



**NHS Next Stage Review
NHS Yorkshire and the Humber**

**Report of Childrens
Clinical Pathway Group**

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Our NHS Our Future

Summary of Children Report

The Clinical Pathway Group was asked to consider two questions from the perspective of a child and family as they travel through NHS children's health care services. Firstly, how do current health services meet their needs? Secondly, how should health services of the future meet their needs in order to provide world class outcomes? This process was informed by those with clinical experience and expertise, published reports, information mainly provided by the Public Health Observatory, and parent's views and experiences. During the course of this work a number of excellent examples of leading edge practice have been captured; many examples have been included in this report.

Context:

There are 1.2 million children and young people in Yorkshire and the Humber. In recent years we have made significant progress in improving health care and health outcomes. Nevertheless there continues to be major challenges in the health and well being of our children. The Public Health Child Health report in 2006 reported Yorkshire and the Humber as regularly being the worst or near the worst performing region in England recognising that England compares poorly to other European countries for measures such as infant and child mortality rates, teenage conception rates, breast feeding initiation and obesity rates.

Further analysis shows that we have some of the highest numbers of children admitted as an emergency to hospital for relatively short lengths of stay. Children with asthma have more admissions to hospital in Yorkshire and the Humber than other regions in England. There is strong evidence that shows that there is significant variation in the measured outcomes of children with diabetes, less than 20% achieving national levels of recommended control, leading to poor outcomes in adulthood. One in 10 children will have emotional or behavioural problems that will need professional support and as many as four in ten 'looked after' children will be referred to mental health services. Yorkshire and the Humber have the lowest number of in patient child and adolescent mental health beds per capita in the country. Many of these indices of poor health have a correlation with poverty and deprivation but we also know that there is an inverse correlation between areas with the highest levels of deprivation and the least number of GP's.

Challenges:

The CPG has identified that there is unpredictable variation in services that children and families receive at all levels of care and throughout all five pathways. The group has emphasised in particular the unpredictable variation within primary care.

- There is a greater than four fold variation in the referral rates GP's make to secondary care
- There is similar variation in children's attendances at A&E.
- Significant variation in the formal education and training of GP's in child health and illness. More than 50% receive no training in secondary paediatric care.
- High levels of emergency admissions for children with long term conditions
- Parents are uncertain how to access the best care for their children, particularly out of hours.
- There are an increasing numbers of children being referred to child and adolescent mental health services; high numbers of young people treated out of area
- The sustainability of expertise in secondary care general surgery and anaesthesia is uncertain

- Variation in the care available to children at home, and to the care available to children with life limiting conditions.

Summary of Recommendations (see body of report for full recommendations)

1. **Primary Care:** To develop 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 and include the following

- Advanced Practitioners with expertise in children
- Comprehensive children's community nursing teams established in all areas.

In order to address the unpredictable variation and inequalities in primary care the report recommends significant change to how General Practice is delivered for children so that each child and their family has the explicit choice of seeing a GP with appropriate and agreed training and competence in children.

The recommendation is that *either*

- i) a new role of Children's GP be developed,
or
- ii) All GPs should maintain and demonstrate a recognised and explicit standard of practice agreed by appropriate Colleges based on a joint competency framework,
and
a smaller cohort of GPs develop expertise to act as a 'beacon' within practices or groups of practices for the generality of GPs, with a clear aim of raising standards and improving outcomes.

2. **Prevention and early identification:** A Risk Assessment Tool to 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.

3. **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 Pathway Group, should include expert assessment of children by GPs (see recommendation 2) and /or paediatricians.

4. **Acute management /treatment:** Workforce challenges will continue to impact on sustainability of some secondary services and specialist services if they are to provide the level of care and expertise required and expected by children and families.

We therefore recommend the following:

- i. Fewer, larger 24-hour comprehensive secondary units. This is of particular relevance to surgery (of all varieties including acute /emergency service), and anaesthesia.
- ii. 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.

- iii. Develop expertise and facilities to meet the health needs of teenagers.
- 5. **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.

- 6. **Long term condition management:** A framework that links commissioners, providers including clinicians with a robust performance management process that develops evidence based pathways with outcome monitoring and peer review:
There will be particular focus on:

- i) Improving outcomes in diabetes by developing a focused Yorkshire and the Humber wide approach.
- ii) 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 'Yorkshire Asthma Summit'.
- iii) Young people's palliative care.
- iv) Children with neuro-disabilities.

- 7. **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;

- i) 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.
- ii) The effective delivery of preventive dental care within primary care dental services needs to be encouraged and supported.

- 8. **Commissioning: There is a need to commission whole pathways of care.** Children are not well served by fragmented provision and competitive commissioning. Current system of PbR and PBC leads to gaming and perverse incentives in most areas under discussion. We are 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.

- 9. **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.

- 10. **Effective Ways to Share.** Sharing examples of leading edge practice is vital and we should find ways to do it effectively and efficiently.

Implementing these recommendations has implications for PCT's, Provider Trusts, SHA, Deaneries, Royal Colleges, and the DH.

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YORKSHIRE AND THE HUMBER

CHILDREN'S PATHWAY GROUP REPORT

1.0 Introduction

Children are more frequent users of health services than adults. They comprise 25% of the total population. In Yorkshire and the Humber there are approximately 1.2 million children and young people up to 18 years of age and each year over 60,000 babies are born. All children access health services for health checks, immunisations and assessment when acutely ill. Typically, pre-school children see their general practitioner six times each year, up to half of infants attend A&E and about 16% of children attend hospital in any one year. Two percent of children have a chronic, life threatening condition. One in ten children has a recognised behavioural or mental health disorder

There have been major advances in child health and life expectancy during the last century. Parents now expect their children to outlive them. Despite this, children remain particularly vulnerable to inequalities in society, as a result of poverty, social disadvantage, chronic illness or disability. An increasing number have complex needs.

Since the middle of the last century there have been numerous publications and initiatives highlighting the needs and vulnerability of children. High profile cases of failures in health and social care during the last decade demonstrate little change. Both the Kennedy Report into cardiac surgery in Bristol, and the Laming Inquiry into the death of Victoria Climbié identified the need for cultural change; for services to focus on the needs of the child and family, not professional or organisational boundaries.

The Children, Young People's and Maternity National Service Framework (2004) restated many of these issues for children requiring healthcare, stressing in particular the need for integrated, cross-organisational working that focused on the individual needs of each child and family.

This is also the clear message in the Children Act (2004). Directors of Children's Services have been appointed in every local authority, charged with the task of focusing on each and every child. More recent guidance puts children's services firmly towards the top of the government agenda and is further supported by new ministerial appointments.

Despite the current emphasis on children, recent international comparisons cast an unfavourable light on children's life experiences in the UK. The UK was 18th of 21 developed countries in the recent UNICEF report (ref), which compared outcomes in children for a range of parameters. We lag behind our European neighbours when it comes to treating conditions such as diabetes and cancer in children, and we lie 15th on the European Union (EU) league table for infant mortality. Our children are increasingly obese; many are leading unhealthy lifestyles; serious health inequalities mean that the worst off in our society are far more likely to experience worse outcomes and ill health throughout their lives.

- The Children Act (2004) promotes 5 key outcomes for every child: -
- Staying safe
 - Enjoying and achieving
 - Being healthy
 - Making a positive contribution
 - Economic well-being

Achieving these outcomes requires a co-ordinated cross-organisational approach linking a range of providers including education, social services, healthcare and justice. The focus of this report is on healthcare but it must be remembered that this is but one key element of services for children.

2.0 Methodology used for this report

This report has been written by a group of clinicians and practitioners nominated by health economies throughout Yorkshire and the Humber. (Appendix one) The group was restricted to around 25 but largely reflects the wide range of healthcare professionals that work with children and young people.

The group was informed by an extensive number of official and independent reports concerning children's healthcare from various bodies including the Department of Health, Royal Colleges and other professional bodies, the Healthcare Commission, and a range of peer reviewed publications.

The work of the group was informed by evidence provided by the Yorkshire and Humber Public Health Observatory and health economies throughout Yorkshire. Additional evidence and views were received from parent focus groups, deliberative events involving the public, and from presentations delivered at various meetings including the NHS Summit on November 21st and 22nd 2007.

2.1 Task of group

The group met on 3 occasions during October and November 2007 with a fourth meeting planned for February 2008. The main focus of the group's work has been to answer the questions "*What would a world class healthcare service for children look like, and how might this be achieved?*" In carrying out this task the group was asked to consider specific pathways that addressed the following 5 areas for children:

- Preventative services e.g. dietetics
- Acute Care
- Mental Health
- Proactive planned care for long term conditions
- Palliative Care

The group was aware of a large number of detailed and very useful pathways for specific diseases, conditions or criteria. There was no intention to try and reproduce or replace these, more to develop a generic approach on to which the disease or condition-specific pathways could be grafted.

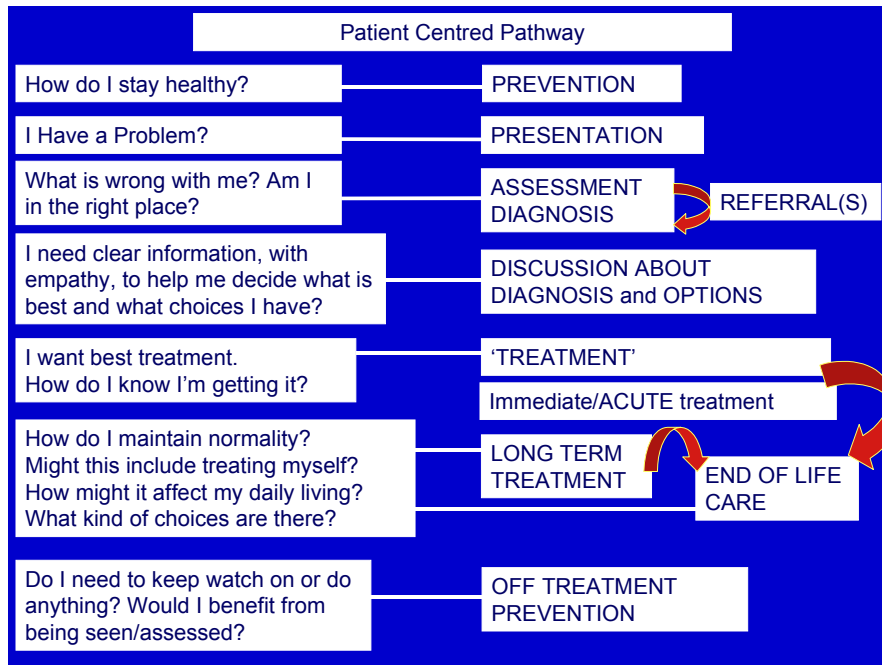
2.2 Pathway development

In addressing this project, the group chose to work with a patient-centred pathway model based on a commonly used pathway but adapted to fit with the parameters of this review.

Step One: the model used the common pathway steps as follows: Prevention; presentation; assessment; referral; diagnosis; information giving; treatment / early management; long term disease management; end of treatment management;

palliative care; but then addresses each step by phrasing a question as asked by patients or their carers. This is illustrated in figure one below:

Figure one: Child- centred pathway model



Step Two. Each step/question on the pathway was considered by asking the following questions.

- **What happens now?**
- **What is needed?**
- **Could it be better?**
- **How might it be better – describe it?**
- **What would it take?**

• **What is the evidence for each of these questions/answers?**

Step 3: Each answer at each step was checked against certain conditions known to be important to patients including children and their families. These are shown below

Figure two: Checklist for pathway interventions

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 explains to me or my family in a way I and they can understand	
5 - dignity	
6 - respect	
7 - the opportunity to do things for myself	
8 - best available treatment	
9 - to be at home if possible - and if not to be in the best place for treating me.	
10 - if in hospital that I am safe from harm (infections)	
11 - someone who knows my family	

Step 4: This approach was used to populate a standard template for each of the 5 pathways the group had been asked to consider. (Appendix two)

Step 5: After the group had completed some work it became apparent that the work for the 5 pathway groups could be merged to create a single high level template and pathway for children and young people. (Appendix three)

Step 6: The group was asked to consider the questions
“What works well and why?”
“What doesn’t work well and why not?”

To answer these questions the group studied examples of good practice known to Medipex and generated additional examples from personal knowledge and experience and from information supplied by the Public Health Observatory and other agencies. (In no way can these be said to be comprehensive. Various examples of excellent practice are contained within the report but we are well aware that there will be many others of which we aren’t aware or have not had space to include).

Step 7: The recommendations have all come directly from the work of the group. They are intended to create debate and discussion. We have clearly not been able to address every area and we are sure that readers will find gaps. Our recommendations address the areas that were agreed by the group as being of most importance and, if implemented, of having maximum impact in improving outcomes for children through a world class health service.

3.0 Health Services for Children in Yorkshire and the Humber

There is enormous social and cultural diversity in the children and young people of Yorkshire. There are pockets of significant wealth but Yorkshire also has some of the most deprived areas in the country. Yorkshire is now home to children from many different backgrounds. In West and South Yorkshire there are a number of long established communities that originated from the Indian sub-continent and the Middle East. More recently there have been increasing numbers of children of Eastern European origins. Overall the childhood population of Yorkshire is predicted to rise over the next 2 decades but this varies from area to area. (Appendix four). These changes bring many challenges if we are to improve our existing services to deliver

world class services, and offer every child the opportunities they each need and deserve.

3.1 Children's Healthcare – A description of the current situation

Children receive healthcare from a wide range of sources and providers. A newborn child will receive an initial assessment by a midwife or neonatal paediatrician. When children are young most families will attempt to access primary healthcare via their health visitor or GP. Some will access via local pharmacies, NHS Direct, 'Surestart' children's centres or go directly to their local A&E Department. Recent changes to primary care services out of normal working hours have led to additional uncertainty for families and children about which route to take.

3.2 Primary and Community Care

General Practitioners can undertake a very wide range of services for children. These include general medical services provision and acute assessment, immunisations, child health surveillance, other preventative health programmes, long term disease management, co-ordination of complex care, and palliative. GPs are often seen as the first point of contact for families and are a key resource with high rates of patient satisfaction. Most GPs nowadays work in teams with a wide range of professionals including nurses and therapists and often link to other services. GPs have an increasingly important role in commissioning secondary and specialist services. Most GPs are trained in specific, general practice training schemes. Formal training in the care of children varies, from extensive to none. In a survey recently undertaken by the Yorkshire Deanery, 47% of GP trainees received formal training in secondary paediatrics of 6 months or less. The other 53% received none. All GP trainees receive some level of additional training in primary care paediatrics. Similar comments apply to other staff working in GP surgeries or health centres.

3.2.1 Health visitors and school nurses also provide primary care for children, often at home, in Surestart sites, children's centres, or at school. Types of service and access vary considerably between authorities. The role of health visitors in some areas is being redefined some authorities and PCTs have programmes targeted towards children and families deemed to be at high risk, whilst others do not. There is little consistency between different areas. The relationships between Health Visitors, GPs, and secondary care are rarely clear.

It is clear that whilst there has been an effort to commission Surestart and Children's Centres in areas of deprivation and high need, there is a proportionally lower number of GPs practising in the most deprived areas compared to the least deprived.

There is a 50% variation in the number of GPs per 100,000 weighted populations across PCTs in Y&H. GPs numbers are strongly (negatively) correlated with deprivation. (Appendix five).

3.2.2 Community paediatric services have developed a range of models, some being integrated alongside secondary paediatric services in Acute Trusts, whilst others are hosted completely separately within Community and Mental Health Trusts or more recently within PCTs. There is considerable geographical variation in service provision. Some areas offer much specialised expertise in child protection or disability, whilst in other areas these are mainly provided by general paediatricians.

3.2.3 A few areas have developed comprehensive community paediatric nursing teams, whilst development of these teams elsewhere is rudimentary. Similarly, access to

therapy and support services for children with disabilities or special needs is immensely variable and apparently arbitrary.

3.3 Secondary Services

Secondary medical care for children covers a wide range of services including assessment and care of the acutely ill child, chronic disease diagnosis and management, child protection services and services for children with disabilities and complex needs. These services can be provided from hospital or a range of community settings and are usually provided by trained paediatricians who are on the Specialist Register of the General Medical Council. There is specific training for nurses who work with children in secondary care and for some therapists.

Many children who require surgery receive care in local DGHs. This may include children with acute surgical presentations, trauma, or those who require planned surgery for relatively simple procedures by general, ENT, orthopaedic, ophthalmic or other surgical specialists. Some surgeons, anaesthetists and theatre support staff receive specific training in children's conditions and in the needs of children but many do not. It is essential that surgeons, anaesthetists and other support staff are competent in carrying out these procedures on a regular basis, can maintain their skills, and avoid 'occasional practice'.

3.3.1 Challenges to Sustainability

All acute Trusts in Yorkshire currently have secondary in-patient and outpatient Children's Services on most, if not all, of their major sites. There are currently twenty, secondary in-patient children's services in Yorkshire, all linked with A and E departments. Nineteen of these sites offer 24 hour admission to local children for both acute medicine and surgery however there is wide variation in local availability of, and access to, planned surgical procedures and specialised paediatric care.

A number of in-patient children's services are potentially unviable in the face of reducing numbers of children requiring in-patient care combined with workforce pressures to maintain rotas that comply with the European Working Time Directive. Calderdale and Huddersfield Trust have addressed this by reconfiguring services, merging in-patient care onto one main site and creating outpatient and assessment areas on the other. There are similar plans to reconfigure services between Pontefract and Wakefield and in Leeds. It is likely that other Trusts will have to consider similar arrangements.

3.4 Specialist (Tertiary) Care

Patterns of referral and provision for specialist care have become established by custom and practice and are highly variable. There are 2 major specialist referral centres, Leeds and Sheffield. Leeds is the major specialist centre serving West, North and East Yorkshire and offers an almost complete range of specialised children's services. Sheffield offers a more limited range of specialised services to South Yorkshire, much of North and North-East Lincolnshire and to North Trent. Children needing services not available in Sheffield access these from Leeds or Nottingham. Hull has traditionally offered a sub-set of paediatric specialised services mainly serving the immediate catchment area. A small number of children from North Yorkshire receive specialist provision from South Tees and Newcastle. A very small number of children requiring highly specialised services (NSCAG) need to travel to other centres.

Most specialist care is carried out in the specialist centres meaning that patients often have to travel quite long distances. Whilst this is necessary for highly technical elements of care, for less technical elements it is possible to offer care closer to home either in local DGHs or in community settings, school or home.

3.5 Child and Adolescent Mental Health Services

We know that one in 10 children and young people has some kind of diagnosable mental disorder. Although there has been some significant progress towards a comprehensive service for children and young people, aided by specific funding, there are still significant gaps in services, particularly for vulnerable groups such as looked after children and those in, or on the edge of the criminal justice system.

- 3.5.1 Child and adolescent mental health services (CAMHs) range in Tiers, from one to four. Tier 1 is a universal primary service delivered by GP's, school nurses, teachers, learning support staff, youth services. In reality there is a general lack of capacity and capability at Tier 1 for all groups of staff in all agencies.

Tier 2 CAMHs are community based but may be provided in a range of settings. Tier 3 CAMHs provide longer term and more complex multidisciplinary interventions to children and young people with complex and challenging needs. In practice the boundaries of which Tier should care for which group is blurred and often results in children and young people and their families being moved from one Tier to another.

Tier 4 specialist services including in-patient units deal with more severe mental health problems such as anorexia, severe depression with suicidality and psychosis. Yorkshire and the Humber have the lowest number of in patient beds compared to the rest of the UK and the current levels of provision of specialist services does not meet the level of need as a number of children and young people have to be placed out of region and often a long way from home. Tier 4 home treatment is limited and there is significant variation in in-reach and out-reach which creates further dislocation for children and young people. A project is underway to get a better understanding of these deficits and should report early in 2008.

- 3.5.2 Increased awareness and recognition of emotional and behavioural problems has led to increased referrals but there is much variation between areas in the thresholds for entry to the specialist CAMHS system from Tier 1. Expectations about what should be dealt with in primary care, community child health, schools and social services, and what should be taken up by CAMHS, vary widely and lead to inequalities in access to CAMH from one area to the next.
- 3.5.3 Within CAMH services clear pathways are starting to be developed for children with specific presentations such as depression, ADHD and autistic spectrum disorders but as with physical health services, this development is patchy and service variable. Transition arrangements with adult mental services are often inadequate, especially for ADHD. There is however, significant a shortage of staff with formal qualifications in psychological therapies and treatments with the strongest evidence base (for example CBT) and a shortage of residential treatment facilities, including residential intensive treatment. Many areas have no formal services for liaison with paediatrics often leaving those families with children in hospital, or with long-term conditions, without appropriate support.
- 3.5.4 CAMHs services are often small and struggle to offer the degree of sub specialisation required to be as effective as the evidence would warrant. Overall per capita spend

is significantly less than that of adult mental health services and varies from place to place.

3.6 Dental Services

- 3.6.1 The majority of children access primary dental care via the General Dental Service. There is considerable geographic variability in the ability to access NHS GDS services, and withdrawal of “children only” contractual arrangements in many areas is likely to make access more difficult. The Salaried (Community) Dental Services (SCDS) have traditionally offered a “safety net” service for children, but this has been considerably reduced in most areas over the past few years, and in many is now only available for children with disability and impairment.
- 3.6.2 There is considerable geographic variation in provision of secondary dental care for children. Some areas have consultant-led services and/or employ GDC registered Paediatric Dentistry Specialists; others provide no specialist-level services at all.
- 3.6.3 There are two main centres providing tertiary dental care for children, based at Leeds Dental Institute and Sheffield Dental Hospital. Both centres offer a full range of specialised paediatric dental services and also provide oral care support to the other tertiary paediatric services based in these cities. Hull and York also have consultant-led services offering a more limited range of specialised care.
- 3.6.4 Dental problems are the most common reason why parents in the Region contact NHS Direct on behalf of their child. Across the region, the average level of dental decay is 24% higher in five-year-olds and 12% higher in 11-year olds than the national average. Some parts of the region have some of the highest levels of dental decay in the country, with more than 50% of five-year-olds having decay. The average child with decay has more than 4 decayed teeth and 7% have active dental sepsis at any one time. In some areas only 5% of decay has been treated, less than half the national average (11%).
- 3.6.5 Access to primary care dental services can be difficult in some areas and this seems to have been made worse by the withdrawal of “child only” contracts by many PCTs. Particular problems are faced by children with extensive dental disease. Primary care GDS dentists tell us that the current contractual arrangements make children with extensive disease financially non-viable to treat in general dental practice, resulting in high levels of referrals to specialised services. Local initiatives have demonstrated that many such children could be successfully managed in the primary care sector and some PCTs are starting to look at ways of commissioning and supporting such activity. Further investigation and proactive development of such initiatives is imperative if resources are to be used most effectively. Referral pathways into specialised services are poorly defined in some areas and need further development.
- 3.6.6 The delivery of preventive dental care in line with DH guidance also needs to be encouraged and supported.
- 3.6.7 Access to secondary dental care services is very variable across the Region. Some areas have well developed secondary care services, whilst in others children either cannot access such services or have to travel to one of the two major centres to receive this level of care. Most centres offering such care have seen a considerable rise in referrals over the past few years with referral volumes exceeding declared capacity at some.
- 3.6.8 Whilst it is entirely practical to treat many children with significant dental caries in the primary care setting, the current General Dental Services contract makes such

treatment financially non-viable, resulting in large numbers of referrals into secondary and tertiary services. Such referrals could be reduced significantly by more appropriate primary care commissioning, and better integration of primary and secondary care services and referral pathways.

- 3.6.9 Primary care dental services need to be developed to decrease referrals to specialised, hospital based services. More appropriate commissioning coupled with suitable training and support would enable development of more effective primary care dental teams. The full potential of the extended dental team (especially using therapists and hygienists to their full potential) needs to be explored, together with better integration with secondary and specialist services.

The Case for Change – Health Care for Children in Yorkshire and the Humber

4.0 Introduction

This chapter seeks to make a compelling case for why healthcare for children has to change. Much of this has a strong national flavour. Children's services in Yorkshire share many of the same issues that face others throughout the country. There have been many excellent reports nationally and locally outlining issues for children and making recommendations about future development for a range of children's healthcare delivery, **however the needs of children have not figured prominently in policy and funding initiatives within the NHS.**

4.0.1 Incentives

The Quality Outcomes Framework is a major lever for improving quality and access in primary care but fails to meaningfully address children's services. There are only limited standard categories and no enhanced categories that concern children.

'Payment by Results' (PbR) is a major lever for commissioning and funding hospital care. PbR has been designed to initially address single healthcare episodes, contains many perverse incentives, and does not have the flexibility essential for ensuring children receive care in the most appropriate setting.

- 4.0.2 The Children's NSF (2004) is a 10 year blueprint for improving healthcare for children and young people but has not been allocated specific funding. Its recommendations have not received the attention or priority accorded to other initiatives such as the Cancer Plan or access targets. Nevertheless, the Children's NSF is still relevant, has widespread support from children's healthcare professionals, and requires implementation. This document is intended to be consistent with its recommendations.

- 4.0.3 Where funding and attention has been focused towards specific areas of children's healthcare, such as CAMHS, neonatal and intensive care networks then there have been demonstrable improvements in service delivery. ('Children's Health Our Future' DH November 2007) However there is concern that as time limited funding initiatives cease such as for CAMHS, there will be less pressure to maintain funding and an associated reduction in service quality.

4.1 Influences

The nature of children's health care has changed significantly over recent years. Some of these changes include:-

- **Improvements in outcome as a result of technical developments** e.g. neonatal intensive care; treatment of childhood cancer; cardiac surgery; paediatric intensive care and many others.
- **Reduction or disappearance of many infectious diseases** due to effective immunisation programmes e.g. measles, H.influenzae.
- **A shift from inpatient to outpatient and day care provision over the past two decades, with increasing emphasis on community based care, at, or close to home.** Children admitted to hospital fall into two main groups a) children admitted with acute illness for short periods of observation and treatment; b) children admitted with complex needs due to chronic disease/disability with long lengths of stay.
- **An increase in children diagnosed as having behavioural or mental health problems.** About one in ten children have a significant emotional or behavioural disorder but whilst most families have consulted a professional (usually a teacher) for advice only a minority are in touch with specialist mental health services. As awareness of the importance of these issues rises, referrals to CAMH services for assessment and treatment are also rising
- A shift to multi-agency care and closer partnership working with social care, education and the voluntary sector. Examples include children with complex needs, looked after children and those with mental health issues. There has been an increased provision of hospice care for children and young people with life-limiting disorders, Yorkshire now having 2 voluntary run hospices with a third one proposed

4.2 The need to improve the health of children in Yorkshire

There is a need to improve the outcomes for children in the UK compared to other countries as delineated in the UNICEF report where the UK was 18th of 21 countries for child well being. The health of children in Yorkshire is worse than the rest of the country and consequently demands even more attention. The following highlights some of the major

- Infant mortality for Yorkshire and the Humber is 5.8 per 1000 live births and significantly higher than England. Ten areas out of a total of 43 featured in the recent report *Implementation Plan for Reducing Health Inequalities in Infant Mortality* (DH, 2007) are in this region because of their high levels of infant mortality between 2002 – 04.
- Childhood mortality (under 15 years) is 60.21 per 100,000 children, significantly higher in Yorkshire than in England.
- Whilst immunisation rates in Yorkshire are slightly better than the England average, there are still around 1 in 6 children who do not receive the MMR vaccine.
- Close to 1 in 5 boys and 3 in 10 girls are predicted to be obese by 2010. For girls in Yorkshire this is nearly twice the national average.
- More children in Yorkshire live in a house where someone smokes cigarettes than in 6 of 8 other regions in England.
- Dental decay in five-year-olds is higher in Yorkshire than the rest of England

4.4 National Comparisons

Yorkshire is also worse than national (England) average for:-

- Child Poverty - worse than European average; 4th worse in England
- Percentage of babies where breastfeeding was initiated;
- Breast Feeding - 3rd lowest at 6 weeks
- Proportion of babies under 2500g (low birth weight);
- Killed or seriously injured - road traffic accident rate (0-15 years);
- Long bone fracture hospital admission rate for males and females (0-14 years)
- Conceptions in women aged under 18 years;
- Educational achievement at 15 years;
- Educational attainment of looked-after-children at 15 years (compared to the figure for all children)

4.5 Inequalities in health and healthcare within Yorkshire and the Humber

- Infants and children up to age 15 years in Yorkshire and the Humber have a significantly higher risk of dying than in the rest of England and Wales. Even within Yorkshire there are significant variations in childhood life expectancy. Babies in the most deprived areas have double the chance of dying during the first 4 weeks of life and three times the chance during the rest of their first year of life compared with the least deprived areas.
- Infants in Bradford, Rotherham and Kirklees have more than double the chance of dying in their first year than those in Hambleton, Selby, Harrogate and Scarborough. Ten of the 43 English districts with highest infant mortality are in Yorkshire and the Humber.
- Children under 15 years in Bradford and Hull have a 50% greater chance of dying than those in Lincolnshire, Calderdale and Leeds.
- Breastfeeding is an independent marker for children's future health yet there are marked geographical variations in how many mothers initiate and maintain breastfeeding. Babies in Calderdale and Sheffield have a 50% greater chance of being started on breastfeeding than babies in Doncaster or Hull.
- Accidents are the second commonest cause of childhood death and there are major variations that appear to relate to areas of highest deprivation. Children aged 5- 14 years in Barnsley, Rotherham, Doncaster, Leeds and Bradford have more than double the risk of being admitted to hospital following serious accidents than those in Craven or York.
- Yorkshire and the Humber has a higher rate of teenage pregnancy than the average for England and Wales. Within Yorkshire – Hull, N-E Lincolnshire and Doncaster have 50% or more teenage girls between 15 and 17 years becoming pregnant than the national average and more than double the number than in North Yorkshire or the East Riding.
- 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. (See appendix five)

- Health Visitor numbers vary throughout Yorkshire and the Humber. There is no consistency between numbers and levels of population deprivation. (Appendix six)
- There are marked variations in numbers of CAMHS staff throughout Yorkshire and in access to 24 hour clinical cover. There is little consistency about the age that services cover, some seeing young people up to age 16 others to 18. This has resulted in young people falling through service gaps with poor outcome.

4.6 NHS services display unpredictable variation

Primary Care

4.6.1 In primary care, quality and access is patchy and unequal with parents and professionals of the view that this is the area that needs most radical change. Whilst many GPs and other primary care clinicians are highly valued by parents and children and offer excellent services, other parents tell us that they are not happy with the service they receive. In particular that the level of expertise in children and their conditions is highly variable and often inadequate leading to high rates of A and E attendance and admission, poor patient experience and expectations, increased hospital outpatient attendance, worse in areas of deprivation.

4.6.2 There is GP practice variation for children referred by GPs to secondary outpatient care. In Doncaster a recent audit demonstrated a 4-fold variation between adjacent practices in percentage of children being referred by GPs to general paediatricians.

In Leeds, for every 1000 children an average of 34 are referred to outpatients by GPs in one year. This can vary 5 fold between practices. In 2006-7 some practices referred as few as 11/1000 children whilst others referred more than 60 in every 1000 children. More children were referred from more deprived areas but again variation between comparable practices was considerable.

4.6.3 There are marked disparities in the experiences of primary care reported by parents, children and young people who develop, or have experience of a more serious condition such as an acute illness, a long-term condition (arthritis, asthma, brain tumour), behavioural issue or concern about their child's development. Some parents or young people report excellent care by their GP, delivered appropriately and speedily. This contrasts with frequent reports from parents and young people of GPs having insufficient knowledge, failing to recognise the seriousness of the condition, not being available for out of hours urgent assessment, delaying referral to more appropriate care, communicating inadequately, and not providing ongoing care for long-term conditions.

4.6.4 It is not that all primary care for children is delivered poorly, indeed much is excellent. The point is that the variation within the current scheme is so great that children and families cannot rely on their particular practice or GP providing equitable or excellent care. The expectation of the NHS is that all children and families should be able to access world class services. This requires systematic change.

4.6.5 If a child becomes acutely unwell, parents tell us that they are confused about where to go and who to contact.

4.7 Acute care

- 4.7.1 There has been a significant fall in patients being admitted following GP referral in recent years but a marked rise in the number of children being acutely admitted directly from A&E departments. (See appendix six)
- 4.7.2 55% of acute admissions of children in Yorkshire are from A&E rather than by GP referral.
- 4.7.3 There has been a marked increase in short stays of less than 24 hours whilst longer admissions have remained relatively stable.
- 4.7.4 A&E attendances by children depend on with which practice they are registered. There is large variation in A&E attendance of up to 10 fold. (Appendix seven)
- 4.7.5 During 2007 in a 6-month period in Leeds, an average of 148 per 1000 children and young people (aged 0–18) attended one of the 2 A&E Departments. This varied. Nine practices had less than 50 of each 1000 children registered who attended A&E Departments. In contrast 14 practices had more than 200 of every 1000 children registered attending A&E. Further analysis confirmed that the higher attendance rates were in areas of higher deprivation but even in practices with comparable deprivation there were up to 4 times as many children directly accessing A&E Services.

4.8 Secondary Care

Concerns around “occasional practice” and clinical governance have led to the increased tendency for clinicians to ‘refer on’. This is true at both the interface between primary and secondary care, and the interface of secondary and tertiary care.

- 4.8.1 In surgical services, guidance from the Colleges of Surgeons and Faculty of Anaesthetists has led to some surgeons and anaesthetists in DGHs declining to operate on children, resulting in increasing and unplanned numbers of children being referred to specialist centres for straightforward procedures. At the same time it has become apparent that other surgeons and anaesthetists have continued to provide a local service but are not carrying out sufficient numbers of procedures to maintain competence. These issues are particularly challenging in ‘adult’ based surgical specialities expected to provide a significant component of service to children such as ENT, orthopaedics, ophthalmic and plastic surgery.
- 4.8.2 Much of secondary and specialist care is excellent but recent data has indicated that outcomes for children with serious or long-term conditions are not as good as for children in other developed countries.
- 4.8.3 Children in England have one of the highest incidences of type-1 diabetes and one of the worst records of diabetic control in Western Europe. The recent national childhood diabetes audit showed that less than 20% of children with diabetes achieve the recommended level of control as measured by HbA1c (glycosylated haemoglobin). A recent publication demonstrated that deaths due to diabetes in children and young people was higher in Yorkshire than in comparable registries elsewhere in Europe
- 4.8.4 In Yorkshire nearly all children with diabetes are treated in secondary care. There is a regional diabetes registry, which serves West, North and East Yorkshire. Analysis of recent registry data shows that only 15% of children with diabetes achieve NICE

recommended levels of control (HbA1c). In addition there is large variation of diabetes control in children treated at different DGH services (Appendix eight). In a third of centres more than half of the patients have poor control. Poor diabetic control in childhood impacts on long term control and increases the risk of major diabetic complications such as kidney failure, the risk of amputation and blindness in early adult life.

4.9 Specialist Care

4.9.1 Cancer is the commonest cause of non-accidental death in children between 1 and 15 years of age. Survival for children with cancer is poorer in the UK than in other countries. A recent publication has shown that only 71% of children with cancer in the UK survive 5 years compared with 75% in Germany and 77% in Scandinavia. The reasons for this are unclear but there are suggestions that children in the UK have more advanced disease at diagnosis than those in other countries. A current international trial in Ewing's sarcoma (a bone cancer affecting mainly children and young people) records information on all patients at diagnosis. Patients from the UK have bigger tumours and more have secondary tumours than those registered in France and Germany. Initial exploration of UK patients suggests that delays in diagnosis can occur in both primary and secondary care.

4.9.2 Cystic fibrosis is an inherited disease that causes abnormalities of the respiratory and intestinal systems and affects about 1000 children and young people in Yorkshire and the Humber. Twenty years ago most died in their teens but many patients now survive into their twenties and thirties as a result of intensive ongoing treatment with drugs, physiotherapy and management of respiratory infection. Infection with a type of bacterium called *Pseudomonas* is associated with a reduction in life expectancy of approximately 10 years. The specialist service in Leeds has worked hard at preventing cross infection, has low infection rates, and is recognised as having survival rates comparable with the best in the world. In contrast, other services are less focused and have much poorer infection rates and higher early death rates. Implementation of the best management policies, strict infection control and early eradication of *Pseudomonas* for all CF children will improve outcomes. This can be best achieved by shared learning, practice and audit through a managed network.

4.10 Healthcare Commission report on Acute Services for Children

In 2006 the Healthcare Commission reviewed children's hospital services in 14 Yorkshire Trusts. (Appendix nine) Only one service in Yorkshire, Sheffield Children's Hospital, was graded as excellent whilst two were graded as good. Ten Trusts were graded as only fair - identifying significant areas requiring improvement; and one was graded as weak. Whilst in-patient care was largely rated as good or better, there were consistent messages about the need to improve emergency care, elective and emergency surgery, day care and outpatient services for children and families.

4.10.1 The most complex and largest children's hospital service in Yorkshire, in Leeds was only graded as 'fair'. It is recognised that ad hoc development in Leeds of children's services on both major sites led to inefficient high-risk services often in inappropriate environments. Facilities for children and families are lacking and patient experience can be poor. An external review (Leeds Review 1995), an internal feasibility study (2003) and an economy supported successful Strategic Outline Case (2004) all recognised the urgent requirement to centralise all major children's specialised services onto one site. Despite some limited investment, the major issues of clinical risk, inefficient services and poor patient experience for particularly vulnerable patient groups remain unresolved. These may be addressed by an emerging proposal to centralise in-patient and specialist services onto one site.

4.11 The hospital is not always the answer

Children could receive much more care closer to home if we had services that met their needs. Too often the default position is to refer children to hospital because of deficiencies in local services, due to lack of perceived or real expertise. There are numerous examples of steps within all pathways where some care could be delivered closer to home if the expertise was greater and if there was appropriate investment in trained staff

4.11.1 Community Nursing Teams

Currently there is variation in children's community nursing teams across Yorkshire to deliver care at home. Rotherham however does have a comprehensive children's community nursing service offering a full 24-hour service every day. In Leeds there is an 8 – 5 service Monday – Friday with a more limited service at weekends or out of normal hours. Other areas have more limited services.

4.11.2 Urgent care

We have already seen that many families access hospital services for their children through A&E for urgent care in preference to more locally based community services. Improving access and expertise, in settings closer to home would provide an improved service. This would require a team of primary care clinicians, including GPs trained in assessing and managing acutely ill children, and children's community nurses, who are able to offer very early follow up at home or close to home for ill children for whom in-patient care has been deemed unnecessary.

4.11.3 Long term conditions

Yorkshire has the highest rates of acute asthma admissions for children in the country and much of childhood asthma care is still carried out in hospital outpatient departments. (Appendix ten) This could undoubtedly be reduced if there was greater integration between secondary and primary care and by specialist nursing support in the community. And enhanced further by all children being registered with a GP who had demonstrable training and expertise in children's healthcare.

4.11.4 The same applies to the significant number of children who have long-term, complex or disabling conditions. It is clear that many GPs defer to hospital services for all or most aspects of care and this is often supported by the actions of parents and carers who often seek hospital advice or admission for most eventualities. This however comes at a cost to families of disruption, increased travel, loss of education for children and income for parents. Increased demonstrable expertise in primary care could only help maintain normality for these families and is more likely to be successful if there is greater integration of primary with secondary care.

4.12 The Need for More and Better Specialised Care:

Sub-specialisation v local services -Many childhood conditions are rare and require complex care in order to achieve best outcomes. This has led towards greater sub-specialisation¹ and the need to achieve a critical mass if outcomes are to be

¹ 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

maximised. This has to be balanced against public and political expectation to have local service provision and the needs of children and families to be able to continue with normal life at home. For children who have conditions that require specialist or tertiary care there are similar opportunities for some care to be carried out much closer to home. Many of these young people have to travel to a tertiary centre for care. Improving networks of care, developing protocols, maintaining education for secondary paediatricians, community nurses and other local professionals should enable more care to be delivered closer to home, either in local DGHs, at school or at home.

4.12.1 Managed Clinical Networks

Recent NICE guidance for childhood cancer, epilepsy and renal disease (as examples) all propose service models whereby children receive the most highly technical care in specialised centres and the less technical aspects of care in settings close to home. These all require care to be carefully integrated, and outcomes monitored, through clinical networks.

4.12.2 Increasing complexity

Children with chronic and life threatening conditions often need more than one specialised service; many of these services are interdependent. To be effective these services have to be integrated. It has been demonstrated that clinical outcome is improved if specialised and integrated multidisciplinary teams provide services.

Developing effective networks is the key to ensuring that children and their families can access the right treatment in the right place at the right time. Networks can also help to break down barriers between primary, secondary and tertiary care and agencies, encouraging greater collaboration, enabling better communication between those caring for children and, ultimately, improving outcomes. (Children's Health, Our Future. DH 2007)

4.13 Yorkshire and the Humber at the cutting edge of medicine – this region has the knowledge, expertise and experience to enable it to be at the cutting edge of health care for children. We need to develop further our ability to deliver the following;

- IT and information systems
- Imaging techniques including PET
- Research and evidence based health services
- Technical developments and new drugs

5.0 Effective Use of Workforce

5.1 Consultant Led Delivery of Care:

Medical workforce changes in junior doctor training; New Deal and the European Working Time Directive are transforming the shape of secondary and tertiary speciality medical staffing towards a consultant delivered service. This will have a major impact in paediatrics where much of the service is high risk, complex and

changed over recent years. Patients and parents expect to be able to access the most specialised care and have internationally comparable outcomes.

acute. In recent years there have been changes to address these issues, including the development of 'Hospital at night' schemes utilising more specialised nursing teams, and moving towards more delivery of care by consultants. These changes are set to accelerate and organisations will have to develop methods whereby most patient care will be provided by consultants including out-of-hours cover. This raises issues for Colleges and Deaneries about how junior doctors will receive adequate training in the future but new methods will have to be found.

5.2 Specialisation:

Throughout medicine, technical advances, the growth of knowledge, patient expectation, and increased accountability through governance, audit and litigation has resulted in clinicians concentrating their expertise into smaller, more specialised areas. This specialisation has led to a reduction in clinicians with generalist skills and the development of larger clinical teams with complementary skills working collaboratively. Similarly it is perceived that pressures towards more specialised expertise in nursing and allied health professionals is also impacting on the shape of services.

- 5.2.1 The paediatric workforce is no different to any other speciality in this regard. A speciality once dominated by clinicians with generalist skills, and unified by them having expertise in the assessment and management of children and families, has become increasingly specialist in all areas.
- 5.2.2 Only a few years ago most secondary paediatricians contributed to care of the neonate requiring high-dependency care. This has now changed in many DGHs so that neonatal care is largely provided by a minority of consultants who have had specialised training.
- 5.2.3 Secondary care of children with diabetes, cystic fibrosis, joint disease, epilepsy and disabilities has all become more specialised. In most DGHs just one or two consultants lead in each disease area.
- 5.2.4 There has been a major growth of nurses and other health professionals who have specialised skills and knowledge and who work with specialised teams e.g diabetes nurses, dieticians specialising in obesity.
- 5.2.5 The recent growth of evidence based psychological treatments (Cognitive Behavioural Therapies, parent training, family therapy as examples) requires a significant additional trained workforce. There are limited training programmes and far too few staff with the necessary skills.
- 5.2.6 In tertiary care there has been a major growth in sub-specialisation. Paediatric neurologists now sub-specialise into areas such as epilepsy, muscle disorders and complex disability. Paediatric surgeons specialise in urology, oncology and thoracic surgery. There are similar pressures in some surgical sub-specialities that have historically been provided by those who work with adults and children. Surgeons who work with both adults and children largely provide neurosurgery for children. There is now increasing pressure to develop paediatric neurosurgery as a separate sub-speciality (Ref). Paediatric orthopaedics and cardiac surgery have already partially travelled this route.
- 5.2.7 These changes create pressures on workforce and service configuration. In both secondary and tertiary care the direction of these pressures is towards having smaller numbers of larger centres where expertise can be concentrated.

- 5.2.8 Commissioners will have to look closely at how to combine local care with access to appropriate expertise. New models of care will have to evolve to achieve this. In secondary care this will almost inevitably mean a reduction in the number of 24-hour comprehensive services but a marked increase in more local clinics, outreach and home care.
- 5.2.9 In tertiary care there will have to be concentration of the highly technical, interdependent elements of specialised services, such as neurosurgery or oncology, onto fewer sites but an increase of specialised clinics and outreach care closer to, or at home.

5.3 Primary care workforce

- General practice and primary care is not immune from these pressures. Community paediatric nursing and school nursing have now separated from general community/district nursing. A significant proportion of Health Visiting practice focuses on children, and their training reflects this. The same has not happened to anywhere near the same extent in provision of general practice medical services. There have been a few examples of GPs with defined special interests in children's medical issues but these are very unusual. There are no agreed standards or qualifications in children's healthcare for GPs and training in paediatrics is not mandatory.
- 5.3.1 There is a demand for GPs to have advanced skills in assessing and communicating with children and families. In focus groups families report identifying which GPs they think are 'better' with children and using them preferentially. There is no obviously consistent way that families can currently make this choice. There is evidence (see section - above) of marked variation in how often GPs currently refer children to secondary care services. Similarly there are marked variations between comparable practices, of families who vote with their feet in order to access expertise for their children via hospital A&E departments.
- 5.3.2 More than 30 years ago in 1976, 'Fit for the Future' (also called the Court Report) proposed that a cohort of GPs should receive additional training in children's healthcare and become GP Paediatricians. GP Paediatricians would address the variation in care, improve the expertise available to children and families, and improve outcomes. That particular proposal did not succeed but the arguments remain about the need to improve expertise and outcomes, as evidenced in this report. For the past 30 years, a number of children's primary care roles have evolved to try and fill the gap identified within the Court Report as being within the remit of general practice. These include community paediatricians, community children's nurses and school nursing. Whilst these have brought benefits, this has not been systematic and has not addressed the population need. The current system has meant that the needs of children do not receive the necessary attention from primary care and resulted in the unpredictable variation evidenced in this report.
- 5.3.3 Other countries have evolved different systems of primary care for children. The USA and a number of European countries have systems of primary care paediatricians that operate largely independently from adult or more general care. Other countries such as Australia have general practice systems more akin to the UK but with more consistent paediatric training requirements. Other systems such as those in parts of New York or in Kaiser Permanente have systems that integrate general practice with immediately available expertise in children's healthcare.
- 5.3.4 The challenge is to develop a system and workforce that reflects and incorporates the best of the UK GP system with the best from elsewhere, to serve the needs of

children and families by improving quality, and addressing variation and inequalities in care. Any improved system of primary care for children must be built around an appropriately skilled, multidisciplinary, integrated, team approach. There is need for strong clinical leadership within these teams and no group would be better placed to provide this than GPs.

- 5.3.5 There are approximately 3000 paediatricians (of all sorts - secondary, community and specialist) in the UK but over 30,000 General Practitioners. That is approximately 1 paediatrician to every 4–5000 children but 1 GP to every 400 - 500 children. If paediatricians were to expand to provide all of children's primary care, there would have to be at least a doubling and probably a trebling of numbers. In contrast, if GPs would take on the leadership role and adapt their practice in order to provide more appropriate and expert children's primary care services then this could evolve with little need to increase the numbers of GPs. This would require a large change in how GPs work and are trained.
- 5.3.6 This report proposes that one option for achieving this would be the development of Children's GPs, doctors trained in the broad-stream of General Practice but with particular expertise in the primary care of children. They will work alongside other GPs in providing a complete range of primary care medical services and alongside other children's professionals in leading and providing an integrated primary and secondary care service to children. These CGPs would also be in an excellent position to work alongside secondary paediatricians in a more integrated manner. Children's GPs will also work closely with those in education, social care and the youth justice system to ensure comprehensive care in line with the 'Every Child Matters'.
- 5.3.7 The other children's professionals in primary health-care include health visitors, school nurses, children's community nurses and a range of allied health professionals including dietitians, speech and language therapists, mental health professionals, occupational and physiotherapists.
- 5.3.8 Thought will have to be given to the workforce implications of providing more care for children in community settings and at home. This will require comprehensive 24/7 children's community nursing teams in all areas, available as recommended in the Children's NSF. There will be opportunities to provide primary health-care services in nurseries, children's centres and schools.

6.0 What Works Well and What Doesn't Work Well

This section firstly gives a summary of what parents consider works well and what they would want to see change in healthcare. It then goes on to give a list of exemplars from Yorkshire of good practice that maybe beneficial to those developing services.

6.1 Focus Group

The views of parents were drawn from a focus group, all of whom had had recent contact with the NHS and in some cases prolonged contact with NHS.

- 6.1.1 Parents commented on General Practitioners more than any other service, which is not surprising when set in the context of most 0 to 5 year olds will see their GP 4 to 5 times a year. The messages about primary care and general practitioners was mixed, ranging from some very positive comments with parents reporting that

some GP's provide excellent care, supported by excellent interpersonal skills to the opposite.

- 6.1.2 Secondary care was reported as overall good. A parent of a 16 year old in receipt of CAMHs services commented

'They have been brilliant! I mean the support is just unbelievable. You have got a psychiatric nurse on the end of the phone ... it goes straight through to the childrens emergency social worker so you are never on your own...'

6.2 Summary of key themes from focus group

In summary the findings of the focus groups are as follows:

- Wide variation in the interpersonal skills of GP's varying from excellent to poor
- Questions over the medical judgement of some GP's in dealing with paediatric illness
- The wait for referral to secondary services too long – particularly for children with urgent problems
- Secondary services and facilities appeared to be mostly good
- Parents appreciate NHS Direct
- Parents appreciate respect and to be listened to but in many instances this doesn't happen.

6.2.1 What parents say they want to change:

- Improve the interpersonal skills of GP's and staff
- Treat patients with more respect
- Improve doctors listening skills
- Someone to follow child though from pregnancy to childhood
- Written information on paediatric services available to parents know who to contact if they need it
- Better referral system
 - Phone call to check patient condition before hospital appointment
 - Give patient estimated length of waiting time for hospital appointment
 - Rapid response in an emergency
- Help line for children with mental health problems
- GP's who specialise in childrens medicine (experts who like children)
- Longer GP opening hours

6.3 Exemplars of Good Practice

The following are some of the examples of good practice that has come to the attention of the Clinical Pathway Group during the course of this work. We know they represent a very small number in terms of good practice in the region.

Rotherham Complex Health Needs Team 0-19 years

Community based, nurse led team who provide services to Children and Young People suffering from a long term condition, life threatening illness or complex health need. The Team comprises of community children's nurses, respite nurses/carers, special school nurses, education nurse advisor and discharge facilitator. The Team works in partnership with children and their families utilising specialist knowledge, providing expertise and care in a variety of settings to suit the child's day to day life. The Team helps facilitate early hospital discharge, preventing hospital admission and providing hospital at home services for children requiring long term ventilation. In 2006 1462 visits/interventions were as an alternative to hospital and 797 as an alternative to GP.

Specialist respite services are provided in and out of the home and recently via extended schools, which are able to quickly respond to increased need during crisis or end of life. These health respite services are one of only a few in the country.

Team involvement is usually from recognition/diagnosis throughout the child's journey and where required throughout bereavement. The Team offers rapid response services with 24/7 on call support for those with a palliative/end of life need with over twice the national average children being supported to die at home. Packages of care are provided out of the borough for children who would otherwise need to be maintained in a PICU.

The Team is committed to real choice, voice and influence ensuring equity for those children.

Children's acute assessment unit in York

The Children's Assessment Unit in York was opened in 1995 in response to a need to rationalise inpatient bed provision due to recommendations for nurse staffing levels; to respond to an increase in referrals of acute admissions with large swings in acute activity and a move from inpatient to day care surgery. There were two adjacent paediatrics wards of 25 beds; one became the Children's Assessment Unit (CAU) open from 0800 to 2100 and the other a 30 bed ward. An audit of the first year's activity¹ showed that despite an increase in emergency admissions of 8.4%, the number of children admitted as an emergency overnight was reduced by 3% in paediatrics and 7.2% in surgery. Midnight occupancy fell 17.7% in paediatrics and 25.4% in surgery. There was a cost saving in nurse staffing costs.

Further progress has been made. The CAU and paediatric ward (now 25 beds) work as a unit with seamless transfer of patients and nursing staff rotating and working closely with a Community Nursing Team. There is a Consultant of the Week on call system with a 2 ward rounds per day on the ward and CAU. There is an urgent outpatient facility whereby GPs can refer directly to a consultant for same day opinions on the CAU. This service is highly valued by families and GPs.

Children's Nurse Practitioner clinic in Surestart /Children's Centre in Grimsby

Since June 2000 there has been a children's nurse practitioner (CNP) working in a Surestart Children's Centre in Grimsby. The service aimed to reduce delays for children and parents when trying to access assessment of childhood illnesses and accidents and ensuring children were given appropriate advice to be seen in hospital or for treatment to be given and care delivered at home after a treatment and management plan has been made in conjunction with the child's carers.

The majority of childhood illnesses and minor injuries can be dealt with by the CNP and has resulted in reduced A&E attendances and/or hospital admissions. For those children presenting with conditions that need further assessment the CNP can refer directly to medical colleagues and other health professionals and a pathway is in place which supports this.

The CNP in the Surestart/Children's Centre setting provides a service developed around the needs of children and their families, and facilitates ease of local access for families living within one of the most deprived areas of Grimsby. User reviews of the service demonstrate the service is consistently highly valued and well regarded.

Health Visiting for the Most Vulnerable Children in Wakefield

The Health Visiting service delivered within Wakefield District PCT captures the philosophy of progressive universalism, strategically focussed on evidence-based practice and targeted at the community and individuals health need. The health visiting teams comprise of a skill mix appropriate to deliver outcome focussed interventions. Utilising the Child Health Promotion Programme as the core / universal offer, whilst additional intervention and therapeutic work is delivered on a needs led basis; ensuring those with more need and /or risk receive greater input from the service. In reality this means that Health Visitors are able to work with the most disadvantaged and those families with complex needs, utilising skill mix for routine client contact. On evaluation of the modern service, clients, staff and GP's experiences were positive, and the service is now achieving in relation to utilising greater skills and resource within families most in need, whilst maintaining a quality service to the universal client group.

Born in Bradford

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

As well as closely monitoring the progress of about 10,000 babies born at Bradford Royal Infirmary in 2007/8 until they are 16, 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 is the first of its kind in the world to research the impact of ethnicity on later development.

They will piece together a picture of each child by examining such factors, 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 was carried out on 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, doctors were reported to only talk to parents and not the young person, they felt that they were a condition rather than a person and their need for independence was often over ridden by others' anxieties about them, and overwhelmingly young people stated that they did not have sufficient information in a form that they could understand. Some young people also reported 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, develop coping strategies and just 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.

Educational Mentor: Teenage and Young Adult Cancer Service. Leeds

Following a focus group about improving services, held in Leeds with young people with cancer and their families, education support during treatment came through consistently as a deficiency in the service. In response to this a local charity funded a first learning mentor post in September 2004. The learning mentor provided essential educational support by acting as a bridge between young people undergoing complex treatment for cancer / other serious disorders and their teachers and colleagues at their usual school. This brought benefits of reduced anxiety and continued involvement in education for these young people. There continue to be many positive outcomes as measured by quantitative evaluations and educational progression, as well as qualitative reports from patients, families and places of education.

This has led to additional new posts being developed for young people with acquired brain injury, jointly funded by a charity and Education Leeds."

Specialist Obstetrics and Paediatrics Services Network; W, N and E Yorkshire.

Before 2002, specialist service patient pathway development had been rudimentary and whilst many of the services had informal arrangements with DGHs including outreach clinics, this was patchy and dependent on clinician interest rather than on a planned basis. The recognition that strategies for specialist children's (and obstetric services) had developed in a disjointed way led to the establishment in 2003 of the Specialist Obstetrics and Paediatrics Steering Group (SOAPS). This group linked providers and commissioners in developing networks for specialist care and taking an overview of these developments. Networks were established linking specialist centre in Leeds and Hull with DGHs for paediatric rheumatology, neurology, and paediatric surgery in addition to nationally driven programmes for neonatal and paediatric intensive care. The SOAPS work programme developed to include oncology, foetal medicine, and cardiac services.

Benefits included more children being treated according to agreed local and national guidelines. More children receiving treatment closer to home with specialist input. Region-wide audits of NICE guidance. Guidance developed for carrying out children's surgery and anaesthesia in DGHs. Less infants and children transferred out of region for intensive care.

Importantly this mechanism included clinical leaders for each area who were able to connect to service commissioners through the Chair (a PCT Chief Executive). This enabled constructive and realistic conversations to take place and encouraged agreed outcomes.

SPEECH AND LANGUAGE THERAPY SERVICES FOR CHILDREN IN AIREDALE

The Speech and Language Therapy Service for children in Airedale NHS Trust was struggling with

increased referral rates, increased waiting times, increased caseload size, services not effective, lack of equity, de-motivated team

In 2001, we discovered the “**Care Aims**” approach to clinical decision making and caseload management (Kate Malcomess). This proved to be a turning point for us.

The model has provided us with a robust tool for clinical decision making, enabling us to:

- apply clear and transparent criteria for decisions about type and level of Speech and Language Therapy support for children with speech, language and communication needs
- use resources equitably and effectively
- actively manage caseloads
- focus on the “risk” i.e. the impact of the problem on the child, family and environment

The model clarifies professional duty of care at pre-referral, referral, assessment, intervention, discharge and post-discharge. It enables clinicians to think about the WHY of intervention, to be clear that they can make a difference in reducing the risk and to be outcome-focussed. The benefits to our service provision have been indisputable, for children, their families and for the team because:-

- referrers are referring the risk NOT the problem
- clinicians are clear about WHY they are intervening
- rationale for clinical decisions is clear to stakeholders
- equity re: level and type of support offered
- reduced waiting times for initial assessment i.e. 8-12 weeks
- meaningful dialogue with partners i.e. health professionals, education and social services.

We are now planning to apply the model to occupational therapy, physiotherapy, nutrition and dietetics and mobility services for children and to use the SLT experience to help us.

For more information, visit the Care Aims website: www.careaims.com

Jean Racktoo Paediatric Therapies Service Manager Airedale NHS Trust

Conclusion

In conclusion we have identified elements of good practice throughout Yorkshire and we are impressed by the commitment and dedication of healthcare professionals who work with children and young people. This is in the face of data that demonstrates that Yorkshire and the Humber have some of the worst measurable outcomes. The evidence demonstrates that there is unpredictable variability in the experience and outcomes for children and young people living in Yorkshire and the Humber who need to use health services. Addressing this requires systematic change in all aspects of healthcare with a major focus on primary care and preventative services. Healthcare needs to be linked with other elements of children's care provision in a coordinated cross organizational approach to be effective. Our recommendations are intended to promote systematic change in order to offer the best outcomes for children and demonstrate that every child matters to those delivering and commissioning health care.

8.0 Recommendations

1. **Primary Care for children is the major theme affecting all pathways.** Quality and access is patchy and unequal with parents and professionals of the view that this is the area that needs most radical change. In particular, levels of expertise in children and their conditions is unpredictably variable and often inadequate leading to high rates of A and E attendance and admission, poor patient experience and expectations, increased hospital outpatient attendance, worse in areas of deprivation. Our view is that this unpredictable variability is inherent within our current system of primary care and needs radical change.

PRIMARY CARE TEAMS – The main recommendation is to develop 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.

There is a need to reduce the unpredictable variation seen in primary care by improving the expertise available to children and their families. This requires that quality of service, ease of access and inequalities are all addressed in order to provide a world class, responsive service. Our work recognises that areas with high levels of deprivation and poorer outcomes will require greater investment. Commissioners and providers need to consider how to adapt the workforce to deliver the services that deliver improved outcomes. Part of this should be to develop expert roles such as Advanced Practitioners with expertise in children.

A very strong theme throughout our work has been the variation in GP expertise, availability and provision under the current system.

Our Group’s initial preferred solution was to develop the role of Children’s GPs. (appendix 11). We think that a proportion of General Practitioners should have extensive and demonstrable, training and competence in the assessment, diagnosis and management of children and young people within their family context and spend all or most of their time undertaking this work. We envisaged that CGPs would work alongside other GPs in large family practices.

Our feedback during the consultation phase has varied. We have had many comments supporting the proposal and in particular recognising that children and families should be able to access GPs with a recognised standard of training and evidence of competence in this area, with the aim of improving patient experience and outcomes. Others have commented that implementing such a radical change in our current GP provision is too challenging, changes the fundamental generic nature of General practice and will result in de-skilling. There was also concern about how this might be achieved in the short term.

The Group has considered alternative proposals. We recognise that there could be other ways of addressing the variation and inequalities. These include

- all GPs maintaining and demonstrating a recognised and explicit standard of practice agreed by appropriate Colleges based on a joint competency framework.
- a smaller cohort of existing GPs developing expertise to act as a ‘beacon’ within practices or groups of practices for the generality of GPs, with a clear aim of raising standards and improving outcomes.
- All practitioners working with children to receive ongoing training to develop their clinical expertise to promote expansion of roles.

There may well be other proposals. Our concern is that any proposal should meet the tests of improving expertise, improving outcomes and allowing each child and their family the explicit choice of seeing a GP with appropriate and agreed training and competence who is working within a properly constituted children’s multi-disciplinary team.

2. PREVENTION AND EARLY IDENTIFICATION:

Risk Assessment Tool to be developed for every child starting from known pregnancy onset through birth, infancy, pre-school, school and into teenage years. Key risk identifiers would include maternal age; parental smoking, maternal mental health, alcohol or drug use; history of high risk sibling; consanguinity; place of residence; prematurity / low birth weight; serious congenital anomaly; repeated acute admissions; poor attachment, evidence of neglect; long-term medical condition; emotional and behavioural disturbance; poor growth or development; repeated school absence; drug or alcohol use. This should not be confused with common assessment which occurs at the point of concern.

Focusing the work of midwives, health visitors, school nurses and GPs on children, young people and families identified as being at high risk of adverse outcomes. This should include parent education on prevention and reducing the risks of ill health e.g bed sharing, recognising ill health, self care and how to access appropriate health services. An exemplar is the existing Family Nurse Partnership programme

This work needs to be the subject of rigorous academic evaluation as it develops to ensure that it is addressing relevant outcomes.

Improving Access and information

There should be a single 3-figure urgent care telephone number for expert advice and explicit signposting (we like 456).
The group considered how to inform and educate parents about key health messages and suggest a TV Health Channel be explored.

3. ASSESSMENT, DIAGNOSIS, AND REFERRAL PATHWAYS

There is a need to have clarity about urgent care provision for children. New models should include GP collaborative, 8 till late services, urgent care assessment and observation centres adjacent to A and E departments. There will need to be robust transfer arrangements to local comprehensive children's service out of normal hours.

Urgent care observation centres will require staffing by trained paediatric staff. Senior trained staff at first contact should see children. There needs to be closer integration of service with closer collaboration between primary and secondary care supported by comprehensive information systems to access health and other relevant records.

4. ACUTE MANAGEMENT /TREATMENT

Workforce challenges will continue to impact on sustainability of some secondary services and specialist services if they are to provide the level of care and expertise required and expected by children and families. Care can be improved by increasing the number of 8 till late sites supported by secondary, tertiary and primary care, day assessment and treatment centres. We will have fewer, larger 24-hour comprehensive secondary units. This is of particular relevance to surgery (of all varieties including acute /emergency service), and anaesthesia.

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. This will require more arrangements where experts in children's surgery and anaesthesia are employed by local DGHs on a sessional basis to undertake suitable work as per the Bradford and Barnsley models.

There is a need to develop expertise and facilities to meet the health needs of teenagers.

5. CHILD AND ADOLESCENT MENTAL HEALTH SERVICES

Further work needs to be undertaken to understand the complexities and variance in CAMHs services. As a minimum the CPG recommend that 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.

Commissioned pathways should demonstrate clarity on access to service at all levels and specifically;

- All staff who come into contact with children in any health, social care or educational setting, should have competency in emotional health and wellbeing, behavioural management and know how to recognise and refer when additional support / intervention is needed.
- Adult and children commissioners should jointly commission services for young people that are age sensitive, incorporate clinical outcomes and facilitate seamless transition to adult services. Formal transition pathways and protocols for young people should be agreed between CAMHs and adult mental health services and commissioned by PCT's. Young people should not fall through gaps.
- There should be targeted CAMHs services for the most vulnerable groups including 'looked after' children, young offenders and children with learning difficulties and disabilities.
- Young people between the ages of 16 to 25 need services and facilities that are age sensitive and this should be taken account of in commissioning plans.
- Specialist mental health services should be commissioned regionally

The workforce strategy for CAMHs should ensure that there are sufficient specialists to deliver psychological and pharmacological therapies.

6. LONG TERM CONDITION MANAGEMENT

There is marked variation and overall poorer outcomes for children with long term or serious conditions than in many other countries. Proposal is that this can be addressed and improved by a framework that links commissioners, providers including clinicians with a robust performance management process that develops evidence based pathways with outcome monitoring and peer review.

There are 2 areas that the CPG propose should be improved in the short term with appropriate support.

- a) Improving outcomes in diabetes by developing a Yorkshire and the Humber wide approach. This would involve clinicians, young people, their parents, with commissioners in a project with clearly defined aims and outcomes of diabetes

management that will include social, psychosocial and educational endpoints in addition to the more generally accepted clinical measures such as HbA1c, acute admissions for ketoacidosis and deaths. The project will link all clinics providing diabetes care in a clinically led network supported by clear guidelines, audit, ongoing expert advice, and a robust information system that will also provide close to real time feedback of outcomes.

- b) 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 'Yorkshire Asthma Summit' to engage those involved with care, examine good practice and develop the scope of the project.

The CPG also strongly supports the recent national recommendations for commissioning and providing children and young people's palliative care. We are also of the view that many of these recommendations can be used to improve outcomes for children with neurodisabilities.

6.1 Transition arrangements

All clinical pathways for children and young people should take into account transition arrangements to ensure a co-ordinated, seamless transition from children and young people's services to adult.

7. Community Nursing Teams

Improving provision of children's community nursing teams. Establishing full teams with 24-hour cover would address many issues re - long term conditions and end of life care but also early discharge and preventative programmes.

Need to pay attention to educational provision by developing system of targeted educational mentors (see good practice example).

8. Dental Health

- 8.1 Primary care dental services need to be developed to better cater for children with significant dental disease within the primary care sector. There also needs to be better integration between primary care and specialised services and referral pathways into the specialised services need to be more clearly defined.

- 8.2 The effective delivery of preventive dental care within primary care dental services needs to be encouraged and supported.

9. Commissioning

There is a need to commission whole pathways of care. Children are not well served by fragmented provision and competitive commissioning. Current system of PbR and PBC leads to gaming and perverse incentives in most areas under discussion. We are 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.

10. 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.

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In addition this pathway has been informed by the knowledge and intelligence available from CPG members

APPENDIX ONE

Clinical Pathway Group for Children

NAME	ORGANISAION	Meetings			
		1st	2nd	3rd	4th
Angela Karck	SCH		x	x	
Angela Lewis	East Riding PCT	x	x		
David Blain					
David Crabbe	Leeds Teaching Hospital				
Dr Chris Ritty	SCH	x		x	
Dr Derek Burke	SCH			x	
Dr Doug Munro	Harrogate FT	x			
Dr Eric Kelly	GP Doncaster	x	x	x	x
Dr John Radford					
Dr Mary Barraclough	Hull and East Yorks FT			x	
Dr Pauline Adiotomre	North Lincs & Goole FT	x		x	x
Dr Rajeev Gupta	Barnsley FT	x		x	
Dr Simon Frazer	Bradford FT			x	x
Dr Rob Smith	York FT			x	x
Dr William Myint	Wakefield PCT	x		x	
Dr Fiona Campbell	Leeds Teaching Hospital	Advisor to group			
Dr Gill Sharpe	Calderdale and Hudd FT	x		x	
Jake Abbas	Public Health Observatory	x		x	
Janet Powell	Calderdale & Hudd FT	x	x	x	x
Jill Hartley	Wakefield PCT	x		x	x
Josephine Johnson	North Yorks PCT	x		x	x
Kath Henderson	Rotherham PCT	x		x	
Matthew Holland					
Mike Miller	Martin House Hospice	x		x	x
Prof David Cottrell	Leeds Uni and MHT	x			
Dr Roly Squires	Leeds Teaching Hospital	x	x	Ad hoc	
Sarah Antemes	Calderdale PCT	x	x	x	x
Sharon Whitfield	Doncaster PCT			x	
Dr Sonia Sharp	Rotherham MBC			x	
Stephen Fayle					x
Steve Jones	SCH			X and ad hoc	x
Joanne Dale	Mid Yorks Trust			x	

PATHWAY TEMPLATE USED FOR 5 PATHWAYS

Pathway Stage	What happens now? Quality; Access; Inequalities	How might it be better? What would it look like?	What would it take? What is needed?	Barriers and enablers	What is the evidence?
How do I stay healthy? PREVENTION					
I have (My child has) a problem. Who do I see, where and when? PRESENTATION					
What is wrong with me / my child? Is this the right place for me? Do I need to go somewhere else for greater expertise? ASSESSMENT; DIAGNOSIS; and REFERRAL PATHWAY					
I need clear information with empathy? Can I get help to make the best choices for me? DISCUSSION ABOUT DIAGNOSIS AND CHOICES					
I want best treatment. How do I know I'm getting it? ACUTE MANAGEMENT / TREATMENT					
How might this situation affect my daily living and that of my family? How can I /my family maintain normality whilst receiving best possible treatment? Might this include treating myself? How can I					

<p>reach my potential? What kinds of choices are there?</p> <p>LONG-TERM CONDITION MANAGEMENT / TREATMENT AND PALLIATIVE CARE</p>					
<p>What choices do we have about end of life care? What support can we receive?</p> <p>END OF LIFE CARE</p>					
<p>Do I need to do anything to prevent becoming ill again? Would I benefit from ongoing assessment / surveillance?</p> <p>OFF TREATMENT SURVEILLANCE / PREVENTION</p>					

APPENDIX THREE

CHILDREN'S PATHWAY TEMPLATE

Pathway Stage	What happens now? Quality; Access; Inequalities	How might it be better? What would it look like?	What would it take? What is needed?	Barriers and enablers	What is the evidence?
<p>How do I stay healthy?</p> <p>PREVENTION</p>	<ul style="list-style-type: none"> ▪ Some targeted intervention work with some children and families at high risk of not achieving ▪ Immunisations – for all but variable uptake ▪ Child Health Surveillance is very variable (HV availability and work patterns) ▪ Accident prevention ▪ Early recognition programmes (meningococcal) ▪ Anti-smoking and alcohol programmes ▪ Healthy eating and exercise ▪ Other preventative programmes 	<ul style="list-style-type: none"> ▪ Identifying each individual baby/child at increased risk of not achieving 5 key outcomes and targeting resources appropriately. ▪ Evidence based risk reduction programme targeted towards babies / children at highest risk at home, school, community in conjunction with DCS. ▪ Health visitors, school nurses working predominantly with high risk children and families. ▪ More early recognition programmes for some common/serious conditions? 	<ul style="list-style-type: none"> ▪ Risk assessment tool for every child starting from known pregnancy onset through birth, infancy, pre-school, school and into teenage years. ▪ Workforce specifically targeted towards highest risk individual families and children during pregnancy, infancy, and school years. ▪ Commissioning targeted towards highest risk groups and areas of deprivation / inequalities. ▪ Integrated information and IT systems. ▪ 24 hour NHS TV channel "The Health Channel" with contacts, numbers and health / healthcare programmes 	<ul style="list-style-type: none"> ▪ Perceptions of 'Nanny State'. ▪ Resource implications uncertain ▪ Complex IT requirements ▪ Directors of Children's Services ▪ Intelligent commissioning 	
<p>I have (My child has) a problem. Who do I see, where and when?</p> <p>PRESENTATION</p>	<ul style="list-style-type: none"> ▪ 'Self' medicate ▪ Ask family / friends ▪ Quite a lot of uncertainty about where to go ▪ Too many points of entry and confusion. ▪ GP /local surgery ▪ Pharmacy ▪ A and E ▪ Out of hours service ▪ NHS Direct ▪ Ambulance ▪ Health visitor ▪ Depends on time of 	<ul style="list-style-type: none"> • Clear information about where to go, when, including out of normal hours ▪ Clear signposting from different start points. ▪ Parents / children have confidence in first point of contact ▪ Competent first assessment by professionals ▪ GPs who can assess children properly ▪ All staff to be competent in children's assessment and 	<ul style="list-style-type: none"> ▪ Single point of well publicised contact for advice i.e. short telephone number / website ▪ Training of professionals likely to be in position of acute assessment ▪ Children's General Practitioners and primary care teams. ▪ Clear referral pathways and algorithms ▪ Increased access to GPs and primary care teams in disadvantaged areas 	<ul style="list-style-type: none"> ▪ Accessing current Out of Hours services ▪ Current GP view of family practitioner dealing with everyone. ▪ Requires change to family practice and individual practitioners developing greater expertise 	<ul style="list-style-type: none"> ▪ Acute admissions to hospital data. ▪ Focus groups ▪ Evidence about presentation by time of day / week and

	<ul style="list-style-type: none"> day/week Depends on where I live 	<ul style="list-style-type: none"> communication Convenient sites for families with child care Reduce inappropriate A and E attendances Out of Hours services to be accessible with competent professionals Reduced unplanned unnecessary admissions Acute assessment units 	<ul style="list-style-type: none"> Out of Hours services for children with acute problems may need differing solutions in urban and rural areas. Urban areas could run alongside or near local A and E but both would require consortia of Children's GPs working together. Publicity /information about what to do Commissioners to request data on contacts /outcomes Commissioning to encourage effective primary contacts 	<ul style="list-style-type: none"> in particular areas of practice. 	<ul style="list-style-type: none"> to where
<p>What is wrong with me / my child? Is this the right place for me? Do I need to go somewhere else for greater expertise?</p> <p>ASSESSMENT; DIAGNOSIS; and REFERRAL PATHWAY</p>	<ul style="list-style-type: none"> Variable +++ depending on where i.e. often not appropriately skilled for acute assessment of children Quite often good Mostly not life threatening so doesn't impact in long term. Some unnecessary admissions Some inappropriate advice If subsequently serious, parents often report unsatisfactory experiences Inappropriate facilities 	<ul style="list-style-type: none"> Trained professionals including GPs working full time or near full time in primary care of children and young people 2 Children's GPs to every 3000 – 4000 children and young people; i.e. minimum practice population size of 15 –20,000. Collaboration between Children's Primary Care Teams for Out of Hours Services. Minimum total population of 70 – 90,000 (14 – 22,000 children and young people). Greater resources in areas of highest need. Acute assessment units with facilities for observation alongside children's A and E services. Much less variability. Assessor can demonstrate 	<ul style="list-style-type: none"> Professionals trained in acute assessment of children Children's General Practitioners and primary care teams Access to appropriate expertise at right time Access to acute assessment facilities More integration between primary and secondary / specialist care. Rapid assessment and clear referral algorithms More rapid access to imaging and other investigations for children. Rapid access to information about each child and young person. Training of all professionals in hospitals having appropriate assessment (and resuscitation) skills for 	<ul style="list-style-type: none"> Current GP view of family practitioner dealing with everyone. Requires change to family practice and individual practitioners developing greater expertise in particular areas of practice. Not all current children's services and sites might be sustainable in future due to workforce constraints. Political and public difficulty with concept of 	<ul style="list-style-type: none"> Variable GP referrals to A and E by practice (Leeds) A and E admission data Events following initial assessment. ? Any info re – what happens to NHS Direct patients and when

		<p>trained competence in children's acute assessment</p> <ul style="list-style-type: none"> Published audit of activity 	<p>children and young people including A and E staff, surgeons.</p> <ul style="list-style-type: none"> Rapid referral and transfer to comprehensive children's service if required. 8 till late services in some existing sites. 	'service loss' / reconfiguration	<ul style="list-style-type: none"> same for other
<p>I need clear information with empathy? Can I get help to make the best choices for me?</p> <p>DISCUSSION ABOUT DIAGNOSIS AND CHOICES</p>	<ul style="list-style-type: none"> Enormous variation in quality of communication reported by focus groups/parents Good and bad Information/Attitude 	<ul style="list-style-type: none"> Parents/carers/children understand information and instructions and have confidence in the information they receive. Professionals have demonstrable training in communication skills required for dealing with children, young people and their families. 	<ul style="list-style-type: none"> All professionals trained for interaction with children and parents 		<ul style="list-style-type: none"> Focus Groups with quotes
<p>I want best treatment. How do I know I'm getting it?</p> <p>ACUTE MANAGEMENT / TREATMENT</p>	<ul style="list-style-type: none"> For acute care - No single care pathway for most conditions across primary and secondary care. Outcomes vary for different families Surgery – problem getting access of paed surgeon in DGH Outcomes for many long term conditions are poorer in UK than elsewhere For CAMHS routine access is slow. Emergency 24/7 access is generally improved but in bigger centres mainly. Paediatric mental health liaison is patchy – poor. 	<ul style="list-style-type: none"> For acute care - Common disease /condition pathways followed through primary and secondary care; more integration between primary care and secondary care professionals; Closer relationship / mentorship between DGH and tertiary centre. All elective surgery and anaesthetics by trained professionals as part of network incorporating specialist children's surgeons /anaesthetists and other professionals Respond to workforce challenges by having fewer larger 24 hour comprehensive 		<ul style="list-style-type: none"> For CAMHS - Small services cannot easily respond to need for specialist skills. 24/7 services. Need specialist services, differentiated across agencies 	

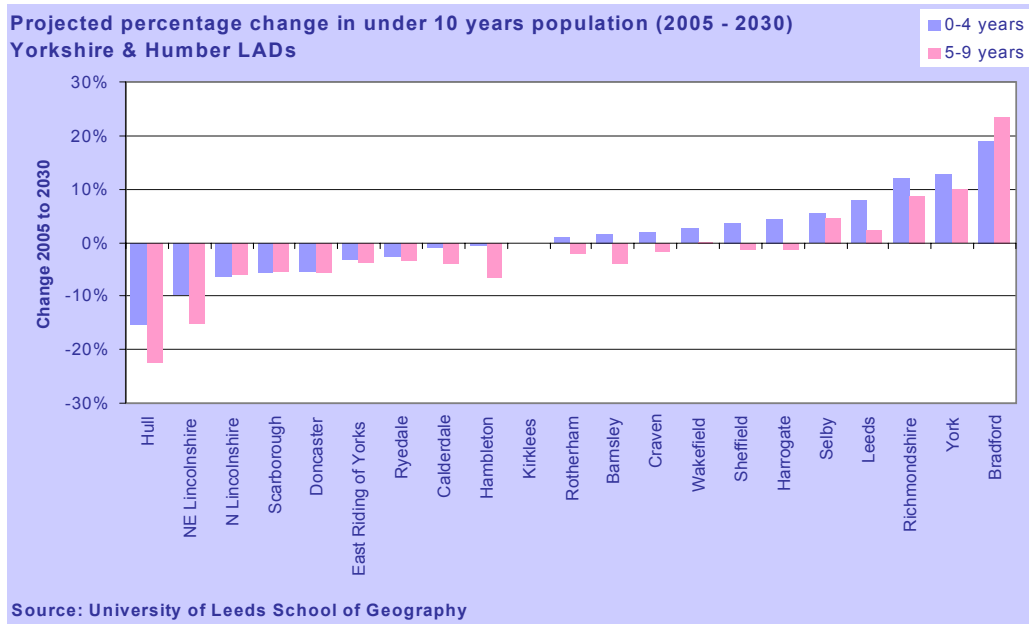
	<p>Access to inpatient beds variable</p>	<p>secondary units but more 8 tillate sites supported by secondary, tertiary and primary care, day assessment and treatment centres.</p> <ul style="list-style-type: none"> • For CAMHS - Rapid access teams; Drop in services; Specialist on call services in all areas; Paediatric mental health liaison; Networks in all areas; Doctors 			
<p>How might this situation affect my daily living and that of my family? How can I /my family maintain normality whilst receiving best possible treatment? Might this include treating myself? How can I reach my potential? What kinds of choices are there?</p> <p>LONG-TERM CONDITION MANAGEMENT / TREATMENT AND PALLIATIVE CARE</p>	<ul style="list-style-type: none"> ▪ Outcomes for many long term conditions are poorer in UK than elsewhere ▪ Many specialist services offer excellent care in centres. ▪ Outcomes are difficult to define in some conditions and therefore difficult to judge service quality. ▪ Some care is evidence based and protocol driven ▪ Some care is network based to try and ensure equitable and expert care 'close to home'. ▪ Variable support close to home dependent on variations in community nursing provision, GP interest, access to therapy, ▪ School attendance variable and links difficult to maintain. ▪ Family support for long 	<ul style="list-style-type: none"> ▪ Self care /expert patient programmes for chronic disease. ▪ Educational mentors to maintain school contact and educational continuity during periods of in-patient care / school absence. ▪ Planned transitional care programmes for teenagers and young adults with long-term conditions 			

	<p>term conditions is variable</p> <ul style="list-style-type: none"> ▪ Very few self-care or expert patient programmes ▪ Patchy transitional care programmes 				
<p>What choices do we have about end of life care? What support can we receive?</p> <p>END OF LIFE CARE</p>	<ul style="list-style-type: none"> ▪ Immensely variable 	<ul style="list-style-type: none"> ▪ Families and children to be given choices about place of care based on clear information about future options and informed by knowledge. ▪ 24/7 availability of support at home from Children's Community Nursing Team. ▪ It is important to have advanced planning using clear Care Plans to ensure that services react in a seamless fashion. ▪ Links to palliative care expertise through a regional Network. 			
<p>Do I need to do anything to prevent becoming ill again? Would I benefit from ongoing assessment / surveillance?</p> <p>OFF TREATMENT SURVEILLANCE / PREVENTION</p>					

CHILDREN IN YORKSHIRE; POPULATION CHANGE FROM 2005-2030

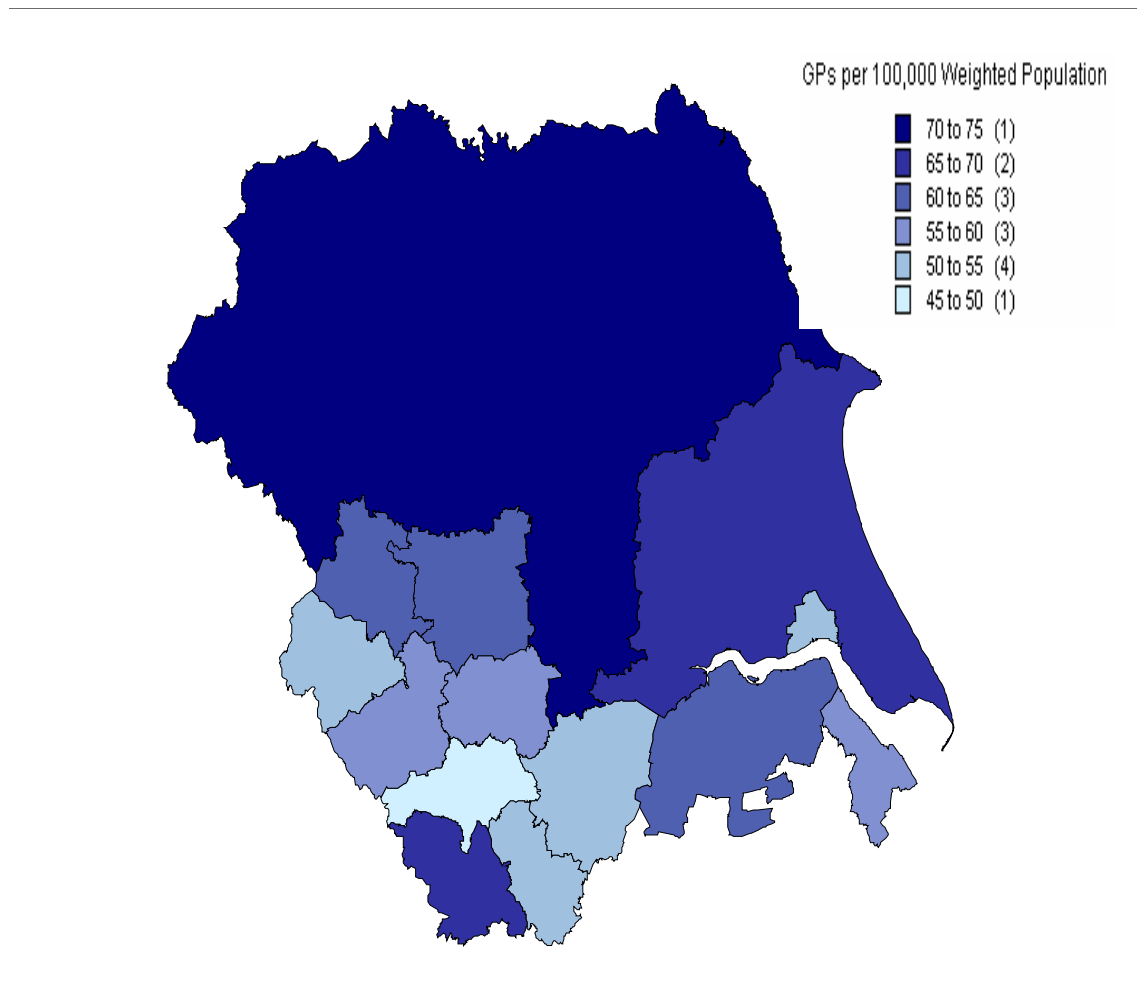


Population change
Wide local variations in pop growth for under 10s (LAs)



Source: Yorkshire and Humber Public Health Observatory

Appendix five
Yorkshire and the Humber showing distribution of GP's per 100,000 weighted population



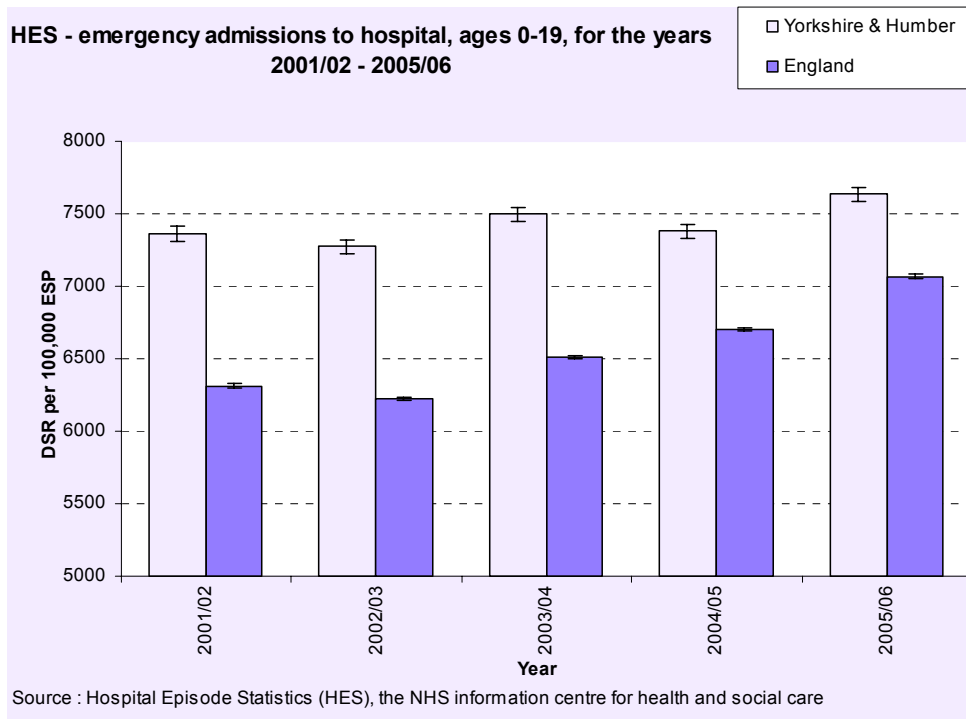


FIGURE: Chart showing increasing rates in emergency admissions for children in Y&H (and nationally)

Source: Yorkshire and Humber Public Health Observatory

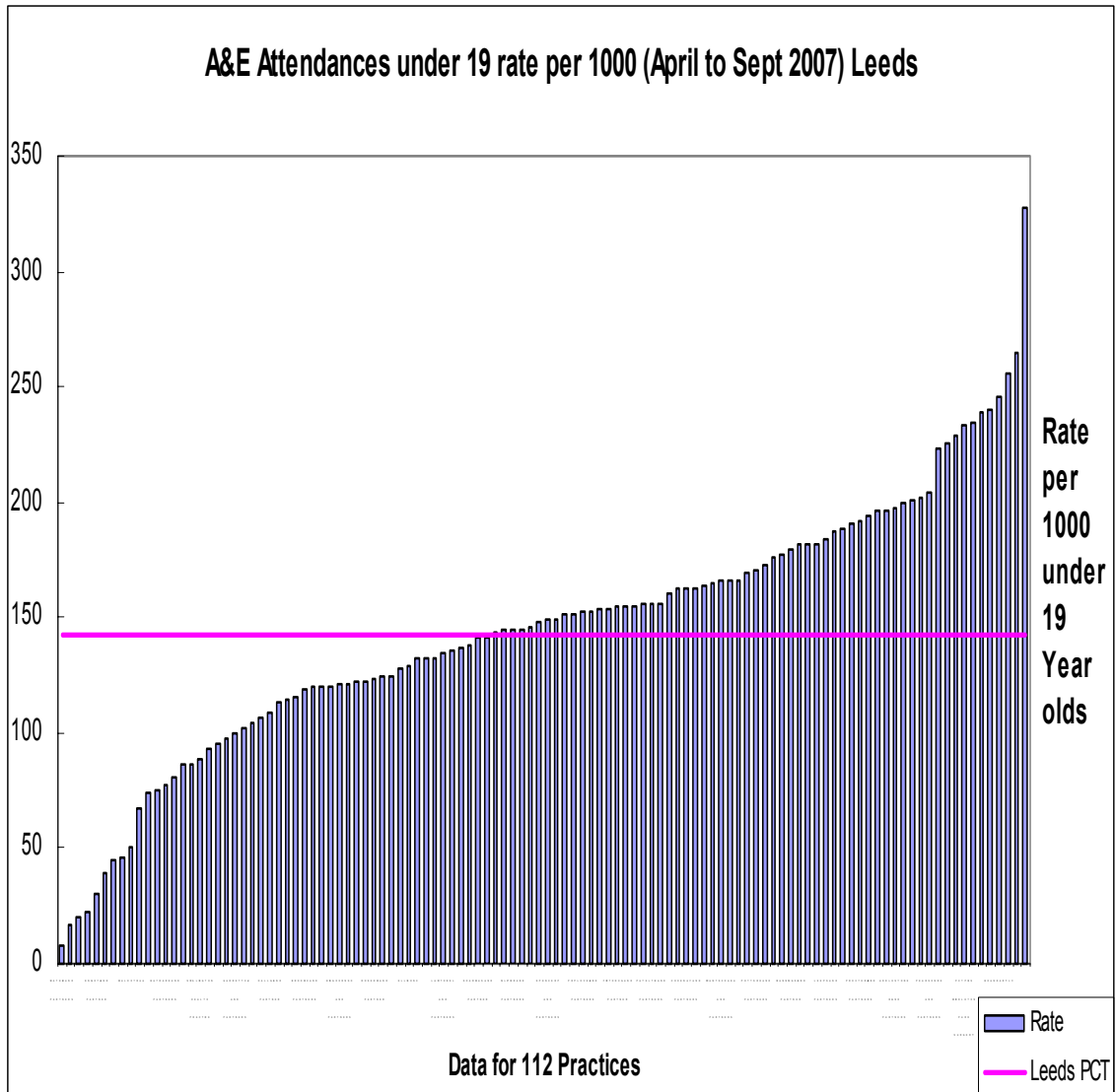
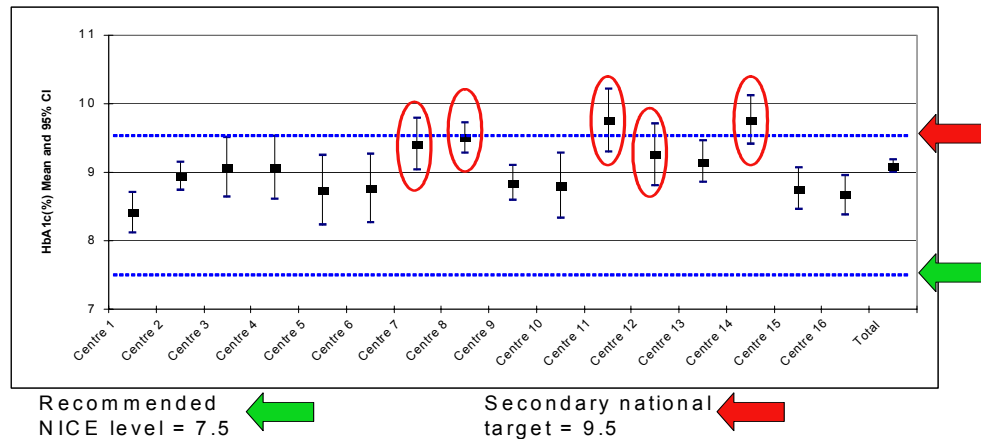


FIGURE: Chart showing variation in A and E attendances by practice of registration for 6 month period in Leeds. Source personal communication Leeds PCT

Appendix seven

FIGURE –Diabetes Control in 16 Paediatric Clinics in Yorkshire

Mean HbA1c & 95% confidence intervals by Centre
West, North, and East Yorkshire 2006-7
Diabetic control in children varies by clinic.



1. – Numbers vary between 60 and 229 patients per centre
2. - In West, North and East Yorkshire there were 1742 children aged 0-18 with all types diabetes. Scaled up for all Y&H from a total population base of 3.8 million gives an estimated total of 2338 children with diabetes.
3. - Examined HbA1c levels by age at diagnosis, duration of diabetes, sex, deprivation, size of centre. There is significantly poorer control in deprived areas. Living in the most deprived areas compared to the most affluent translates into an increase in mean HbA1c of 0.5%. However, even if one trust took all patients from the most deprived areas it would only shift the mean HbA1c level by 0.5% - possibly within the measurement limits!

Source: Professor Trish McKinney, Leeds University

Appendix nine

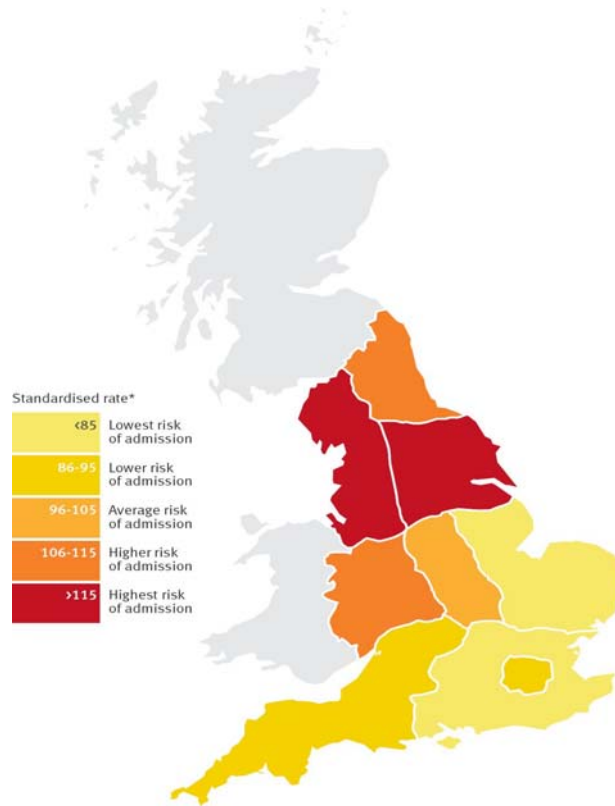
Summary of Healthcare Commission - Review of Hospital Services for Children
Scores for Yorkshire and the Humber

Provider Service	Overall Score	Emergency care setting	Day Case care setting	In Patient care	Out Patient Setting	Emergency Surgery	Elective Surgery
Airedale	2	2	3	3	2	2	2
Barnsley	2	2	3	4	1	2	2
Bradford	3	3	4	3	2	2	2
Calderdale and Huddersfield	2	2	2	4	2	2	2
Doncaster + Bassetlaw	2	2	3	3	1	2	2
Harrogate	2	2	2	4	2	2	2
Hull and East Yorks	2	3	1	3	1	2	4
Leeds	2	1	2	3	2	2	3
Mid Yorks	2	1	1	3	1	2	2
North Lincs and Goole	2	1	2	4	2	2	2
Rotherham	3	4	3	3	2	2	2
Scarborough	1	1	1	1	1	2	2
Sheffield Childrens	4	4	4	3	4	2	4
York	2	2	1	3	2	2	3

4 = Excellent
3 = Good
2 = Fair
1 = Weak

Source: Healthcare Commission

FIGURE – Yorkshire has the highest admission rates for asthma in England



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

*The Asthma Divide
Asthma UK May 2007*

Appendix 11: Original proposal re Children's GPs

We think this offers an unprecedented opportunity for some GPs to be leaders in the field of children's care. They will be trained and committed to working in an integrated system with 'secondary' care, specialist care and other children's focused agencies. They will collaborate in delivering acute services and services to children and young people with long-term conditions, including those with mental health issues or requiring end of life care. They will have knowledge, skills and behaviours to lead and support a primary care team in the delivery of preventative services working alongside social care and education. The primary care team would work in an integrated manner with secondary services. This will work best in a system where a full range of services is integrated around the needs of each child and family.

It is proposed that there should be an average of 2 FTE Children's GPs to every 3000 – 4000 children and young people; i.e. minimum practice population size of 15 – 20,000. This ratio should increase in areas of higher deprivation, perhaps 2 FTE Children's GPs to every 2000 children and young people. Children's GPs would need to collaborate together to provide out of hours or urgent care services. We think that a children's collaborative could serve a total population of 80 – 100,000 (16 – 24,000 children and young people).