

## Community indicators of child health

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During this century, the pattern of childhood illness in the industrialised countries of Europe and the World has changed dramatically<sup>1</sup>. The infectious diseases endemic and epidemic in nineteenth century Europe and still prevalent in developing countries have been eradicated in most parts of Europe. Mortality rates in childhood have shown a precipitate fall so that in many areas death in childhood is a rare event<sup>2</sup>. Death and acute illness persist particularly in poorer communities<sup>3</sup> but they have declined in relative importance and chronic morbidity and the so-called “new morbidity”<sup>4</sup>, resulting from psychological and emotional disturbances of childhood, now predominate presenting new and different challenges to child health care services. Against this background, it is widely accepted<sup>2</sup> that traditional indicators of child health, perinatal mortality rate (PNMR), infant mortality rate (IMR), post-neonatal mortality rate (PNNMR), under-5 mortality rate (U-5 MR) and 5–14 mortality rate (5–14 MR), inadequately reflect child health differences within and between developed countries and deaths are too infrequent to provide sensitive measures of the effectiveness of different models of service delivery. Collection of these data remains essential for international comparisons for example in the UNICEF publication “The State of the World’s Children”<sup>5</sup>. However, other measures are required which incorporate chronic morbidity and the “new morbidity” and measure health rather than lack of it<sup>6</sup>.

The shift from mortality to morbidity indicators is problematic; mortality is easy to define, though numerator problems can arise particularly in perinatal mortality data, whereas morbidity presents significant problems of definition. Morbidity is as much a measure of lack of health as mortality and there have been recent efforts to develop measures which reflect well-being and health directly<sup>6</sup>. Even greater definitional problems are evident in these measures than for morbidity data.

Accompanying the debate on measures which reflect health directly has been the debate related to who should define health<sup>6</sup>. Health indicators have been medically, or at least professionally, defined in the past. This prerogative is under challenge and the validity of parent/patient defined health has been argued<sup>6</sup>.

This paper will review the need for child health indicators and the characteristics of “good” in-

dicators. Available indicators and possible alternatives will be discussed critically. The paper will conclude with a discussion of potentially valuable indicators of child health in populations, areas of further research and means of encouraging their adoption within European countries.

### Why have indicators?

Indicators are frequently collected mechanically and with minimum thought; inappropriate use and collection of data can mislead rather than enlighten<sup>7</sup>. At best, the collection of data which cannot be interpreted is a waste of time and, at worst, a barrier to service development and change. Routine data collection should be subject to constant review and critical analysis to ensure its relevance to the questions it is aiming to answer. Child health indicators need to be capable of monitoring change and identifying important differences within and between child populations. The health and well-being of children in a population is a broad measure of the overall health experience of the whole population and has been used to characterise the developmental level of specific populations and countries<sup>5</sup>. Equally, comparison can be made over time allowing change to be quantified and causative pathways to be studied<sup>8</sup>. From studies of this kind, an attempt can be made to quantify the relative effects of social and service change on child health. Social paediatricians are committed to a population-based approach to child health moving the focus from the individual child and their illness to the health and well-being of child populations. Indicators are key to this approach.

Without the routine collection of local, national and international data, however imperfect, the international comparisons made in “The State of the World’s Children” would be impossible and the effectiveness of interventions such as immunisation programmes in specific communities could not be evaluated. Routine collection of child mortality data in an industrial country such as the UK has enabled long-term trends to be studied and has contributed to an understanding of the major determinants of health as well as casting light on health inequalities<sup>9</sup>.

The Health For All 2000 programme is founded on reliable data collection. Without reliable data, the

value of such programmes in comparison to curative services is impossible to evaluate.

### Characteristics of “good” indicators

What then are the characteristics of “good” population-based child health indicators? It is important at the outset to distinguish between indicators used for research purposes and for the evaluation of the effects of specific services and those designed for continual monitoring of the health of child populations by routine collection. The ensuing discussion relates to the latter though indicators which are currently research instruments will be considered later in the paper.

Indicators must be readily available, applicable to the whole child population and simple to measure. The requirements sound straightforward and uncontroversial. As the ensuing discussion of currently available indicators will confirm, these apparently simple criteria are difficult to meet. Availability is dependent on reliable data collection and storage systems and cooperation at all levels of data collection. In some countries, private or independent practitioners may be uncooperative in data provision thus reducing the validity of the data. In other situations, data may be lost or inadequately stored. Availability is also influenced by the stability of the population under study; a highly mobile sub-group within the child population, such as travelling families, may limit data availability.

Simplicity of measurement is an essential prerequisite of a “good” child health indicator. Data collected on whole populations necessarily involve large numbers of individual collectors and collection points. The likelihood of interobserver and/or recording error increases dramatically with increasing complexity of the measure. Blood pressure measurement is an example of a deceptively simple measure which is difficult to standardise. Weight and height, though not as difficult, are more open to error than is often appreciated<sup>10</sup>.

It is self-evident that child health indicators should measure an aspect of health. However, a great deal of current data collection relates more to process and service performance than health. There is an unwritten assumption that high uptake of preventive services is equivalent to high health status; in the case of immunisation this is a justified assumption<sup>7</sup> but for measures such as the number of children attending for child health surveillance there is no evidence to relate uptake directly to health.

If one of the major uses of child health indicators is to monitor and evaluate change over time and between populations, the indicators must be capable of reflecting change and distinguishing significant trends from random variations<sup>7</sup>. Unless very large populations are being monitored, events such

as postneonatal deaths, congenital dislocation of the hip or cerebral palsy, occur too infrequently for consistent significant trends to be identified except over long periods of time. Thus, these may be useful comparisons between large populations and over five or ten years but are not capable of reliable interpretation in smaller population groups. Indeed, inappropriate use of these indicators to justify a particular intervention can prove seriously misleading<sup>7</sup>. International comparisons, though posing their own methodological problems<sup>11</sup>, are a potentially valuable means of assessing trends and change. “Good” indicators should be capable of “crossing” national and cultural barriers.

### Current indicators and their limitations

#### *Mortality data*

As indicated above, mortality rates, particularly infant mortality, have been the mainstay of child health statistics and have been used to compare the health status of whole populations<sup>5</sup>. MRs remain important in comparisons between countries and large child populations within countries. In developing countries child death is relatively common; regional and social differences within countries can be identified readily and trends analysed. The IMR for the children of agricultural workers in Senegal was 87 in the 1970s compared with 22 for the children of professional workers<sup>12</sup>. With such large numbers and gross differences, more detailed analysis would be feasible to identify particularly vulnerable groups. In the UK, though there is a two-fold difference in IMR between the most and least privileged children, the numbers are too small for detailed analysis of subgroups.

PNNMR, perhaps the most sensitive indicator in developed countries of socio-economic differences in mortality, can only be interpreted in large populations. The very small numerator means that, in relatively small populations, a few deaths more or less occurring by chance can lead to large changes in the rate<sup>7</sup>.

PNMRs have been compared between European countries and trends over time analysed in detail. The perceived poor performance of the UK compared with France and other European countries provoked a fierce debate and led to a major review of child health and neonatal services<sup>1,13</sup>. However, international comparisons of PNMRs are particularly problematic as a result, among other things, of lack of standardisation in gestational age estimation and age of viability – i.e. a still-birth in one country would be classified as a miscarriage in another<sup>11</sup>.

Cause specific mortality has been used to highlight inequalities; deaths by accidents and trauma in children 0–4 years of age in the UK demonstrate a

particularly steep social class gradient<sup>14</sup>. However, between country comparisons are complicated by classification differences. Even within countries, diagnostic fashions and classification differences adversely affect the interpretation of mortality data<sup>15</sup>. In recent years Sudden Infant Death Syndrome (SIDS) has displaced bronchopneumonia as the major cause of death between one month and one year and it has been suggested that this has more to do with diagnostic fashion than a true shift in cause of mortality.

### *Morbidity data*

The problems of morbidity data are well known<sup>6</sup>. Though morbidity occurs more frequently than death in childhood, definition and classification present major difficulties. Disease classifications such as the ICD codes, even when modified for paediatric practice<sup>16</sup>, focus on rare pathologies and are inappropriate for the classification of a significant minority of children admitted to hospital. The codes are even less useful for the classification of community-based morbidity data. Incidence and prevalence data have been based principally on hospital surveys. The British National Cohort studies have produced morbidity data based on more representative samples<sup>17</sup> but morbidity classifications have not been standardised and are open to challenge.

In addition to classification problems, severity also poses a difficulty. Not only are there difficulties grading severity between different groups of illness but also within group severity grading. For example, objective criteria for grading illness severity in asthma, now the commonest childhood respiratory illness in developed countries, are unsatisfactory and are frequently based upon assessments made in hospital settings<sup>18</sup>. Even greater problems arise in comparing the overall effect of illness of a child with asthma with that of a child with another chronic condition such as eczema. In an attempt to overcome this difficulty and to test the effects of new treatments, researchers have developed measures based on the parent or patient assessment of changes in the condition and the effect of the illness on daily living<sup>19</sup>.

Self-reporting of morbidity and its functional effects, whilst overcoming some of the shortcomings of professionally defined measures, suffers methodological problems of its own. The same question has different meanings to different groups rendering the responses invalid at least for comparing between-group differences<sup>20</sup>. However, a range of measures have been developed based on self-reporting which have been used in community studies<sup>6</sup>. Few of these measures are applicable to children.

Self-reporting has permitted researchers to move beyond the traditional limits of mortality and

morbidity measures as the only means of studying the health of groups and populations. Quality of life measures, which attempt to quantify positive aspects of health rather than the absence of ill-health, are necessarily subjective and self-reported. Quality of life measures have been adapted for use with children and have been tested in a large Scandinavian study<sup>21</sup>. At present, these measures are experimental and not readily applicable to routine use in large populations.

### *Birth weight and growth measures*

Birth weight is measured in most European countries. Though not a direct measure of morbidity, the strong association of low birth weight (LBW) with adverse health outcomes in infancy<sup>11</sup> makes it a good proxy measure of child health. High LBW rates are closely correlated with high PNMRs. LBW has the advantage of being far more common than perinatal or infant mortality and thus differences between regions and populations are more readily monitored and increase the likelihood of distinguishing between real changes and random fluctuation<sup>7</sup>. The strong association of LBW with social and material deprivation<sup>3</sup> allows its use as a measure of health inequalities between regions and child populations.

Despite the universality and apparent simplicity of the measurement, birth weight is not immune from process and methodological problems. Equipment and observer errors are common and definitions other than the internationally accepted LBW definition (< 2500 gms) are used<sup>22</sup> which limit the comparability of data sets.

Occipito-frontal circumference (head circumference) is routinely measured in infancy in some European countries and weight and height measured throughout childhood in most of Europe. Occipito-frontal circumference is unlikely to be of value as a marker of health in child populations though it has been advocated as a screening tool in the early identification of hydrocephalus and microcephaly<sup>23</sup>. Routine weighing in childhood is not of proven value<sup>23</sup> as a screening procedure for growth abnormalities and mean weights of child populations are unreliable markers of health because of the multitude of variables capable of exerting a short-term effect on weight and the poor technique employed in routine weighing. By contrast mean height attained at particular ages during childhood is potentially valuable as a marker of overall health of child populations<sup>24</sup>. Measurement problems arise in routine population measuring<sup>11</sup> and are minimised by regular standardisation. Mean height demonstrates a gradient across socio-economic groups in developed and developing countries<sup>24</sup> and can be used to monitor health inequalities provided large enough samples are studied<sup>25</sup>.

*Other measures*

Birth weight and growth are not in themselves direct measures of health but are acceptable as proxies when measured across populations. Other proxies have been considered; immunisation uptake rates, particularly for pertussis and MMR (measles, mumps and rubella) because of their close relationship with levels of the specific disease within a child population, are suitable measures<sup>26</sup>. Uptake of antenatal services has been related to pregnancy outcome but this is difficult to measure accurately in large population groups and varies so much in quantity and quality even within regions that it is not a reliable and consistent indicator. Uptake of child health surveillance is even more inconsistent and has not been shown to greatly influence health outcomes. Measures, such as the mean age of diagnosis of sensori-neural hearing loss, are service performance indicators. They affect the developmental progress of a very small group within the child population and are only useful for comparing very large populations. In addition, reliable data are difficult to obtain further reducing the potential value of these measures. Such performance indicators could be compared in specific international research projects with standardised data collection and these might furnish valuable data from which conclusions related to service provision could be made. In general, the wide variation in type and standard of data collected routinely in child health services precludes the use of performance measures, other than immunisation uptake, as proxies for health.

**Suggested child health indicators fulfilling characteristics of “good” child health indicators**

*Mortality*

The rapid reduction in infant and child deaths in developed countries has limited the value of mortality rates as comparative child health indicators. However, mortality data are routinely collected and rates published and remain an important indicator of child health if care is taken in comparing rates between populations and over time. In developed countries, where few children die after early infancy, the infant mortality rate (IMR), the traditional measure used for international comparison, remains the most useful indicator if interpreted with caution. IMR is sensitive to health inequalities but numbers limit its usefulness for this purpose. PNNMR is even more sensitive as a measure of health inequalities but small numbers is a greater problem even than for IMR. Cause specific mortality suffers from these same problems as well as difficulties of definition; however, child accident mortality related to specific causes, such as pedes-

trian road accidents, accidental poisoning and drowning, and for which known and proven preventive measures are available, should be collected even if mainly as a political tool with which to advocate legal enforcement of prevention<sup>27</sup>.

One device for overcoming the difficulty of small numbers in small populations is to aggregate mortality data into 5 or 10 year periods. This has the advantage of increasing numbers but the disadvantage of delaying recognition of trends.

UNICEF have adopted U-5 MR for the preparation of their regular report<sup>5</sup>. U-5 MRs are thought to more accurately reflect the period of heightened vulnerability in developing countries than IMRs. U-5 MRs have not been used routinely in developed countries as deaths fall sharply after one year of age. However, they can be compiled from existing data to allow comparison with developing countries<sup>5</sup>.

*Morbidity*

No currently collected routine morbidity data fulfill the criteria for “good” child health indicators. Hospital-based morbidity data are over-dependent on local practice as are data collected in primary health service settings. In many countries, primary curative services for children are private and data are difficult to acquire and impossible to interpret. Data on specific well-defined conditions, such as sensori-neural hearing loss, are available in some countries but small numbers and definitional problems render comparison difficult. Self-reported morbidity is not routinely collected, interpretation is controversial and, at present, morbidity profiles applicable to children are entirely in the experimental stage. Morbidity data related to children have been widely collected but only as part of research projects such as the cohort studies in the UK<sup>17</sup>. Measures of life quality are also in the experimental stage; they are suitable for use in research projects but not developed to the point where their routine use can be recommended. In addition, these measures are complex and are likely to be highly culture specific. Direct comparisons between countries and between groups within countries will prove problematic.

Immunisation uptake is collected in many countries. Uptake of early childhood immunisations is an acceptable proxy health indicator and can be compared within and between countries, though problems exist with different data collection techniques and the validity of data produced. Where valid data collection techniques are used, immunisation uptake is also a useful marker of the effective overall coverage of the child health services.

*Height*

Mean height at specific ages remains a valuable indicator of the health of a child population and

permits reliable between group comparisons<sup>24</sup>. Height measurement is already an established practice in many countries and is simple, cheap and relatively reproducible. Within-country child health inequalities can be monitored using mean heights though this may be complicated in countries with large immigrant populations as mean heights of first generation immigrants reflect the socio-economic conditions of their country of origin rather than their adopted country.

### *Birth weight*

Birth weight is universally measured and most European countries routinely collect the data centrally. It is frequently presented as LBW (< 2500 gms) percentages. Though useful, more information can be gathered from banding of birth weight into 500 gm bands. This allows overall birth weight trends to be monitored and studied and permits attention to be directed to specific groups such as Very Low Birth Weight (VLBW) infants (< 1500 gms). VLBW infants, though a relatively small group, make disproportionate demands on neonatal services and resources and contribute significantly to perinatal mortality. Optimal birth weight in survival terms seems to lie between 3000 and 4500 gms<sup>28</sup> and banding allows comparison of percentages falling within this range. The large numbers involved have the added advantage of "washing out" any errors in data collection and there are none of the problems associated with definition which arise in the VLBW group. Birth weight distribution is a sensitive measure of health inequalities and can be used to study changes over time.

### **Conclusions and further questions**

The above discussion raises as many questions as it answers. This is entirely appropriate; indicators which are incapable of measuring what they purport to measure or are open to misinterpretation are often more of a hindrance than a help to effective child health service delivery and to the interpretation of child health trends. The small number of indicators suitable for routine collection and useful in comparing health of children across populations are summarised below:

- Mean height* attained at specified age
- Birth weight distribution* by 500 gm bands
  - % LBW infants (< 2500)
  - % infants falling outside optimal birth weight range (3000–4500 gms)
- Infant Mortality Rates* (by year and by 5-year aggregates)
- U-5 Mortality Rates* (for international comparison)

*Mortality Rates (for age group 1–14) for pedestrian accidents/accidental poisoning/drowning (by single year and 5-year aggregates)*

*Early childhood immunisation uptake rates*

If consistent and reliable data were available across Europe for all the above, this would constitute a major advance and allow an authoritative and informed assessment of the current health of Europe's children, similar to that produced for children in Sweden<sup>21</sup>, and provide the basis of monitoring future trends. However, the above list is the product of one critical look at available routinely collected data. An essential prerequisite of reliable data collection at all levels is consensus. Data collection has been greatly enhanced where consensus has been established<sup>29</sup> not just between epidemiologists and demographers but across the professional disciplines who actually collect the data. On a Europe level, a consensus group, perhaps under the auspices of ESSOP, would be a useful first step towards the goal of a minimum child health data set for all European countries.

This paper has centred on the identification of routinely collected child health data appropriate for use as child health indicators. Valuable data giving important insights into the health of child populations can be obtained from well-designed research projects where data collection, variable definition and sampling can be carefully controlled. Longitudinal studies, such as the British cohort studies<sup>17</sup>, have proved a rich source of data and subsequent follow-up has permitted a wide-range of health-related issues to be studied longitudinally<sup>30</sup>. Though less productive than longitudinal studies, the much cheaper alternative of cross-sectional studies can provide important information about the health of child populations. The identification of a significant group of undiagnosed and untreated asthmatics in a survey of schoolchildren<sup>31</sup> not only revealed service inadequacies but also called into question the validity of previously accepted hospital-based asthma prevalence figures. Further research is particularly important in developing reliable morbidity and quality of life measures which can be used in research between countries and might, in future, be added to the above list.

### **Summary**

Indicators of health in child populations are critically reviewed and the potential for routinely collected morbidity and life quality data discussed. A short list of currently available, routinely collected child health data is proposed which, if available for all European countries, would form the basis of a useable and comparable European child health data base. A European consensus group on child health indicators is proposed and further research into

morbidity and life quality measures relevant to children recommended.

## Résumé

### Indicateurs de santé communautaire chez l'enfant

Les indicateurs permettant de juger l'état de santé d'une population d'enfants sont examinés de manière critique et les possibilités de collecter des données de morbidité et de qualité de vie sont discutées. Une courte liste de données actuellement collectées de routine est présentée qui, si elle devenait disponible dans tous les pays européens, formerait le socle d'une base de données européenne, utilisable et comparable, concernant la santé des enfants. La création d'un groupe de consensus européen sur les indicateurs de santé chez l'enfant est proposée, et de nouvelles recherches sur la mesure de la morbidité et de la qualité de vie sont recommandées.

## Zusammenfassung

### Indikatoren für Kindergesundheit

Bestehende Indikatoren für Gesundheit bei Kindern werden kritisch überprüft und die Möglichkeiten für routinemässig erhobene Daten über Morbidität und Lebensqualität werden diskutiert. Eine kurze Liste von momentan erhältlichen regelmässig erhobenen Daten über Gesundheit von Kindern wird vorgestellt, die – vorausgesetzt sie ist für alle europäischen Länder vorhanden – die Grundlage für eine brauchbare und vergleichbare Datenbank für Gesundheitsdaten von Kindern in Europa bilden wird. Vorgeschlagen wird eine europäische Studiengruppe zur Koordination von Indikatoren über Gesundheit von Kindern und weitere Forschungsprojekte über Morbidität und Lebensqualität werden empfohlen.

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