropriate plans are in place for children and young people in a health condition related crisis.

Guidance for commissioners:

- It is essential that children and young people and their families are involved in commissioning and service design (as well as providing feedback to services). Children, young people and their families, including those who have yet to access services, can help commissioners prioritise and identify any service gaps and blocks to access, assisting providers in improving services and evaluating change.
  - Commissioners should consider the diversity of the CYP population for which they are responsible; not only cultural and ethnic diversity, but all of the factors that may influence the risk of developing physical/mental health problems now and in the future.

- This specification is written to support the commissioning of services that can support appropriate nursing care closer to home.

- Not all children and young people will require nursing care. However, when they need it, provision must be timely with a range of multiprofessional clinical and multiagency care and support pathways that allow interface with other professionals around the family.

- Although it has been developed using an NHS template, its content can be used by other commissioners as appropriate and it aims to acknowledge the multiagency commissioning and delivery required to support children and young
people with nursing needs. In the development of this specification, commissioners will need to take account of local commissioning and provision across the whole system, including education establishments, local authority and health.

• Commissioners should include children, young people and their families, as well as providers, in developing the specification further to suit local circumstances and needs.

• The resulting specification should be clear about what the service provider is commissioned to provide, but also what the provider will not provide. This provision should be clear for all parties the scope and deliverables. All information given to children, young people, parents and referrers about the services should reflect what has and what has not been commissioned.

• The specification and performance against quality markers will need to be reviewed regularly by commissioners and providers with input from service users, using the support of the Strategic Clinical Networks.

• This specification requires endorsement from the children and young people programme boards in CCGs.
Service specification

1. Population needs

This specification embraces both the changes in complexity of need and the transition continuum requirements up to 25 years for children and young people, who present with acute illness, are diagnosed with a long-term condition or disability, or who require palliative and end of life care. Local needs can be found within local Joint Strategic Needs Assessments.

2.0 National/local context evidence base

In February 2013, HM Government, NHS England, Public Health England (PHE), professional bodies and organisations, local government organisations and providers signed up to the ‘Pledge’ for better health outcomes for children and young people.

The Pledge sets out five shared ambitions to improve physical and mental health outcomes for all children and young people.

1. A comprehensive CCNS needs to demonstrate evidence of alignment with the five pledges
2. Children, young people and families should be at the heart of decision making
3. There should be high quality services from pregnancy through to young adulthood
4. There should be good mental and physical health interventions
5. There should be clear leadership, accountability, governance assurance and partnerships

International and national population statements

- The UK has one of the worst childhood mortality rates in Europe.
- The UK is bottom of the league for childhood emotional wellbeing
- The UK has significantly worse diabetic control markers compared to other countries.
- The Joint Epilepsy Council in 2011 reported that up to 40 per cent of children referred to tertiary centre epilepsy clinics did not have epilepsy. NICE
also cited research that stated that 59 per cent of all sudden unexpected deaths in epilepsy were potentially avoidable.

- A 2008 the review of child deaths reported that ‘identifiable failure in the child’s direct care’ was found in 26 per cent of deaths and that there were potential avoidable circumstances in 43 per cent of deaths.
- Errors or inadequacies included deficient children’s training, supervision and the recognition and management of the severely ill child.
- As many as 1,500 children a year might not die if the United Kingdom performed as well as Sweden in relation to illnesses that rely on first-access care, such as asthma and pneumonia (Wolfe et al 2011).
- In 2013, the Children and Young People’s Health Outcomes Forum Report cited research from Asthma UK which stated that up to 75 per cent of hospital admissions for children with asthma could have been prevented with better primary care, stating that a third of short stay admissions in infants for minor illnesses could have been managed in the community.
- A review of NHS South England urgent and emergency care services (2013) highlighted an increase in demand for urgent care for both children and adults. The admission rate for children between 1999 and 2010 saw an increase of 28 per cent in England. The rise was mainly due to common infections requiring very short hospital admissions. Regionally, there was a 52 per cent increase in admissions for children under 12 months and a 25 per cent increase in 1-4 year olds. Overall in the last four years the region has seen a 9 per cent increase in the growth of general paediatric admissions to hospital.
- National research indicates that 7 per cent of the 0 to 19 year old population is classified as disabled, although a relatively small number would require support from a CCN service.
- Over the last five years there have been significant advances in medical interventions that have led to an increase in the number of children surviving the neonatal period and being discharged from hospital with highly complex health needs, requiring specialist care and support from services such as a children’s community nursing.
- The Department of Health stated in 2007 that, of those conditions likely to require palliative care in England, around 7,000 (74 per cent) of those under 20 years (excluding neonates) died in hospital, 1,800 (19 per cent) died at home and 390 (4 per cent) died in hospices. It also identified that an estimated 63 per cent of children and young people requiring palliative care have a need for social care services (11,000 children/young people aged between 0-19).
Figure 1 - CCN teams across the South East

CCN and Hospice Teams across Kent, Surrey and Sussex

Kent and Medway
- CCN Team
- Epilepsy Team
- Respiratory Team
- Bladder and Bowel Team
- Diabetes Team
- Continuing Care Teams East and West
- Home based short breaks
- Residential short breaks team
- Special school teams
- School Health Team
- CCN Outreach Medway
- Dementia Hospice
- Dartford and Gravesham CNS (not CCN)
- Maidstone and Tunbridge Wells Team
- Ellenor Lions Hospice Dartford

Surrey
- CCN Team Virgin
- CCN Teams
- CHC Team
- Special Schools Nursing
- CCN Ashford and St Peters
- CCN Epsom and St Helier
- Chase Shooting Star

Sussex
- SCT West Sussex CCN Service:
  - Core community nursing
  - Specialist community nursing
  - Special school nursing
  - Continuing care and short breaks
  - Children's continence
  - Palliative care
  - Brighton Complex Disabilities (SCT)
  - CCN BSUH
  - WSHT Outreach CNS
  - ESHT Hospital at home team CCN Eastbourne
  - ESHT Hospital at Home Team CCN Hastings
  - Dementia Outreach
  - Chestnut Tree Outreach and in reach
  - SASH Outreach CNS
2.1 NHS outcomes framework domains and indicators

The CCN service, within a vision for modern children’s nursing, will support delivery against the NHS and PHE outcomes frameworks. The 2013/14 indicators as described below remain in the 2015/16 NHS Outcomes Framework.

Table 1
NHS Outcomes Framework in relation to CCN

<table>
<thead>
<tr>
<th>DOMAIN THEME</th>
<th>CCN ROLE TO SUPPORT OUTCOME</th>
</tr>
</thead>
</table>
| 1 Preventing people from dying prematurely              | • CCNs work closely with medical colleagues to intervene early to reduce infant mortality especially for respiratory and sepsis  
Overall outcome: To reduce potential years of life lost from causes amenable to health care. Reducing deaths in babies and young children. |
| 2 Enhancing quality of life for people with long-term   | • CCNs support CYP and families to self-care with robust management plans.  
conditions Overall outcome: To reduce unplanned time spent in hospital by children with specific long-term conditions that should be managed outside hospital.  
NHS 2.3.ii Rate of emergency admissions episodes in people under 19 (0 to 18 years) for asthma, diabetes or epilepsy per 100,000 population. | conditions Overall outcome: To reduce unplanned time spent in hospital by children with specific long-term conditions that should be managed outside hospital.  
NHS 2.3.ii Rate of emergency admissions episodes in people under 19 (0 to 18 years) for asthma, diabetes or epilepsy per 100,000 population. |
| 3 Helping people to recover from episodes of ill-health or following injury Overall outcome: Preventing lower respiratory tract infections in children from becoming more serious. NHS 3.2 Using Quarterly HES Data Age standardised rate per 100,000. Emergency admissions to hospital of children with selected types of lower respiratory tract infections (Bronchiolitis, bronchopneumonia and pneumonia). Collects 0 to 18 years. | • CCNs implement acute respiratory illness pathways for bronchiolitis  
• CCNs can be valuable in raising awareness of bronchiolitis with parents |
| 4 Ensuring people have a positive experience of care     | • CCNs can evidence CYP experience of community nursing services  
Overall outcome: Improving children and young people’s experience of healthcare. This family and friends indicator is being tested and will be rolled out in 2015. | Overall outcome: Improving children and young people’s experience of healthcare. This family and friends indicator is being tested and will be rolled out in 2015. |
Treating and caring for people in a safe environment and protecting them from avoidable harm

Overall outcome

5.6 Harm from failing to monitor children properly in an acute setting. (This has been removed from 2015/16 work continues with Safety Barometer).

Increasing incident reporting.

- All nurses play a part in preventing harm using paediatric early warning scores within acute and community services.
- All nurses will use the high volume pathways supporting clinical decision making.
- All nurses are involved in reporting incidents and learning from these are reviewed locally and nationally.

CCG outcome indicators (2015 was released on 19 March 2015)

C 2.7- Unplanned hospitalisation for asthma, diabetes and epilepsy (under 19s).
C 3.4- Prevent lower respiratory tract infections (LRTI) in children from becoming serious – emergency admission for Children with LRTI

Click here to view data on the domains from February 2015

For further Information current NHS and PHE Outcomes Data across SE access CYP Health Benchmarking Tool.

Further Indicators are being developed by the CYP Outcomes Forum:

- Time to diagnosis
- Children and young people’s experience
- Transition to adult services
- Confident to manage their care
- Age-appropriate settings
- Integration
- Indicators for social care

Table 2 Public Health outcomes framework in relation to CCN

<table>
<thead>
<tr>
<th>DOMAIN THEME</th>
<th>CCN ROLE TO SUPPORT OUTCOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain 1: Improving the wider determinants of health</td>
<td></td>
</tr>
<tr>
<td>1 Sickness absence rate (indicated here in relation to acute or chronic health/mental health issues)</td>
<td></td>
</tr>
<tr>
<td>2 Pupil absence children in poverty (indicated here in relation to health outcomes after a period of acute or chronic illness)</td>
<td></td>
</tr>
<tr>
<td>3 Seriously injured causality on England’s roads.</td>
<td></td>
</tr>
<tr>
<td>4 Low birth weight term babies</td>
<td></td>
</tr>
<tr>
<td>CCNs support CYP to stay in school with a healthcare plan supporting school readiness</td>
<td></td>
</tr>
<tr>
<td>CCNs support care post recovery after road traffic accidents</td>
<td></td>
</tr>
<tr>
<td>CCNs support neonatal nurses with preterm babies at home on oxygen</td>
<td></td>
</tr>
</tbody>
</table>

Domain 2: Health improvement

Hospital admissions caused by unintentional and deliberate injuries in children under four years

Prevention of Ill Health: 27 A&E attendances

All nurses work will local safeguarding policies

CCNs can prevent attendances to A&E

Click here for data

For further Information current Public Health Outcomes across SE access the SCN Profile for 2014

Further information can be found in the CYP Outcomes Forum Second Annual Report within the Health Outcomes Group Annex A
2.2 Local defined outcomes

In the 2011 Improving Children and Young People's Health Outcomes: a system wide response was published. The government recognised the role that failures of care have played in poor outcomes for children and young people and pledged to better suit the NHS Outcomes Framework towards achieving these goals wherever possible. The CYP Forum's annual report for 2014 can be found here.

The development of a CCN service should be informed by a local vision for children's nursing services. This should be owned and developed in partnership with children, families, commissioners and provider organisations.

Examples of locally defined measures that providers would need to work with each other to meet are:

- Existing disparate nursing teams brought together to achieve a 'critical mass' of staff with the flexibility to adapt the service when children move from one group to another and to meet the changing needs at times of crisis, deterioration or end-of-life.
- Agreeing consistent referral and assessment process across the five counties of SE to allow for cross boundary working if appropriate.
- Locally agreed pathways to deliver a coordinated and cohesive service to children, young people and their families.
- Development of one shared plan for a child, across the system.
- The establishment of agreed pathways between CCNs and GPs. Children's nursing teams and GP practices working together on protocols of care, referral pathways and out-of-hours care arrangements 24/7.
- The Palliative and End-of-Life Care Model recognises the specialist skills and expertise of the voluntary sector, particularly children's hospices, in palliative care and, more specifically end-of-life care and bereavement support. Local community nursing services together with local specialist third sector/charitable organisations should form partnerships with shared outcomes to meet the population needs for end of life care. SE should develop a children's palliative care and EOLC model which includes specialist; community and universal provision.
- To drive forward whole system provider partnerships to reduce average length of stay for hospital admissions by discharge from hospital to community settings.
- To deliver an out-of-hours/weekend service and/or emergency on-call service, providing a telephone advice service for concerned families.
- To provide care in a variety of community settings: child's home, school, nursery, community position clinics and GP surgeries.
- To have an accessible training and education service for families and other professionals through expert nurse educators to support children with complex and additional needs in community settings.
- To include commissioning of resources for supplies and equipment services to ensure the provision of community nursing and care in the home.
3.0 Aims and objectives of service

The overarching aims are:

- To provide a high quality responsive CCN service to families who have children and/or young people within the four groups of need [NHS at Home](#) has identified in the population, accessible seven days a week.
- To prevent avoidable admission, attendance or re-admission/attendance to secondary and tertiary care, bringing care closer to home.
- To facilitate and support timely discharge from secondary and tertiary care (emergency, inpatient and neonatal care).
- To empower families of children/ young people to lead independent lives.
- To work in partnership with families, carers, education, social care and other health professionals working around the child.
- To safeguard and promote the welfare of the children and young people known to the service, giving recognition to the increased vulnerability of children with complex needs.
- To promote a child's quality of life during a period of illness and for children who have a life-limiting condition to provide them with a comfortable, dignified death and with choice of where they wish to die.
- To provide healthcare education, expert advice, support and nursing interventions to manage individual health needs and promote self-care when appropriate.
- To work as an integrated multidisciplinary and multiagency team around the child ensuring the child/young person’s needs are managed in a holistic manner.
- To undertake assessment and treatment management delivered within the community preventing unplanned admission/ readmission/ ward attendance for those children and young people within the identified population.
- To ensure young people are supported through transition into adult services and/or onward into adulthood.
- To develop on-going relationships with commissioners to ensure high quality, effective and value for money services.
- To provide clear, up to date and accessible information and advice to enable children, young people and their families/carers to play an active role in the development and implementation of their care plan and prevent future hospital admissions.

3.1 Referral pathway

1. Identification of the lead consultant/GP that is responsible for the current and future medical treatment plan (this could be local and/or tertiary level).
2. Identification of the lead professional who is responsible for the shared health, education and social care plan.
3. Referrals can be made by telephone, fax, or email to a secure nhs.net account/fax following safe haven requirements.
4. Preliminary triage against the need for nursing criteria should be carried out by the service upon receipt; an individual patient record file is then created. Depending on the acuity and urgency of the referral a decision will be made re response time for example routine within two days and urgent within two hours.
5. Initial contact is made to the family, prioritised to individual need, for example immediate contact essential if facilitating discharge for home intravenous therapy.
6. A nursing needs assessment is undertaken during first visit (within seven days, unless urgent) with referral to other organisations as required. ‘Agreement to share information’ is formally requested and signed.

7. A plan of nursing care and review times is then agreed with the family/carers within two working days of the assessment.

8. A visiting schedule for follow up is confirmed with planned reviews within five working days of the assessment.

9. Referrals to the service can be made by the following groups:

   **Main referrers are:**
   - GPs
   - Community Paediatricians
   - Tertiary and Local Paediatricians
   - Nurses (Primary Secondary and tertiary)
   - For advice, support and signposting
   - Health Visitors
   - School Nurses
   - Therapists
   - Parents/carers
   - Voluntary services with permission from the parent/carer
   - Self-referral – parents/carers of young people if they are known to the service
   - Social Services
   - Education Services – Including staff in special educational settings

### 3.2 Service description/care pathway

CCN seeks to develop, implement, monitor and review multiagency pathways for priority needs for children and young people and their families ensuring clarity of roles and responsibilities, reducing duplication and eliminating gaps. There must be a core focus on the four groups of children who should be able to access a comprehensive CCN service.

Table 3 below shows the complexity of commissioning these four pathways of care while understanding the inter-professional relationships required. To understand this more the table aims to pick out the tariffs available, the interventions from nurses and which commissioning structure and staff would need to be involved to have a comprehensive service.
<table>
<thead>
<tr>
<th>TYPE OF CARE TARIFF PATHWAY</th>
<th>TYPE OF INTERVENTION</th>
<th>COMMISSIONER STAFF NEEDED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute elective care</td>
<td>• Home visits for management following fractures or orthopedic surgery, including spinal fusion operations and for children/young people in plaster or traction.</td>
<td>Specialised and Public Health (PH) commissioning, Clinical Nurse Specialist (CNS), CCN, Health Visitor (HV), Specialist Nurse (SN)</td>
</tr>
<tr>
<td>Acute elective care</td>
<td>• Home visits following day case surgery including for wound care.</td>
<td>CCG Commissioning/ GPs/Practice Nurses</td>
</tr>
<tr>
<td>Acute elective care</td>
<td>• Post-transplant visits and local case management.</td>
<td>Specialised commissioning, CNS, CCN</td>
</tr>
<tr>
<td>Acute outpatient follow up</td>
<td>• Home visits to train and demonstrate wet wrap technique for children with eczema.</td>
<td>CCG and PH commissioning, CCN GPs, HV, SN</td>
</tr>
<tr>
<td>Acute post-elective care</td>
<td>• High Volume Conditions follow up assessment, health education and support/interventions/ telephone/ visit of children.</td>
<td>CCG and PH commissioning, GPs, CCN, APNP, CAU and A&amp;E Nurses, HV, SN</td>
</tr>
<tr>
<td>Acute post non-elective care</td>
<td>• Home visits to administer intravenous (IV) antibiotics where necessary.</td>
<td>CCG Commissioning, GPs, CCN, Advanced Pediatric Nurse Practitioner (APNP), Clinical Assessment Unit (CAU) &amp; Accident and Emergency (A&amp;E) Nurses</td>
</tr>
<tr>
<td>Acute elective care outpatient follow up</td>
<td>• Home visits to administer subcutaneous medications, for example children with rheumatic conditions and to take blood samples to monitor conditions.</td>
<td>Specialised commissioning, CCG commissioning, CNS, CCN, GPs</td>
</tr>
<tr>
<td>Acute outpatient follow up</td>
<td>• Short-term monitoring of clinical observations, for example blood samples, blood pressure in children and young people.</td>
<td>CCG commissioning, CNS respiratory, Specialised commissioning Specialist neonatal nurse</td>
</tr>
<tr>
<td>Acute elective surgery</td>
<td>• Training and support for parents and carers to care for children and young people with nasogastric, tracheostomy, and gastrostomy tubes, including how to change tubes when necessary. This will include carers in schools, short breaks units and other community settings that are providing a service to this patient group.</td>
<td>CCG commissioning, Specialised commissioning, CCN, CNS</td>
</tr>
<tr>
<td>Primary and community care pathways</td>
<td>• Minor Injuries Units</td>
<td>CCG commissioning, ENP, APNP, CCN</td>
</tr>
</tbody>
</table>

Table 3 Commissioning CCN Pathways
### Non-elective long-term condition pathways

- **Diabetes** - involvement will depend on where employed and what Service Level Agreement (SLA) is in place.
- **Epilepsy** - requires joint approach to CYP with Epilepsy (links with Special School Nursing).
- **Asthma** – requires joint approach to ensure pathway incorporates primary care.
- **Allergy** requires joint approach to ensure pathway incorporates primary care.

**CCG & PH commissioning**

- CCN
- CNS
- Special School Nurses
- SN

### Community pathways complex disabilities equipment and training

- Assess needs for equipment/consumables and set up supplies and equipment for children following discharge from tertiary centres. Coordinate stock and maintenance of electrical equipment by telephone.
- Establish a supportive care package at home for child and family, facilitating the transition home.
- Provide training for nurses and carers in the specific needs of children who are technology dependent and have very complex health needs.

**CCG and PH commissioning**

- Joint commissioning
- CNS CCN

**Wider team**

- Community pediatrician
- Therapists
- Local Authority Commissioning (LAX)

### Public Health pathways

- **Special School Nursing**.
- Supporting children with medical needs in special school settings: school health care plans; emergency protocols; training the wider children’s workforce; community nursing in schools.

**Local authority commissioning**

- NHS England/
- Special School
- Health visitors
- School nurses

### Continence pathway

- **Level 1** day nocturnal enuresis, constipation and toilet training
- **Level 2** Children’s community continence service
- Complex Needs Assessment
- Day and Night-time wetting - complex
- Constipation – complex
- **Level 3** referral to a specialist pediatrician community, secondary or tertiary

**Local authority/PH Commissioning**

- Health Visitors School Nurses
- NHS England
- CCG commissioning
- Specialised

### Acute prevention of admission complex disabilities

- **Level 1** day nocturnal enuresis, constipation and toilet training
- **Level 2** Children’s community continence service
- Complex Needs Assessment
- Day and Night-time wetting - complex
- Constipation – complex
- **Level 3** referral to a specialist pediatrician community, secondary or tertiary

**CCG Wider CYP Team**

- Act as the nominated health assessor for continuing care assessments, coordinating the multi-disciplinary involvement to produce a holistic assessment of the child or young person’s needs.
- Training wider children’s workforce within home, nursery school and short break settings.

**CCG commissioning**

- CCN
- Community pediatrician

**Joint commissioning**

- Link with education and social care CCN community pediatrician

### Life-threatening and Life-limiting

- **Home visits** for children and young people requiring palliative care
- **Work** with local third sector teams to meet the needs of children and young people requiring palliative and end-of-life care.
- **Access** to specialist bereavement support service

**CCG commissioning**

- Hospice staff CCN
- Pediatricians
3.3 Population covered

- 0 to 25 years (Long-term conditions, disabilities and complex conditions and Life-limiting and Life-threatening).
- 0 to 16yrs (Acute and Short-term conditions –Please note that this is mainly high volume conditions that affect 0 to 5year olds).
- All children and young people registered with a GP and be accessible to residents who are not.
- If the child or young person is visiting or on holiday and referred into the service by their local team, this will be accepted and re-charged back to the local CCG. For those children who are placed into any of the CCG areas by another authority, the ‘Responsible Commissioner Guidance 2013’ applies.
- Young people over the age of 18 years can be referred to an adult service if that is their choice.
- Be available to all children young people without regard to gender, sexuality, religion, ethnicity social or cultural determinants.

3.4 Any acceptance and exclusion criteria and thresholds

The service will be available 365 days per year within the parameters set out as follows:-

- A service operates between the hours of 8am and 8pm seven days for advice and support and visits as required
- Children requiring end-of-life care will have access to an on call service 24/7 in partnership with other providers.
- Children requiring acute Illness support will have access to advice and support with visits as required 24/7 in partnership with primary care.

Other thresholds

There must be an identified nursing need for support or direct intervention.

Children/young people shall be discharged from the service when:

- They no longer require nursing support to manage their health need.
- When they move residence and/or GP beyond geographical area covered by CCG.
- In all cases, notification of discharge is sent to the original referrer and key workers within two working days of discharge.
- Where a child is not eligible for the CCN team, the expectation will be that the child/young person’s health needs will be met through universal health services such as GP, Health Visiting or School Nursing.
- The CCN service does not provide emergency care. Where this is required, the child/young person will need to access hospital care either via an ambulance or through their own means.

3.5 Interdependence with other services/providers

Delivering nursing care closer to home through an agreed care pathway necessitates collaborative working with an extensive range of health, social care and education professionals, children and their families as shown in Figure 2.
Figure 2.
Health, Social Care and Education Professionals involved in Care

**Primary care**
- GP
- Practice Nurses
- Pharmacists

**Secondary care**
- Specialist Children’s Nurses
- Acute Pediatricans
- Neonatalists
- Specialist Doctors
- Childrens Nurses
- Advanced Nurse Practitioners
- Dietitians

**Community care**
- School Nurses
- Health Visitors
- LAC and FNP
- Other Providers of children’s continuing care packages
- Physiotherapists,
- Occupational Therapists
- Speech and Language Therapists
- Community Paediatricians
- Specialist equipment suppliers and loan stores
- District Nurses

**Other Sectors**
- Portage Workers
- Social Workers
- Specialist Teachers/SENCOs/Classroom Teachers
- Early Help
- Preventative services
- Short break staff/Palliative Care Consultant/Hospice staff
- Housing Officers
- Support groups and local voluntary sector organisations
- National charities
4.0 APPLICABLE NATIONAL AND LOCAL STANDARDS

National standards are covered in 4.3 Local standards with the exception of NICE

4.1 Applicable standards set out in guidance and/or issued by a competent body (for example Royal Colleges)

These are covered in 4.3 Local standards and references please note the Facing the Future Together for Child Health Standards is to be launched in April 2015 at the Annual Royal College of Paediatrics and Child Health conference.

Table 4.

<table>
<thead>
<tr>
<th>LOCAL STANDARDS</th>
<th>POLICY SOURCE</th>
<th>SCN LINK ADVICE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  The children’s community nursing service should provide seven day access</td>
<td>Department of Health (DoH) (2011) <em>NHS at Home: Community Children’s Nursing Service</em></td>
<td>Visiting Access 8am to 8pm and evaluate need across KSS.</td>
</tr>
<tr>
<td>to advice and support for families and carers between 8 am and 8pm and in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>end of life care, 24 hour visiting as required.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2  The CCN service should offer a visiting service between 8am and 8pm with</td>
<td>DoH (2011) <em>NHS at Home</em> Community Children’s Nursing Service</td>
<td>8am to 8pm for visiting: Evaluate and risk assess staff safety; evidence of need particularly at weekends/BH (12 hours).</td>
</tr>
<tr>
<td>telephone advice OOH, by people who are knowledgeable about children’s</td>
<td></td>
<td></td>
</tr>
<tr>
<td>services and the individual child, with the ability to make a home visit if</td>
<td></td>
<td></td>
</tr>
<tr>
<td>needed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3  The CCN service should include trained nurse prescribers.</td>
<td>DoH (2011) <em>NHS at Home</em> Community Children’s Nursing Service</td>
<td>HEE and Providers to work together to determine level of prescribing and numbers.</td>
</tr>
<tr>
<td>4  The CCN service and families should have access to equipment to enable</td>
<td>DoH (2011) <em>NHS at Home</em> Community Children’s Nursing Service</td>
<td>Patient specific equipment is included in budget planning Work with NHS England regarding patient specific specialist medical devices e.g. ventilators and cough assists.</td>
</tr>
<tr>
<td>sustained home support.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5  The CCN service and families should have clear protocols in place to</td>
<td>DoH (2011) <em>NHS at Home</em> Community Children’s Nursing Service</td>
<td>Agreed approach between tertiary, secondary, primary and community care.</td>
</tr>
<tr>
<td>facilitate/support access to hospital care when necessary for children who</td>
<td></td>
<td></td>
</tr>
<tr>
<td>have complex care needs and are normally cared for at home; Pathways should</td>
<td></td>
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</tr>
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<td>be in place for children’s community services, primary care services and</td>
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<tr>
<td>families for urgent or unscheduled care.</td>
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<td></td>
<td>The CCN service should have access to advice from specialist nurses for children with diabetes, asthma, epilepsy, cystic fibrosis, continence and cancer.</td>
<td>DoH (2011) <a href="https://www.nhs.org">NHS at Home</a> Community Children’s Nursing Service</td>
</tr>
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<tr>
<td>7</td>
<td>The KSS Children's Nursing Group will develop local recommendations for staffing levels for community children’s nursing and health visiting service based on the recommendations of the RCN (2013) “Defining staffing levels for children and young people’s services.”</td>
<td>RCN (2013) “Defining staffing levels for children and young people’s services”</td>
</tr>
<tr>
<td>8</td>
<td>The CCN services should work closely with health and children’s service colleagues including health visitors, school nurses, therapists and GPs.</td>
<td>Improving Children and Young People’s Health Outcomes: A System wide response (DoH, Feb. 2013).</td>
</tr>
<tr>
<td>9</td>
<td>Children’s community nurses should be part of the acute services discharge planning process for those children requiring complex care.</td>
<td>Sussex Children and Young People Clinical Reference Group</td>
</tr>
<tr>
<td>10</td>
<td>There should be a training programme provided for staff working in children’s services to ensure there is an awareness of needs of children with disabilities and their families.</td>
<td>DoH (2011) <a href="https://www.nhs.org">NHS at Home</a> Community Children’s Nursing Service</td>
</tr>
<tr>
<td>11</td>
<td>Children and young people with complex needs and their families should have access to the full range of multi-disciplinary services to support planned and timely discharge from acute care.</td>
<td>DoH (2011) <a href="https://www.nhs.org">NHS at Home</a> Community Children’s Nursing Service</td>
</tr>
<tr>
<td>12</td>
<td>Telephone support should be available for GPs from a senior paediatrician within 30 minutes of telephone contact for patients whom the GP believes cannot be sent home without receiving advice from a paediatrician.</td>
<td>Sussex Children and Young People Clinical Reference Group</td>
</tr>
<tr>
<td>13</td>
<td>There should be good access for parents, children and young people to primary care services during the week and at the weekend, particularly between 3pm and 8pm.</td>
<td>A Review of the NHS South of England Urgent and Emergency Care services (Kings Fund, March 2013)</td>
</tr>
<tr>
<td>14</td>
<td>The training needs of primary care (GPs and practice nurses) services in relation to children and young people should be reviewed and a training programme set up to meet those needs. Commissioning a good child health service.</td>
<td>(Royal College of General Practitioners, Royal College of Paediatrics and Child Health and Royal College of Nursing, March 2013)</td>
</tr>
<tr>
<td>15</td>
<td>Clear pathways should be developed and implemented for common childhood illnesses including wheezing, asthma, diarrhoea and vomiting, fever, bronchiolitis and minor head injury</td>
<td>Commissioning a good child health service (Royal College of General Practitioners, Royal College of Paediatrics and Child Health and Royal College of Nursing, March 2013)</td>
</tr>
<tr>
<td>16</td>
<td>There should be out-reach paediatric outpatient services and closer integration of acute Trust paediatric services (medical and nursing) and CCN service.</td>
<td>Sussex Children and Young People Clinical Reference Group</td>
</tr>
<tr>
<td></td>
<td>Local pathways should be in place for diabetes, cystic fibrosis, gastroenterology, neurology and epilepsy, paediatric surgery and access to psychology support for long-term conditions.</td>
<td>Opening the Door to Better Healthcare: Ensuring General Practice is working for Children and Young People (The National Children's Bureau, June 2013)</td>
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</tr>
<tr>
<td>17</td>
<td>There should be a children’s long-term conditions strategy in place to improve the health and wellbeing of children and young people including those with severe mental health conditions.</td>
<td>Children and Young People’s Health Outcomes Forum (2012)</td>
</tr>
<tr>
<td>18</td>
<td>There should be integrated care (for children and young people with a long-term condition, disability or complex needs) for each child or young person with a long-term condition, disability or special educational needs. Each looked after child or young person should have a coordinated package of care including a quality assessment and access to key working and appropriate equipment. This should be delivered in a timely manner and the individual's and their family's experience of the service should be measured.</td>
<td>Children and Young People’s Health Outcomes Forum (2012)</td>
</tr>
<tr>
<td>19</td>
<td>There should be clear protocols developed and implemented for transition of children to adult services including the monitoring of whether children and young people continue to receive the care they need following transfer from paediatric services.</td>
<td>Children and Young People’s Health Outcomes Forum (2012)</td>
</tr>
<tr>
<td>20</td>
<td>All acute trust services delivering care for children with diabetes should meet the Paediatric 13 diabetic best practice tariff standards.</td>
<td>Best Practice Tariff for Paediatric Diabetes (2012) NHS Diabetes and the Paediatric Diabetes Networks and the Department of Health</td>
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<td>21</td>
<td>All acute trust services delivering care for children with diabetes should meet the Paediatric 13 diabetic best practice tariff standards.</td>
<td>Best Practice Tariff for Paediatric Diabetes (2012) NHS Diabetes and the Paediatric Diabetes Networks and the Department of Health</td>
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<td>22</td>
<td>All acute Trusts should meet the RCPCH Epilepsy12 standards.</td>
<td>Child Health (2012) Epilepsy12</td>
</tr>
<tr>
<td>23</td>
<td>There should be a local co-ordinated pathway for neuro-disability and neurology, reducing admissions to acute care or ensuring the timely discharge of patients.</td>
<td>Sussex Children and Young People Clinical Reference Group</td>
</tr>
<tr>
<td>24</td>
<td>All Trusts should meet the RCPCH ‘Facing the Future’ standards.</td>
<td>RCPCH (2011) Facing the future Revision of the Facing the Future Standards 2014</td>
</tr>
<tr>
<td>25</td>
<td>The KSS Children's Nursing Group will develop local recommendations for ALL staffing levels for trust children's nursing services based on the recommendations of the RCN (2013).</td>
<td>“Defining staffing levels for children and young people's services” Royal College of Nursing (2013)</td>
</tr>
<tr>
<td>26</td>
<td>The KSS Children’s Nursing Group will develop a toolkit, based on the CQC 16 Essential Standards and the Association of Chief Children's Nurses (ACCN) policies pertinent to children and young people in hospital (2013) to reflect local needed and implement an audit against the agreed standards in 2014/15.</td>
<td>The Trusts will complete the Association of Chief Children’s Nurses (ACCN) Universal Children’s and Young People’s Health Audit Tool</td>
</tr>
<tr>
<td>27</td>
<td>All trusts to meet the standards for children and young people in emergency care settings.</td>
<td>Standards for Children and Young People in Emergency care settings (2012)</td>
</tr>
</tbody>
</table>
28 All trusts meet the Principal recommendations of the NCEPOD report “Are we there yet: A review of organisational and clinical aspects of children’s surgery.”

NCEPOD (2011) Are we there yet: Not applicable to CCN unless post op care required

29 All trusts will meet the Royal College of Surgeons of England standards.

Standards for Children’s Surgery The Royal College of Surgeons of England (2013) Not applicable to this programme

30 All Sussex Short Stay Paediatric Assessment Units (SSPAU) should have consistent pathways and coding in place for investigations, activity and transfers to an inpatient facility or discharge to primary care.

Locally agreed by the Clinical Reference Group Further work must be done re contracting and funding inequities

31 All health organisations must demonstrate how they have listened to the voice of children and young people and how this will be used to improve their health outcomes.

Children and Young People’s Health Outcomes Forum (2012) All CCN teams must implement family and friends test and benchmark across the SE

32 Primary, secondary and community services should continue to work closely together and meet regularly to review clinical practice and share best practice initiatives.

Locally agreed by the Clinical Reference Group The existing network groups continue to meet

33 Primary, secondary and community services will meet the RCPCH/RCGP/RCN standards for unscheduled care for acutely mild to moderately unwell CYP.

RCPCH/RCGP/RCN 2015 Focus is on acute short-term conditions group within CCNS

### 4.3 Key Performance Indicators

Data collection related to community services provision has historically been poor and this can be compounded by contracts that have lacked incentives for providers to track quality and costs. Several commissioners across England have said they have gone through an arduous and time-consuming process to ‘unpick’ community services to try to understand the quality and efficiency of current services. At a system level, the entire sector needs better data about costs, activity and patient outcomes to enable a shift to new ways of providing care. This includes data that would allow commissioners and providers to see a patient’s contacts with all points in the system, including with community services.

Monitor is publishing a guide to help local areas create person-level linked datasets that will support local health economies to understand the patterns of care and associated costs of their local populations across all settings.

The CYP Outcomes Forum recommends linked data sets across age groups.

Examples of performance and activity data collection include:

- Referral data: who and need, timeline between referral and intervention
- Admission and discharge from the service
- Case complexity and caseload numbers; nursing/transition/CP/CIN and early help. Consider measuring high volume conditions as primary or secondary presenting condition.
- Contact activity for example visits, telephone follow up, MDT clinical meetings
- Training child, parents/carers and/or the wider workforce
- Cases discharged to other CCGs
All data needs to be:

- Produced for each age set
- Aligned to each CCG and
- Provided at district level to monitor equity over time

It was stated in *Improving Community Services*, written by Monitor in 2015, that commissioners had a number of reasons why they need better data about community services:

- To understand patients’ needs and use of services to enable planning and prioritising
- To manage performance of contracts, for example to understand whether providers are providing quality care that achieves good outcomes for patients and offers value for money
- To develop new currencies or payment mechanisms
- To prepare to use a competitive tender process, and provide information to prospective providers so that they can offer a sound bid

The types of data that commissioners may need to support these functions will vary, but commissioners said they may include:

- activity data (for example number of contacts specified by service line)
- information on the costs of services provided

- data to measure quality of care, including outcomes and experiences of patients
- staffing information and other human resource information
- information on premises and facilities
- data to benchmark their own services

Some of our providers across the South East do not collect data specific to their service or it is an add-on to adult data and therefore less relevant. This could be related to:

- Information technology (IT) systems in place that limit data collection scope
- KPIs have not been agreed from which to target data input
- appropriate practices or capacity within a service are not in place to gather and record robust data

Provision of data could be significantly improved if clinical staff had access to handheld devices for timely data input.

The SCN are proposing this set of KPIs to support a baseline of service information and the need for a dashboard.
### 4.4 Draft KPIs for discussion

#### Table 5 Draft Key Performance Indicators.

<table>
<thead>
<tr>
<th>AREA OF WORK</th>
<th>INDICATOR</th>
<th>PRESENTED</th>
<th>TARGET</th>
<th>MEASURE</th>
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</thead>
<tbody>
<tr>
<td>Caseload activity</td>
<td>No of children and young people on total caseload on 1 day of the month</td>
<td>Graph grouped by age range 0-5 6-11 12-16 17-19 19+</td>
<td>No target baseline data</td>
<td>Quantitative process</td>
</tr>
<tr>
<td>Caseload activity</td>
<td>Primary group is the reason for referral</td>
<td>Graph grouped by category according to NHS at Home Categories (Acute Illness, Long-term condition, complex health Care, end-of-life care)</td>
<td>Per cent per category No target Baseline Data</td>
<td>Quantitative Process</td>
</tr>
<tr>
<td>Caseload activity</td>
<td>Caseload flow in and out flows, including transition to adult services</td>
<td>No. of referrals and No. of discharges per month, including transitions to adult services</td>
<td>No target baseline data</td>
<td>Prevention, quantitative, process</td>
</tr>
<tr>
<td>Caseload activity</td>
<td>Caseload complexity profiling per cent of complex, high medium low cases</td>
<td>Evidence of names link team for each area with clear referral pathways per CCG Referral satisfaction surveys</td>
<td>Audit of referrals and source No of visits to GPs every year Baseline data</td>
<td>Quantitative, qualitative process</td>
</tr>
<tr>
<td>Access and support</td>
<td>A named CCN TEAM for: every Hospital, every GP Practice, every CDC, every School, every Universal Service</td>
<td>Evidence of on call arrangements</td>
<td>No target baseline data</td>
<td>Quantitative process</td>
</tr>
<tr>
<td>to other professionals</td>
<td>Referral response times for urgent and routine cases Access 24/7</td>
<td>Graph showing response times met Clear narrative if not met and why Evidence of on call arrangements</td>
<td>90 per cent Urgent within two hours 90 per cent Routine in 2 days No of visits outside 8am to 8pm</td>
<td>Quantitative process</td>
</tr>
<tr>
<td>Caseload care planning</td>
<td>A nursing needs assessment is undertaken during first visit (within seven days, unless urgent) with referral to other organisations</td>
<td>No of assessments undertaken by routine and urgent categories Narrative if not achieved</td>
<td>90 per cent of first visit assessments undertaken in seven days</td>
<td>Quantitative process</td>
</tr>
<tr>
<td>Caseload care planning</td>
<td>A plan of care/ review is agreed with the family/carers within two working days of the assessment</td>
<td>No of care plans discussed with families in two working days</td>
<td>90 per cent of care plans discussed and competed in co-production with families</td>
<td>Quantitative process</td>
</tr>
<tr>
<td>Access and response</td>
<td>No of single shared care plans across health and across health, education and social care</td>
<td>No of shared care plans for CYP with LTCs; complex needs and palliative care</td>
<td>Increase in numbers across a locality</td>
<td>Quantitative process</td>
</tr>
<tr>
<td>Prevention of admissions further detail</td>
<td>No of episodes of care that prevented the need for a hospital admission.</td>
<td>No of prevention of assessment and or admission Grouped by Intervention Direct Nursing Care, Telephone Advice Grouped by source Escalation to GP, Clinical Assessment Unit (CAU), A&amp;E, Ambulance, Rapid Access Outpatient Tertiary Consultant Inappropriate Referral</td>
<td>Number grouped by intervention Baseline data</td>
<td>Prevention, quantitative, qualitative process</td>
</tr>
<tr>
<td>Post-hospital care</td>
<td>Supported early discharges from secondary care tertiary care</td>
<td>No of early discharges grouped by CYP four groups.</td>
<td>Baseline data</td>
<td>Quantitative, process</td>
</tr>
<tr>
<td>Feedback from children and young people</td>
<td>Every child has the opportunity to feedback on their experiences</td>
<td>Questionnaire Pictures Assessment tools Interactive Social Media</td>
<td>Family and friends Baseline data</td>
<td>Quantitative, qualitative.</td>
</tr>
<tr>
<td>Training the wider workforce Whole CCN Service Areas)</td>
<td>Every child has the opportunity to feedback on their experiences</td>
<td>No. of training sessions delivered and No. of attendees No. of Competency assessments completed (new and refresher)</td>
<td>Baseline data</td>
<td>Quantitative, qualitative.</td>
</tr>
<tr>
<td>Continuing are assessment</td>
<td>Improving CHC commissioning outcomes for statutory requirement</td>
<td>No of CHC assessments done quarterly (Review and New) No of hours spent per assessment</td>
<td>Baseline data</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Professional development</td>
<td>Per cent staff with qualifications mapped to RCN guidance</td>
<td>No. and per cent of APNP/ACCNs No. and per cent of staff with CCN qualification No. of staff with physical assessment No. of Non-Medical Prescribers Qualification profile of the service</td>
<td>Baseline data</td>
<td>Quantitative</td>
</tr>
</tbody>
</table>

Source: from other specifications and existing local data being collected

### 4.5 Family and Friends Test – Horizon Scanning

NHS England has produced guidance for Children and Family services across the following areas: children’s community nursing, children’s physiotherapy, children’s speech and language therapy, children’s occupational therapy, paediatric medical services.

Further information published in July 2014 can be found here [NHS England Guidance](#).
5.0 Applicable quality requirements

Needs further discussion between commissioners as should be same as other services if applicable to CYP.

5.1 Applicable CQUIN goals

To discuss further between commissioners

- There may be an opportunity once baseline data is collected to propose a CQUIN for 16/17. Guidance explaining the aims, objectives and financial framework can be found here: Commissioning for Quality and Innovation Guidance (14/15).
- The South East Commissioning Support Unit has been commissioned by NHS England’s Patient Experience Team to undertake a questionnaire. is to understand how local financial incentives are being used to improve patient experience, the quality and impact of children and young people’s services.
- The results from the survey mentioned above will be used to inform discussions within each NHS England Region around how financial incentives are being used, identify best practice examples and explore how they could be further developed to incorporate patients’ views on the quality of the health services they received.

6.0 The provider’s premises location

- Parents/carers and young people should be offered a choice of locations for visits which best meet their needs. For example: children’s centres, community clinics, primary care, school and home.
- Locations must be easily accessible for all children and families.
- The core service will operate standard hours of 8am to 8pm but will offer flexibility between the hours of 8pm and 8am.

7.0 Individual service user placements

Needs further discussion between commissioners as should be same as other NHS services contract.

8.0 Indicative activity plan

- To discuss further with commissioners post baseline data
- This data needs to be interpreted accurately to reflect the workload activity
- Datasets also need to be built that address the acuity and clinical dependency of the growing number of children living at home with increasingly complex medical conditions
- Demonstrating changes in activity, caseload acuity and complexity must influence commissioning, service planning and service development

8.1 Activity planning assumptions

- To discuss further with commissioners and providers
- Dependent on outcomes from recent Monitor guidance and planning guidance
9.0 Essential services

- Needs further discussion between commissioners as should be same as other NHS services contract.

9.1 Essential services continuity plan

- To discuss between commissioners and providers
- Must include system resilience planning

10.0 Clinical networks

- To discuss with clinical leads and clinical director re future planning post CAG and when we know what the service improvement structure will be.
- The SCN are proposing that there could be a role for a Children’s Nursing Network similar to midwifery. This could be part of an operational delivery type approach reporting to the commissioner’s forum.

11.0 Other local agreements, policies and procedures

- Needs further discussion between commissioners as should be same as other NHS services contract.

12.0 Transition arrangements

- Needs further discussion between commissioners as should be same as other NHS services contract.

13.0 Exit arrangements

- Needs further discussion between commissioners as should be same as other NHS services contract.

14.0 Social care provisions

- Needs further discussion between commissioners as should be same as other NHS services contract.
- This must include joint working relationships.

15.0 Transfer of and discharge from care protocols

- Needs further discussion between commissioners as should be same as other NHS services contract.

16.0 Safeguarding policies

- Needs further discussion between commissioners as should be same as other NHS services contract.
## References and resources

### Acute and short-term conditions

<table>
<thead>
<tr>
<th>DOCUMENT</th>
<th>WEB LINK</th>
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<tbody>
<tr>
<td>NHS Confederation, Urgent and Emergency Care, Ripping off a Sticky Plaster (2014)</td>
<td>NHS Confederation 2014</td>
</tr>
<tr>
<td>National Children’s Bureau, Opening the door to better healthcare: A snapshot of innovations in primary and first access care for children and young people (2014)</td>
<td>National Children’s Bureau 2014</td>
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<tr>
<td>NHS Institute for Innovation and Improvement, A whole system approach to improving emergency and urgent care for children and young people (2011)</td>
<td>NHS Institute for Innovation and improvement</td>
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<tr>
<td>NHS Institute for Innovation and Improvement, Focus on: Children and Young People Emergency and Urgent Care (2010)</td>
<td>NHS Institute for Innovation and Improvement</td>
</tr>
<tr>
<td>NHS England, Improving General Practice Section on Children and Young People (2014)</td>
<td>Improving General Practice Section on CYP</td>
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<tr>
<td>The Kings Fund, Community services how they can transform care (2014)</td>
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</tr>
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<td>The Kings Fund, Commissioning and Funding General Practice (2014)</td>
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</tr>
<tr>
<td>Quality Watch and Health Foundation, Focus on A&amp;E Attendances – Why are Patients Waiting Longer? (2014)</td>
<td>Changes to the health visiting service</td>
</tr>
<tr>
<td>British Journal and Medicine, Information needs of parents for acute childhood illness: determining ‘what, how, where and when’ of safety netting using a qualitative exploration with parents and clinicians (2014)</td>
<td><a href="http://www.nuffieldtrust.org.uk/publications/focus-on-ae-attendances">www.nuffieldtrust.org.uk/publications/focus-on-ae-attendances</a></td>
</tr>
<tr>
<td>Biomedical Centre, The safety netting behaviour of first contact clinicians: a qualitative study (2013)</td>
<td>bmjopen.bmj.com/content/4/1/e003874.full</td>
</tr>
<tr>
<td>Spotting the Sick Child (free e-learning resource)</td>
<td><a href="http://www.spottingthesickchild.com">www.spottingthesickchild.com</a></td>
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Long-term conditions

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<thead>
<tr>
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<tbody>
<tr>
<td>Department of Health, Improving the transition of young people with long term conditions from children's to adult health services (2006)</td>
<td>Transition: getting it right for young people - Improving the transition of young people with long term conditions from children’s to adult health services</td>
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Life-limiting and Life-threatening conditions

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<tr>
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<tr>
<td>NICE, Improving outcomes in Children and Young People with Cancer (2005)</td>
<td>NICE</td>
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## Complex disabilities

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<tr>
<td>Department for Education, Medicines in Schools (2014)</td>
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<td>Department of Health, Improving the transition of young people with long term conditions from children’s to adult health services (2006)</td>
<td>Transition: getting it right for young people - Improving the transition of young people with long term conditions from children’s to adult health services</td>
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<td>Royal College of Physicians of Edinburgh, Think transition - Developing the essential link between paediatric and adult care (2008).</td>
<td>Think transition Developing the essential link between paediatric and adult care</td>
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<td>Contact a Family</td>
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<tr>
<td>Department for Education, Easy read guide for children and young people (2014)</td>
<td>The SEND Information Packs</td>
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<tr>
<td>National Parent Partnership, Parent Carer Forums</td>
<td>National Network of Parent Carer Forums</td>
</tr>
<tr>
<td>Department for Education, The Preparing for Adulthood programme</td>
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### Nursing and workforce

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<tr>
<td>Department of Health NHS at Home Children’s Community Nursing Services (2011)</td>
<td>NHS at Home</td>
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<tr>
<td>Department of Health, Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values (2014)</td>
<td><a href="http://www.rcn.org.uk">www.rcn.org.uk</a>__data/assets/pdf_file/0003/78627/002454.pdf</td>
</tr>
<tr>
<td>Royal College of Nursing, Health care service standards in caring for neonates, children and young people (2014)</td>
<td><a href="http://www.rcn.org.uk">www.rcn.org.uk</a></td>
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<tr>
<td>Royal College of Nursing, Defining staffing levels for children and young people’s services: RCN standards for clinical professionals and service managers (2013)</td>
<td><a href="http://www.rcn.org.uk">www.rcn.org.uk</a></td>
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# Children’s healthcare and other relevant sources

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<tr>
<td>Royal College of Paediatric and Child Health, Standards for Emergency Care Settings (2012)</td>
<td><a href="http://www.rcpch.ac.uk/emergencycare">www.rcpch.ac.uk/emergencycare</a></td>
</tr>
<tr>
<td>Royal College of Paediatric and Child Health, Facing the Future: Standards for Paediatric Services (2011)</td>
<td><a href="http://www.rcpch.ac.uk/facingthefuture">www.rcpch.ac.uk/facingthefuture</a></td>
</tr>
<tr>
<td>Royal College of Pediatrics and Child Health Not just a phase: A Guide to the Participation of Children and Young People in Health Services , (2010).</td>
<td>Not just a phase</td>
</tr>
<tr>
<td>National Confidential Enquiry into Patient Outcome and Death, Are We There Yet?: A review of organisational and clinical aspects of children’s surgery; (2011)</td>
<td>Are We There Yet?: A review of organisational and clinical aspects of children’s surgery; National Confidential Enquiry into Patient Outcome and Death 2011</td>
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<td>Reference</td>
<td>Access</td>
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<tr>
<td>UCL Institute of Health Enquiry, Marmot: Fair society, healthy lives:</td>
<td>Marmot Indicators</td>
</tr>
<tr>
<td>strategic review of health inequalities in England (2010)</td>
<td></td>
</tr>
<tr>
<td>Public Health England, General Practice Data</td>
<td>Finger tips tool General Practice</td>
</tr>
<tr>
<td>NHS Atlas of Variation in Healthcare for Children and Young Adults has</td>
<td>Child Health Atlas</td>
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<tr>
<td>been developed in collaboration with the Child and Maternal Health</td>
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<td>Observatory</td>
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<tr>
<td>NHS Citizen, Enabling citizens to influence NHS decision making</td>
<td>NHS Citizen</td>
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<tr>
<td>NHS England Youth Forum</td>
<td>NHS England Youth Forum</td>
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<tr>
<td>National Children’s Bureau, Guidelines for Research with Children and</td>
<td>Guidelines for Research with CYP</td>
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<tr>
<td>Young People (2011)</td>
<td></td>
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<tr>
<td>National Children’s Bureau, Involving Children and Young People in Policy,</td>
<td>Involving Children and Young People in Policy, Practice and Research</td>
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<tr>
<td>Practice and Research (2015)</td>
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<tr>
<td>Implementation of the UNCRC in England: Implications for children and</td>
<td>Young Health Participation</td>
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<td>young people’s participation in health services (2015)</td>
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<tr>
<td>Healthwatch Children Toolkit and Resources Guide (2013)</td>
<td>Health Watch opportunities</td>
</tr>
<tr>
<td>Projections for England (2014)</td>
<td></td>
</tr>
<tr>
<td>British Journal of Medicine, Increase in emergency admissions to hospital</td>
<td>Archives of Disease in Childhood</td>
</tr>
</tbody>
</table>

**Appendix 1 - CCN audit**

**CCN audit document**
Appendix 2 – High volume conditions data

The following data within appendix 2 has been provided by The South of England Quality Observatory in 2014.

A&E attendances 0 to 5 years: no investigation or treatment

<table>
<thead>
<tr>
<th>A&amp;E attendances with no investigation or treatment for under 5s 2013/14</th>
<th>SPEND ACROSS SE</th>
<th>ACTIVITY ACROSS SE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£ 1,980,527</td>
<td>39,193</td>
</tr>
</tbody>
</table>

Cost per child on average - £50.53

A&E attendances under 5 years old with no treatment or investigation
High volume conditions 0 to 5 years: non-elective admissions

The graphs below have been produced by the Quality Observatory. They show the rate per 10,000 population for admissions regarding the high volume conditions across SE CCGs. The first graph relates to all of the high volume conditions mentioned.

<table>
<thead>
<tr>
<th>ADMISSIONS TO HOSPITAL WITH ZERO DAYS LOS FOR UNDER 5S 2013/14</th>
<th>SPEND ACROSS SE</th>
<th>ACTIVITY ACROSS SE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost per child on average - £1,198.49</td>
<td>£55,559,884</td>
<td>£46,358</td>
</tr>
</tbody>
</table>

Zero length of stay for high volume conditions admissions

![Admissions to hospital with zero days LoS for under 5s 2013/14](image-url)
Abdominal pain

![Graph showing admissions to hospital with zero days LoS for under 5s 2013/14 Abdominal Pain: Rate per 10,000]

Asthma and wheeze

![Graph showing admissions to hospital with zero days LoS for under 5s 2013/14 Asthma & Wheeze: Rate per 10,000]
Bronchiolitis

Fever and minor infections
Gastroenteritis, and diarrhoea and vomiting

[Graph: Admissions to hospital with zero days LoS for under 5s 2013/14 - Gastroenteritis/Diarrhoea & Vomiting: Rate per 10,000]

Head injury

[Graph: Admissions to hospital with zero days LoS for under 5s 2013/14 - Head Injury: Rate per 10,000]
Urinary tract infections

Further resource: Commissioning for Value

The Commissioning for Value work programme is a partnership between NHS England, Public Health England and NHS Right Care and the initial work was an integral part of the planning approach for CCGs. Commissioning for Value is not intended to be a prescriptive approach for commissioners, rather a source of insight which supports local discussions about prioritisation and utilisation of resources. It is a starting point for CCGs and partners, providing suggestions on where to look to help them deliver improvement and the best value to their populations. Click here for commissioning for value packs for each CCG and spend on under five years admissions.