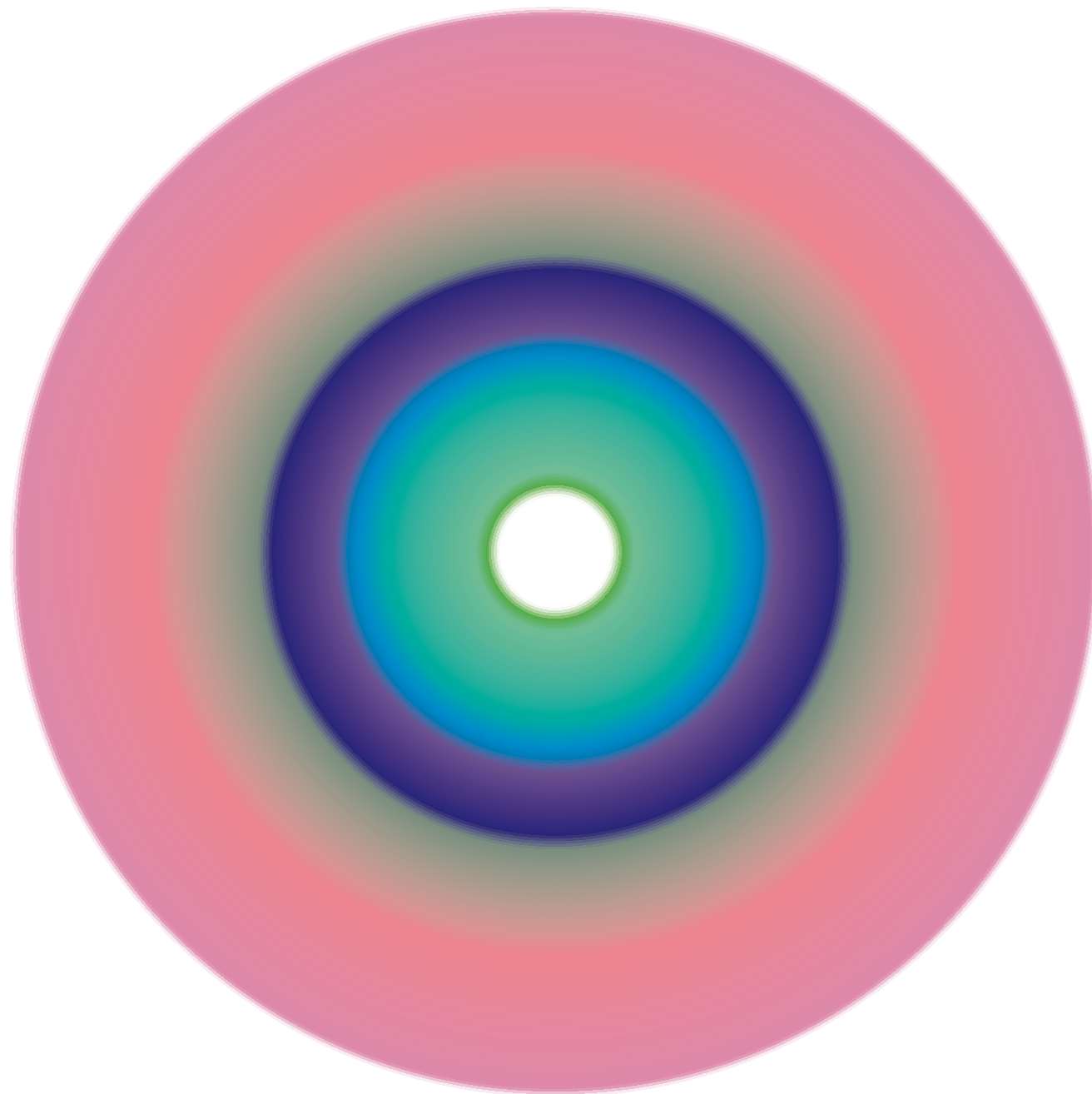




The Children's Pathway



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Getting the best for our children

1
This chapter (based on the work of the Children's CPG – full report available at www.yorksandhumber.nhs.uk) sets out our ambition to make radical improvements to the physical and mental health and well being of children living in Y&H. The Children's CPG highlighted very many examples of excellent care being provided for children across Y&H in their report, but there are still major challenges to be overcome to ensure all children receive the best possible care. These challenges are set out in the case for change below.

2
The case for making changes to children's services could not be clearer – our children's health is amongst the worst in the country.

The Case for Change

3
A few key facts demonstrate the need to change vividly:

- Infant mortality (at 5.8 per 1000 live births) is significantly higher in our region than in England as a whole. Even within Y&H there are significant variations – babies in our most deprived areas have double the chance of dying during their first 4 weeks of life and three times the chance during the rest of their first year of life compared with our least deprived areas.
- Whilst absolute numbers are very small, childhood mortality (deaths under 15 years) at 60.21 per 100,000 children is higher than England as a whole. This varies significantly – children under 15 years in Bradford and Hull have a 50% greater chance of dying than those in Lincolnshire, Calderdale and Leeds.
- Close to 1 in 5 boys and 3 in 10 girls in the region are predicted to be obese by 2010. For girls this is nearly twice the national average.
- There are significant unexplained variations in use of services e.g. attendances at A&E by children can vary ten-fold depending on which GP practice a child is registered with.

Y&H has high rates of acute asthma admission for children; much childhood asthma care is still carried out in hospital outpatient departments.

- In common with the rest of England only 15% of our children achieve NICE recommended levels of diabetic control. Poor diabetic control in childhood increases the risk of major complications such as kidney failure, or the risk of amputation and blindness in early adult life. Nearly all of our children with diabetes are treated in secondary care rather than being managed in community settings closer to home
- Y&H the high rates of acute asthma admission for children; much childhood asthma care is still carried out in hospital outpatient departments (figure 25 opposite).

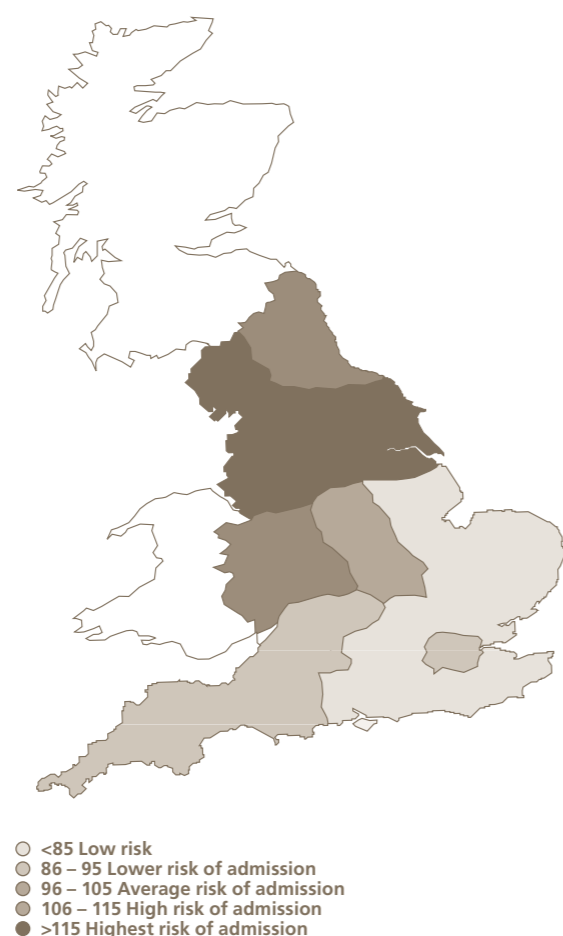
4 Y&H is also worse than national (England) average for:

- Killed or seriously injured in road traffic accidents (0-15 years).
- Conceptions in women aged under 18 years.
- Educational achievement at 15 years.

5 There are large variations in numbers of GPs. The areas of greatest deprivation and need for healthcare have the lowest numbers of GPs for their population density. This is particularly relevant for children, as under 5s are likely to see their GP twice as often as males aged 25-45.

6 A recent publication demonstrated that deaths due to diabetes in children and young people was higher in Y&H than in comparable registries elsewhere in Europe.

Figure 25. Hospital admission rate for asthma per head of population. Standardised for regional differences in age and sex. The average for England is assigned a rate of 100 / Source: Asthma UK May 2007



Key Recommendations

7 Prevention and early identification: The CPG recommended that a risk assessment tool should be developed for every child starting from known pregnancy onset through birth, infancy, pre-school, school and into teenage years. This would inform targeted primary care and social support. Parents and particularly vulnerable parents should be offered parenting education on the prevention, recognition and care of sick children.

8 Assessment, diagnosis, and referral pathways: Access to services for children and families should be improved. Children should be able to access primary care services from 8 to late; thereafter there should be a single phone line for advice on children staffed by an experienced children's practitioner. Urgent Care Centres, as proposed by the Acute CPG, should include expert assessment of children by GPs and /or paediatricians.

9 Primary Care: The CPG advised we need properly constituted children's multidisciplinary primary care teams that include health visitors, midwives, school nurses, community children's nurses, paediatric therapists and GPs. This team requires strong leadership from within primary care.

10 The CPG recommended a range of ways in which standards in primary care could be raised to the levels of the very best on offer in Y&H. This includes strengthening the training requirements of GPs in respect of pediatrics; asking a cohort of GPs to develop expertise to act as a 'beacon' within a practice or groups of practices with a clear aim of raising standards and improving outcomes; or potentially piloting a specific new role of a Children's GP.

11 Acute management/treatment: 30 years ago children stayed in hospital for a wide range of common conditions such as whooping cough. Now, children are unlikely to stay in hospital unless they have a severe or urgent condition which requires the care of specialists such as paediatric surgeons and anaesthetists. Whilst the vast majority of children can be treated in their local hospital, some will need the expert skills available in tertiary centres; networks will need to be in place to link these centres with local hospitals. The CPG therefore recommends that:

- For planned surgery, Trusts and PCTs need to create more opportunities for children to have surgery carried out in local hospitals by competent surgeons and anaesthetists. Occasional practice should cease.
- For the small numbers of children that may require specialist surgical care, better outcomes may be achieved through concentrating care into larger units.
- We need to develop expertise and facilities to meet the health needs of teenagers.



12 Child and adolescent mental health: Children and young people should have the same thresholds and access to services across the region. In addition there should be rapid access teams, drop in services, specialist on-call services in all areas and paediatric mental health liaison for children and young people with physical health conditions. Services should be age sensitive and focus on prevention and early intervention.

There should be investment in training for professionals and non professionals in order to improve the emotional and behavioural support for children and young people in primary health care, schools and communities.

13 Long term condition management: The CPG recommend a framework that links commissioners, providers including clinicians, together with a robust performance management process that develops evidence based pathways with outcome monitoring and peer review. There should be particular focus on:

- Improving outcomes in diabetes by developing a focussed Yorkshire and Humber wide approach.
- Improving outcomes in childhood asthma, with a clear aim of reducing acute admissions and improving overall disease control. The proposal is similar to diabetes but in this instance would also involve primary care to a much greater extent. The first step would be to hold a 'Y&H Asthma Summit'.
- Young people's palliative care.
- Children with neuro-disabilities.

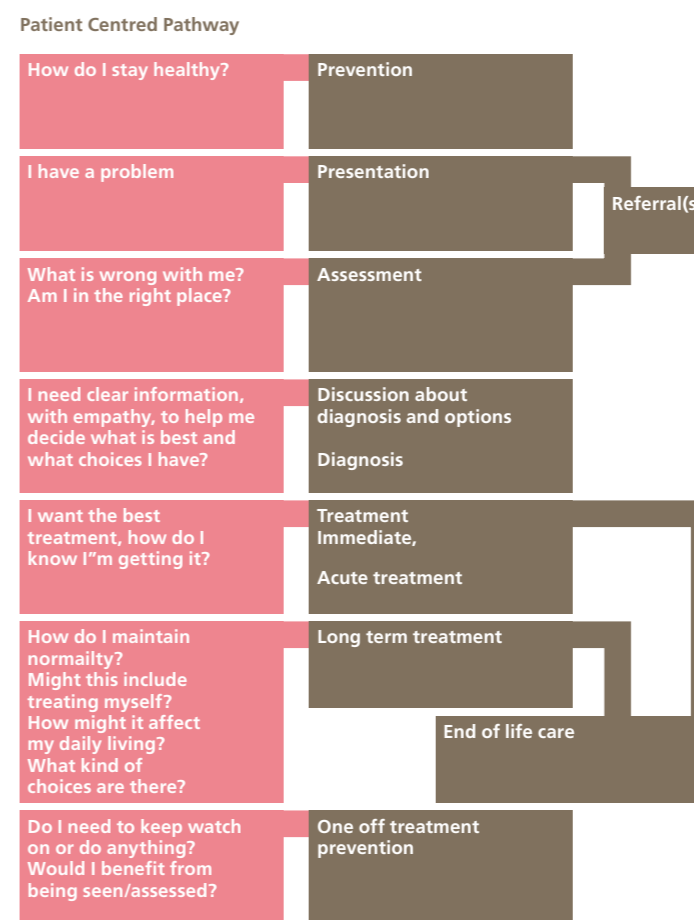
14 Dental Health: Primary care dental services need to be developed to better cater for children with significant dental disease within the primary care sector. Additionally:

- There needs to be better integration between primary dental care and specialised services. Referral pathways into the specialised services need to be more clearly defined.
- The effective delivery of preventive dental care within primary care dental services needs to be encouraged and supported.

15 Commissioning: There is a need to commission whole pathways of care. The CPG were not opposed to some elements of pathways being provided by different providers as long as commissioners are clear about the whole pathway and that performance management and incentives are directed towards providing a service integrated around the needs of each child and family.

16 Effective financial levers: There is a need for clear outcome measures – of both clinical relevance but more importantly of relevance to each child and family. This demands involvement of users in determining and being aware of outcomes.

Figure 26. Child - centred pathway model. /Source: Y&H Children's CPG



The Children's Pathway

17 The CPG have devised a model which we believe can ensure a focus on each patient's needs at every stage of their care pathway. This is shown in fig 26 and 27 and explained in more detail in the next section.

The Pathway in Practice

18 The key actions clinicians want to take forward at each of the stages shown in the model are described below. This is a ten year programme of action.

Prevention

19

The CPG proposed the following actions:

- Develop a personal risk assessment tool which could be used with every baby and child to identify those at increased risk of not achieving the 5 key outcomes promoted in the Children Act and target resources appropriately. The key risk identifiers we should use are set out in the full report from our Children's CPG.
- Develop an evidence based risk reduction programme targeted towards babies/children at highest risk at home, school, community in conjunction with Directors of Children's Services.
- Target the work of health visitors and school nurses so that they work predominantly with high risk children and families. Community support for child care was thought to be "essential" by the parents who took part in our focus groups³.
- This work should be the subject of rigorous academic evaluation to assess the impact on outcomes.
- Ensure that there is clear information about where to go, when children are unwell or injured including out of normal hours. This should include clear signposting from different start points.
- Ensure parents/children have confidence in first point of contact by ensuring that the first assessment is undertaken by highly skilled professionals – supported by good communication with the same standards applying 24 hours a day.
- Reduce unplanned unnecessary admissions and avoidable A&E attendances.
- Develop acute assessment units to ensure that children receive expert assessment and care.



Figure 27. Patient Centred Pathway
Source: Y&H Children's CPG

Patient Centred Pathway At each stage, I (the patient) need:
1. Expertise in me (child/teenager)
2. Expertise in my likely condition
3. Things to happen quickly (rapid access)
4. Someone who talks to me or my family in a way I and they can understand
5. Dignity and respect
6. The opportunity to do things for myself
7. Best available treatment
8. To be at home if possible – and if not, to be in the best place for treating me
9. If in hospital that I am safe from harm (infections)
10. Someone who knows my family

Assessment; Diagnosis and Referral Pathway

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The CPG identified that variations in both primary and secondary care had an impact on outcomes for children. To address this in primary care, the clinicians on the group originally proposed the development of a new role of a Children's GP. This courted some controversy but everyone agrees that there is a need to ensure that professionals dealing with children have the appropriate level of paediatric expertise. What is key is to ensure that outcomes improve across Yorkshire and the Humber to the very best that is already provided.

A number of proposals have been put forward therefore about how this could be achieved. These include making paediatrics a mandatory component of GP training; identifying a cohort of GPs to develop expertise to act as a beacon for other practices; or for interested health economies to pilot a new role of a Children's GP. What matters is that children and their families should be able to readily access the level of expertise they need for their physical and mental well being.



Discussion about Diagnosis and Choices

21 Parents, carers and children should understand and have confidence in the information and instructions they receive, and that professionals have demonstrable training in communication skills required for dealing with children, young people and their families.

Acute Management/Treatment

22 Common acute disease or condition pathways should be followed through primary and secondary care, supported by more integration between these sectors and closer relationships and mentorship between local hospitals and tertiary centres.

23 All elective surgery and anaesthetics should be provided by highly trained professionals who work as part of a network incorporating specialist children's surgeons/anaesthetists and other professionals. For the small numbers of children that may require specialist surgical care, better outcomes may be achieved through concentrating care into larger units.

24 Child and adolescent mental health services could have: rapid access teams; drop in services; specialist on call services in all areas; paediatric mental health liaison; and networks in all areas.

Long Term Condition Management, Treatment and Palliative Care

25 There are a range of self care programmes for children with chronic disease, which should be widely available.

26 Educational mentors should maintain school contact and educational continuity during periods of in-patient care/school absence.

27 Planned transitional care programmes should support the movement between children's and adult services for teenagers and young adults with long-term conditions.

End of Life Care

28 Families and children should be given choices about place of care based on clear information and a range of options, with 24/7 availability of support at home from Children's Community Nursing Teams.

29 There should be clear advanced care planning to ensure continuity of high quality care that meets the needs and preferences of children and their families.

30 Links to palliative care expertise would be readily available through a regional network.

Good Practice

Born in Bradford

Medical researchers will track the lives of more than 10,000 babies born in Bradford until they are 16 years old.

As well as closely monitoring the progress of these babies born at Bradford Royal Infirmary in 2007/8, the study will also follow parents and grandparents - enabling doctors to explore the causes of common conditions like diabetes, heart disease and cancer.

By involving a diverse community such as Bradford, the project will be the first of its kind in the world to research the impact of ethnicity on later development.

The research will piece together a picture of each child by examining factors such as genes, diet, lifestyle, schooling, neighbourhood and upbringing to help the world of medicine understand the causes of childhood illnesses and adult diseases.

'Getting Sorted' Self Care Workshops for Young People with Diabetes - Bradford and Leeds Metropolitan University

An action research project to establish the value of an expert patient group for children and young people with diabetes in Bradford.

Young people were asked about the impact of the disease on their lives and the extent to which they felt they were in control. Overall children reported that they did not feel in control as they felt others i.e. parents and medical staff did not trust them and that doctors talked only to parents. They felt that they were a condition rather than a person and that their need for independence was often overridden by others' anxieties about them. Overwhelmingly young people said that they did not have sufficient information in a form that they could understand. Some young people also said that they were scared, fearful and confused.

This project went on to develop a self help support group whereby the children and young people helped each other to understand and develop coping strategies to live with diabetes. Given the success of the project it is envisaged it will now be rolled out to other groups and include children and young people with asthma.

Sources

1 This chapter is based on the work of the Yorkshire and the Humber Children's Clinical Pathway Group. Report available at www.yorksandhumber.nhs.uk. Membership of the group is shown at Appendix 1.

2 Yorkshire and Humber Focus Group Reports – September and December 2007

3 Staying safe, enjoying and achieving, being healthy, making a positive contribution and economic well being

4 Public Health Child Health report in 2006

5 Children Act (2004)

6 Children, Young People's and Maternity National Service Framework (2004)

7 UNICEF report

8 'Children's Health Our Future' DH November 2007

9 Implementation Plan for Reducing Health Inequalities in Infant Mortality, DH, 2007

10 National guidelines and protocols, adherence to CEPOD recommendations, and the perception of risk by clinicians following the events in Bristol have all promoted sub-specialisation. Public expectations have also changed over recent years. Patients and parents expect to be able to access the most specialised care and have internationally comparable outcomes.

11 'Fit for the Future', (also called the Court Report), 1976

12 'Every Child Matters'

Conclusion

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The Children's CPG have been clear that their child centred pathway, which looks at what children and parents themselves need, at every stage, is critical to improving services and outcomes. Parents too, told us that linked services, all working together in the interests of children was what they wanted. All agencies, not just the NHS, have a role to play.

34

Children are the future. Over the next ten years we need to use the work of our clinicians set out here to improve their physical and mental well-being, and to make their experience of care as good as possible.

35

Our pledge in taking forward this pathway will be to cut the number of hospital admissions for children with asthma.

Barriers to Change

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The CPG identified a number of barriers to change, which are outlined in their detailed report. In particular, the group believed that the current model of GP family practitioners dealing with everyone would need to adapt to incorporate more clinicians with special expertise in the care of children, if the recommendation for children's GPs was taken forward.

Others, commenting on the report, highlighted the strength of general practitioners in dealing with the health of the whole family and the holistic approach.

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The CPG also highlighted that small CAMHS services cannot easily respond to the need for specialist skills, 24/7, so there will be a need for specialist services, differentiated across agencies.

Children are the future. Over the next ten years we need to use the work of our clinicians set out here to improve their physical and mental well-being, and to make their experience of care as good as possible.