



Facing the Future:

Standards for children with ongoing health needs

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 RCPCH

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Foreword

Facing the Future: Standards for children with ongoing health needs provides a vision of how paediatric care can be delivered to provide a high-quality service that meets the needs of infants, children and young people with ongoing health needs.

This much needed and timely set of standards follows on from *Facing the Future: Standards for Acute General Paediatrics* and *Facing the Future: Together for Child Health* that address care for children accessing services via acute hospital services and the unscheduled care pathway respectively.

Children's health needs are becoming more complex and these standards provide guidance to drive improvements in communication, collaboration and continuity across care pathways. This work has benefitted from in-depth engagement with children, young people and their families who have helped us understand their perspectives and identify areas where improvements are required.

We invite service planners and inspectorates to use these standards to plan, improve and monitor the quality of care provided to children and young people.

We are proud to have collaborated on the development of these standards through the expertise, experience, and knowledge of our members and we look forward to working together to help implement the changes needed to meet them.

Professor Neena Modi, President, Royal College of Paediatrics and Child Health

Professor Helen Stokes-Lampard, Chair, Royal College of General Practitioners

Ms Cecilia Anim, President, Royal College of Nursing

Professor Jane Dacre, President, Royal College of Physicians

Professor Wendy Burn, President, Royal College of Psychiatrists

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Executive summary

The RCPCH has come together to develop new standards with the Royal College of General Practitioners, Royal College of Nursing, Royal College of Physicians and Royal College of Psychiatrists. These standards expand the Facing the Future suite of service standards updated and published in 2015, which to date has focussed on acute and unscheduled care. The suite now includes standards that apply to children who are awaiting diagnosis or are under the care of child health services to manage their ongoing health needs.

The standards are organised around the child's journey and aim to ensure children's healthcare provision is coordinated and joined up, that communication between healthcare professionals and services is connected to ensure more valuable and effective care is provided for children, including continuity of care for young people transitioning to adult services or requiring referral to mental health services. The standards will ensure that child health services are proactive and planned; that children are represented at executive level and are involved in designing and evaluating care so that services are built around their needs.

There are 11 standards in total. Standards one to three focus on ensuring prompt and correct diagnosis, with local networks and improved communication between professionals ensuring that children and families are supported to manage their own health as close to home as possible.

Standards four to eight focus on improving the long term care and management of children under the health service, particularly around access to and between specialist children's health services, transition planning and mental health services.

Standards nine to eleven focus on connecting the whole system to ensure children's health services are championed at the top of every health organisation to improve patient experience and the integration of services.

These standards must be seen as a whole rather than in isolation, as they work to underpin each other to promote a high-quality child health service experience throughout the child's patient journey. Service planners, providers and commissioners must work together to ensure that every contact with the child health service is valuable and effective. We hope that child healthcare professionals and service planners will be supported by these standards as a tool in which to plan and deliver care that puts the child at the heart of everything we do.

Dr David Shortland

Past Vice President for Health Services, Royal College of Paediatrics and Child Health

Melissa Ashe

Policy Lead, Royal College of Paediatrics and Child Health

Case for change

Children tell us that health services are confusing. For children with ongoing health needs, difficulty in accessing and obtaining information relating to their diagnosis and management of their condition can be troubling^{1,2}. Children want to be involved in discussions and decision making on all aspects of their care planning and management. If we are to put children at the centre of services that care for them, increasing the education of children and their families to self-manage their health and to improve local knowledge of what is available, what the referral pathway is and to be able to identify where there are gaps to feed into service evaluation and planning is key.

The number of children with ongoing health needs is increasing alongside the proportion of children dying as a result of their complex, chronic or long-term conditions^{3,4}. *The State of Child Health 2017* report, published by the Royal College of Paediatrics and Child Health (RCPCH), shows evidence that the UK has fallen behind other wealthy European countries on key measures for child health including mortality among children with ongoing health needs⁵.

Care for people with long term conditions in England accounts for 50% of all general practice (GP) appointments, 64% of outpatient appointments and 70% of the overall health and social care spend⁶. In Scotland, 80% of all GP consultations are attributed to long term conditions⁷. Wales currently has the highest proportion of people with long term or life limiting conditions in the UK, which attributes to the most expensive component of NHS care provision for that nation⁸.

Whilst the rate of children presenting at emergency care settings with multiple health needs has remained relatively stable, recurrent readmissions for children with chronic conditions contribute substantially to total emergency admission rates^{9,10}. Just under a quarter of young people between 11 and 15 years old in England report having a long term illness or disability; with asthma, epilepsy and diabetes among the most common long term medical conditions in children¹¹. Ensuring that children are cared for as close to home as possible will often mean that children will be cared for in community settings, though poor communication between secondary care providers and GPs have exacerbated workloads for primary care professionals¹².

Young people transitioning from children's to adult services are often at risk of experiencing poor health outcomes when their transfer is not appropriately supported and coordinated¹³. It is well reported that transition arrangements are often poor for children with only half of all children receiving support from a lead professional to ensure a smooth transfer¹⁴.

The State of Child Health report 2017 highlighted mental health as a major concern for children, and children with ongoing health needs have told us how important it is to have strong links with mental health support services to enable them to better manage their diagnosis^{1,5,15}. Children's mental health services are fragmented and in order to identify children in need of mental health support, services must work together and align referral pathways to ensure children receive support at the right time¹⁶.

The commissioning and planning arrangements of NHS services have resulted in pathways of care becoming fragmented and disjointed, with a lack of clarity over who should be responsible for providing which service. Boundary disputes over which organisation is responsible for provision of services can lead to poor communication with children and their families and can often lead to poor patient experience and inconsistency in how children should be managing their condition.

The RCPCH *Facing the Future: Standards for Acute General Paediatric Services*¹⁷ and *Facing the Future: Together for Child Health*¹⁸ addressed the changes needed within the acute and unscheduled care pathway settings respectively. Powerful evidence has emerged from the audit of these standards that advocates for service planners, commissioners and health organisations to work together to design and deliver services for children in all care settings¹⁹.

Connecting the system will empower children and their families to access timely advice for the management of their condition. Ensuring communication is better facilitated across the child health system will support integrated, networked care that is far reaching, consistent and meets the needs of its local population²⁰.

Workforce pressure

Paediatrics

The RCPCH Medical Workforce Census, undertaken every two years since 1999, provides us with evidence that there are substantial paediatric vacancies at both consultant and trainee levels. Based on figures revealed by the report *State of Child Health: The Paediatric Workforce*²¹, there are currently an estimated 261 whole time equivalent career grade vacancies across the UK, with at least 752 whole time equivalent extra consultants required to meet the RCPCH Facing the Future and other service standards^{17,22-24}. The RCPCH Rota Gaps Survey (2017) found that a worrying 23.4% of tier 2 posts in general paediatrics and neonatology were vacant²⁵.

Attracting trainees to paediatrics is vital to sustain sufficient paediatric workforce numbers. However, findings show that from 2013 to 2016 there has been a 27% fall in the number of foundation year one (FY1) doctors planning to apply to paediatric specialty training²⁶.

Hospital admissions for children continue to rise, but the numbers of doctors in post to meet this demand is not keeping pace^{21,27}. RCPCH recruitment data shows the number of European Economic Area graduate applicants to paediatric training declined from 97 in 2015 and 43 in 2016 to 41 in 2017 (a 58% fall in 2 years) reflecting concerns about future immigration policy once the UK leaves the European Union (EU).

General practice

With demand growing in primary care, general practice continues to be under pressure. NHS England's commitment to expand and invest in a sufficient workforce to deliver the General Practice Forward View²⁸ was welcomed, especially in regards to additional investment. However, in reality the GP workforce is decreasing with 700 fewer full time equivalents recorded in England between June and September 2017²⁹.

There are numerous schemes in place to increase the number of GPs. For example, a programme of international recruitment has been substantially expanded, and more doctors are going into GP training than ever before. We know that parents prefer to seek advice from their GP³⁰, but general practice needs support to deliver quality care to patients without increasing the strain on hardworking GPs.

Nursing

There are now more nurses and midwives leaving the Nursing & Midwifery Council than registering, with further attrition expected as the UK leaves the EU³¹. The Royal College of Nursing (RCN) has provided powerful evidence to show how gaps in nursing staff rotas actively prevent nurses from providing high quality care to patients³².

The removal of student nurse bursaries in England is likely to deter students from applying for nursing education and with record level nursing vacancies reported in the NHS, it has never been more crucial to attract people into the nursing profession. A reduction in continuing professional development funding available at a local level prohibits children's nurses gaining access to specialist and advanced practice programmes to acquire additional knowledge and skills.

The number of fulltime NHS school nurses fell by 16% (590 posts) between 2010 and 2017 with significant health visiting posts falling from 10,309 in October 2015 to 8,449 by July 2017³³. Registered children's nurses, school nurses and health visitors are critical to supporting children's health services across the UK and investment in these roles is vital to ensure a properly resourced workforce can achieve the standards laid out in this document.

Physician

The Royal College of Physicians (RCP) 2016-17 census of UK consultants and higher specialty trainees reveals a concerning trend³⁴. There were 15,579 consultants, an increase of almost 7,000 over 10 years, but 56% of consultants reported that trainee rota gaps occur 'frequently' or 'often'. Over one fifth of these stated that the gaps have a significant impact on patient safety, and 30% had 'acted down' to cover these gaps.

Almost half (45%) of recruitment drives to consultant posts were unsuccessful, with 65% of those due to no applicants. This may be due to fewer doctors receiving certificates of completion of training (CTT) than advertised posts.

While the Government's announcement of an additional 1,500 medical school places a year is welcome, this will not deliver new consultants before 2030. The RCP is therefore concerned that the situation may worsen before it improves.

Psychiatry

The consistent rise in demand and increased complexity of presentations have been putting pressure on service delivery in child and adolescent mental health services (CAMHS) with added strain imposed by gaps in the mental health workforce. Data reported by the Royal College of Psychiatrists 2017 census has marked a significant 9% increase in the number of vacant and unfilled consultant psychiatrist posts across the UK, up from 7% in 2015 and 5% in 2013³⁵.

Whilst greater understanding of the importance of providing Child and Adolescent Mental Health Services (CAMHS) services has been reflected in NHS budgets, the budgetary increases have not been ring fenced with risks to funding being diverted to acute care³⁶.

The Royal College of Psychiatrists (RCPsych) are actively working to encourage medical students to choose psychiatry as a career option through the Choose Psychiatry campaign³⁷. New initiatives are being piloted to encourage recruitment into psychiatry, such as Thinking Together and the CAMHS Run-Through Training pilot³⁸. However, without sufficient investment in CAMHS services as a whole, RCPsych will struggle to respond to the current workforce pressures and rise in demand.

Aims and scope

These standards apply to children with ongoing health needs across the UK. These are children who are referred from primary care to secondary care services for a diagnosis and who remain under the child health service for onward healthcare support and management of their diagnosis.

The standards take a pathway approach drawing on patient voice, available written evidence and expert opinion and are key to driving change and improvement. Standards are best used as a complete set, rather than in isolation, alongside *Facing the Future: Standards for Acute General Paediatrics*⁷ and *Facing the Future: Together for Child Health*⁸. This ensures children's health services are planned and delivered using the whole-pathway approach spanning care for the acutely unwell child, children using the unscheduled care pathway and these new standards for children with ongoing health needs.

The royal colleges play an instrumental role in developing standards that are motivating, meaningful and measurable. *Facing the Future* standards support child health services implementation by providing rationale, guidance, metrics, practice examples of care planning and the paediatric workforce requirement necessary for the standards to be met.

Implementing the standards will ensure prompt and correct diagnosis, with children seen in the right place, by the right person, at the right time. Local networks with improved communication between professionals should ensure children and families are supported to manage their own health with support as close to home as possible. These standards look more widely at connecting the whole system by improving communication and coordination between child healthcare professionals and services. Standards have been developed around the needs of the child to ensure the voices of children and their families are intrinsic to the planning, development and evaluation of services.

These standards can be used to develop relationships with service planners and commissioners and as a framework in which to develop service level agreements. Standards provide an opportunity for services to monitor their own progress locally and the RCPCH is committed to audit these standards nationally in 2020 to inform any revision and update to the standards in 2021.

How to use the standards

Implementation of each of the standards is supported by rationale, guidance, metrics, practice examples and resource implications.

The metrics include the relevant structures, processes and outcomes that should be used in auditing whether the standard is being met. The measurable impact describes the areas where implementation of the standards might lead to an improvement or change. These changes may accrue over a period of time, and other factors may affect these trends. These impact measures are intended to inform quality improvement metrics for individual services, rather than as part of the formal audit of standards.

Practice examples aim to illustrate where and how standards can be met. Contact details have been included to enable services to connect and share examples.

Resource implications describe the medical workforce requirements needed to meet each of the standards. Where possible, nursing and primary health implications have been included in addition to any administrative or financial resource that will be required.

Definitions

Child or children	Infants, children and young people under the age of 18 across the UK. Young people up to the age of 25 may be seen in children's services if their needs are not met by adult services.
Child health service	The service providing healthcare to the infant, child or young person, including all providers in the primary, acute and community care setting.
Clinical nurse specialist	A registered children's nurse practising at an advanced level who can provide expert advice and care related to specific conditions or treatment pathways.
Healthcare professional	A clinically qualified person who is working within the scope of practice as determined by their relevant professional body and who is registered with that body as competent to practise, for example, the General Medical Council (GMC), Nursing and Midwifery Council or Health and Care Professionals Council.
Parents and carers	To identify and acknowledge those who hold parental responsibility but who may not be the biological parent.
Primary healthcare professionals	General practitioners, health visitors, school nurses, public health nurses, clinical nurse specialists, community children's nurses, practice nurses and allied healthcare professionals.
Senior trainee	Doctors who are in year four or above of paediatric specialty training, also referred to as ST4+.
Service planners	Organisations responsible for planning, commissioning and providing health services in a local area.
Urgent advice	Advice that is available immediately by telephone, email or other telecommunication.

Summary of standards

1. Service planners ensure referrals to the child health service are triaged and responded to within five working days. From receiving the referral, the paediatrician becomes jointly involved in the child's care. Where appropriate, this should include advice regarding treatment and further investigation.
2. Service planners ensure children under the care of the child health service, their parents/carers, and primary healthcare professionals have access to a single point of contact in the child health service for clinical advice within three working days.
3. Service planners ensure children under the care of the child health service, their parents/carers, and primary healthcare professionals have a single point of contact to the child health service during peak hours for administrative queries in relation to clinical care.
4. Service planners ensure paediatricians have access to urgent specialty paediatric advice by telephone 24 hours a day, seven days a week through clinical networks. For less urgent advice, a member of the specialist team provides an email or telephone response within three working days.
5. Service planners ensure non-urgent clinical communication is sent to the child's GP and referring healthcare professional within five working days. Where a child's condition is unpredictable or requires further review within that time, the paediatrician must alert the GP within one working day.
6. Service planners ensure there is a designated person within the child health service who is responsible for ensuring that developmentally appropriate transitional care is provided and coordinated by both child and adult services.
7. Local health systems ensure healthcare professionals assessing or treating children in any setting have timely access to the child's shared electronic healthcare record.
8. Service planners ensure children have timely access to a range of mental health and psychosocial services that are integrated with children's health services and that all healthcare staff have sufficient competences to support the psychological needs of children and recognise when involvement of mental health services is required.
9. Service planners and health organisations have a dedicated lead for children at executive or board level.
10. Service planners ensure child health services are codesigned, planned and evaluated with involvement from children and their parents/carers.
11. Service planners ensure systems are in place to monitor, review and improve the effectiveness and integration of local child health services. This must involve representatives of children and families and all agencies responsible for ensuring the health and wellbeing of children.

STANDARD 1

Service planners ensure referrals to the child health service are triaged and responded to within five working days. From receiving the referral, the paediatrician becomes jointly involved in the child's care. Where appropriate, this should include advice regarding treatment and further investigation.

Who is the child

Any child who has been referred for a specialist appointment to the child health service.

Aims

- Ensure senior expertise is at the front end of the care pathway
- Child health services are used more effectively
- Unnecessary investigations are prevented
- Improved service user satisfaction
- Improved paediatric expertise in primary healthcare professionals

'The initial diagnosis was not positive at all, there was wrong diagnosis made and no directions were given. We (the family) had to wait 12 months for an appointment with a different consultant.'

RCPCH &Us voice bank, 2016

Rationale and evidence

The number of patients waiting for clinical appointments in outpatients and child development centres is rising with patient waiting times exceeding national targets^{39,40}. Better resourcing for the management of referrals will support subsequent efficiencies and a reduction in waiting times to ensure children are seen at the right time, in the right place, by the right person.

Perverse incentives for tariff and commissioning arrangements of children's services need to be overcome so that clinical decision making optimises the most appropriate pathway for every child. New models of care to ensure integration between primary care and the child health service are emerging as a way of reducing hospital attendance and unnecessary admissions, in addition to children being cared for closer to home⁴¹.

Guidance

Referral letters received by the child health service or child development centre must be reviewed and considered within five working days for the following actions:

- communicate with referring healthcare professionals when more information is required
- advise on how to manage the child without outpatient attendance
- refer to primary care for further investigation prior to attendance to the child health service with clarity on how to order, respond to and manage the appropriate tests
- arrange for an appointment to the child health service
- refer the child to an alternative child health service that is more accessible and appropriate for the child.

The referring healthcare professional must be able to refer children directly for a clinical consultation with the child health service should the referring clinician deem that necessary.

Increasingly, children's services are operating under a 'single point of access' when triaging referrals. The management of complex referrals are most appropriately organised through weekly multidisciplinary meetings and service planners must consider the resources required to facilitate this process.

Who benefits and how

Children and their families will experience swifter diagnosis and fewer inappropriate investigations, reducing the pressure on parents to take leave, arrange childcare or organise transport. Primary health professionals will increase their knowledge and education by ensuring senior paediatric advice is available at the front of the care pathway. Service planners will benefit by improving efficiency in resources.

Metrics

Structures	Process	Measurable impact
Evidence of a system (including departmental policy and administrative support) for collection of referral or response dates.	Proportion of referrals from primary care with response sent within five days of receipt.	<p>Proportion of referrals managed in alternative ways (eg advice in primary care, pre-order investigations.)</p> <p>Mean duration from referral to treatment.</p> <p>Rate of service complaints relating to delayed referral responses.</p> <p>Mean (and range) of duration (in days) from referral receipt to response.</p>

Practice example

Advice and guidance system, Musgrove Park Hospital Taunton and Somerset NHS Foundation Trust

The advice and guidance system was set up at Musgrove Park Hospital to manage the high rate of paediatric referrals being made for outpatient appointments. With perverse contractual incentives for secondary care providers and limited or no incentives for primary care professionals to reduce referrals to the paediatric service, demand and waiting times to outpatient appointments was increasing.

For the child health service to ensure prompt and correct diagnosis with children seen in the right place, at the right time and by the right person, new initiatives to reduce paediatric demand were considered.

The team found that 40% of referrals made by GPs for advice and guidance do not require a secondary care outpatient appointment but are better supported in primary care with the clinical advice provided by the paediatrician. Detailed parent information leaflets including signposting services to independent or charitable sector websites, online support and community delivered services are provided alongside clinical advice including information to refer to other locally commissioned children's services.

The advice and guidance system at Musgrove Park Hospital looks more widely at connecting the whole system and improving patient experience. It uses existing IT systems (NHS e-referrals) to facilitate secure electronic communication between primary healthcare professionals and secondary care.

Musgrove Park Hospital has found the advice and guidance system to be a cost effective, high quality and well received way of reducing demand for secondary care outpatient referrals.

Advice and guidance ensures senior expertise is at the front end of the care pathway with advice often provided within 24 hours. Not only does it empower the patient but it provides individual education programmes for GPs and primary healthcare professionals as well as providing evidence for understanding the needs and demands of the local population.

Contact

Dr Rebecca Mann, Consultant Paediatrician
Musgrove Park Hospital
Rebecca.Mann@tst.nhs.uk

Resource implication

Advice and guidance system, Musgrove Park Hospital Taunton and Somerset NHS Foundation Trust

Advice and guidance offers immediate triage of GP referrals and decides on a bespoke management plan that may involve:

- provision of written advice and guidance (40% of referrals)
- face to face clinic appointment with a paediatrician at the GP surgery (40% of referrals)
- triage to a sub-specialist clinic at the hospital (20% of referrals).

It takes, on average, 20 minutes to generate an individualised management plan (advice and guidance). These are shared with primary care via the online NHS e-referrals platform, so there are no additional administrative costs.

Workload, activity and response times (two days) can be monitored using NHS e-referrals, so the system is administratively lean. Several template action plans and advice leaflets have been developed for the most common conditions, improving efficiency and standardising care. The independent sector and online resources and websites are signposted extensively.

When a face to face review seems necessary, but triage has suggested that the child is unlikely to need long term follow up, the paediatrician arranges review in a primary care paediatric clinic. The paediatrician attends the surgery once every eight weeks to run the clinic alongside a member of staff from the practice (a GP, GP trainee, nurse practitioner or practice nurse). The patients are reviewed in their surgery and clinical information entered directly onto the patient electronic record.

Consequently, primary healthcare professionals have increased their confidence in managing common paediatric problems which has resulted in a reduction of children referred for outpatient review or into the urgent and emergency care setting.

The real benefit of this service is simply the development of relationships between primary and secondary care that means patients are discussed and jointly managed rather than automatically 'referred'. The savings generated by improving quality and reducing inefficiencies in the management and processing of lower risk outpatient referrals has resulted in the need to deliver fewer general paediatric clinics.

There have been significant cost savings in outpatient department staffing, administration and other overheads, as well as a 30% reduction in paediatric consultant time. The savings made to medical staffing time has been diverted to consultant delivered twilight lists, which have supported trainees, improved quality and reduced length of stay within the acute unit.

Contact

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Dr Sarah Bridges, Consultant Paediatrician
Taunton and Somerset NHS Foundation Trust
Sarah.Bridges@tst.nhs.uk

STANDARD 2

Service planners ensure children under the care of the child health service, their parents/carers, and primary healthcare professionals have access to a single point of contact in the child health service for clinical advice within three working days.

Who is the child

Children under the care of a child health service (may include open access or joint care arrangements).

Aims

- Promote self-management, resilience and understanding of any health condition for the child and parent/carer
- Support the healthcare professional to seek advice on how to manage the child prior to or following review in the child health service
- Provide advice and share information with the healthcare professional who is jointly responsible for the patient
- Improve health outcomes and psychological wellbeing
- Improve communication between healthcare professionals

Rationale and evidence

The royal colleges recognise that children with ongoing healthcare needs will often interact with a range of professionals, in and out of the health system, that will be supporting and promoting their health and wellbeing. Health promotion approaches, such as *Making Every Contact Count*⁴² requires all professionals to encourage healthy behaviours.

‘My wish list idea is to make sure there is a holding service between diagnosis and being seen by a specialist. You go into limbo with no information, no support, dealing with the grief of the diagnosis.’

RCPCH &Us voice bank, 2016

Children, young people and parents have told us that the time between a diagnosis and the specialist appointment is particularly troubling and that providing relevant, timely and accessible health resources relating to their condition or medical uncertainty would help⁴³. It is important to provide information to enable children and their families time to adjust to receiving a diagnosis or being under the care of a child health service by signposting them to evidence based, up to date information that will help them manage their condition.

Guidance

There is a single point of contact to the child health service for information on the diagnosis, management and treatment of the condition. Children’s GPs and other primary healthcare professionals must be able to access clinical advice from the child health service to appropriately manage the child in the community setting prior to and after attending their child health service review. Children and their families can access this advice once they have been seen in the service.

Clinical advice is provided by a consultant paediatrician, children’s clinical nurse specialist or senior trainee within 3 working days. The child healthcare professional making a diagnosis must share resources and information with children and their parents/carers in a form that is accessible to the child and that they understand. It should be the responsibility of a named member of the child health service to ensure that a comprehensive and contemporary database of health resources is maintained. Details of

the type of information and where the patient has been signposted to should be included within the clinical letter or discharge summary. A list of useful websites and resources is included in Appendix 2.

A voicemail or email facility should be provided to enable children and their parents/carers to make enquiries during out of hours that can be responded to by the child health service. Healthcare professionals must ensure they follow secure information sharing protocols outlined by their health organisation.

We acknowledge the sensitivities of providing information to children and their families when a diagnosis is made and acknowledge that child healthcare professionals may need to provide information several times, in a variety of different settings and in different formats.

Who benefits and how

Children and their families will have timely access to appropriate expertise and advice in relation to their clinical care in addition to avoiding unnecessary referrals or attendance to the urgent or emergency care centre. Clinicians will benefit from fewer inappropriate consultations and service planners should expect to see increased capacity in clinics and appointments. The quality of service will be improved and should be reflected in improved patient satisfaction feedback.

Metrics

Structures	Process	Measurable Impact
<p>Evidence of a contact number or named person (and operative working hours).</p> <p>Evidence of contact details being communicated to families.</p>	<p>Proportion of calls returned within three days.</p>	<p>Mean (and range) of time to respond to request (audit).</p> <p>Proportion of service complaints relating to clinical communication.</p> <p>Rate of non-elective hospital admission and emergency department attendance for children with ongoing health needs (by trust, board, clinical commissioning group (CCG), or health organisation).</p> <p>Patient or family experience audit.</p>

Practice example

Children's Assessment & Referral Service, Evelina London Children's Hospital Guy's and St Thomas' NHS Foundation Trust

The Children's Assessment & Referral Service (CARS) provides telephone and email advice for all GPs who are local to Evelina London Children's Hospital and Guy's and St. Thomas' NHS Foundation Trust. From Monday to Friday, telephone advice is available from 11am to 7pm and emails are responded to within 24 hours. The service is not currently available on weekends.

GPs can communicate with consultant paediatricians for support relating to children and young people. Consultants provide advice about the most appropriate referral pathways and how to manage children within primary care settings.

This service has delivered positive outcomes in the area, ensuring that children are seen in the right place, at the right time, by the right person. Children requiring urgent hospital care are identified and appropriately referred to urgent appointments.

'I have used the CARS services a few times now and have found it to be excellent.'

Service User 2017

In 2015, as a result of the telephone advice, 27 children were offered a paediatric outpatient review who otherwise would have been managed solely in primary care without their need for paediatric review being identified. It was apparent that without the advice service, GPs would have referred 19 children through different pathways but through discussing the child with the GP, the CARS team was able to offer them an urgent appointment instead of GPs referring them for routine review.

Another benefit to the service was the better management of children in the primary care setting, without the need for paediatric outpatient review. In 2015, 53 children were effectively managed in the primary care setting, and GPs were able to prevent at least 19 children from being sent to the emergency department, as they were able to discuss their concerns with a paediatrician in a timely manner.

The number of outpatient referrals have avoided as a result of providing this advice has steadily increased from an average of 1.9 per month in 2015, to 3 per month in 2016.

Both GPs and consultants find the service valuable in supporting the service that they provide for children and young people. GPs are supported to feel confident in the care they offer, while consultants are assured that urgent cases are prioritised. GP feedback has praised the speed and effectiveness of responses from the consultant paediatricians.

Contact

Dr Ronny Cheung, Consultant General Paediatrician
Evelina London Children's Hospital
Ronny.Cheung@gstt.nhs.uk

Resource implication

Young Diabetes Connections

Evelina London Children's Hospital, King's College Hospital, University Hospital Lewisham, and Princess Royal University Hospital

Service: This consultant delivered, out of hours paediatric diabetes phoneline was established in April 2013 using the central switchboard with call-back capability that operates during the week between 5pm and 9am and throughout the weekend. Young people use this telephone line to request clear guidance on any issues with their condition and the consultant will provide advice and any criteria for when to call back. This is followed by an email the next day to the young person's clinical team, to alert them to the call and the advice given.

Workforce requirement: On call consultants cover the phone line, and receive a small additional pay supplement to cover the service.

Resource implications: Consultant delivered, currently by six consultants across the hospitals. The consultants are contracted at a band B rate with a 3% supplement, for participating in the out of hours rota. To provide this service, a small number of centres work together which provides economy of scale, without needing to amalgamate services and thereby losing local autonomy.

Outcome: A recent audit has showed a 50% reduction in emergency department attendances of paediatric diabetes cases.

Limitations: Some of the target patient population do not engage with the phoneline due to language barriers.

Contact

Dr Michal Ajzensztejn, Consultant in Paediatric Diabetes and Endocrinology
Evelina London Children's Hospital
Michal.ajzensztejn@gstt.nhs.uk

Dr Tony Hulse, Endocrinology and Diabetes Consultant
Evelina London Children's Hospital
Tony.Hulse@gstt.nhs.uk

STANDARD 3

Service planners ensure children under the care of the child health service, their parents/carers, and primary healthcare professionals have a single point of contact to the child health service during peak hours* for administrative queries in relation to clinical care.

Who is the child

Children under the care of the child health service.

Aims

- Provide a time efficient mechanism for the use of child health service resources
- Reduce frustration with administrative arrangements
- Provide advice and assistance when navigating care systems
- Allow families to contact services at a time that is convenient for them

'There's no liaison with the hospital, communication is key for us to know what is going on. We always had to call up and ask to keep track of our appointments.'

RCPCH &Us voice bank, 2016

Rationale and evidence

Children and parents/carers have told us that navigating the system is problematic and that a single point of access is required⁴³. With services becoming increasingly fragmented, children and their parents/carers find it difficult to know how to access support across health settings. Consultation with children and their families have resulted in suggestions to help children navigate the health system more easily:

- information on who to contact and at what time
- information on the named paediatrician responsible for care of the child
- an indication of referral waiting times
- friendly information that the child will understand
- better communication between healthcare professionals already involved in care.

Providing a single point of access will help to reduce the burden on primary care to mediate between differing administrative systems.

Guidance

During peak hours, the children's health service runs a telephone line that is staffed to deal with patient enquiries around appointments, referrals administration and whether results have been received. The person dealing with these enquiries will be able to share administrative information and refer queries to the appropriate clinical colleagues.

Service planners must ensure the administrative resource is available to staff the single point of contact service during peak hours. A voicemail or email facility should be provided to enable children and their parents/carers to make enquiries during out of hours that can be responded to by the child health service the next working day.

*This time should be defined locally as the hours that families are most likely to contact the service, but is recommended to operate Monday to Friday, 8am to 6pm.

Who benefits and how

Children will have timely access to the administrative information that is required to coordinate their care that will help to improve choice when attending appointments in addition to reducing the potential to miss appointments. Children's healthcare professionals will benefit from a reduction in missed appointments and service planners should expect to see increased capacity in clinics and appointments as a result. The quality of service will be improved and should be reflected in improved patient satisfaction feedback.

Metrics

Structures	Process	Measurable Impact
<p>Evidence of a contact number or named person (and operative working hours).</p> <p>Evidence of the contact being made available to families (eg clinic letters).</p>		<p>Rate of service complaints relating to administrative queries.</p> <p>Patient or family experience audit.</p>

Practice example

Just One Number Norfolk Healthy Child Programme

Just One Number is open between Monday and Friday, 8am to 6pm and on Saturdays between 9am and 1pm. The telephone number is available for both service users and professionals with a voicemail facility. A call centre structure ensures call volumes are monitored to keep response times to a minimum (on average within two minutes) and to ensure voicemail messages are responded to within one hour.

The service is staffed by clinical (experienced health visitors and school nurses) and administrative call handlers. Call handlers answer calls and manage the administrative procedures on the clinical record. If required, the call handler will pass the call to a clinician for advice and support. A single email address is promoted with the service and response times to emails is also within a one hour period with all professionals alerted to the information governance legislation regarding contact. Every contact is recorded on the SystmOne child health record that is accessible to all health services across the county.

Just One Number hosts a digital resource base that enables access for professionals and service users to validate information and resources that are shared by professionals to encourage and empower self-management of children's health needs.

Since the launch of Just One Number in March 2017, over 40,000 calls have been received. An average of 4,000 calls are taken per month, with an average wait time of just two minutes. Voicemails left out of hours on Saturday evenings and Sundays are prioritised within the first operating hour on Monday. Appointment booking and appointment changes are managed through Just One Number which has resulted in increased clinical capacity for community clinicians.

Evaluation has shown that 90% of children and parents using the service would be likely or highly likely to recommend the service. Calls are logged by themes or needs as well as the age of the child or young person using the service and the data are fed back to communities to support better understanding of localised health needs in addition to providing evidence for commissioners to mobilise workforce and resources to address those needs. An evaluation of the service has shown that 80% of contacts are managed with one single call (without the need to refer the call out to other agencies or professionals).

The setting up of such a service requires several key components to ensure success, including engagement and involvement from service users, health professionals and a shared health record system. The knowledge of staff is a great asset to ensure that capacity modelling and service design is future proofed, as is service user involvement to ensure children and families are at the heart of how services are designed and provided. Constant evaluation of the service will inform updates and improvements to ensure health professionals and the public continue to embrace the service.

The service employs five whole time equivalent clinicians and 14 whole time equivalent administrative call handler staff to cover a population of 189,000 children and young people.

Contact

Dr Sian Larrington, Head of Service
Norfolk and Cambridgeshire Children and Young People's Health Services
Sian.Larrington@nhs.net

Resource implications

Workforce and resource implication for Just One Number, Norfolk Health Child Programme

Setting up a similar scheme to the practice example below, Just One Number, would require 'pump priming' of the administration and call handling support to ensure the project builds momentum.

The experience in Norfolk is that the scheme has meant better utilisation of clinical time including fewer missed appointments resulting in reduced need to rebook patients, reducing travel time and shifting of administration to more appropriate staff, in turn facilitating the streamlining of appointment booking systems. Staff numbers will vary according to the population size.

STANDARD 4

Service planners ensure paediatricians have access to urgent specialty paediatric advice by telephone 24 hours a day 7 days a week through clinical networks. For less urgent advice, a member of the specialist team provides an email or telephone response within 3 working days.

Who is the child

All children requiring specialist clinical review.

Aims

- Improve communication and collaboration between secondary and tertiary services
- Ensure that paediatricians have access 24 hours a day to appropriate specialist advice
- Improve health outcomes by ensuring timely clinical advice
- Ensure paediatricians feel supported when dealing with children presenting with complex medical problems

‘The tertiary care support is really good but because they’re so specialised it’s difficult to access.’

RCPCH &Us voice bank, 2016

Rationale and evidence

The 2013 and 2017 audits of *Facing the Future: Standards for Acute General Paediatrics* provides powerful evidence to illustrate the challenges in accessing immediate advice by specialist services^{19,44}. Findings from those audits have resulted in some specialty groups developing standards to improve access and equity to specialist care⁴⁵.

Successful clinical networks are highly reliant upon collaboration across care settings to enable services to make local agreements for information sharing and shared care protocols. There is a strong case that clinical networks provide a framework for clear accountability, governance and financial control in addition to facilitating the sharing of expertise and knowledge across child health services⁴⁶.

Guidance

Paediatric specialist services must establish clinical networks to ensure immediate advice is accessed by paediatricians 24 hours a day, seven days a week. The specialist service must be available out of hours to ensure general paediatricians are supported in the appropriate referral and management of patients.

Access to the following paediatric specialties must be available:

- cardiology
- endocrinology
- gastroenterology, hepatology and nutrition
- intensive care
- nephrology
- neurology
- neurosurgery
- oncology and haematology
- palliative care
- respiratory
- rheumatology.

Advice must be documented to support clinical governance, via email or through the shared electronic health record. For less urgent advice, a member of the specialist team provides an email or telephone response within three days. Advice can be sought from a senior trainee, paediatric consultant or children's clinical nurse specialist.

Who benefits and how

Children should have access to expert care and advice that will provide reassurance and confidence in services. This should improve health outcomes by allowing the early recognition and management of comorbidities. Children's healthcare professionals will be clearer about their roles and responsibilities and should allow for more rapid consultation with peers over complex presentations with increased opportunities for collaborative working and studies. Service planners are provided with clear specifications on the services and expertise available for specialist and rare diseases that must be appropriately resourced. Children with specialist health needs will have better care to enable them to access educational and vocational activities into adulthood.

Metrics

Structures	Process	Measurable Impact
<p>Established clinical network responsibility for all trusts for each specialty (ie geographical network coverage).</p> <p>Evidence of network advice standard operating procedure and published rota.</p>		<p>Rate of incidents relating to lack of urgent specialist input.</p> <p>Professionals experience audit within specialist network.</p>

Practice example

Clinical access system, Paediatric Liver Centre King's College Hospital NHS Foundation Trust

The Paediatric Liver Centre at King's College Hospital (KCH) NHS Foundation Trust in London provides 24/7 access to clinical opinion and advice for healthcare professionals via a handheld mobile phone.

During week days and at weekends between 9am to 5pm registrars hold a mobile phone service to provide clinical advice that is backed up by rapid consultant support 24 hours a day.

Shared care consultants meet with registrars twice a day to discuss and keep an electronic record of conversations made via telephone which is added to the electronic patient record. The clinical access system can be used as a good learning opportunity for junior trainees and is fully supported by a dedicated consultant.

The service is available to all general paediatric units and specialist paediatric gastroenterology, oncology and neonatal units in England, Scotland, Wales and Northern Ireland that refer to KCH.

Contact

Dr Alastair Baker, Clinical Lead of Paediatric Hepatology
King's College Hospital NHS Foundation Trust
Alastair.Baker@nhs.net

Resource implication

Quality standards, RCPCH and British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)

Standards developed jointly with the RCPCH and the BSPGHAN lay out what is required to provide specialty paediatric advice by telephone 24 hours a day, seven days a week via clinical networks⁴⁷.

As an example, to ensure access to specialist advice is available 24 hours a day, seven days a week through clinical networks, investment of approximately 3.375 whole time equivalents will be required to provide resident consultant time Monday to Friday, 9am to 6pm with access to consultant at home for the rest of the week (seven days). Additional resources will be required for a weekend review and after hours (overnight) on call.

The establishment and running of a clinical network will require a network lead with one programmed activity per week included in their job plan to manage portfolios and protocols of the network and shared care arrangements.

Contact

RCPCH Policy Team
health.policy@rcpch.ac.uk

STANDARD 5

Service planners ensure non-urgent clinical communication is sent to the child's GP and referring healthcare professional within five working days. Where a child's condition is unpredictable or requires further review within that time the paediatrician must alert the GP within one working day.

Who is the child

Children with ongoing health needs.

Aims

- Improve patient care and health outcomes
- Improve patient experience
- Improve clinical support for primary healthcare professionals

'My best experiences have been when being cared for in a joined-up service that involved multidisciplinary teams.'

RCPCH &Us voice bank, 2016

Rationale and evidence

If children are to be appropriately managed in primary care or the community, child healthcare professionals must have timely access to the clinical information and decisions made during clinics and paediatric outpatient consultation.

In line with the *Five Year Forward View*, 'Paperless 2020' will require health organisations in England to invest in and make better use of information and technology by ensuring health systems are paper free by 2020⁴⁸. Alongside the required investment in joined up digital information systems, standards for digital outpatient letters have been developed by the Professional Record Standards Body to enable clinical information to be recorded, exchanged and accessed consistently across care settings⁴⁹.

Guidance

Service planners must ensure resource is available to ensure clinical communication regarding diagnosis and treatment from the child health service is sent to the child's GP within five working days. Adequate time must be built into each clinical contact to enable child healthcare professionals to share information with others involved in the child's care. For children presenting with conditions that are unpredictable or that require further review (including any changes to medication), the paediatrician or children's healthcare professional must alert the GP within one working day. It is recognised that detailed reports for children with complex needs that require multi-professional input will take longer, and in this instance the child's GP and referring healthcare professional must be kept informed.

A copy of appropriate communication should be given to the child and their parent/carer in a language that they understand. Where appropriate, a copy of all clinical communication should be sent to the child's school nurse and community children's nursing team as appropriate to include in the child's care plan.

Electronic communication via secure email is the preferred method for sending clinical documentation to GPs and the direction of travel for safely transferring clinical information.

Who benefits and how

Children's patient safety and wellbeing are underpinned by accurate information recording and transfer resulting in better interactions and satisfaction with primary care professionals. Communication between healthcare professionals in all settings is

improved and service planners will regard this as part of good clinical practice. Better information sharing across health services will improve efficiency and reduce error reporting costs across the NHS.

Metrics

Structures	Process	Measurable Impact
Evidence that proportionate administrative time is allocated for each outpatient clinic.	<p>Proportion of GP letters dated within five days of outpatient appointment date.</p> <p>Proportion of letters copied to relevant professionals and family.</p>	<p>Rate of service complaints relating to clinical communication.</p> <p>Patient or family experience audit.</p> <p>Mean (and range) duration (days) of time from appointment to letter despatch.</p>

Practice example

Outpatient letter standards

The Professional Record Standards Body (PRSB)

The PRSB has developed standards to improve the content of care records, including outpatient letters. These have been developed to ensure that health and care professionals, patients and carers receive consistent and reliable, high quality information.

PRSB standards represent the consensus view of a wide range of clinicians, professionals and patients/carers about what information to share in a patient's record in any care setting.

As more care and a wider range of specialist services are delivered out of hospital, the importance of well-structured outpatient letters is essential to good communications between clinicians, care professionals and patients. They are the main method of contact between hospital staff and GPs and communicate to the patient a record of the consultation and decisions. They are often the sole record of the consultation held by the outpatient department and hospital.

To view the outpatient letter standards, visit www.theprsb.org

The PRSB asked clinicians from relevant specialties to compose examples of outpatient letters representing different types of appointments to demonstrate how the information in an outpatient letter might be best structured.

These letters were assured by the PRSB assurance committee and an example of a community paediatric outpatient letter using the PRSB outpatient letter standard can be found here: www.prsb-dev.riviam.com/wp-content/uploads/2018/02/Outpatient-Letter-Examples.pdf

Contact

The Professional Record Standards Body
support@theprsb.org

Resource implication

For hospital clinics, it is recommended that a minimum of 30 minutes administration time is allocated for each four hour clinic.

Based on evidence from the 2016 UK survey of community child health services⁵⁰ it is recommended that a minimum of one programmes activity (PA) is allocated for clinical administration per PA of clinic time.

STANDARD 6

Service planners ensure there is a designated person within the child health service who is responsible for ensuring that developmentally appropriate transitional care is provided and coordinated by both child and adult services.

Who is the child

Young people using children's health services with conditions that require transfer to adult services for onward care.

Aims

- Ensure young people are supported with developmentally appropriate, coordinated transition arrangements starting in early adolescence, transferring smoothly to adult services and completed in adult services
- Improve health outcomes and prevent clinical deterioration at the time of transfer
- Enable the young person to become more responsible in managing their care as their development capacity allows them to and enable their care givers to support them in doing so

'My wish list idea would be to have help in how you talk to people planning transition in adult services.'

RCPCH &Us voice bank, 2016

Rationale and evidence

Young people have told us that they are concerned about the arrangements made for their transition into adult services⁴³. It is well known that young people are at risk of experiencing poorer health outcomes when transition between children's and adults' services is not coordinated and planned with the young person¹³.

Transitional care will be required for young people up to the age of 25 to ensure they are cared for in the most age and developmentally appropriate environment. Developmentally appropriate care addresses the biopsychosocial development of the young person that is adjusted as they progress through adolescence and young adulthood, empowering them by embedding health education and health promotion into care⁵¹. Involving young people in transition planning is crucial for increasing knowledge about their health and the condition (patient education), promoting self-management and ensuring longer term engagement with adult services⁵².

Guidance

Service planners must ensure that services are jointly planned for all young people making a transition from children's to adults services and that the necessary supporting infrastructure in both children's and adults services is in place⁵³.

Service planners must ensure there is a designated person (of any professional background) within the children's healthcare team who is responsible for transitional care. This must be reflected in the person's job description as a recognised role (by a minimum of 0.5 PAs per specialty or team) and responsibilities will include:

- sharing and updating transition policies
- ensuring all professionals within the team are planning for transition with their patients
- coordination of transition with other specialties (in child and adult services) for young people with complex and multisystem conditions

- ensuring national guidance is followed and audited (National Institute for Health and Care Excellence (NICE) guidance in England⁵³)
- holding regular meetings with adult services in relation to transition services.

Longer consultation times are required for young people to enable the healthcare professional to include time for transition planning and to see the young person independently and with their family as appropriate⁵⁴.

Primary healthcare professionals must be kept informed from the start and throughout transition planning. Communication must be copied to the GP regarding updates or progress to transition planning, self-management or continuity of care, i.e. if a young person is being seen independently of their family.

Service planners must ensure that there is a system in place to monitor whether young people are successfully transferred into adult care. If the young person misses their first appointment in adult care, the children's health service must be informed in order to make contact with the young person and family, and their transition plan reviewed. Contact should ideally be made by a healthcare professional known by the young person.

Who benefits and how

Children will undergo a smooth transfer to the appropriate adult service with concerns around continuing care reduced and support given to the young person developing autonomy in managing their condition. Children's healthcare professionals foster improved communication and working relationships with adult service colleagues and other specialties. Service planners join up working between health organisations and paediatric and adult services. Children are empowered to self-manage their condition, live autonomously and take opportunities in further education and employment.

Metrics

Structures	Process	Measurable Impact
<p>Evidence of transition recognised in the job description of a designated person within each children's healthcare team (by a minimum of 0.5 PAs per team or specialty).</p> <p>System to ensure successful transfer to adult services (ie 'was not brought' letters copied to the child health service).</p>	<p>NICE quality standards audit (QS140).</p> <p>Letters are shared with the GP in relation to transition arrangements and progress including details of agreed developmentally appropriate care arrangements.</p>	<p>Proportion of young people with ongoing health needs who attend their second appointment with adult services.</p> <p>Rate of admission or attendance for children and young people aged 16-21 years who have transitioned to adult services.</p> <p>Rate of service complaints relating to administrative or clinical queries for young people aged 16-21 years under care of adult services, with less than three paediatric appointments in past three years.</p>

Practice example

Making Healthcare Work for Young People Northumbria Healthcare NHS Foundation Trust

Making Healthcare Work for Young People: A toolkit to support delivery of developmentally appropriate healthcare can be found here: www.northumbria.nhs.uk/dahtoolkit

Following on from transitional care research funded by the National Institute for Health Research (NIHR)⁵⁵, this toolkit gives practical suggestions about how healthcare can be tailored to young people's needs as they develop and change through adolescence into young adulthood.

The toolkit is designed to support everyone working in the NHS, from clinicians to chief executives, to promote the health of young people and to play their part in making healthcare work for this age group.

Contact

Northumbria Healthcare NHS Foundation Trust transition services
transition@ncl.ac.uk

Resource implication

At a minimum, 0.5 programmed activities in job description of designated person that is responsible for transition.

STANDARD 7

Local health systems ensure healthcare professionals assessing or treating children in any setting have timely access to the child's shared electronic healthcare record.

Who is the child

All children.

Aims

- Enable timely and effective clinical decision making for children interacting in a variety of health services
- Improve health outcomes
- Reduce the need for duplicating information
- Ensure the healthcare professional has access to all appropriate clinical information when making decisions

'Mum expressed surprise that it wasn't already all part of the 'same system' and that GPs and paediatric departments were not automatically connected to the same IT systems and that referrals were not smoother.'

RCPCH &Us voice bank, 2017

Rationale and evidence

Ensuring connectivity between primary care, hospital and community services requires health information to be readily available in any setting. Clinical decision making is best informed when sufficient information is provided by all health service settings that children interact with. Evidence from the *Facing the Future Audit 2017* suggests that services are struggling to access children's shared electronic healthcare records without the required investment to information systems¹⁹.

Information on a child's school and education needs in addition to their social care, safeguarding arrangements, psychological input or emergency care plans will ultimately enable better clinical decision making that will offer a more holistic approach to caring for children in healthcare settings.

Guidance

The shared electronic healthcare record (EHR) includes, as a minimum:

- the unique patient identifier number: NHS number in England and Wales, Community Health Index number in Scotland or Health and Care number in Northern Ireland
- name, address and date of birth
- GP details
- active diagnoses
- medications: prescription medication, allergies and bad reactions to any medication
- encounters: recent admissions or visits to hospital, emergency department or out of hours centres attendances, appointments booked for the future
- any emergency care plans or personal healthcare plans (for example, for children with long term or complex conditions)
- safeguarding information including whether the child is, or has been, on or have been the subject of a child protection plan, are looked after or are care leavers and the name of the responsible local authority.

Guidance on the content and clinical structure of patient records is provided by the Academy of Medical Royal Colleges⁵⁶.

Service planners and health organisations must ensure investments are made to information systems infrastructure to ensure information is easily accessed and shared by all healthcare professionals treating children.

Who benefits and how?

Children have access to information using shared technology that helps to better manage their ongoing health needs, with more complicated information such as medicine history stored and available to share. Children's healthcare professionals have immediate access to health information that enhances medical decision making to provide timely advice and treatment including information on safeguarding. Service planners invest in a system that ensures health information is stored safely and care for children with ongoing health needs is coordinated across health and social care settings.

Metrics

Structures	Process	Measurable Impact
<p>Proportion of local GP practices with access to local hospital electronic health record.</p> <p>Proportion of GP practices whose EHR records are accessible to local hospital practitioners.</p> <p>Proportion of community trusts whose EHR is accessible to local hospital practitioners (and vice versa).</p>		<p>Rate of service complaints relating to clinical communication.</p>

Practice example

My Medical Record University Hospital Southampton (UHS) NHS Foundation Trust

The 'Ready, steady, go' programme is designed for young people to empower and equip them with the skills and knowledge to take control and manage their own healthcare. Equipping young people with these skills will improve their longer term health, both in terms of engagement with the health system and in terms of self-management.

My Medical Record is an open platform designed to share data between patients and the health services providing care to them, and includes personal information including the patient's contact details, allergies, emergency contacts and family history. Patients have full control over their record and who accesses their information, which is only shared upon patient consent. The record includes information on upcoming appointments, including the facility to cancel appointments. Letters and clinical notes, including discharge summaries, are stored as documents within the record.

'I think it's a really useful tool that allows patients to be aware of what is happening with their treatment and why certain decisions are made. Especially for someone like me who is in the transition process, it really puts me in control so I have all the information available on hand.'

17 year old patient, UHS, 2018

A particular benefit of My Medical Record is the list of medications that are prescribed to patients (both current and previously used medications). For patients with inflammatory bowel disease, a food diary is included in the record which can help patients to manage their own conditions.

'If patients are having treatment elsewhere/outside the usual care team, recent blood results, discharge summaries etc are available to access if required. As parents, we don't have to chase doctors or nurses.'

Parent, UHS, 2018

A messaging facility within the record provides an easy access point for patients to contact healthcare professionals involved in their care.

My Medical Record has over 8,000 registered patients across adult and paediatric services, with approximately 50 new users added every week.

Contact

Dr Arvind Nagra, Consultant Paediatric Nephrologist and Clinical Lead for Transitional Care
University Hospital Southampton Foundation Trust
ReadySteadyGo@uhs.nhs.uk

Resource requirement

Investment in interoperable information systems across healthcare settings is required.

- England: *Personalised Health and Care 2020 – A Framework for Action*⁵⁷.
- Scotland: *Digital Health and Social Care Strategy 2017-2022* is under development.
- Wales: *A Digital Health and Social Care Strategy for Wales* is available⁵⁸.
- Northern Ireland: Electronic Care Record has won industry awards and more information can be found via www.ehealthandcare.hscni.net.

STANDARD 8

Service planners ensure children have timely access to a range of mental health and psychosocial services that are integrated with children's health services and that all healthcare staff have sufficient competences to support the psychological needs of children and recognise when involvement of mental health services is required.

Who is the child

Children under the care of a child health service (in any setting).

Aims

- Ensure psychological needs and mental health difficulties of children with physical health or developmental conditions are recognised and addressed
- Ensure all children's healthcare professionals are working in a psychologically informed way to promote adjustment and reduce distress
- Ensure that the mental health needs of vulnerable children in contact with the children's health service, either as part of safeguarding practice or statutory looked after children work, are recognised and addressed
- Ensure all children's health services demonstrate a non-stigmatising approach to psychological adjustment and mental health through the integration of mental health services as part of standardised holistic care

'With mental health conditions, it is important to know that people with long term conditions are more prone to having a mental health condition so check in how they are feeling and use games and work book to explain.'

RCPCH &Us voice bank, 2016

Rationale and evidence

Children with ongoing health needs are particularly vulnerable to developing mental health difficulties, which can be exacerbated during difficult stages in the child's illness, such as when a diagnosis is given or around a hospital admission^{59,60}. Poor mental health can affect both children and their families and, if not addressed in a timely manner, difficulties can persist that may negatively impact the child's physical health.

Mental health services should be considered as an integral part of children's healthcare^{61,62} in both acute and community settings. Addressing the emotional needs of the child and their family alongside the child's physical health needs helps to increase the quality and satisfaction of care, and can attribute to better health outcomes^{15,59,63,64}.

A growing body of research demonstrates the clinical effectiveness of a range of talking therapies including cognitive behavioural therapy, motivational interviewing, acceptance and commitment therapy, and family therapy for children with a range of medical conditions^{59,65-69}. Having an appropriately resourced multidisciplinary mental health team able to deliver these therapies alongside physical healthcare is essential. In addition, training all paediatric healthcare staff to understand the psychological impact of health difficulties, support psychological needs as part of holistic care and recognise children who are vulnerable to developing mental health issues is key to enabling prompt and appropriate preventative support^{59,70}.

Paediatricians perform many functions which may broadly come under the umbrella of mental health. In community settings, they are in most districts the main service for the assessment of children for autism spectrum disorder, a condition with a mental health comorbidity rate of 80%⁵⁹, and most community paediatric services also provide

diagnostic services for attention deficit hyperactivity disorder and are involved in psychopharmacology⁶⁵. Community paediatricians also provide services to children who have been abused or neglected, or who are looked after by local authorities, both groups with high prevalence of mental health difficulties¹⁵.

Guidance

Service planners must ensure a sufficiently resourced paediatric psychology and paediatric liaison mental health service is provided in all child health settings with adequate and appropriate space for children and families, including those in crisis.

Service planners must ensure mental health services are delivered by multiprofessional mental health teams to include psychology, psychiatry, nursing, family therapy, psychotherapy and other therapists who are able to deliver evidence based psychological and pharmacological therapies to respond to a range of mental health difficulties that build resilience, promote adjustment and prevent and treat mental health difficulties. Occasionally this may include use of the mental health and child protection legislation.

Service planners must ensure there is a designated person (who could be of any professional background) within the children's health service who is responsible for identifying training needs of all staff in recognising mental health need and utilising evidence based strategies for supporting psychological needs as part of holistic service delivery. This must be reflected in the person's job description as a recognised role and responsibilities include sharing updates to mental health guidance, organising joint meetings between the children's health service and the appropriate mental health team (eg Paediatric Psychology, Paediatric Liaison Psychiatry or CAMHS) where more complex mutual referrals can be discussed, and regular auditing of mental health service provision with children's health services.

Who benefits and how

Children interacting with health services will have access to healthcare professionals who are trained to identify their needs and make a timely referral to the appropriate mental health and psychosocial services. Children's healthcare professionals will be trained to recognise children with mental health needs and make referrals to the appropriate services. Service planners have the specification required to ensure mental health services are delivered by multi-professional teams and integrated with children's health services.

Metrics

Structures	Process	Measurable Impact
<p>Evidence of system (including departmental policy and administrative support) for collection of rates of referral to mental health services.</p> <p>Must be designated 'mental health lead' in every children's health service reflected in job description.</p> <p>Evidence of departmental use of goal based outcome measures and experience of service questionnaires.</p> <p>Proportion of child health workforce who have received training both in recognition of mental health difficulties and in delivery of low level evidence based strategies for supporting low level emotional and behavioural difficulties as part of holistic care.</p>	<p>Rate or number of referrals to mental health services for children.</p> <p>Rate or number of re-referrals to mental health services for children.</p> <p>Time from referral to first assessment for mental health problems in children.</p>	<p>Improvement in outcome measures in psychological adjustment and mental health (ie strength and difficulties questionnaire, paediatric quality of life measure, experience of service questionnaire, children's global assessment scale, health of the nation outcome scales for children and adolescents⁷¹).</p> <p>Reduction in hospital admissions (and duration of hospital stay) for children and young people due to mental health reasons.</p> <p>Reduction in all cause hospital admissions (and duration of hospital stay) for children who have mental health problems.</p>

Practice examples

Cystic fibrosis and mental health Royal Hospital for Children in Glasgow

The cystic fibrosis team at the Royal Hospital for Children in Glasgow has access to a range of mental health and psychosocial staff from the point of diagnosis. This includes an embedded paediatric psychologist who can deliver evidence based psychological therapies to families as well as consultation and teaching to the paediatric healthcare team via regular psychosocial meetings and delivery of teaching modules in psychosocial interventions for adjustment, adherence and self care⁷². The team also has a dedicated social worker; a play specialist and access to a multidisciplinary paediatric liaison mental health team for children and young people who are demonstrating psychiatric need or require a multidisciplinary mental health response.

Contact

Dr Janie Donnan, Consultant Clinical Psychologist
Royal Hospital for Children in Glasgow
Janie.Donnan@ggc.scot.nhs.uk

Intensive care unit (ICU) admissions St George's University Hospitals NHS Foundation Trust

ICU admission is recognised to be comparable to other life threatening events, with around a third of children (and parents of children) admitted to the ICU demonstrating symptoms of post-traumatic stress disorder (PTSD) after discharge and one in 10 developing clinically significant PTSD^{73,74}.

Integrated multidisciplinary mental health services situated within the hospital can respond quickly to different levels of psychological and psychiatric need; and are able to train medical and nursing colleagues to promote adjustment and recognise and respond to distress.

Contact

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Integrated children's health services Peterborough Children's Health Services

CAMHS and paediatric services in Peterborough are integrated for the assessment and management of neurodevelopmental disorders, with joint paediatrics and CAMHS clinical leadership and joint commissioning.

Contact

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Peterborough Children's Health Services
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Resource requirement

These standards would require redirection of the necessary joint paediatric and CAMHS resources to fund paediatric psychology and paediatric liaison mental health teams. Furthermore, they would require the provision of assessment and therapy offices in paediatric wards.

Some medical specialties have developed specific standards for psychology provision and some CCGs have included psychological provision in service specifications.

For example, 1.0 whole time equivalent (WTE) per 80 newly diagnosed per year in oncology, 1.0 WTE per 150 births in cleft services, 1.0 WTE paediatric clinical psychologist per 80 patients for acute and complex cardiac conditions.

RCPsych specifies what is required to provide mental health services to paediatric services⁷⁵ with the proviso that self-harm and other emergency services require additional resources, including:

- District general hospital paediatric service per 20 beds (covering inpatients and outpatients): 0.2 WTE consultant child and adolescent psychiatrist (usually as part of job plan for generic CAMHS work), 0.2 WTE CAMHS practitioner or nurse, 1.0 WTE paediatric psychologist or psychotherapist.
- Designated paediatric liaison service in teaching hospital and regional centre or specialist children's hospital per 80 beds (covering in-patient and out-patients): WTE consultant child and adolescent psychiatrist (with psychiatric trainees), 1.0 WTE specialist CAMHS practitioner, 3.0 WTE CAMHS practitioners (skill mix: systemic family therapy, mental health nursing and occupational therapy), 8.0 WTE paediatric psychologists.

The provision of mental health services to support community paediatric work is complex and variable. For neurodevelopmental work paediatrics and CAMHS need to participate in a joint integrated care pathway and specific provision will vary from district to district. For vulnerable children provision by community, CAMHS will vary according to the numbers of looked after children or children on child protection plans in a particular district.

Note: This standard was developed by RCPsych's paediatric liaison network and the British Psychological Society paediatric psychology network.

STANDARD 9

Service planners and health organisations have a dedicated lead for children at executive or board level.

Who is the child

All children.

Aims

- To look at the all the issues relevant to the child including their mind, body and social needs
- Agencies and organisations delivering child health and well-being services work together to benefit the needs of children
- Children are represented strategically in decision making for health services

'Voice helps everyone do their jobs better, whether it's a doctor, or a young person or a parent...talking and discussing ideas and working together gets better results for children and young people's health and wellbeing.'

RCPCH &Us voice bank, 2017

Rationale and evidence

The RCPCH *Medical Workforce Census 2015* reported 78% of organisations have a board level champion for child health services, most commonly in form of a nursing director, medical director or directorate director⁷⁶. Organisation, health providers and local systems must have the governance structures in place to ensure services for children are safe, effective and meet the needs of its local population.

The London Acute Care Standards for Children and Young People recommends that each trust has a named executive at board level with dedicated responsibility to represent children⁷⁷. Similarly, the Royal College of Nursing recommends that each organisation has a children's champion at executive board level⁷⁸. In doing so, the quality, safety and safeguarding of children is considered in strategic decision making including the planning and managing of annual budgets.

Guidance

Health organisations, providers and local systems must have a dedicated named lead for children at executive or board level to represent the health and wellbeing needs of children. The executive lead will consider all the issues relevant to the child (including their mind, body and social needs) to ensure agencies and organisations are working together to deliver high quality services. The executive lead is responsible for developing and publishing health strategies and policies, including transition, and a named person in senior management is accountable for implementing them.

Who benefits and how

The voice of children will be included in strategic decision making enabling them to be influential in the decisions that affect their health. Children's healthcare professionals have a structure and system in place to empower the needs of their patients. Service planners will ensure children are represented across agencies and organisations to inform joint working.

Metrics

Structures	Process	Measurable Impact
<p>Evidence of named children's lead in governance structure.</p> <p>Evidence of named person in senior management accountable for implementing strategies and policies developed from the executive.</p> <p>Evidence of named person in Terms of Reference of executive or board.</p>		<p>Evidence of children's health services in published plans and reports.</p>

Practice example

Dr Rosemary Thwaites, consultant paediatrician and strategic lead for children, young people and young adults, James Cook University Hospital

I sit on the Operational Board as Strategic Lead for Children, Young People and Young Adults and am responsible for including children and young people in the strategic planning and delivery of services, including care provided for adults up to the age of 24 years old to cover transition. The Operational Board feeds into the Trust Board and is attended by the hospital's chief executive, and three medical directors covering emergency, planned care and community services.

I have recently developed a strategy for children, young people and young adults that looks more widely at putting children at the heart of service provision laid out under four workstreams that covers emergency medicine, transition, specialty surgery and children's outpatient services.

For example, in relation to devising a strategy for transition services, close working with the matron of children and young people meant that we were able to send questionnaires to patients to understand where young people and young adults are being seen in adult services. Questionnaires were also sent to staff members and results from these activities were used to inform the strategy.

Once the strategy is signed off by the Operational Board, I will be responsible for ensuring that the medical directors covering emergency, planned care and community services are accountable for implementing the strategy. Championing children at a strategic level has led to the establishment of a transition working group that will work to refine and improve transition services for young people and young adults, and the strategy will recommend the recruitment of a transition lead responsible for ensuring the strategy is implemented throughout the hospital.

The best part of my role as strategic lead is being able to work across different specialities within the trust and with partner agencies to improve children and young people's care. The engagement of other directorates and young people has been very positive. Having direct support from the chief executive has also raised the profile of children and young people within the trust.

Contact

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STANDARD 10

Service planners ensure child health services are co-designed, planned and evaluated with involvement from children and their parents/carers.

Who is the child

All children.

Aims

- Build child health services around the needs of the child and their parents/carers
- Offer choice in child health services
- Ensure signposting and information is provided in clear formats that are easy for children to access and understand
- Increase patient experience and satisfaction

'[The young man] felt very strongly about the lack of Wifi in the ward. Without it he felt quite isolated and very bored. He felt that they should really sort it out. He had raised it loads of times but it still was not sorted out. He would be willing to contribute into discussions about how to make the hospital better for teens in transition.'

RCPCH &Us voice bank, 2017

Rationale and evidence

Article 24 of the *United Nations Convention on the Rights of the Child* states that all children have the right to the best health care possible⁷⁹. Coproducing children's services can enhance patient-centred care and result in improved patient experience. Since the update to the Health and Social Care Act in 2012⁸⁰, NHS trusts in England have the duty to include the views of patients within the decisions that will affect their care or treatment.

The levels of involvement and participation of children and parents/carers into healthcare planning is broad and will differ depending on service type, location and specialty. The RCPCH Children and Young People's Engagement Team offer a variety of practical toolkits and resources to support initial thinking around engagement and capturing the voice of children and parents/carers to help shape service design and provision⁸¹.

Guidance

The voice of children (of all ages) and their parents/carers must be used to influence the design of services with opportunities to feedback on services. This feedback must be used proactively to influence strategic decision making and quality improvement. Services should look to develop alternative models of care that optimises the service being provided to children (by widening choice of use by electronic communication options for example).

Who benefits and how

Children are aware of their rights to access high quality health services that account for their health, wellbeing and social needs. Healthcare professionals provide services that are built around the needs of their patients, increasing engagement with children and providing care in appropriate environments. Service planners develop services that are cost effective and appropriate for children whilst incorporating meaningful evaluation and audit activities.

Metrics

Structures	Process	Measurable Impact
Evidence of policy and mechanism to involve children and young people and their parents and carers in the design of new services.		<p>Proportion of new child health services which included children and young people in planning process.</p> <p>Patient and family experience audit.</p>

Practice example

Children and young people involvement Royal Hospital for Children, Glasgow

The new Royal Hospital for Children in Glasgow was opened in June 2015 and benefitted from involvement with children, young patients and families to influence and inform the design of the new children's hospital. Scoping exercises to determine and understand what children, young people and families required from a new hospital was undertaken and engagement with patients and the public via focus groups, questionnaires, and an audit of complaints regarding the physical environment of the old hospital was completed in order to collect the views of patients and the public to feed into the design of the new children's hospital at an early stage.

An established group of users of the old Yorkhill Hospital called the Family and Youth Panel became partners in planning the new hospital by engaging with the project manager of the new build. They underwent training and fact-finding visits to develop their understanding of hospital design across the UK. The collective views of this group produced guidance ahead of the tendering process that needed to be incorporated by bidders during the tender.

Once the architects were appointed, they met with children, young people and families to get feedback on their design. Rooms were mocked up by designers and 'road tested' by members of the Family and Youth Panel and feedback was used to inform final decisions on design.

The involvement of children, young people and families are reflected in the final design and current operation of the Royal Hospital for Children in Glasgow. Better space for families visiting at bedside was incorporated including specific engagement with wheelchair users and other disabled patients. Facilities built into the new hospital design included better facilities for families visiting patients in the hospital and were built around the holistic needs of families including a family lounge, family resource centre, quiet space and interview rooms for counselling and comfort.

For more information on the involvement of children, young people and families in the development of the Royal Hospital for Children in Glasgow, search 'You said, we did' via <http://library.nhsggc.org.uk>.

Contact

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Resource implications

Expenses for travel and attendance of children, young people and their parents at meetings.¹

¹ For more information for commissioning services with children visit www.participationworks.org.uk

STANDARD 11

Service planners ensure systems are in place to monitor, review and improve the effectiveness and integration of local child health services. This must involve representatives of children and families and all agencies responsible for ensuring the health and wellbeing of children.

Who is the child

All children

Aims

- Hospital, community and primary care services work together to reduce unwarranted variation in health outcomes
- Services are integrated between primary, community and hospital settings to improve health outcomes
- Patient experience is monitored and used to evaluate and improve services and patient satisfaction
- Paediatric standards of care are monitored and audited
- Adult services are involved in planning and delivering transition services

‘There have been communication issues between hospitals and services which haven’t supported anyone in managing the condition.’

RCPCH &Us voice bank, 2016

Rationale and evidence

The whole pathway approach identifies opportunities to integrate services to improve patient flow and better health outcomes for local populations. Ensuring the correct process and structures are in place for detecting the poor management of conditions will help services to tackle inefficiencies using local, regional and national peer review and audits to support quality improvements.

Guidance

The meetings must be held biannually, with agendas published on trust and health board websites with a mechanism for children and their parents/carers to suggest items. The main objective of the meeting is to monitor, review and improve the effectiveness and integration of local child health services. The meeting will cover quality issues such as monitoring the poor management of conditions, improving connectivity between children’s health and social services including transition processes with adult providers, and CAHMS in addition to monitoring staff and patient experience.

Though not exhaustive, membership of this meeting must include all agencies responsible for delivering health and wellbeing services to children, including health services in primary, secondary and specialist care settings, public health services, education and social care services.

Who benefits and how

Children are provided with opportunities to influence the services that are delivered in children’s health settings. Children’s healthcare professionals can monitor and improve integration of health services whilst having a forum to discuss, monitor and audit service standards. Service planners gain an improved population level oversight of children’s health services.

Metrics

Structures	Process	Measurable Impact
Evidence of (minimum biannual) children's topics discussed at board level for all organisations that care for children (eg GP practices, trusts, commissioning bodies, STPs and integrated care systems).	Evidence that population level meetings have considered and planned for the introduction of measures to comply with <i>Facing the Future</i> standards.	Improved population level oversight of children's health services.

Practice example

Nottingham and Nottinghamshire Children and Young People's Health Network

The Nottingham and Nottinghamshire Children and Young People's Health Network was originally set up in 2009 as one of the recommendations from the local response to the NHS Next Stage Review, initiated by Lord Darzi.

Nottinghamshire includes two local authorities, three acute trusts providing paediatric care, several community care providers delivering specialist care for children, a mental health trust providing CAMHS, as well as universal and primary care services.

The concept was to establish a forum for commissioners and providers to work together to provide clinical input to local strategic development to include developing care pathways, guidelines and protocols relating to children's care across boundaries, to help inform commissioning decisions and to share information and good practice across the city and county.

The Network is chaired by a consultant in public health, with membership including:

- lead clinicians from all the providers
- CCG children's leads
- children's commissioning leads from each commission agency
- representatives from the local authority children's services
- representatives from the local ambulance trust, workforce teams and regional children's network have been included as appropriate.

While children and young people do not attend the network meetings, their voice is represented through targeted consultation and input is sought usually in relation to specific services, such as the MH:2K initiative that engaged young people in conversations around mental health.

The Network is recognised as being a source of strategic health advice to the local health economy and reports to the health and wellbeing boards.

Examples of work that has been commissioned or shaped by the network:

- multiagency pathway for children with concerning behaviours
- school nursing review
- phlebotomy services for children
- Nottingham and Nottinghamshire referral guidelines for paediatric outpatients from primary care.

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Resource implication

Designated person responsible for attending these meetings has a minimum of two programmes activities per annum allocated to attending and actioning these meetings.

Overarching principles

To promote the resilience and self-management of the health conditions encountered by children, all healthcare professionals must ensure the overarching principles below are integral to their practice.

Child protection

Every professional who comes into contact with children and families has a responsibility to promote the welfare of the child and to protect them from harm⁸². Guidance from the RCPCH on safeguarding and child protection is well documented and is regularly updated to support healthcare professionals to promote the welfare of all children and to protect them from harm⁸³.

Children are best protected when professionals are clear about their roles and responsibilities. Timely access to a paediatrician with the appropriate training and experience in child protection is essential in order that needs assessments can begin quickly when concerns arise. Consultant and career grade paediatricians should be competent to Level 3 in Safeguarding Children and Young People and should continue to acquire competencies throughout their professional development⁸⁴.

Key guidance available to professionals involved in a child's care:

- RCPCH *Child Protection Companion*⁸⁴
- RCPCH *Fabricated or Induced Illness by Carers: A Practical Guide for Paediatricians*⁸⁵
- NICE *Child maltreatment: when to suspect maltreatment in under 18s*⁸⁶
- GMC guidance *Protecting children and young people: doctors' responsibilities*⁸⁷
- HM Government *What to do if you're worried a child is being abused*⁸⁸
- The Scottish Government *National Guidance for Child Protection in Scotland 2014*⁸⁹
- The Welsh Government *Working Together Under the Children Act 2004*⁹⁰
- Northern Ireland *Cooperating to Safeguard Children*⁹¹
- RCN *Protection of Nurses Working with Children and Young People*⁹².

Multiprofessional working

Service planners must ensure services treating children are staffed by multi-professional teams to ensure children have timely access to expertise from a range of healthcare professionals. Core to children's health services is multiprofessional input and working within teams, between teams and across health education and safeguarding children.

Children must have access to support from a range of allied healthcare professionals including physiotherapy, occupational therapy and speech and language therapists according to need. Mental health services should be integral to every child health service and must be adequately resourced with multiprofessional teams to include psychology, psychiatry, nursing, family therapy, psychotherapy and other therapists that are trained to respond to a range of mental health difficulties.

Clinical networks

To ensure care is provided to children as close to home as possible and to ensure expertise is shared across political and geographical boundaries, health services must be organised within clinical networks. The RCPCH has long advocated through its report *Bringing Networks to Life*⁹³ that networks, supported by strong clinical leadership and sound management, are fundamental to improving the quality of paediatric care. The report provides clinicians and service planners with the principles, guidance and supporting

evidence needed to establish or mature existing clinical networks to drive up quality and efficiency across care pathways.

Implementation of the standards

Whilst previous *Facing the Future* standards asked what the paediatrician and child health service could do for the child, these standards focus on what the service planner must do to ensure communication between children's health services enables children and their families to access timely information on the diagnosis and management of their condition.

The royal colleges will need to work with health organisations, commissioners and clinical networks alongside other key stakeholders to provide support with implementation. The RCPCH, RCGP, RCN, RCP London and RCPsych are committed to improving child health at local level, service level, nationally and through engagement with children and their families.

A detailed plan for implementation can be found on the RCPCH website: www.rcpch.ac.uk/facingthefuture

Standards provide an opportunity for services to monitor their own progress locally and the RCPCH are committed to audit these standards nationally in 2020 to inform any revision and update to the standards in 2021.

The RCPCH are here to support services who do not meet the standards and our RCPCH Invited Reviews team helps employers, commissioners, managers and clinicians work together to design services that meet the needs of local populations: www.rcpch.ac.uk/invitedreviews

RCPCH &US

The RCPCH &Us team puts infants, children and young people at the centre of everything the College does by informing, influencing and shaping health policy and healthcare practice. The team strives to educate, collaborate, engage and change to improve children's outcomes and give them the best start possible.

The United Nations *Convention on the Rights of the Child*⁶⁴ sets a clear standard for infants, children and young people's rights to provision, protection and participation. Ratified in the UK in 1991, the RCPCH is proud to champion and advocate for these rights.

It is important that rights are more than a set of statements, but become an active and evolving part of the RCPCH's work. Across our work with infants, children and young people we:

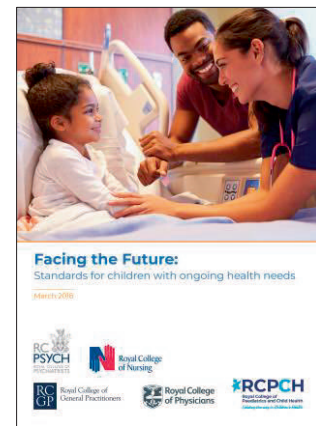
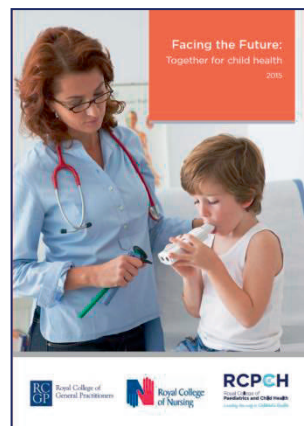
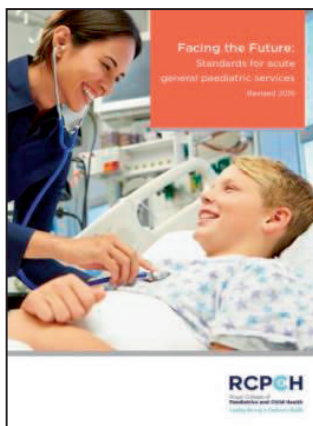
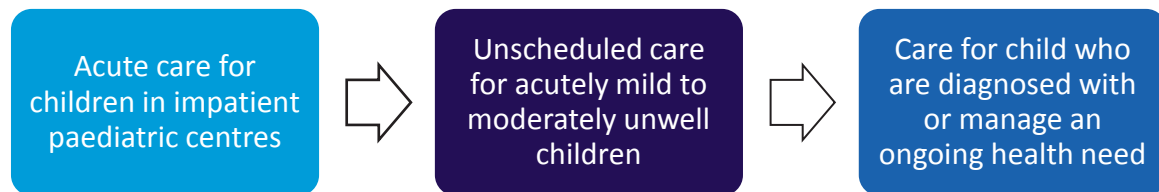
- strive to inform about rights and responsibilities
- consult on views, wishes and needs
- become involved in identifying solutions
- and represent their voice to influence change.

Article 12 (involvement in decision making) and Article 24 (best healthcare possible) drives our work.

RCPCH has developed an engagement programme that works with patients, families and healthcare professionals called the &Us Network and the Engagement Collaborative for professionals. We have a number of resources, information guides and support available via www.rcpch.ac.uk/and-us-resources.

Related work

The Facing the Future suite of standards is a programme working towards whole system change. All standards should be considered together when developing service models and pathways of care across child health services.



Facing the Future: Standards for Acute General Paediatric Services sets out 10 minimum standards for acute general care. These aim to deliver high-quality, safe and sustainable acute general paediatric services and ensure that every child in hospital is seen in a timely manner by a suitably experienced doctor.

Facing the Future: Together for Child Health sets out 11 minimum standards for unscheduled care services. These aim to ensure connectivity between primary care, the hospital and community services to ensure children are cared for as close to home as possible.

Facing the Future Audit 2017 shows how paediatric services are meeting standards laid out in the Standards for Acute General Paediatric Services and Together for Child Health documents. Alongside evidence for how services are meeting standards, practice examples are included to support members with implementing standards.

Facing the Future: Standards for Children and Young People in Emergency Care Settings sets out standards in its fourth edition to improve the experience and outcomes of children in their journey through the urgent and emergency care system. The update will be published in June 2018 and aim to ensure urgent and emergency care services are integrated to support a sustainable emergency care system.

Visit www.rcpch.ac.uk/facingthefuture

Project Board membership

Dr David Shortland (Chair)	Past Vice President, Health Services, Royal College of Paediatrics and Child Health
Emily Arkell	Head of Policy, Royal College of Paediatrics and Child Health
Melissa Ashe	Policy Lead, Royal College of Paediatrics and Child Health
Dr Ronny Cheung	Clinical Advisor Child and Maternal Health Intelligence Network
Dr Carol Ewing	Vice President Health Policy, Royal College of Paediatrics and Child Health
Dr Jonathan Fisher	Trainee representative, Royal College of Paediatrics and Child Health
Dr Helena Gleeson	Chair of Young Adults and Adolescents Steering Group, Royal College of Physicians
Professor Anne Greenough	Vice President for Research, Royal College of Paediatrics and Child Health
Dr Sian Harris	PiMM Committee Member, Royal College of Paediatrics and Child Health
Dr Tim Horsburgh	Clinical Lead Partners in Paediatrics, GP representative
Dr Shashi Kiran	Faculty of Child and Adolescent Psychiatry, Royal College of Psychiatrists
Professor Nigel Mathers	Honorary Secretary, Royal College of General Practitioners
Dr Janet McDonagh	Chair of Young People's Health Special Interest Group, Royal College of Paediatrics and Child Health
Rachael McKeown	Health Policy Assistant, Royal College of Paediatrics and Child Health
Fiona Smith	Professional Lead for Children and Young People's Nursing, Royal College of Nursing
Dr David Vickers	Convenor, British Association for Community Child Health

The project board would like to thank the children and families that took part in developing and consulting on these standards with the RCPCH &Us team.

Appendix 1

Development of the standards: process and methodology

Stage one: analysis

Literature review

A comprehensive systematic literature review was undertaken between November 2015 and January 2016 to establish, 'What interventions by paediatricians and child health specialists improve outcomes for children with long-term conditions that present in primary or secondary care?'

The search strategy included infants, children and young people aged up to 24 years with long-term conditions (including diabetes, epilepsy and asthma) with exclusions made to adults, palliative care, cancer and transplantation. Interventions included within the search strategy were parents and children's self-management of their long-term conditions, valuable and effective contact with professionals, integrated care and improving transition from children's to adult services. Outcomes included within the search strategy were reduced variation in care, improved health outcomes/quality of life, reduced mortality, improved patient experience, reduced emergency hospital attendances and emergency admissions and increased education attainment.

Key databases including Medline and Embase were searched in February 2016. Results from the literature search were compiled and put through a critical appraisal process between February and August 2016. For more information on this process contact health.policy@rcpch.ac.uk.

Call for evidence

In December 2015, a call for evidence was issued online and communicated to members asking for new ways of working and innovative service models that have made a difference to patient outcomes. A hand search of relevant websites carried out with results from the call for evidence were included in summary tables and put through the same critical appraisal process as the literature.

Views of children and parents and carers

Between January to April 2016, the RCPCH engaged with 141 individual children, young people, parents/carers and teachers to explore and collect their views on long-term conditions to support the development of standards within the UK. Their views, experience and ideas were collected using a mixed methods approach that included a ballot paper survey, an online survey, activity based workshops and semi-structured interviews. Themes from engagement activities were fed back to the project board and included as evidence before developing the standards. The views of children and parents/carers are included throughout this document and raw data is stored by RCPCH &Us.

Stage two: formulation of draft standards

Evidence from the literature review, call for evidence and views of children and parents and carers was evaluated by the project board. Drawing on the best available evidence, a set of draft standards were developed. Where there was insufficient evidence, standards were agreed by consensus. The draft document was presented to a number of targeted stakeholders and RCPCH committees to ensure the standards are: relevant and

achievable; specific and measurable; clear and consistent; and to identify any gaps and suggestions for additional standards.

Stage three: consultation

In July 2017, draft standards were circulated to key medical royal college committees (see Appendix 2) and to external stakeholders to ensure that they are: relevant and achievable; specific and measurable; clear and consistent; to identify any gaps and suggestions for additional standards; and to engage users and key stakeholders. Standards were refined based on this consultation and re-circulated via a targeted consultation in November 2017. Children, young people and parents/carers were consulted on draft standards in September 2017 through two clinic visits using semi-structured interviews with 27 people providing feedback.

Appendix 2

Key RCPCH committees and specialty groups included: British Association for Community Child Health, British Association of General Paediatrics, British Association of Child and Adolescent Public Health, Child Protection Standing Committee, Clinical Standards Committee, Executive Committee, Informatics for Quality Committee, Ireland Executive Committee, Paediatricians in Medical Management Committee, Remote and Rural Special Interest Group, RCPCH Specialty Board, Scottish Executive Committee and Wales Executive Committee.

Key RCN committees included: RCN Children and Young People's Specialist Care Forum, RCN Children and Young People's Staying Healthy Forum, RCN Children and Young People's Acute Care Forum, RCN Children and Young People's Continuing and Community Care Forum, and RCN Children and Young People's Professional Issues Forum.

Key RCGP committees included: Associate in Training Committee

Key RCP committees included: Young Adults and Adolescents Steering Group and Young Persons Health Special Interest Group.

Key RCPsych committees included: Faculty of Child and Adolescent Psychiatry, Paediatric Liaison Network.

Please contact health.policy@rcpch.ac.uk for more information on external stakeholders.

Appendix 3

Children and their families should be provided with sufficient appropriate resources to guide the self-management of their care. The following resources may be drawn upon to support the dissemination of information.

For general advice, Health for Kids⁹⁵ have developed numerous resources to promote health and wellbeing in children (mostly aimed at those aged 4-11 years of age). Health Talk⁹⁶ provides a forum platform for young people with long-term health conditions to share and discuss anything related to their illness in a safe, open and supporting environment.

Transition

NICE guidance *Building independence through planning and transition* is designed to support for healthcare professionals through the transition process⁹⁷.

PHONE	READ	WATCH	DISCUSS
	<p>Preparing for Adulthood provide Education Health and Care Plans to download.</p> <p>The Care Quality Commission (CQC) has a 'From the pond into the sea' leaflet.</p> <p>Social Care Institute for Excellence provide key transition resources.</p> <p>Council for Disabled Children provide good practice Education Health and Care Plans and a <i>Future Choices</i> magazine.</p>	<p>Health Talk videos of young people explaining their experience of transition with ongoing health needs</p> <p>Social Care Institute for Excellence video diaries.</p>	

Mental health

'Right Here' provides good practice examples for healthcare professionals working with young people's mental health⁹⁸.

PHONE	READ	WATCH	DISCUSS
<p>Childline helpline: 0800 1111</p> <p>NSPCC helpline for parents:</p>	<p>NHS Choices provides an information hub of advice for young people. The 'mood</p>	<p>Time to change videos for young people to end mental health discrimination.</p>	<p>Kooth offers anonymous online support and a chat function with counsellors.</p>

PHONE	READ	WATCH	DISCUSS
<p>0800 800 5000</p> <p>Youth Access helpline: 020 8772 9900</p> <p>PAPYRUS 'Hopeline' for suicide prevention: 0800 068 4141</p> <p>Stressheads app is a game which provides advice.</p> <p>StepFinder highlights local services.</p> <p>Butterfly app to record feelings.</p> <p>Mood track app records mood changes.</p> <p>Calm Harm app provides support for those considering self-harm.</p>	<p>zone' offers advice for self-help and a questionnaire to understand emotions.</p> <p>Young Minds provides a guide to looking after yourself, to support and for CAMHS. Also offers techniques to relax and campaigning events.</p> <p>Youth Access offers numerous resources.</p> <p>MIND provides booklets for children and young people.</p> <p>The Children's Society provides '5 ways to well-being' advice for parents and resources for children of different age groups.</p> <p>Youth Wellbeing Directory lists local available organisations for those up to the age of 25.</p> <p>The Mix provides resources relating to different illnesses.</p> <p>PAPYRUS offers resources for prevention of suicide in young people, including: safety plans, 'hope box', coping</p>	<p>It's okay to not be okay video.</p> <p>Social Care Institute for Excellence discussion of transition in mental health services.</p> <p>NHS Devon CCG - Joe's story.</p>	<p>The Mix has a discussion board and a 'your voices' section.</p>

PHONE	READ	WATCH	DISCUSS
	<p>strategies, conversation starters for parents, prevention guides for schools, and a colouring book.</p> <p>MindEd provides advice and guidance for parents.</p> <p>Place2Be provides resources for schools, including 'fink' cards to help teachers initiate conversations with young people.</p>		

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