Royal College of Paediatrics and Child Health (RCPCH) submission to the Specialised Services Commission on the future for NHS specialised care

January 2016

We are pleased to contribute to the work of the Specialised Services Commission towards addressing the challenges and opportunities facing NHS Specialist care. The RCPCH is hopeful that the review will result in a more intuitive, patient-focussed approach that will address 'boundary' and communication problems between specialist and non-specialist services and result in much needed improvements in outcomes for Infants, children and young people and their families.

At all times the focus must be on the experience and outcomes for the child and their family moving in and out of specialist services rather than on the institution, staff team or funding arrangements. Families with disabled, seriously or chronically ill children face immense difficulties ensuring that the care their child needs is timely, accessible and imposes as little disruption as possible to family life and the following responses reflect both this 'life course' approach and the practical expertise and input from members of the 17 specialty groups which are affiliated to the RCPCH.

N.B. the term 'child' or 'children' used below means infant, child and/or young person.

Safety, Quality and Money

1. **How should specialised services be defined?**

- All care should be high-quality care delivered at the appropriate time and place. Children should be able to access high quality services, regardless of when and location.

- Specialist services for children provide care for conditions which are rare and/or need expert multi-professional input in terms of highly trained clinical teams, specialist equipment and/or investigations and specialist drugs. These individuals and services contribute to a pathway of care and may not necessarily all be located at a single tertiary or quaternary site.

- The boundary between specialist services and services commissioned by CCGs must be transparent and clearly defined to prevent perverse incentives where children who deteriorate are no longer a cost pressure for CCGs as their care is picked up by NHS England, e.g. the boundary between CAMHS Tiers 3 and 4.

- Taking the example of neonatology, 10% of infants receive some level of care, but the natural boundary that all three levels of care are funded centrally. This smooths bureaucracy and saves NHS costs.

2. **Is growth in expenditure on specialised services necessarily faster than the general rate of NHS growth? If so, by how should this be accommodated?**

- We do not have detailed data on expenditure on specialised services so cannot comment directly.

- NICE provides a standardised measure for assessing the cost-effectiveness of drugs, treatments and interventions. and standard national specifications and (ideally) pathways should mitigate expenditure and improve quality by centralising diagnostics, avoiding unnecessary tests, timely diagnosis and delivering only approved treatments.

- Robust governance of the CRGs should provide the mechanisms for assessing and influencing the relative spends on specialist and non-specialist services.

- The RCPCH believes it is essential that discussions within specialised commissioning create robust and sustainable planning for National Intensive care services within the UK. Specialist commissioning is the only organisation that can integrate national strategy planning with workforce planning for the future. Services should be benchmarked to allow scrutiny of unexpected variation in cost.

- Some RCPCH members have also raised concerns about the level of top up payments released by MONITOR for specialist services such as gastroenterology and hepatobiliary services if the conditions are not part of cancer, cardiac, respiratory or neurosurgical specialties.

- Expenditure must be shared appropriately across geographical regions, recognising the costs to establish a managed clinical network model to direct the delivery of a specialist service - this has to be balanced against savings to the patients and families in delivering care closer to home. With the development of a functioning clinical network model, improved specialist care delivered locally through ‘shared care clinics’ with less frequent out-patient reviews and fewer but more focused investigations. Without shared-care pathways, the alternative is the provision of a local service which may be of lower quality. Patients and families also need to travel large distances to a regional paediatric unit with the consequent impact of increased travel costs and days lost from work and education.

- Any model proposed must be as flexible as possible to allow for innovation and appropriate funding of specialist care wherever it is delivered. In paediatric disability, a substantial amount of specialist care is delivered in localities, and the funding for specialist services goes to the regional centres, with no reimbursement at district level for the specialist services that they are delivering.

- Adequate training in research skills should be provided for all specialty professionals and capacity for research delivery built into job plans of all consultants.

3. **How can quality best be embedded in specialised services? Should national standards remain in place and how should quality be assured?**

- In terms of the best future model of care to deliver the range of paediatric subspecialties, the RCPCH advocates the implementation of the managed clinical network model (MCN) working within an Operational Delivery Network such as for neonatal and paediatric intensive care. The MCN can deliver needs-led specialist care using a pathway approach across secondary and tertiary care boundaries so that the children are seen in the right place by the right people with the right expertise. Managed clinical networks can deliver safe and high quality care and can be an effective way of using precious resources. In Scotland, there are a number of established managed clinical networks.

- National standards and national service specifications must be clearly articulated for professionals and the public what is and is not included. The establishment of properly governed clinical working groups to advise on these national standards, if appropriately resourced and facilitated effectively, should provide an assurance of equity across the country.

- The RCPCH seeks to influence regulatory bodies to adopt such measurable standards to be used by inspection teams to seek evidence of quality and safety, poor and good practice across all areas of child health care. The CQC has a programme of inspection of specialist children's hospitals but is unlikely to pick up problems in specialist services. The RCPCH suggests a programme of peer review, overseen by CRGs. The Royal Colleges would be effective both for spreading learning and providing expert visiting. This model has been developed for paediatric networks and Tier 4 CAMHS services.

4. How and at what level should clinical leadership and patient involvement be embedded for specialised service planning?

- There must be clinical leadership for within each MCN with appropriately resourced training, support and time. Clinical leads should work with commissioners to understand individual service issues and facilitate shared working between provider services.

- Specialised paediatric services within organisations and networks should have a clear accountability framework and be able to demonstrate quality by providing data, using peer review and evidence-based research against national audit and other benchmarks.

- Patient involvement should be encouraged across all social and ethnic demographic with service provision, evaluation and influence workforce development. Support to develop these effective groups and support patients to feel competent to participate. The RCPCH has a dedicated webpage to assist this process (http://www.rcpch.ac.uk/improving-child-health/us-voice-children-young-people-and-families/us-voice-children-young-people-an).

Provision and integration

5. What role should providers play in the management of specialised care in future?

- In principle, care is best managed when a robust, aligned relationship exists between providers and commissioners. Current care pathways for patients that require care across a number of providers have poorly developed financial and provider pathways. Unless clinical activity is owned by the network providers, there will be no incentive to improve outcomes and patient experience. Implementing a bottom-up network requires the re-writing of SLAs to bring all aspects of the service under specialist commissioning.

- Current models of service delivery include much work that is under the radar of commissioning and technically unfunded, such as a daily large volume of telephone or email support to local healthcare professionals or families themselves. Some units are attempting to classify this work as "telephone clinics" and further work in robustly capturing this activity is urgently needed.

6. **How should the provider landscape change? What role will New Care Models play?**

- Providers and NHSE/Specialised commissioning should work jointly together but an even more effective approach is to establish co-commissioning frameworks with the CCGs to provide a holistic whole patient pathway approach.

- There should be a provision of local care with guidance from the MCN so that quality standards. Provision, including use of new technologies to support remote care and enable efficiency as well as of support between appointments for patients and clinicians is available to reduce unnecessary appointments. Professional time must be allocated to support non face to face patient care and development of such models.

7. **How should payment systems adapt to support better specialised care in future?**

- Introduce a mechanism to commission care across health care boundaries

- Currently all GP care is tariff driven and secondary/specialized care is contract driven. GPs should support all aspects of patient care to avoid unnecessary use of specialist care for minor complaints and prescribing

- Many units have locally-agreed tariffs at the same price as general paediatric services and frequently without any multi-professional uplift. In contrast to most other specialist paediatric services, there is no national tariff for e.g. paediatric nephrology out-patient clinics despite the highly multi-disciplinary nature of children’s kidney care. Most locally agreed tariffs are set considerably lower than the national tariff for adult nephrology. Re-writing SLAs to create bottom-up networks would therefore result in loss of income to tertiary providers.

8. **What measures would best support an integrated experience of specialised care for patients?**

- Applying the MCN model to deliver pathway care which is co – commissioned, and against a set of agreed outcome measures

- Well trained teams working across primary, secondary and tertiary care e.g. to give effective support between clinic appointments

- Share educational resources and use IT opportunities

- Research participation opportunities which focus on improving patient care from scientific, therapeutic and service design and patient participation perspectives

Accountability and engagement

9. **How will accountability for patients and the public be assured in a more plural world?**

   Accountability should remain at the point of care monitored within a whole system approach where system weaknesses and failings (e.g. when delegation does not work) could be identified and addressed within the accountability framework.

- Regional MCNs effectively delivered through a steering group structure that directs the collection of data allows both the clinical service and clinical care to be measured against agreed service and clinical practice standards and outcomes. Transparency, care and communication/joint working between e.g. health, education, social care and local ownership, and this should involve more streamlined use of the multidisciplinary team resource with established channels of communication. detailing compliance with agreed measures of service and care

10. How should devolution affect specialised services and what safeguards will be required?

- Devolution of health and social care could potentially help children with complex needs who need to navigate through health management, education and social circumstances. The complexity as to 'who does what' is currently concerning and the impact of additional devolution arrangements must not make systems more complex or, inequitable, must allow for innovation and most importantly the impact of devolution must be robustly evaluated. There are some conditions which are rare and 'simple' that can easily be identified. In many cases there is a spectrum of disorders with overlapping symptoms or combined co-morbidities which makes the current function of separate commissioning bodies unclear and not joined up.

- National standards must be defined to ensure equal access to and delivery of specialist services, together with mandatory completion of audit cycles with clear recommendations for quality improvement. There must then be a peer review or external scrutiny to ensure national standards are met.

11. Where should the buck stop and how will patients and the public know who to engage with?

- Financial accountability should lie with the Trust/organisation holding the budget, to ensure specialist services are appropriately resourced, and allocated funds are available to the specialist teams.

12. How should the Commission consider innovation within the above programme, without duplicating the work of the Accelerated Access Review?

- Specialist service professionals can identify and lead advances in rare disease management (http://www.rcpch.ac.uk/bpsu).

- Remote working and technology can support specialist team and network working and communication. If the "role of technology' in key policy themes is to be achieved there needs to be a ring fenced budget for it.