UNIVERSITY OF
NEWCASTLE UPON TYNE

HEALTHACTION
TYNE & WEAR

Child Health Information Development

Developing child health information for Tyne and Wear Service Providers

Interim Report and Recommendations February 2002

Executive Summary

- Information on the health of local children is considered by service planners and providers to be incomplete, inaccessible, and of little utility.
- A development project, funded by Tyne & Wear HAZ is exploring this issue by focusing on six exemplar topics, chosen to cover a range of issues.
- Birthweight, teenage smoking, severe injury, cerebral palsy, teenage pregnancy, and the health of looked after children across Tyne & Wear were the subject of separate reports.
- These reports formed the basis for a variety of consultation exercises with child health professionals and public service planners.
- The conclusions from this process are that:
    - Child growth data where available are almost uninterpretable. The minimum requirement is comparison to relevant growth charts.
    - We know very little of our children's exposure to important health risks. There is an urgent need for continuous representative risk monitoring by local sample survey.
    - Analysis of non-fatal injury frequency using the government's indicator is seriously misleading. As with other acute health events a minimum severity case definition is essential for analysis of health records.
    - The participation of children with cerebral palsy is hardly recognised as a legitimate health outcome. All children with severe chronic disability should be accurately ascertained and their participation established.
    - Relatively good information is available on teenage pregnancy. However we know little of the longer-term outcome for children who conceive when under 16 years of age.
    - The health of looked after children – a second highly vulnerable minority – is almost undocumented. Some means may be necessary to follow the health careers of these small groups of vulnerable children (approximately 2%).
- There are other important yet under-exploited sources of local child health data, such as the perinatal mortality/fetal abnormality/children's cancer registries, and the child health system records on immunisation and screening coverage.
- Project work is now focused on:
    - Methods to improve access to and utility of two exemplar datasets
    - The feasibility of an Internet based survey instrument for local schoolchildren
    - The detailed exploration of participation and context measures relevant to children with cerebral palsy
- The overall recommendation at this point is that there should be an Observatory of children's health at a regional level, linked to the Public Health Observatory and with a remit to collate existing data, add value by analysis and linkage to evidence for effective interventions, commission new surveillance methods (such as an omnibus or panel questionnaire survey) and conduct R&D on new indicators and data utility.

Table of Contents

Child Health Information in Tyne and Wear - Overview

Concepts

The health of children is of vital interest to a society. These are the raw materials for future civilisation. Maximising the healthy participation of every child citizen and caring for them when well or ill are the common interests for everyone.

There are a few overarching reviews of child health in the UK, but little consensus in these publications as to what indicators of health should be included (refs 1 – 3). The UK Child Health Informatics Consortium (9) has developed a set of 14 key indicators for monitoring the health of children (only 2 or 3 of which are currently available). Different approaches have been taken in other countries (Australian Child Health indicators, European WHO health of youth survey (8), EC CHILD project, US Youth risk behaviour surveillance (7) etc).

The situation in the UK is changing. Public Health Observatories offer an important new opportunity for information development. The impending National Service Framework for Children has revealed a pressing requirement for better data. The Cabinet Office Social Exclusion Unit has identified 'policy action teams' for young people (10) and for information (11). The latter team's PAT18 report led to the creation of the Neighbourhood Statistics Unit at ONS offering an exciting commitment to accessible small area statistics including health.

Measuring the health of children is not straightforward. The single essential attribute of such a measure is that positive change is unequivocally 'healthier'. 'Health' is not usually defined in statistical reviews of health, but the WHO have defined health as *'a complete state of physical, psychological and social well-being and not merely the absence of disease or impairment.'* This definition does not lend itself to easy measurement! Similarly, the EU Child Health Indicator of Life and Development (CHILD) project suggests a guiding principle that '*to monitor children's health and to be able to protect and promote it, the use of medical and negative indicators is not enough. Broad multi-scientific, multi-professional and inter-sectoral aspects on health and well-being should be used, not only indicators of deaths, diseases, disabilities and disasters*.'

It is proposed that there are several pragmatic dimensions of children's health that encompass much of what is understood by this concept.

- Children grow physically and develop psychosocially in a pattern that may be more or less optimal, as judged by comparison to referenced norms. Several such measures exist, such as birthweight, weight and height. The achievement of developmental milestones though measurable is not often monitored at a population level.
- Children can be more or less exposed to a variety of known risks to their health (eg tobacco smoke, poor nutrition, lack of exercise, un-calmed road traffic, unprotected sex, and unwanted pregnancy).

- Children can be protected from a number of dangers to their health by prophylactic immunisation, by pre-clinical screening, and by correction of dietary deficiency (eg pre-conceptual folate). Lack of protection marks an unhealthy society, but not necessarily an unhealthy individual.
- Acute incidents of disease or injury are clearly unhealthy, not least when they carry the threat of death (eg malignancy) or long-term damage (eg head injury).
- Chronic morbidity due to persistent or recurring disease states or permanent disabilities will represent an impediment to healthy living for many individual children (and to their families).
- In addition, there is a need to measure the wider factors that determine children's health (eg educational attainment and family circumstances). Routine statistics are produced at national and local authority level on all children's educational attainments and on those children with special educational needs. The Child Poverty Index, which is available at local authority ward level, gives a small population level measure of family income (12). Local statistics on looked after children and those on child protection registers can indicate groups with specific vulnerability to health problems. Definitional issues make interpretation of some of these statistics problematic (13).

Introduction – ‘How healthy are children in Tyne & Wear?’

If we are to answer this question, then we need to recognise some of the issues that arise when we attempt to obtain local information using some of these pragmatic approaches to children’s health.

- Apart from perinatal mortality, death in childhood is so rare that it can be hardly used as a local indicator of child health in the UK. Increasingly, we are looking to indicators of non-fatal morbidity in childhood, together with indicators of positive health – ie those elements of health beyond illness and disability.
- There appear to be many available indicators of local children’s health but those that are better-developed cover relatively narrow aspects (eg perinatal mortality, congenital malformations, childhood cancer, immunisation and neonatal screening). There are large gaps in population data on the majority of ill health in childhood (eg acute ill health or chronic disability).
- A consultation conference was held amongst Northern & Yorkshire child health professionals with an interest in child health information in 1997. The conclusions from this process were that: -
  - Insofar as there were data available they were considered inaccurate, inaccessible and very difficult to interpret.
  - There is a need for pilot studies to develop better indicators of children’s health.

Utility of Child Health Information

Information on children’s health must have some utility to justify the cost of data collection and interpretation.

The purposes of routine information on the population health of children might be categorized as follows:-

- Monitor the health of the population
- Investigate the causes of good and bad health
- Inform development of services and policies
- Evaluate effectiveness of interventions

Even if accurate and appropriate indicators of child health were available it is not self evident that local continuous data collection is necessary or sufficient to any of these purposes.

Health monitoring

Oversight of population health can be justified as a legitimate requirement for a service with health as its object. Revealing the extent to which the local population (ill) health burden is attributable to different conditions and to known risk factors can focus attention on broad priorities for action. However there are two caveats:-

- The extent of local data collection should be confined to unequivocal indicators of health (or of known risks to health) together with the minimum variables for their accurate interpretation.
- The scale of data collection should be the least required (eg district level health oversight). This may entail samples or occasional census rather than universal monitoring.

These latter samples may occasionally be localities with enhanced continuous data collection such as a regional disease register. Here the issue is whether their findings (say on the incidence or consequences of Cerebral Palsy) can be extrapolated elsewhere.

For the most part the requirement for district level information will mean representative local data collection about a range of child health indicators. It is very questionable whether major public health strategies can be delivered without local oversight of the target outcomes such as smoking prevalence or injury frequency.

Causes of good and bad health

Apart from blackspot identification (acute local clustering of health events) it is difficult to justify routine data collection for this purpose. Most identification of causal factors of good/ poor health at population level require deliberate, circumscribed studies. The main classes of health data, which fit this “blackspot” purpose (ie where the trigger to action is local data dependent), are infectious disease reports, congenital malformation notifications and road traffic collision injuries. There is a popular view that all types of injury should be subject to such surveillance. Unfortunately the evidence is lacking that effective prevention or treatment can be developed in this way. On the contrary continuous analysis of injury (or any other health event) circumstances is probably best reserved for a few very severe examples (eg Confidential Enquiry into Stillbirths and Deaths in Infancy).

Other investigations of the causes of local poor health may use routine data already collected as part of health monitoring (see above) or may require the establishment of new data collection. In particular when looking at behaviour (smoking, alcohol, drugs), cross sectional population surveys will be required. The question then is how ‘routine’ such surveys should be and in particular how often repeated. More elaborate epidemiological studies in relation to cause may also build on routine data but will usually require additional data collection or specific studies.

Development of services and policies

Local planning should entail translation of evidence based good practice into a local context. From a public health point of view this context also includes public services / policies beyond health and may well have a local political dimension. In practise describing the local health burden will be an important element in advocacy for changes.

The health information necessary for local planning is likely to be characterised by:-

- Robust local prevalence/incidence data as the basis of health needs assessment.
- The need for health indicators specific to a service or policy (as outcomes or impact measures)
- Local variations in the susceptibility to or frequency of the target condition, knowledge of which will improve targeting of scarce resources.
- The requirement that the services and policies have an evidence base determining not only that an outcome can be achieved but also how this is done.
- The consequence that indicators of “health” will include process measures of the extent to which the known effective intervention has been actually delivered.

Evaluation of effectiveness

The formal demonstration of effect (even in a field setting) is properly the subject of carefully controlled trials. In some settings (eg cancer care) treatment protocols have been developed to such an extent that virtually all routine clinical management is part of a trial. Some cruder evaluations of local service quality include health outcome monitoring (eg surgeon specific mortality rates) but these can only realistically be conducted at very large scale with careful adjustment for case mix (eg Confidential Enquiry into Perioperative Deaths).

At the local level service evaluation can rarely use population health outcomes when these are subject to so many external influences. Rather the audit cycle is used to conduct a “formative” evaluation using process and impact measures designed to demonstrate the implementation of evidence based practice. Some “summative” measures of patient satisfaction or quality of life may provide important qualitative information in such audits.

The exception is population (rather than individual) health interventions. Incidence of infectious disease (identified by routine monitoring) is vital for population level monitoring of the effectiveness of immunisation eg the recent introduction of Meningitis C vaccine. Likewise, evaluation of traffic calming and other engineering methods to reduce traffic accidents requires population level data on road injuries.

The Utility of Information

In the end the utility of information is best judged by its effective use. To this end information systems themselves should incorporate a systematic audit of their accessibility and use by potential clients. It may well turn out to be more important to have the capacity for short term investigation of specific problems using reliable information tools, than to invest in expensive universal data collection beyond a set of key health indicators. However, without basic reliable information on local prevalence of illness and underlying determinants of health, systematic planning is not possible.

The Child Health Information Project

With the institution of the Tyne & Wear Health Action Zone, the opportunity was taken to develop a study of key indicators of health of children in Tyne & Wear. The objective is to identify gaps in both the range of information available and the processes by which it is made accessible and useful. This Child Health Information Project is funded by the Child Health Core Group of Tyne & Wear HAZ.

Six exemplar issues were chosen, after consultation, to represent different aspects of children's health. For all children: -

- Their growth and development
- Their exposure to known health risks
- Their experience of acute ill health
- The extent of morbidity amongst those with severe long-term health impairments.

In addition, two identifiable groups of health vulnerable children are included: -

- The 1% of girls aged 13-15 years who become pregnant each year
- The 1% of youngsters who, at any one time, are being 'looked after' by Local Authorities

Other aspects of child health were not chosen as exemplars because data sources were too sparse (eg pre school screening coverage, breast feeding) or were already relatively well developed (see page 38).

Exemplar Issues

Within each of the chosen aspects of child health, the actual exemplar chosen was restricted by the need to have at least one relatively accessible, comprehensive dataset, covering children in Tyne & Wear.

For growth and development, the chosen focus was on birthweight, otherwise there are no satisfactory local data to assess children's physical growth (eg height and weight) nor are there any data at all on achieved norms of psychomotor development.

For a common risk to children's health where there are at least some local data, the chosen exemplar was tobacco smoking in secondary schoolchildren. There is some data from similar sources (ie self completion questionnaires) on children's nutrition and other health related behaviours, but there is little doubt that the health risk from smoking is the most easily quantified and serious risk to current and future health of the young people in Tyne & Wear.

Acute ill health events, which lead to emergency hospital care, are what many would describe as 'serious illness' in childhood. One of the commonest reasons for acute admission of local children to hospital, and certainly the most dangerous (ie with the highest fatality risk) is severe unintentional injury. Other common causes of urgent hospitalisation amongst children, such as acute respiratory problems (bronchiolitis, pneumonia, severe asthma) are also important. Hospital Episode records are the chosen source for the severe injuries used in this exemplar, and their analysis illustrates some of the problems which attend any use of hospitalisation data to describe acute morbidity.

To demonstrate the chronic morbidity of children with long-term health impairments, we have used data from a local, long-running survey of children with cerebral palsy. This is the only source of comparable data across Tyne & Wear for any type of disability in childhood. The wider 'disability registers' held by Local Authorities (and by some health agencies) are generally recognised to be incomplete and unstandardised.

For teenage pregnancy, the principal source is the centrally collated, anonymised dataset on conceptions (ie completed pregnancies plus therapeutic abortions) compiled by the Office of National Statistics (ONS). Some local information on relevant services is also collected and published by the National Teenage Pregnancy Unit. Similarly, for looked after children, the principal set of comparable data across Tyne & Wear are the published national returns from local Health and Social Services Departments, as required under the 'Quality Protects' guidance for implementation of the Children Act 1989.

Exemplar Reports

For each exemplar issue a Report was prepared, presenting simple, descriptive analysis of each health indicator by person (age, sex), place (District, rates, Ward maps, social deprivation quintiles), and time (year). Relevant supplementary information was included where available from the same data source (eg teenage pregnancy, looked after children) or, occasionally, where more detail was available in national sample survey sample reports (eg smoking). The objective was not to conduct an exhaustive analysis, but rather to identify obvious deficiencies of content or difficulties in interpretation and to act as stimulus for potential data users to identify their requirements.

Consultation

All six reports are published and have been widely disseminated (the first five as printed reports, the last by e-mail). They are now mounted on the Tyne & Wear Health Action Zone web side as pdf documents, to allow free download/printing.

Report Title	**Date**	**Web Address**
Low Birthweight Report	Aug 2001	http://www.haz.co.uk/content/programme/CHI/Low Birthweight Report.pdf
Cerebral Palsy Report	Sep 2000	http://www.haz.co.uk/content/programme/CHI/Cerebral Palsy Report.pdf
Smoking Prevalence Report	Jun 2001	http://www.haz.co.uk/content/programme/CHI/Smoking Report.pdf
Severe Injury Report	Jan 2001	http://www.haz.co.uk/content/programme/CHI/Severe Injury Report.pdf
Teenage Pregnancy Report	Sep 2001	http://www.haz.co.uk/content/programme/CHI/Teenage Pregnancy Report.pdf
Quality Protects Report	Dec 2001	http://www.haz.co.uk/content/programme/CHI/Quality Protects Report.PDF
Consultation Comments Report	Dec 2001	http://www.haz.co.uk/content/programme/CHI/Consultation Comments Report.PDF
Meeting Report	Dec 2001	http://www.haz.co.uk/content/programme/CHI/Meeting Report.pdf
In-depth Report	Dec 2001	http://www.haz.co.uk/content/programme/CHI/In-depth Report.pdf
Interim Report	Feb 2002	http://www.haz.co.uk/content/programme/CHI/Interim report.pdf

We have attempted to get feedback on the report contents and on their implications for future child health information development by several means.

- Early drafts of several reports were modified to take into account advice from topic advisory groups.
- Many recipients of printed reports have responded with individual or group comments (see Consultation Comments report).

- A Tyne & Wear consultation conference was attended by 50 invited participants in September 2001, with a focus on the severe injury, cerebral palsy and low birthweight reports (see Meeting report).
- The Tyne & Wear HAZ task force for Looked After Children conducted a half-day workshop on the Quality Protects report and the proceedings are included in that report.
- Based on the cerebral palsy report, an in-depth consultation exercise has been undertaken using postal and interview questionnaires. This was an attempt to explore with potential data users how they plan and deliver services relevant to children with cerebral palsy (see In-depth report).

Specific lessons from each exemplar

Growth and Development - Low birthweight

Executive Summary from main report

- Birthweight is a key indicator of the health of babies. Perinatal and infant mortality and morbidity are strongly associated with birthweight. Low birthweight also shows a steep social gradient. Improvements in birthweight and reductions of inequalities in birthweight are integral parts of Government health targets (eg SURESTART, and the new inequalities targets).
- Traditionally, birthweight has been used to represent the growth of babies. However, it is really a measure of size at a specific age since conception (gestational age at birth). If length of gestation changes, birthweight will change also. If gestational age (GA) is recorded with birthweight, it is possible to compare the birthweight for gestation to normative growth charts and thereby estimate fetal growth at the time of birth.
- If GA is recorded, it is also possible to see if the duration of pregnancy is changing (either spontaneously or due to obstetric inductions).
- Interventions to increase birthweight may operate by improving intrauterine growth, or by increasing duration of pregnancy.
- There are three potential sources of such data concerning all babies: birth tapes from ONS (based on registration), local child health systems (based on birth notification), and maternity hospital episode system (HES data – based on the obstetric/neonatal minimum dataset).
- Birth tapes do not include GA, maternity HES data are not returned by all hospitals, and local child health systems data are not standardised, aggregated, or accessible.
- Analysis of birthweight in Tyne and Wear over the last 20 years shows that there are wide local variations in the proportion of births that are low birthweight (< 2.5 kg) or very low birthweight (< 1.5 kg). Newcastle has rates of low birthweight that are 15% higher than those in Gateshead – a situation that has developed since the mid-1980s.
- Underlying this, there appears to be a general increase in low birthweight rates across the whole of Tyne and Wear during the 1990s specifically affecting the more disadvantaged social groups, and thereby increasing the social gradient, especially for very low birthweight babies.
- These two factors combined mean that those Local Authority Wards with significantly high rates of low or very low birthweight are concentrated in the socially deprived areas, particularly in Newcastle.
- Analysis at ED level (approximately 200 households) shows that some of this excess can be located to quite small areas distributed across the whole of Tyne and Wear.
- To show the potential for analysis of fetal growth rather than birthweight, data extracted from the child health systems south of the Tyne were used. These results are not definitive – there are numerous unresolved differences from the more accurate birth tape data, also current, rather than birth date location information has to be used.

- Compared to local growth standards generated in the late 1980s, those babies born at term (ie 40 weeks gestation) are generally fully-grown. However, preterm (32-37 week gestation) babies are on average, slightly small for dates.
- When the data are mapped, several Local Authority Wards are seen across Gateshead and South Tyneside where there is poor fetal growth. Again, these Wards are concentrated in socially deprived areas, but now include places where crude birthweight based indicators do not reveal a problem.
- There are also important differences over time, with a gradual decrease in the proportion of slower growing babies between 1980-1990.
- The explanation for the paradox, that fetal growth is improving while low birthweight rates are increasing, appears to be that the proportion of babies born prematurely is increasing, especially in mothers from socially deprived areas.
- It is proposed that future analyses of birthweight should be based on much improved data collection, to include accurate information on GA at birth – preferably collected in both maternity HES and child health data systems.

Commentary

Beyond the primary recommendation that gestational age at delivery is essential to the most basic understanding of weight at birth, several other themes surfaced during consultation about this Report.

- The importance of birth data cannot be overstated. Birthweight, like other measures of growth, is a continuously variable indicator of the physical health of the whole population of children. All children are measured, and these frequent data can be analysed at a very local level.
- Other important variables, however, are needed for the simple interpretation of population data on fetal growth and gestational age at delivery. For instance, it is important to know postcode at birth, mode of delivery, maternal smoking, age and parity.
- The primary feedback loop of birthweight and gestational age records should be to data providers – preferably with immediate added value and quality checks.
- Presentation of data and its interpretation must be suitable for users with a wide range of skills and needs. A glossary of technical terms, such as Townsend quintile, perinatal mortality, statistical significance etc is required.
- Access should be at several levels, from raw data to standard tables and maps.
- An R&D facility is needed to collate and improve Regional data collection, to develop new indicators, to support and train data users, and to add value by interpreted feedback and by reference to the effectiveness literature.

Wider implications

Birthweight is being used here as an exemplar of a whole class of information on children's health. We should also try to identify other high priority indicators of child growth and development. It is astounding that we have so little accessible and useful local routine information on physical growth in childhood. Although babies are frequently weighed during infancy and older children have their height routinely measured at school entry, there is no current collation or interpretation of these statistics at population level. Research studies suggest that the key refinement to these measures for clinical and screening purposes is repeated observations to detect growth velocity. For detection of the population level health of children as represented by their growth, even one accurate measurement of height related to standard norms would be very desirable (at age 8 years, say) Reading, R et al (4).

More sophisticated measures of child development, such as achievement of motor, psychosocial, and language skills are not routinely collected. Although development in this whole organism sense is one of the defining characteristics of healthy childhood, we have no routinely available information about it. This is at least partly due to imprecision in the developmental tests suitable for preschool children, but more particularly to the ethical requirements that universal checking of children's progress is expected to fulfil the stringent criteria for a valid screening test (eg there must be beneficial treatment). However, for the purposes of monitoring the health of the child population (rather than identifying treatable pathology) we should consider sample surveys of the developmental progress of intermittent cohorts of children.

Health risk prevalence – smoking in secondary schoolchildren

Executive Summary from main report

Cigarette smoking is a modern epidemic. Before 1930, very few adults smoked, and they were virtually all men. The consequences of the massive increase in cigarette smoking by both sexes since the 1940s is seen in our current waves of adult cancers, heart and respiratory diseases.

This legal addiction has its origins in childhood and once established is extremely difficult to reverse. Furthermore, passive and active smoking in childhood has immediate effects on children's health due to low birth weight, sudden infant deaths, asthma, meningitis, and ear infections.

This report examines what we know about this threat to our children's health in Tyne and Wear. Information is drawn from local surveys of secondary schoolchildren most often using the Exeter HRBQ survey. Some tables are based on the very small numbers of local respondents in larger, national sample surveys. The results are as follows:

- There is no regular and representative data source by which to accurately compare smoking rates amongst Tyne and Wear children over time or between places.
- National and local surveys show that Northern children smoke 15% more than the national average.
- By age 15, over 30% of children in Newcastle, Sunderland and Gateshead are smokers (either regular or occasional) and this has changed little in recent years.
- In South Tyneside, by contrast, a recent survey has found rates of smoking have fallen by almost 50% since 1995. For North Tyneside there is no smoking survey data.
- Although average smoking rates amongst 11-15 year olds appear to have fallen slightly since 1996 (nationally and locally), this obscures continuous increases in the rate of smoking amongst 12 year olds from 6% (1994) to 11% (2000). This may presage a further expansion in teenage smoking.
- Most teenage smokers acquire the addiction between age 13 and 14 years, and girls smoke 25% more than boys.
- At age 14 years (year 10) most child smokers obtain their cigarettes from shops and report little difficulty in these illegal purchases.
- A significant proportion of cigarette supply is from 'bootleg' sales through mobile shops, ice cream vans, and door sales.
- More than 50% of current teenage smokers want to give up smoking, but most think that they will need nicotine patches or cessation clinic support to achieve this.
- Across Tyne and Wear, 2/3rds of teenagers, whether or not they smoke themselves, live in households where at least one adult smokes.
- In Gateshead (the only District to conduct a fully representative survey) there are wide variations in smoking prevalence rates according to the Local Authority Ward of residence.

In summary, there is rapid and widely sanctioned addiction of Tyne and Wear children to tobacco between the ages of 12 and 15 years. We have only intermittent information on this, the most likely killer of our future adults. Illegal sales of cigarettes are commonplace, and only a small proportion of schoolchildren live in houses where adults do not smoke. There are worrying signs that there may be yet further growth in smoking in the next generation of teenagers, as well as local pockets with very high smoking prevalence rates in childhood.

Commentary

There was one major theme that ran through the consultation responses respecting smoking – the need for a locally agreed and properly resourced regular survey of children's smoking.

The survey method chosen should ideally: -

- Be comparable to ONS methods
- Provide school level data at regular (eg biannual) intervals
- Be population representative and allow disaggregation at other geographies than school (eg by social deprivation, Primary Care Trust, Ward)
- Cover the full age range of smoking acquisition (ie also top primary school years)
- Preferably capture longitudinal data for individuals
- Be managed jointly across a large enough area to provide comparative analysis (as shown for the first time in this Report).

The survey method might also allow some local (eg school) tailored questions to be introduced to temporarily examine the specifics of, for example, local cigarette sales and school staff attitudes.

Wider implications

Teenage smoking is here being used as an exemplar of all types of prevalent risks to childhood health. Other important issues of health related behaviour, such as diet, exercise, substance abuse etc, are currently covered by the same questionnaire used in main analysis (Exeter HRBQ). It may be appropriate here to consider whether these represent all the important health risk information that could be captured, where the priority for collecting such expensive data should lie, and whether there are more efficient data collection methods (eg sampling, electronic data collection). Whatever is decided, it is clear that we are currently ignorant of the true extent to which local children are exposed to a number of known risks to their health. This makes it impossible to plan and monitor primary prevention/health promotion initiatives, or to track important changes in these risk factors.

It might for instance be argued that

- Health ‘risks’ should be extended to include risk of injury (eg how do you travel to school)
- Health related ‘behaviour’ could be expanded to health related ‘environments’ both social and physical
- Measures of the conditions necessary or desirable for healthy child development might be defined and measured (eg independent access to peers and the external environment)
- Better use could be made of school pupil access to Internet sites as a way of delivering, collating and feeding back health-related questionnaire data.
- There are important risks to younger children’s health which can only be ascertained from surveys of parents.
- Some health risk survey data might be captured for 100% (or as representative sample) of children at universal service contacts (eg maternal smoking at delivery, pre school injury risks at routine development checks).

Acute Morbidity - Severe Injury

Executive Summary from main report

Injury is the commonest cause of death in children and young people, at least three times as common as cancer. Between 1979 and 1996, there were 700 injury deaths in young people under 20 years of age in Tyne and Wear (approximately one third of all deaths in this age group). Government Public Health and Road Safety Strategies have targets to reduce both fatal and non-fatal injuries. However, we have no clear picture of the true frequency of injuries on which to base our efforts.

This Report illustrates how routine hospital admission data can be used to fill this gap. Two types of 'severe' non-fatal injuries are identified from amongst the 100,000 injury admissions over the last 20 years amongst young people in Tyne and Wear – 16,400 severe fractures and 18,200 'serious' injuries of any type where the length of stay in hospital exceeded 3 days.

The results show that:

- Data quality has greatly improved since 1995 and it is now possible to use hospital admission data to examine details of the causes of injuries.
- Between 1987 and 1990, hospital records were incomplete as coding systems changed.
- Across all three Tyne and Wear Health Authorities, the rate of severe fracture injuries has increased by about 50% over the last 20 years.
- The proportion of these severe fractures, which lead to hospital stays of more than 3 days, has declined from 80% to 30%.
- During the same period, the rate of injuries of any type requiring a hospital stay longer than 3 days has decreased by more than one third (Government's 'serious injury' definition).
- This decline in 'serious injury' admissions is an artefact of reducing length of stay, and does not mean the frequency of injury is falling.
- There is a marked concentration of both severe fractures and 'serious' injuries in young people from socially deprived areas in all Districts.
- Severe fracture rates are nearly twice as high in boys as girls, with an increasing difference as they get older.
- Severe fracture rates are highest (about 1% each year) amongst boys aged 10-14 from the most socially deprived areas.
- There appears to be a particular concentration of severe fractures in South Tyneside.
- The only obvious excess cause of these injuries is 'falls from skating and skateboarding'.

- These differences between Districts are not present in the ‘serious injury’ (> 3 days LOS) analysis.
- Amongst children > 4 years of age, the commonest injury leading to hospital stay greater than 3 days is a fracture, followed by open wounds (boys) and poisoning (girls).
- For children < 5 years of age, fractures are the second commonest cause of such prolonged hospital stays after burns.

Injuries from blunt trauma, leading to severe fractures among young people are increasing. These are particularly concentrated amongst 10-14 year old boys in socially deprived areas, and there is a largely unexplained excess in South Tyneside. Other types of ‘serious’ injury, which require long hospital stays, are burns (< 5 years), intracranial injuries (5-9 year olds), open wounds (boys > 10 years), and poisoning (girls > 10 years). It is impossible to be certain how the frequency of these other injuries has varied over time or by place, as there have been major changes in the lengths of hospital stays, which may differ between injury types and by place of treatment.

Commentary

There were numerous issues raised during the consultation exercise concerning injury. These fall into several themes.

- There was a general desire for more comprehensive and multi-agency based surveillance of injuries. There are at least five separate local agencies holding independent injury records. Surveillance should be coordinated by a central body, with rapid access/turnaround of ‘real time’ data relevant to different constituencies (eg school, PCT ward etc). It was frequently stated that there was ‘no reliable data for planning injury prevention’.
- More details of the circumstances of injury were considered necessary for interpretation of injury data, especially the time (school/leisure), activity and location. There should be cross-disciplinary discussion with practitioners as to their minimum information ‘needs’ and an attempt to specify the tools necessary for short-term in-depth studies.
- There was a strong emphasis on the needs of data providers to integrate those injury data they need - for (1) clinical audit for improved care (2) planning of networked acute services (3) follow up and outcome surveys - with the needs of public health and safety practitioners.
- There were several references to the requirement for a linked evidence base of what works in injury prevention, plus cost benefit studies of different potential approaches. Otherwise, why target injury ‘blackspots’ if we don’t know what to do?
- Exposure data was also raised, both in the sense of (1) how dangerous is this activity/what are the characteristics of safer practice (eg football). For this, we need population or control data on football playing to determine exposure specific risk. (2) How much are children exposed to known hazardous situations which

might be the direct subject of campaigns (eg unrestrained passenger travel in cars, children living in housing with no functional smoking alarms).

- There was a request for information on minor injuries seen in A&E or Primary Care. These are at least ten times as common as inpatient data, and therefore suitable for very local analysis. However, their collection is problematic, and an alternative route to very minor injury data such as by population survey, should also be explored (10% of all children have had injuries causing at least 24 hours discomfort in the previous month).

Wider implications

It is clear from this exercise that Hospital Episode statistics, although the most accurate data on Health Service contacts for acute ill health, are hardly used in this high priority Public Health setting. They are considered inaccessible and difficult to interpret. What is also clear is that extraction of appropriate indicators of child health from HES requires the use of a minimum severity ‘case definition’ to confine attention to those clinically more severe injuries (or other health events) which will always be admitted to hospital. This principle should also be applied to other causes of acute morbidity in childhood (eg acute respiratory and gastro-intestinal illnesses). There is an important research and development agenda to fully exploit these rich data for indicators of the common causes of acute illness in childhood. Often there will be profitable links to other routine data (eg communicable disease reporting, police reports of RTAs) but there is no point in creating new data sources when HES data are so poorly exploited.

Children with Chronic Disability - Cerebral palsy

(This report was the first to be completed and the only one published without an Executive Summary – the following summary will be included in the Web accessible version.)

Executive Summary

Cerebral palsy is one of the commonest causes of physical disability in childhood, with a current local rate of 2.5 per 1000 livebirths. This represents a doubling of the frequency since 1980, largely due to increased survival of vulnerable small babies. Very little is known about the daily lives of these children as they grow up, but the Lifestyle Assessment Questionnaire (LAQ) used in the North of England survey of cerebral palsy (NECCPS) is a potential source of useful data.

- About 30 children are diagnosed with cerebral palsy each year in Tyne and Wear. Data from LAQ were extracted for the 126 children born between 1991 and 1994.
- The LAQ includes questions about children's participation (or handicap) in terms of physical independence, mobility, schooling, social integration etc.
- Analysis of these data demonstrates that the typical pattern amongst local children with cerebral palsy is for problems of physical independence and mobility to seriously interfere with participation. The most obvious consequence of this is the lack of social integration for the child and family.
- There are important variations in the patterns of participation between children, which might indicate areas suitable for intervention. For instance, some families have disproportionately large economic problems.
- There is also a suggestion that the average levels of participation amongst children with cerebral palsy may vary between locations. For instance, Newcastle children with cerebral palsy report greater physical independence and considerably higher levels of social integration.

Commentary

The principal form of consultation undertaken for the cerebral palsy exemplar was a more detailed qualitative study undertaken in Newcastle. This was to explore ways that such information might be made useful or usable by those responsible for the planning and delivery of services relevant to children with cerebral palsy.

- Fourteen families (50%) of Newcastle children born from 1991 – 1994 with cerebral palsy responded to a postal survey.
- Their use of relevant services was related to their participation (LAQ) scores.

- There are several children with very limited participation in terms of economic burden, mobility, physical independence and social integration, who make almost no use of relevant services.
- Managers of 14 local services relevant to children with cerebral palsy were interviewed. They were asked how they planned and monitored their services.
- All of these 14 service managers wanted (but did not have) estimates of the numbers of potential clients and their ‘degree of disability’ in order to plan services. In the absence of these estimates, services rely on referrals or direct requests, but cannot otherwise identify any potential clients with unmet needs.
- Some respondents were very interested in the use of LAQ profiles of clients (eg housing and welfare rights) but the data were not considered sufficiently specific by others (eg Education felt it did not define ‘level of need’, while Transport would prefer to know ‘journey purpose and mode’). The Planning Department preferred information on the ‘disabled population as a whole’ rather than specific categories, while Therapy services saw potential uses of the LAQ profiles, but felt under pressure to ration, rather than expand services.
- Whilst three of the 14 services undertook structured user consultation surveys and eight of the 14 gauged outcomes in terms of individual fulfilment of professionally assessed ‘needs’, there was very little use of any formal evidence base for service effectiveness.
- In respect of organisational policies around disability ‘awareness’, there was general appreciation by Local Authority (but not Health) staff, that physical, social and attitudinal environments matter in promoting participation. On the other hand, there are no structured measures of quality or performance in achieving disability friendliness within services or across whole cities.

Overall, the impression gained is that achieved participation is not an outcome which any service really saw as appropriate or measurable in a way relevant to them.

Further feedback from the consultation meeting in September 2001 and from direct correspondence raised other issues:

- The need for information on associated impairments (eg cognitive and sensory) in those children with complex disabilities.
- The lack of linkage of LAQ profiles/participation to ‘assessed need’ as the driver for service provision.
- The importance of not waiting until clients or providers cannot ‘cope’ as a way of developing services.
- The requirement for the views of children to be identified as distinct from those of their parents.
- The need for a joint Health, Education and Social Services Disability Register.

An overview of this exercise with cerebral palsy as an exemplar of children with disability would suggest that there is an almost complete data vacuum for those wishing to plan services rationally. They have no reliable information on the numbers of potential clients; they have little systematic evidence base of which services are likely to ‘work’;

there is hardly any concept that increased participation (or relief of handicap) might be a generic objective; there is no measurement of service performance in terms of outcomes for clients; services are not so much planned, as adapted to cope with demand. Professional assessment of need is used to filter and prioritise clients, while volume of service/waiting lists is considered sufficient justification for continued or expanded provision. There is a clear wish on the part of managers to move to a more rigorously informed planning model and the current drive is towards integrated disability registers. However, without a clear link to the potential benefits and outcomes from services, an account of the numbers and characteristics of clients will be of doubtful use.

Wider implications

It is salutary to remember that cerebral palsy is just one of a large number of conditions which create long-term chronic morbidity amongst children. It was chosen here because it is virtually the only condition for which there is reliable local documentation. We need to take three important steps to change the situation:

- The major disabling conditions in childhood should all be subject to accurate surveillance, using a clear-cut case definition (eg based on the more severe and readily identifiable cases).
- There should be an agreed minimum dataset created (with parent and child consent) to meet multi-agency requirements and held in a joint register (or linked set of registers) with regular reporting, quality control, and utility audit.
- There must be recognition that participation of children is the final common pathway or objective for all services. A simple self-completion questionnaire about participation levels and important barriers to participation should be established for all registered children and their parents. The chosen questionnaire elements must be linked to relevant service outcomes and to the data required for planning.

Vulnerable Children - Teenage pregnancy

Executive Summary from main report

In Tyne and Wear, there are about 1200 teenage pregnancies (conceptions amongst girls under 18 years) each year. This represents a rate double that across the rest of the country, and at least ten times that in the Netherlands. In some parts of Tyne and Wear, virtually no 15-17 year old girls become pregnant, but in several socially deprived Wards, more than 12% of 15-17 year olds are pregnant each year. In secondary schools in these Wards, one-third of all girls will become pregnant at least once before they leave school.

It has been argued that primary prevention of pregnancy for teenagers is not a major public health priority and that the focus should be on social and educational support for these vulnerable mothers. However, pregnancies before the age of 18 are unplanned in at least three-quarters of cases. One third of these conceptions result in therapeutic abortion. For those pregnancies that are completed, the mothers are much more often supported by their parents than by their partners, their education usually ceases, and 40% of them will experience clinical depression in the first year. Furthermore, their babies will suffer even poorer health outcomes than those of older mothers in similarly socially deprived circumstances.

About one-quarter of these pregnancies (250 each year in Tyne and Wear) are amongst girls under the age of 16 years. These are children having abortions or bearing their own children. The scale of morbidity represented by these figures is important, and is now subject to intense central and local public sector activity.

From an information perspective, teenage pregnancy is a positive exemplar. Not only are there accurate and confidential data concerning conceptions, births and abortions, but also most Local Education and Health Authorities have invested in regular (albeit unrepresentative) self-completion questionnaire surveys in secondary schools that yield important information on relevant risk factors and attitudes amongst young people. Furthermore, there are standardised data available from the National Teenage Pregnancy Unit on the availability of local contraceptive/family planning services, and their accessibility to young people.

Nevertheless, the conception rate amongst women under 18 years of age has not noticeably fallen, and there are significant information gaps. We have no reliable data source on contraception use, and we know almost nothing about the fathers of these pregnancies. Information on services is not clearly linked to an evidence base of what works in avoiding unwanted pregnancy, and we have little systematic data on the local health outcomes of this vulnerable group of teenage mothers and their babies.

Commentary

This is one of the last two reports to be published. As noted, teenage pregnancy is a positive exemplar, in that there is a strong information base from which to work. Many of the most important local data come from the Exeter

Health Related Behaviour Questionnaire, used in secondary schools by most local health authorities. The need to expand and establish this (or a similar) survey method in a representative and more accessible form across all local districts was rehearsed in the commentary on the teenage smoking report (see above).

Vulnerable Children - Quality protects

Executive Summary from main report

‘Looked after children’ is a term that was introduced by the Children’s Act 1989 to describe children who are in public care. In 1998, the ‘Quality Protects’ programme was introduced to set mandatory national objectives for services for children and young people in the looked after sector. Amongst these objectives was Objective 4 ‘To ensure that children looked after gain maximum life chance benefits from educational opportunities, health care and social care’ and this included a sub-Objective 4.2 ‘To ensure that children looked after enjoy a standard of health and development as good as all children of the same age living in the same area’.

A number of earlier research studies have shown that children who are looked after away from home have greater levels of health need than their peers, yet are less likely to receive adequate health care. Indeed the House of Commons Health Select Committee in 1998 concluded that *‘the failure of local authorities to secure good health outcomes for the children and young people they look after is a failure of corporate parenting’.*

A number of types of routine data are now published about the implementation of Quality Protects Performance Assessment Framework Indicators are available at http://www.doh.gov.uk/public/stats3.htm.

Using these data, it is clear that, in the Authorities covered by the Tyne & Wear HAZ, the proportions of children in the looked after sector are about 30% higher than the rest of the country. There is some small variation amongst the local authorities within Tyne & Wear, but all of them have relatively high rates, with just under 1% of all people under the age of 18 being looked after at any one time. This includes a large number of children on agreed short-term placements, but also includes about 25% of the children who have been looked after continuously by the Local Authority for more than four years. Thus, there are something approaching 2,000 children in Tyne & Wear who are looked after at any one time, and of these, about 450 have been looked after continuously for more than four years.

Children in the looked after sector move around between placements frequently, with about 20% having three or more placements per year (the government target for this is less than 16%). Mostly, they are placed with foster parents (about 65%) and a further 10-20% in community homes. The reason that many of these children are in care is to do with abuse or neglect, and their numbers increase as children get older, with the largest group now being 10-15 year olds.

Insofar as they are known, the outcomes for these children are relatively poor. For instance, 70% leave full time education with no GCSE or GNVQ equivalents as compared to less than 10% of the general population of young people aged more than 16 years.

With respect to the health outcomes, very little is known, and only four routine indicators are required by central government, ie the percentages of those with complete primary immunisation, those who have had routine dental checks, those who have had an annual health assessment, and those who have had a comprehensive health assessment when they entered the looked after sector.

On these criteria, Authorities in Tyne & Wear show some variation, with between 60 and 90% of children looked after fulfilling the first three of these criteria. This compares to about 95% of children who are in the non-looked after sector, who will have had complete primary immunisation and dental checks.

What is most striking about these data is, first, their sparsity - this is all that is known routinely about the health of this group of children. Second, feedback from a consultation session with a number of local professionals suggests that it is very difficult to generate reliable information about the health of children in the looked after sector for a number of reasons.

- There is not always clear transfer of information from Social Services to Health Authorities concerning the identity of children in the looked after sector to allow their health to be monitored.
- Although we have considerable information about resident children who attend hospital or who have been offered immunisation through Community Child Health services, it is rarely known which of these children are in the looked after sector.
- The records, which are held about all children as they make contact with health services, do not have a unique identifier. Thus linkage to a separate confidential database of looked after children cannot be made.
- The situation is complicated by the fact that this vulnerable group of children is transient and highly mobile; with many children entering, leaving and changing care each year.

To deal with this, most local Health and Social Service departments have set up collaborative arrangements to ensure that there are regular health assessments for these children. Information systems are being developed, based on these individual personal records. Compiling more comprehensive records by linkage to other useful data systems is theoretically possible but unlikely until logistic and ethical issues are clarified.

Commentary

The Quality Protects report represents the opposite picture to that from Teenage Pregnancy. Here is an identifiable group of highly vulnerable children about whom we know all too little. The HAZ task force on looked after children were consulted on the document and had a number of comments:

- To fulfil their corporate responsibilities (in loco parentis) Local Authority Social Services Departments must have, or provide the means, to link looked after children to their medical records.

- One proposal was to use the NHS number on both medical and social services records as an anonymous linkage field. Whatever method is used, this linkage process should be handled with strict confidentiality, at a Regional level.
- Failing this, there is scope to increase the quality and range of PAF (Performance Assessment Framework) indicators (eg specify the age range for dental checks, include smoking prevalence and referrals to drug and alcohol teams).
- There was strong support for the type of presentation achieved in the Quality Protects report, based on existing data. This would be greatly facilitated by a continued Task Team presence (due to disband with the expiry of HAZ) and by ensuring Internet access for all concerned professionals.
- Good practice in individual record keeping and health reviews for looked after children should be shared and agreed across Tyne & Wear.

Wider Implications

Although there is now a general emphasis on whole population indicators of child health rather than identification of “at risk” groups, there is a case to be made for specific surveillance of a small groups of highly vulnerable children. Those children in long-term care and the less than 1% of girls under 16 years who conceive might form such a group. Clinical systems to coordinate and record service contacts will be in place but the information required for health oversight may be derived in other ways. For instance a structured sample might be offered interviews or postal questionnaires to explore a variety of aspects of their health including service contact, health status and quality of life. Alternatively, some confidential arrangement could be made to link all their electronic clinical records using unique identifiers or other matching methods. The object would be to develop representative district level indicators of the health of this minority of children to ensure that their priority is recognised and monitored.

General Themes from the Exemplar Reports

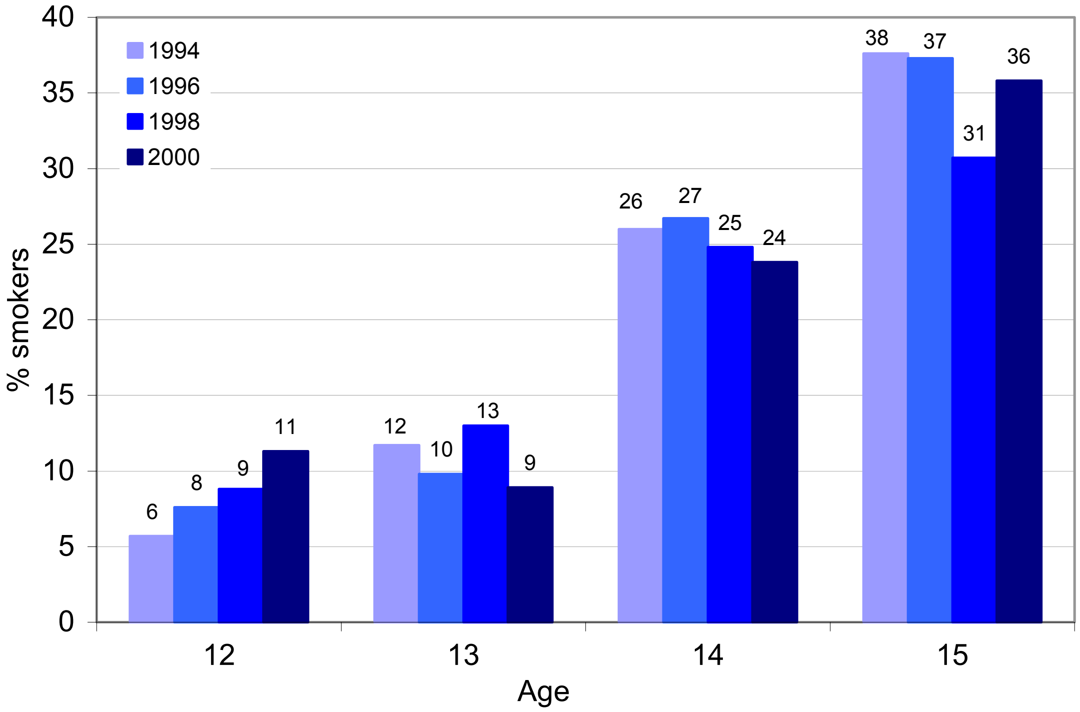
Four major themes emerged from the initial exercise of producing the six exemplar reports. First, even for these relatively well-documented issues, there are still important weaknesses within the original data, and their conventional interpretation. Second, not all children are equal in the requirement for information about their health. There are some identifiable but neglected groups at considerably greater health risk in childhood. A third theme, perhaps not so obvious, is concealed by the very fact that these exemplars were confined to available data – that is, there are important elements of children's health where there is virtually no information. A fourth theme is that existing sources of data about children's health are often underused and poorly coordinated.

Weaknesses in existing data

Amongst the six exemplars, there are instances where child health data are incomplete, misleading and sometimes inappropriate.

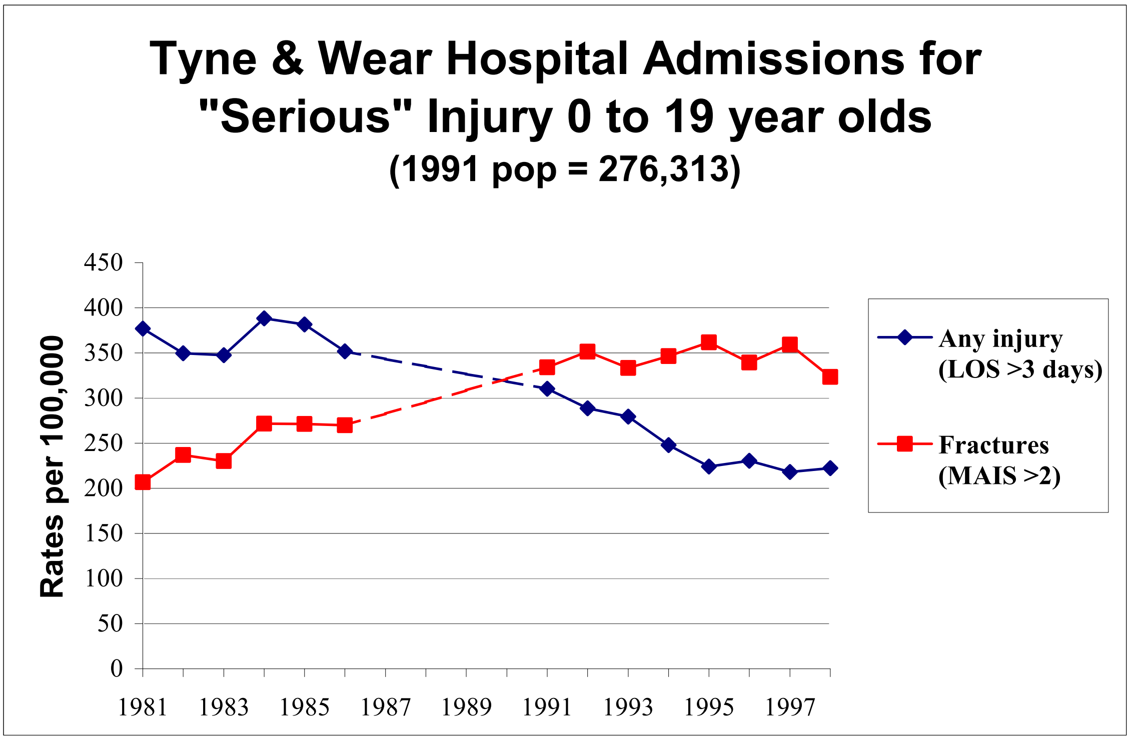
Smoking in young people is a modern addiction which will eventually kill or permanently damage the health of a huge proportion of the next generation. Despite this, our local picture of this pervasive child health risk is seriously incomplete. The most elaborate data in Tyne & Wear (from Sunderland) are derived from biannual self-completion questionnaire surveys of pupils in a stable set of secondary schools. Even these data are not based on structured samples to represent all Sunderland teenagers, but at least important time trends (suggesting an explosive future increase) can be detected (figure 1). Most authorities had less frequent surveys with a changing group of participating schools. On occasion this produced bizarre results; one local authority district had no local survey data at all.

Figure 1 Percentage of regular smokers in Sunderland HRBQ surveys – (note the trend in 12 year olds)



Sometimes there is misleading interpretation of existing data. Threat of injury is the most serious danger to children's present health. Injuries cause three times more deaths than cancer in local young people, but our efforts to contain this are mislead by corrupt statistics. The Government target for injury reduction defines as 'serious' non-fatal injuries those which lead to hospital stays of more than three days. Such injuries are declining in numbers, but serious injury is no less common. On the contrary, using a different case definition based on the subset of severe blunt trauma injuries which inevitably lead to hospital admission, it appears that serious injury is increasing (figure 2), and that there are local 'hotspots' which completely elude the Government indicator.

Figure 2 Changes in Rates of Severe Injury Over Time



Another serious deficiency in our approach to child health information is that we use statistics which are inappropriate as actual health outcomes for children. For most children with long-term disability, the original cause, once identified, is of little consequence. However, our present data on disability are very much focused on counting the numbers of children with particular diseases, injuries or congenital malformations. What really matters, however and without exception, is the extent to which these young people can live and participate. Such 'taking part' is hardly used in medical vocabulary. The WHO have recently adopted the ICIDH2 (now ICF – International Classification of Functioning, Disability and Health - www3.who.int/icf/icftemplate.cfm) to highlight the importance of representing the healthy participation of young people, and also the ways in which their environmental 'context' can inhibit or facilitate this. This is the new currency which must be adopted when attempting to gauge and redress chronic morbidity amongst our children. Our analysis of such data for children with cerebral palsy suggests that there are important local variations in participation (figure 3) as well as identifiable individuals not taking up relevant services (figure 4).

Figure 3 Profile of average participation scores of children with cerebral palsy in Sunderland (n=26) and Newcastle (n=28) – NB “0” equals full participation

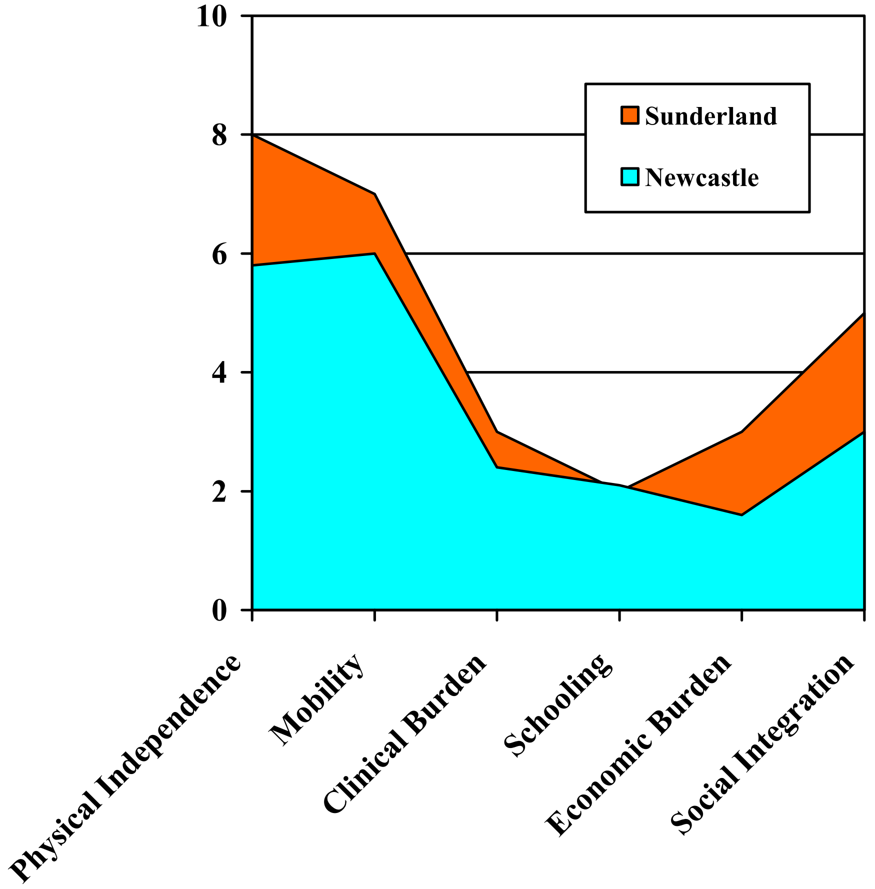
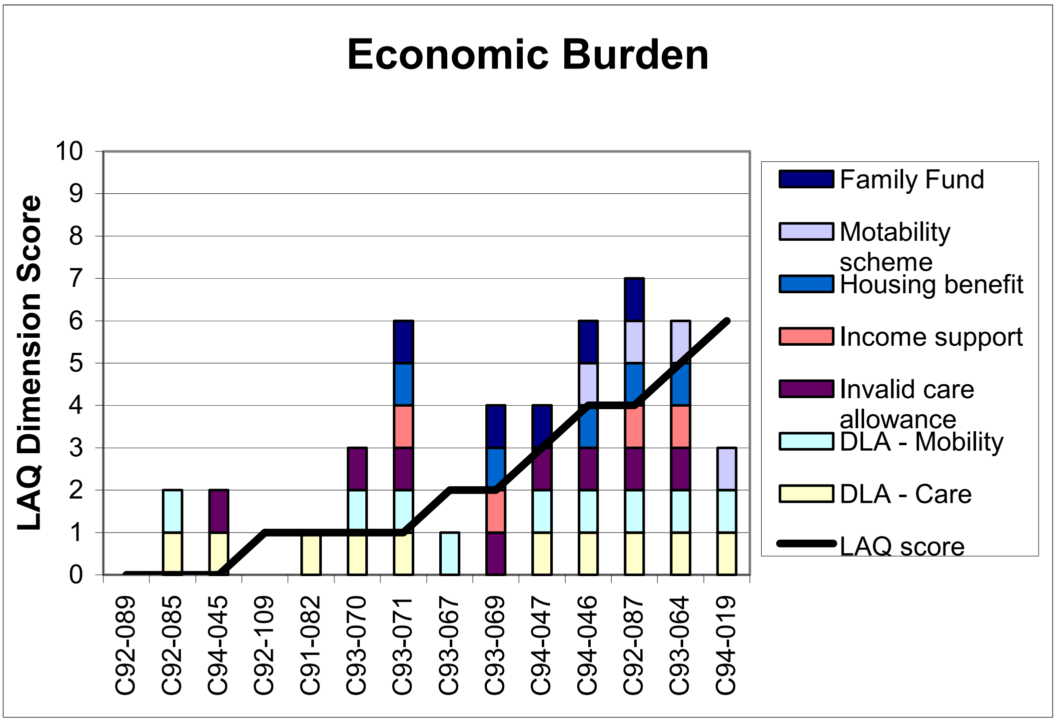


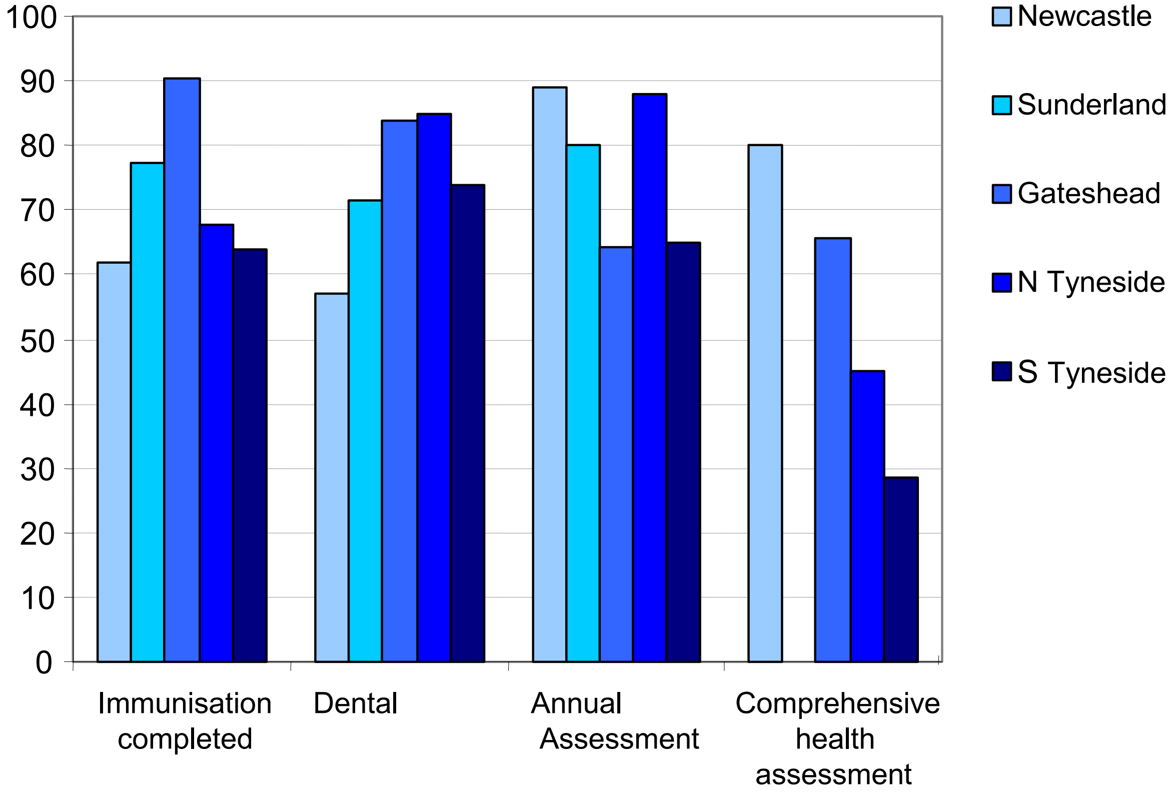
Figure 4 Economic Burden and its Relationship to Service Use (14 individuals in Newcastle)



Those at greatest health risk

Information about the health of our children can be dry stuff. Much of it is the by-product of Health Service activity, and some of it linked directly to monitoring of service performance (eg immunisation coverage data). There is no natural priority to such data. Rather, it appears that the most health vulnerable children are those about whom we know least. Poor health congregates with material deprivation, poor education, family breakdown and social exclusion. Children who are 'looked after', who live in temporary accommodation, who truant from school, who conflict with the law, or who live rough, are at high health risk, but are often detached from formal Health Services. Information about such children's health can only be gained by active, purpose-designed data systems. As well as targeting appropriate services, documenting their health experience is a high priority, and clearly inadequately performed at present. Local Authority, Police and voluntary sectors may know of these children, but there are rarely transparent mechanisms to share such sensitive data with the health sector. It is currently impossible to analyse any routine health data in ways which will separate out these high risk groups. Even for those children 'looked after' by local authorities who are specifically targeted by the central government Quality Protects initiative, there are only very sparse comparative health data available (figure 5).

Figure 5 Health indicators (%) for children looked after in Tyne and Wear 1999 (this is the full set of indicators)



Another identifiable and acutely vulnerable group is teenage girls in socially deprived areas (at high risk of unwanted pregnancy as well as increasingly high rates of tobacco and alcohol abuse). Our data sources about these vulnerable girls and their babies have been much improved recently with accurate local information on conceptions, abortions and contraception services together with some survey data on relevant attitudinal and behavioural patterns. However, we still lack outcome data for the mothers and babies from these pregnancies as well as contraceptive service uptake information.

New thinking is required to allow us to obtain appropriate and useful health information about vulnerable groups of young people. Perhaps we should be directly approaching these children and their carers for the information. Another method might be the creation of sample 'panels' of such children with the means to identify sentinel health events amongst them through confidential linkage of routine health records.

Health not known

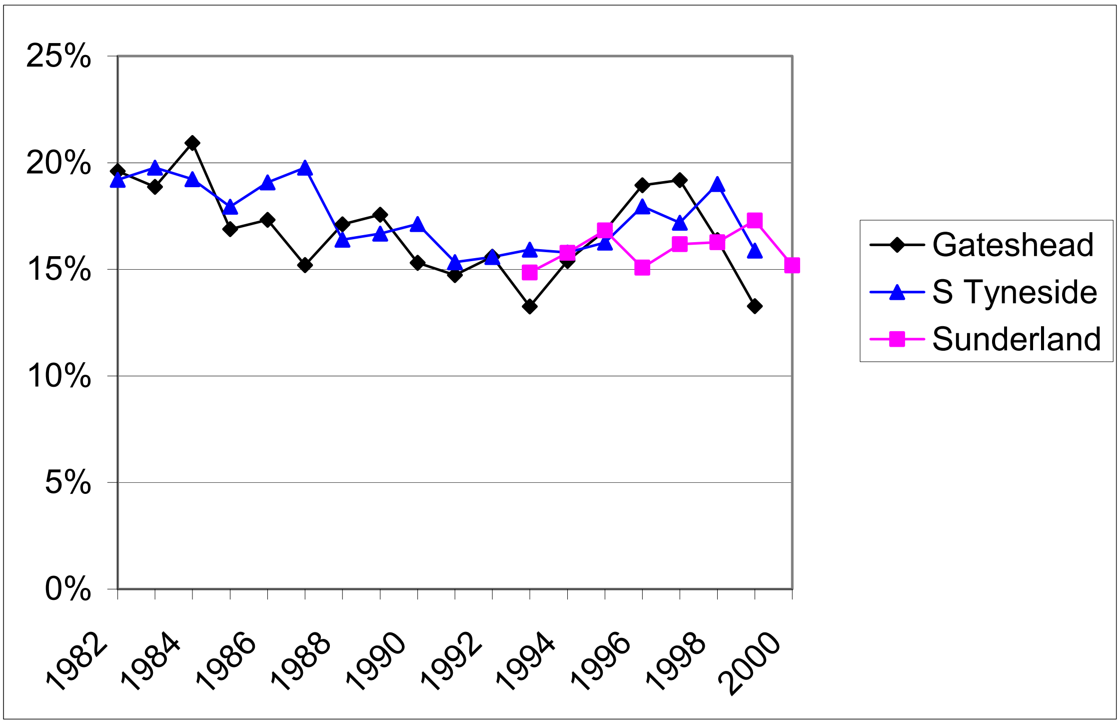
A characteristic in our current child health information systems is the almost complete absence of some whole categories. When trying to compare the health of communities of children over time or between places one overriding conclusion is reached. We know hardly anything about common acute or chronic illness of children. We may be able to find out if they are dead, have cancer, have had measles or whooping cough, were screened for several diseases, or have been immunised, but we know almost nothing about frequency of the commonest conditions leading to acute hospital admission, nor about the extent of chronic disabling health conditions. There is little analysis of hospital (or primary care) contact data to create and extract indicators of acute ill health. For most children with disabilities there is simply no reliable and representative source of information even on who they are. These deficiencies are a disaster for the planning, delivery and evaluation of the bulk of child health services.

A further category of largely absent data about the health of the child population is the extent to which they grow and develop normally or optimally. Exploration of birthweight data reveals that these are uninterpretable without information on gestational age at delivery. Though a component of the minimum data set for maternity hospital data and often recorded in child health systems, population data on gestational age distribution is still virtually unobtainable. Yet this can be the key to understanding recent increases and social differentials in low birthweight rates (figure 6)

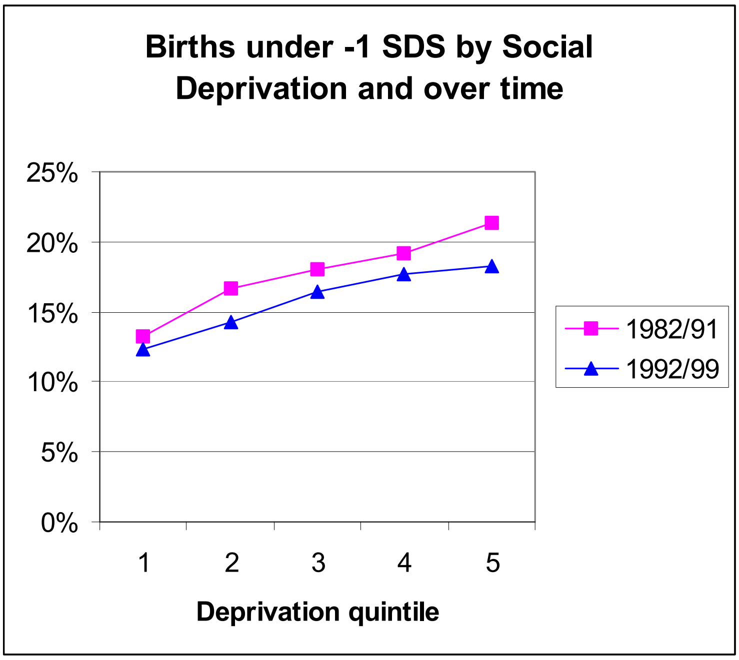
Figure 6 Percentage of live born babies each year with poor fetal growth (< -1 SDS birthweight for gestational age)

(This analysis is only possible in the few districts able to provide GA data)

a) By District



b) By Social Deprivation



Otherwise, we may have some crude data on children's weight and height at older ages to indicate their physical development, but where are the indicators of children's language, motor and psychosocial development? What do we know of the nature and local distribution of the conditions necessary for optimal growth of these highly plastic organisms? At the very least, we should attempt to identify and monitor some indicators of healthy development amongst representative sample cohorts of children. Here, we should be working closely alongside colleagues from education – the other great investment in our future society.

Data Not Coordinated or Interpreted

The six exemplar issues have made use of data from a variety of sources: - **national** birth registrations, Hospital Episode Statistics and the Performance Assessment Framework data for Quality Protects, the **regional** North East Collaborative Cerebral Palsy Survey, **local** Child Health Systems outputs and **school** level Exeter HRBQ surveys. There is presently no repository for such data nor coordinated resource to analyse and present indicators of local children's health derived from them.

There are several existing sources of local child health information which were not used as exemplars because they are already relatively well-developed.

- The Maternity Surveys Office manages regional data from the Perinatal Mortality and Northern Congenital Abnormality Surveys with regular reports on their findings.
- The North East Children's Cancer Registry contains details on all paediatric neoplasms since 1950 and is widely used for research.
- Immunisation coverage data for local children are regularly returned to and published by the Communicable Disease Surveillance Centre (CDSC) in London. However there is little analysis of local data beyond District rates.
- Notifiable infectious diseases (including measles and whooping cough) are reported via local Consultants in Communicable Disease Control to the CDSC and published weekly at District level.
- Population Census data give us detailed accounts of the number and social circumstances of resident children. These are enhanced by updated estimates at District level from the Office of National Statistics (ONS).
- Several other non-health agencies hold data relevant to children's health eg Traffic Accident Data Unit (RTAs), police (Youth Crime and Cautions), education (statements of Special Educational Need, exclusions and school absences), social services (children at risk and disability registers).

These elements of information and the expertise to analyse and disseminate them should be brought together. The techniques of data collection, quality control, statistical manipulation, epidemiological interpretation, user access and publication are common to all elements. There is, in addition, an important and under recognised need for research and development of new indicators across sectoral boundaries.

Synthesis

These deficiencies are symptomatic of deeper problems.

- We do not know about local children's health because we are not interested. It is wrongly assumed that all is well with children, and priority is given to crisis management of Health Service pressures, largely generated by elderly adults.
- Central Government has sufficient information (from large scale sample surveys) to ignore local deficiencies in information. The Health Survey for England (6) and national (sample) surveys of growth, smoking, and nutrition etc, provide valuable material for central oversight, but are useless for local population purposes.
- There is no apparatus for regional health information management or development. There are large neglected and potentially useful datasets concerning local births, deaths, hospital admissions, immunisation, growth and screening. These are poorly maintained, inaccessible, and badly analysed. There is now some recognition that this is a priority issue with the development of Public Health Observatories. From April 2002, the Northern & Yorkshire PHO will take on responsibility for the Northern Congenital Abnormality Survey, the Perinatal Mortality Survey, the North of England Collaborative Cerebral Palsy Survey and the Diabetic Pregnancy Survey amidst concern about long term funding. Other excellent local initiatives such as Injury and Autism Spectrum Disorder registers are still unsupported. Often these registers lead to important advances in management, but there is no funding stream to support them despite commitment to development of 'disease registers' in Our Healthier Nation (5).
- Finally, there is no recognition or capacity within NHSE information authority, DoH, or major research funders of the need for R & D on local child health information. Issues, such as child mental health, have hardly surfaced. Most current indicators of child health other than mortality are unreliable or inappropriate. Crucial issues such as the utility of information in planning and delivering child health related services, are barely touched.
- **For the most part therefore we do not know 'how healthy are children in Tyne and Wear' or if this is changing over time. When this fundamental purpose of data collection about child health is not met we can hardly aspire to understand the local causes of poor child health nor to develop and evaluate better services to tackle them.**

Further work in the Child Health Information Project

1 A pilot project is looking at methodologies for improving access to and facilities for analysis of two existing datasets (HES data on injuries, birthweight data from ONS). **[Lead, Dr Philip Lowe]**

Access to data is part of the key to developing it's utility. Several important and available datasets relevant to children's health are hardly used at a local level. Potential users have very different levels of skill – in the past, the solution to this has been to introduce expert interpretation. However, we now wish to explore methods of dissemination and multi-level access, which allow both naïve and adept users to interact with the raw data. It is this process of direct exploration which could drive better-informed data collection.

An important objective for such rapid access and feedback is to serve the needs of those who generate the original data – data quality is heavily dependent on their interests and perception of added value. Beyond this, there is a wide range of potential users with unpredictable data needs, uncertain access and unknown skills. Increasingly the Internet offers a route to centrally managed datasets, with user-friendly 'front ends', which may meet their needs. A good example of such a website front-end is at http://www.statistics.gov.uk/neighbourhood/home.asp.

It is also apparent that a 'missing link' in the data interpretation sequence is the evidence base of what services, environments and policies are effective in improving child health. We will explore the feasibility of linking raw data access to relevant evidence-based websites.

The scale of available information is also important here. Many health professionals plan and deliver services to relatively small catchment populations of children. Health event and risk data to meet their requirements must reflect frequent events (minor injuries, GP managed infections) or common attributes (eg height, smoking etc). We will examine the logistics of offering data users the facility to define tailored localities for their individual analyses.

2 A feasibility study is being undertaken of an Internet based survey to obtain questionnaire data directly from school-aged children. **[Lead: Neil Hamilton]**

Survey data collected direct from children are a vital but under-developed source of information on children's exposure to health risks (eg smoking, diet, exercise) as well as on their experience of health events and use of health services. These methods are increasingly used for national (7) and cross national (8) child health statistics. Paper questionnaires and remote processing could now be replaced by an on-line Internet questionnaire, with very rapid data aggregation and confidential feedback. Some types of detailed contextual data important to the understanding of health events (eg location and activity at the time of injury) are very unlikely to form part of clinical records, but are easily introduced as conditional questions in a computer-assisted survey instrument. Other types of denominator data to calculate exposure-specific risks (eg the safety of football versus rugby) could be the subjects of appropriate questions to (samples of) the non-injured population. This feasibility study is a collaborative project with Northumberland Education and Health Authorities.

3 An in-depth study continues to explore appropriate methods for describing the circumstances of children with cerebral palsy for service planning and monitoring. In particular, we are examining direct measures of the contextual factors which may determine participation. **[Lead: Brenda Welsh]**

Research and development of new forms of child health information has several urgent tasks to address. We need to generate outcome indicators which accurately represent the 'health product' of a variety of child health related services. For example, there is still no agreement on a valid instrument of the population frequency of non-fatal injury. We cannot claim 'accident' reduction as a national public health priority when we do not know whether injuries are increasing or decreasing.

An issue of immediate importance is to develop valid indicators of participation of children with disabilities and of the 'contexts', physical, social and attitudinal, which facilitate participation in one environment rather than another.

We must also understand better the way these indicators of child health can be fitted into the process of service planning. This type of 'ecological' measure of the extent to which one place is healthier than another may be of more direct relevance to planners of public services important to disabled children (eg transport, education).

4 A further issue for development is the exploration of methods to conduct active surveillance of the health of highly vulnerable groups of children. **[Unfunded]**

There are some relatively small groups of children whose health is at such known risk that high priority should be attached to information about them. These 'vulnerable' children – probably totalling less than 2% of the population – are very likely to escape the attention of mainstream health services. They may be in care, homeless or perhaps vulnerable because of health events, such as teenage pregnancy. We need to consider ways to offer active surveillance of their individual health careers. There is no easy solution to this, but we certainly know too little at present. One characteristic of these vulnerable children is that many different agencies interact with them. A multi-sectoral information system is required, with agreed protocols for data exchange. Possible methods include sample surveys of children and their carers, or unique identifiers to allow confidential linkage to routinely held data.

5 We are partners in a scoping study for the Northern & Yorkshire Public Health Observatory to develop an agenda for future work on child health information. **[Lead: Dr Louise Parker]**

Behind all these strands – the need for improved access to existing data, for new survey instruments, for R&D of novel indicators, and for active health surveillance of some highly vulnerable children – lies the unifying requirement for a single, expert focus. We believe this will need investment in a Child Health Observatory, as part of the Public Health Observatory. This should have the responsibilities for maintaining rolling extracts of routine datasets relevant to children's health, with facilities for research and development, analysis and feedback.

The key characteristics of such an Observatory are: -

- To act as a single route for access to a variety of data sources concerning children's health (including close attention to the health of a defined, vulnerable minority)
- To add value to these data by epidemiological interpretation, by linkage to the relevant effectiveness literature, and by active dissemination through means appropriate to potential users
- To commission (and monitor) new data sources, such as an omnibus interview survey of school-age children's health, health risks and health relevant exposures.
- To conduct research into novel indicators of children's health and the processes by which these can inform improved services.

References

1. Botting B, editor. *The health of our children: a review in the mid-1990's*.Botting B. London: Office of Population Censuses and Surveys (invited chapter), 1996.

2. Woodroffe C, Glickman M, Barker M, Power C. *Children, teenagers and health. The key data*. Buckingham: Open University Press, 1993.

3. Welsh Office. *The health of children in Wales. Panel Chairman: Dr JK Richmond*. Cardiff: Welsh Office, 1997.

4 Reading R, Jarvis S and Openshaw S. (1993) Measurement of Social Inequalities in Health among children in Northumberland. *Arch Dis Child*, **68**, 626.

5 *Saving Lives: Our Healthier Nation.* Department of Health, July 1999.

6 *The Health of Young People 95- 97, Health Survey for England.* Joint Health Surveys Unit, HMSO

7 Kann L et al. *Youth Risk Behavior Surveillance – United States, 1999.* J School Health, 2000; **70**; 271 - 285

8 King A et al. *The Health of Youth – A Cross-National Survey,* WHO Regional Publications, European Series No 69

9 Child Health Informatics Consortium and RCPCH. *Monitoring the Health of Our Nation's Children.* CHIC, May 2000

10 *Report of Policy Action Team 12: Young People*: National Strategy for Neighbourhood Renewal, March 2000.

11 *Report of Policy Action Team 18: Better Information*: National Strategy for Neighbourhood Renewal, April 2000.

12 *Towards a Healthier North East*; Northern and Yorkshire Public Health Observatory, October 2001

13 *Occasional Paper No. 3 - Inequalities in the Health of Children & Young People*; Northern and Yorkshire Public Health Observatory, June 2001