

Facing the Future 3

Background

The project will expand the Facing the Future suite of service standards (which to date has focussed on acute and unscheduled care) to include standards for infants, children and young people with ongoing healthcare needs (including long term conditions and complex needs). The standards focus on reducing unwarranted variations in care and improving the health outcomes and quality of life for children across the life course. These standards apply to all of the health services children interact with in any setting.

Aims

The implementation of the standards will support the delivery of children's health services by providing rationale, guidance, metrics and practice examples of care planning.

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.
- Focus on improving the long term care and management to ensure care is planned and proactive. Particularly with improving communication and education for both the child or young person and family and communication between professionals.
- Look more widely at connecting the whole system and improving patient experience.
- Include the voice of children and parents/carers in the development of services.

Scope

The standards have been developed to:

- Be motivating, meaningful and measurable.
- Be framed in terms of 'what the children's health service can provide' with paediatricians proactively contributing to the healthcare of all children in their area and improved communication and collaboration with other health professionals.
- Take a pathway approach drawing on patient voice, available evidence and expert opinion.
- Be key to driving change and improvement.
- Support children's health services with implementation by providing rationale, guidance, metrics, and practice examples.

Key principles

The standards are organised around the child's journey and aim to ensure children's healthcare provision is:

- Holistic and child/family centred
- Developmentally appropriate (setting and service)
- Proactive and planned (preventing deterioration)
- More valuable and effective for children and their families (making every contact count)
- Coordinated to ensure continuity of care (including transition)
- Closer to home through networks
- Adopting parity of esteem for mental and physical health

Development of the standards: process and methodology

Stage one: analysis

Literature Review

A comprehensive systematic literature review was undertaken covering nine areas: access to specialist advice; continuity of care; transition; empowering children, young people and their parents to self-manage; governance; mental health; recognising and managing deterioration; school; and supporting primary care to care for children in the community.

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. For more information on this process contact health.policy@rcpch.ac.uk.

Call for Evidence

A call for evidence was issued online using the RCPCH website and a hand search of relevant websites carried out. Results were included in summary tables and put through the same critical appraisal process as the literature.

Views of children and parents and carers

The RCPCH engaged with 141 individual children, young people, parents/carers and teachers with views collected, using a mixed methods approach, between January to April 2016. Themes from engagement activities were fed back to the Project Board and included as evidence before developing the standards.

Stage two: formulation of draft standards

Evidence from the literature review, call for evidence and views of children and parents and carers were 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 College 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.

Definitions

'Child' or 'children'	Infants, children and young people under the age of 18 across the UK and may extend up to 25 depending on transition arrangements.
Consultant paediatrician	A consultant paediatrician or equivalent staff, associate specialist or speciality doctor who is trained and assessed as competence to work on the paediatric consultant rota.
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.
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 practice, for example, the General Medical Council or the Nursing and Midwifery Council.
Parents and carers	To identify and acknowledge those who hold parental responsibility but who may not be the biological parent.

Summary of Draft Standards

- 1. The child health service must respond proactively to referral letters to ensure children are managed in the appropriate setting and timescale.**
- 2. GPs have access to advice within 24 hours from a consultant paediatrician to optimise diagnosis and management and to ensure children are referred through the appropriate pathways.**
- 3. Paediatricians have access to specialty paediatric advice by telephone 24 hours a day 7 days a week through clinical networks.**
- 4. Once a diagnosis is made, children and their parents/carers under the care of the child health service have access to clinical advice and information within 72 hours.**
- 5. Children and their parents/carers and primary care providers have a single point of contact to the paediatric service during peak hours for administrative queries and support.**
- 6. Following any non-urgent clinical review clinical communication must be sent to the child's general practice surgery within one week. Where a child's condition is unpredictable or requires further review within that time, a letter to the GP must be sent electronically within 48 hours with the paediatrician alerting the GP of its urgency.**
- 7. Children's healthcare professionals assessing or treating children in any setting have access to the child's shared electronic healthcare record.**
- 8. All children's health services must be co-designed and produced with input from children and their families.**
- 9. Regular meetings are held and documented to monitor, review and improve the effectiveness and integration of local children's health services. Meetings should be attended by senior healthcare professionals, service planners and commissioners from hospital, community and primary care services and representatives of children and families.**

STANDARD 1

The child health service must respond proactively to referral letters to ensure children are managed in the appropriate setting and timescale.

Aim: To ensure children are seen at the right time, in the right place, by the right person.

Rationale/evidence

- Number of patients waiting for outpatient / clinical appointments rising¹
- Patients waiting longer than national targets²
- Need to reduce hospital attendance and unnecessary admission³
- Need to overcome perverse incentives for tariffs / commissioning of services

Guidance:

Referral letters received by the children's health service must be reviewed and considered within seven days for the following actions:

- Refer back to GP for more information
- Advice on how to manage without outpatient attendance
- Refer back to GP for further investigation prior to outpatient attendance
- Refer for outpatient appointment

For children where it is clinically required, GPs should be able to refer directly for clinical consultation at the paediatric service. Increasingly, children's services are operating under a 'Single Point of Access' in order to triage referrals. The management of referrals are most appropriately organised through weekly multi-disciplinary meetings.

In England, the NHS e-Referrals system 'Choose and Book' enables patients to book specialist clinic and hospital appointments if recommended by the GP. The specialist service must accept, reject or re-book these appointments within seven days.

Metrics

- *Suggestions for inclusion are invited*

Practice example: *Suggestions for inclusion are invited*

STANDARD TWO

GPs have access to advice within 24 hours from a consultant paediatrician to optimise diagnosis and management and to ensure children are referred through the appropriate pathways.

Aim: To ensure access to senior paediatric advice for GPs for the management of semi-urgent problems where that advice will improve the management, reduce anxiety and ensure an appropriate referral pathway.

Rationale/evidence:

- Results of 2017 audit of standard 1 from Together for Child Health.

Guidance:

- Advice may be by phone, email or a virtual clinic.
- Responsibility of the GP to ensure advice is gained within 24 hours where child needs rapid assistance and ensure any necessary tests are completed.
- Consultant paediatric advice may be open to other health professionals (e.g. health visitors, school nurses and community children's nurses) by local agreement.

Metrics:

Metrics

- *Suggestions for inclusion are invited*

Practice Example: *Suggestions for inclusion are invited*

STANDARD THREE

Paediatricians have access to specialty paediatric advice by telephone 24 hours a day 7 days a week through clinical networks.

Aim: To improve communication and collaboration between secondary and tertiary services

Rationale/evidence:

- Results from 2017 audit of Facing the Future Together for Child Health Standard 9 – Specialist paediatricians are available for immediate telephone advice for acute problems for all specialties, and for all paediatricians 24/7.
- Results of 2013 audit showed 27% of units across the UK are unable to access immediate telephone advice for gastroenterology and respiratory specialties.

Guidance:

- Specialist services must ensure advice is available out of hours to ensure general paediatricians are supported in the appropriate referral and management of patients.
- Advice must be documented to support clinical governance.
- For less urgent advice, specialist paediatricians provide email/phone response within 72 hours.
- If 24/7 access to specialist advice cannot be provided by the local tertiary service, these services should develop networks to ensure paediatricians have access to specialist advice whenever it is required.

Metrics

- *Suggestions for inclusion are invited*

Practice Example: *Suggestions for inclusion are invited*

STANDARD FOUR

Once a diagnosis is made, children and their parents/carers under the care of the child health service have access to clinical advice and information within 72 hours.

Aim: To promote self-management, resilience and understanding of managing the condition with the opportunity to ask questions about treatment and medication.

Rationale/evidence:

The College recognises that children with on-going 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 the *Making Every Contact Count*⁴ approach from Health Education England, requires all professionals to encourage healthy behaviours.

Children and young people 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 would help⁵. It is important to provide information to enable children and their families time to adjust to receiving a diagnosis 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 or treatment of the condition.
- Clinical advice is provided by a consultant paediatrician, children's clinical nurse specialist or senior trainee.
- The child health professional delivering a diagnosis to a child or young person must share resources and information with them and their parents/carers in a form that is accessible and that they understand.
- Details of the type of information / where the patient has been signposted to should be included within the clinical letter discharge summary.

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

Metrics

- *Suggestions for inclusion are invited*

Practice Examples: *Suggestions for inclusion are invited*

STANDARD FIVE

Children and their parents/carers and primary care providers have a single point of contact to the paediatric service during peak hours for administrative queries and support.

Aim: Children and their parents/carers are able to speak directly with a service regarding administrative coordination of their care.

Rationale/evidence:

Children and young people have told us that navigating the system is problematic and that a single point of access is required⁵.

Guidance:

- Between peak times as locally appropriate, paediatric services run 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.

Metrics

- *Suggestions for inclusion are invited*

Practice Example: *Suggestions for inclusion are invited*

STANDARD SIX

Following any non-urgent clinical review clinical communication must be sent to the child's general practice surgery within one week. Where a child's condition is unpredictable or requires further review within that time, a letter to the GP must be sent electronically within 48 hours with the paediatrician alerting the GP of its urgency.

Aim: To ensure up to date information about the child's diagnosis and management of the condition is available to facilitate appropriate clinical decision making in primary and community care settings, including the community children's nursing team.

Rationale/evidence:

For children with ongoing health needs, it is likely that the child will be treated in a range of settings making the need for connectivity between the GP and child health service essential in order to communicate updates to the management of the child's condition.

New standards for outpatient letters are being developed by the Professional Record Standards Body.

Guidance:

In order for children to be appropriately managed in primary care or the community, child health professionals must have access to the clinical information and decisions made during clinics and paediatric outpatient consultation.

- Or more urgently if clinically necessary
- Copy to child or young person and family in a language they understand
- Copy to the child's school nurse / community children's nursing team
- Communication must include a 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.

Metrics

- *Suggestions for inclusion are invited*

Practice Example: *Suggestions for inclusion are invited*

STANDARD SEVEN

Children’s healthcare professionals assessing or treating children in any setting have access to the child’s shared electronic healthcare record.

Aim: To enable timely and effective clinical decision making for children interacting in a variety of health services.

Rationale/evidence:

Results of Facing the Future 2017 audit of Together for Child Health Standard 9

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 of the health service settings that children interact with.

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 providing healthcare for children.

Guidance:

The shared electronic healthcare record 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, date of birth
- GP’s details
- Medications (prescription medication, allergies, bad reactions to any medication)
- Active diagnoses
- 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 on 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 Colleges⁶.

Organisations must ensure investments are made to information systems infrastructure to ensure information is easily accessed and shared by all health professionals treating a child, including community children’s nurses and school nurses.

Metrics

- *Suggestions for inclusion are invited*

Practice Example: *Suggestions for inclusion are invited*

STANDARD EIGHT

All children’s health services must be co-designed and produced with input from children and their families.

Aim: Health services for children are built around the needs of the child and their parents/carers.

Rationale/evidence:

A key lesson that resulted from the Francis report was the need for health providers to develop more equal partnerships with users of services. Co-producing children’s services can enhance patient-centred care which as a result will improve patient experience. Increasingly NHS Trusts and Health Boards are including children’s representatives and parents/carers on their Boards to ensure their views and experiences are captured in decision making that effects service planning and delivery.

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 provision⁷.

Guidance:

- All health organisations must ensure the voice of children (at all ages) and their parents/carers is captured and used proactively to design services
- Children and their parents/carers must be offered opportunities to feed back on the service, with views being included in strategic decision making.
- Services should look to develop alternative models of care to optimise the use of the service (by widening choice of use by electronic communication options for example).

Metrics

- *Suggestions for inclusion are invited*

Practice Example: *Suggestions for inclusion are invited*

STANDARD NINE

Regular meetings are held and documented to monitor, review and improve the effectiveness and integration of local children’s health services. Meetings should be attended by senior healthcare professionals, service planners and commissioners from hospital, community and primary care services and representatives of children and families.

Aim: Hospital, community and primary care services work together to reduce unwarranted variation in health outcomes for all children.

Rationale/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. Local, regional and national peer review and audits will help to support quality improvements.

Guidance:

The meetings monitor, review and improve the effectiveness and integration of local children’s health services. The meetings must be held twice annually with agendas published on Trust and Health Board websites with a mechanism for children and their parents/carers to suggest items for the agenda.

As a minimum, meetings are held every six months and will cover quality issues such as monitoring the poor management of conditions, improving connectivity between children’s health services including transition processes with adult providers, and monitoring staff and patient experience.

Membership of this meeting must include senior representation from children’s health services in the acute, community and primary care setting, adult physicians with a special interest in transition, local service planners and children’s commissioners and the voice of children and their parents/carers.

Metrics

- *Suggestions for inclusion are invited*

Practice Example: *Suggestions for inclusion are invited*

Overarching Principles

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

Mental Health

Mental health assessment, advice and support is available for any child or young person with an ongoing health need that is having a significant impact on their life whether in terms of burden of illness, psychological impact of diagnosis or where there are clear psychological aspects that are affecting physical and mental health.

Children's health professionals must consider the mental health of every child they interact with in all settings. Children with on-going health needs will often be interacting with a variety of services and it is important that mental health is "everybody's business" in order to adopt a parity of esteem with the management of children's physical health.

Transition

Children have told us that they are concerned about the arrangements made to plan their transition into adult services⁵. Children transferring into adult services will be expected to become more independent in managing their transition and should undergo a structured transition process beginning in early adolescence (during year 9) to maximise their adult potential including engagement with adult services. Children's health services should work closely with adult services in order to achieve this, which must involve the child and their parents/carers.

For children with complex care needs or for those whose needs are not met by adult services, appropriate arrangements should be made, such as involving primary care in transition processes and discussions with commissioners, and NICE guidance followed⁸.

Practice example: The Southampton Transition Model 'Ready, Steady, Go'.

Child Protection & Safeguarding

Guidance from the RCPCH on safeguarding and child protection is well-documented and is regularly updated to support health professionals to promote the welfare of all children and to protect them from harm⁹. Every professional who comes into contact with children and families has a responsibility to promote the welfare of the child and to prevent them from harm¹⁰.

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 development¹¹.

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

- RCPCH *Child Protection Companion*
- RCPCH *Fabricated or Induced Illness by Carers: a Practical Guide for Paediatricians*
- NICE *Child maltreatment: when to suspect maltreatment in under 18's*
- GMC guidance *Protecting children and young people: the responsibility of all doctors*

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- HM Government's *What to do if you're worried a child is being abused*
- The Scottish Government *National Guidance for Child Protection in Scotland*
- The Welsh Government *Working Together Under the Children Act 2004*
- Northern Ireland *Co-operating to Safeguard Children*

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