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**The Development of Social Class Sensitive Proxies**  
**for Infant Mortality at the PCT Level:**

**An Appraisal of Candidate Indicators for**  
**The Commission for Health Improvement**

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**October 2003**

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## **Summary and conclusions (with recommendations)**

This work has been commissioned by the Commission for Health Improvement and undertaken by the London Health Observatory in partnership with The University of Kent's Centre for Health Services Studies. The main aim of the work is to identify social class-sensitive proxies for infant mortality at Primary Care Trust level that could be used in the CHI performance ratings process for PCTs in 2003/4.

Our selection and appraisal of indicators is based on the following requirements:

- We have worked within the parameters and timescales set by the CHI ratings process for PCTs. We have taken a wide view of the CHI ratings process and have assessed potential indicators for their suitability for different parts of the CHI ratings process.
- We have selected indicators that are currently (or will soon be) routinely measurable across England's PCTs.
- We have prioritised indicators that are likely to be modifiable at PCT level.

We have developed an initial set of 18 candidate indicators (some preliminary and not further developed) based largely on existing datasets. We have then undertaken an appraisal of each as follows:

- A number have been rejected at the outset primarily because of their non-modifiability at PCT level and these are indicated in Section VII of the report.
- The remaining indicators have each been subjected to appraisal against a number of criteria of suitability for selection (see appendix 2 in full report for full details). These are:
  - Epidemiological justification for an association between the indicator and social class differences in infant mortality
  - Relevance to health and health policy
  - Constructability
  - Technical issues relating to data quality/completeness and frequency and data availability
  - Is the risk modifiable at PCT level – including PCTs working in partnership with others?

- Is the indicator open to manipulation/perverse interpretation?
- Relevance to specific PCT functions
- Readiness for incorporation into the CHI ratings, review and inspection process

The development and initial appraisal of candidate indicators – social class sensitive proxies for infant mortality at the PCT level - was undertaken and discussed at an early stage with members of the LHO’s Maternal and Child Health Peer Review Group. A long list of 18 potential indicators was prioritised and appraisal sought via membership of the peer review group.

Findings from this appraisal process have now been incorporated into a final report and include an analysis of the scoring system. The following “long list” of candidate indicators were initially selected for formal appraisal. Indicators accompanied by the symbol (†) were not fully investigated:

- Smoking in pregnancy (depending on quality of data collected under DSC Notice)
- Completion of maternity tail
- Response times for reporting to CESDI (CEMACH) (depending on how reported & if useful)†
- Mother: support status and/or parenting intention (using registration type as proxy)
- Cause group†
- Mother’s age (<20)
- Midwifery staffing (some measures, depending on availability of disaggregated returns)†
- Health Visitor staffing (some measures, depending on availability of disaggregated returns) †
- Well babies†
- Babies requiring augmented care†
- Hospital admissions in infancy (intensity, frequency, and cause) †
- Late initiation of antenatal care
- Number of antenatal visits (or number of visits missed)
- Gestational age at first primary care contact for antenatal care
- Unbooked women
- Postnatal care contacts†

- Initiation/duration of breast feeding
- Efficiency of computerised maternity information systems†

Appraisal responses were received from a total of 9 people, 3 of whom completed the scoring grid. Comments were focussed on the 10 indicators described in the report that it would be feasible to use immediately:

- smoking in pregnancy;
- mother's age <20;
- mother: support status and parenting intention;
- completion of the “maternity tail” (the routine maternity data reported within Hospital Episode Statistics (HES));
- response times for reporting to CEMACH – the Confidential Enquiry into Maternal and Child Health;
- midwifery staffing; health visitor staffing;
- the “cause group” (including causes such as immaturity-related conditions, congenital malformations, or more specific causes (e.g Sudden Infant Death Syndrome) suggested in the consultation)
- well babies, and babies requiring augmented care; hospital admissions;
- breastfeeding

### **Indicators for Immediate Inclusion**

Our appraisal indicated that the strongest candidates for immediate inclusion in the performance ratings were:

- Smoking in pregnancy
- Initiation of breastfeeding
- Teenage pregnancy (and similar indicators, e.g. mother's age)

Further, there was strong support for the addition of an indicator that measures the quality and completeness of the Maternity Tail in HES – for which there is evidence from some parts of the country that a high level of completeness is now feasible.

It is clear that most of these indicators are either already included in the performance ratings process or have already been selected for inclusion in the provisional list of indicators for 2003/04.

**We recommend :**

- **These indicators are suitable for inclusion on the basis of the evidence although quality assurance of the data itself will be required for smoking in pregnancy and initiation of breast-feeding.**
- **We further recommend that the quality and completeness of the “maternity tail” be developed as an indicator, using a completeness threshold percent (based on a combination of key fields) and also percent reporting date of first antenatal assessment (possibly in the range of 80% or more completeness)**

#### **Indicators which merit further development**

Other indicators which attracted significant support were:

- Those relating to antenatal booking and care. The evidence base would support the development of indicators relating both to time of booking of antenatal care and numbers of visits (care would need to be accorded to defining the first antenatal booking and to a critical number of visits that reflects proposed changes to the current pattern of antenatal visits that is now being considered in National Service Framework developments). It was mainly the non-availability of data that presented current barriers to inclusion in CHI ratings in the near future.
- There is evidence of high levels of completeness of ethnic coding for HES for some parts of the country and some acute trusts. This is essential for preparing the ground for monitoring ethnic differentials in booking and frequency of antenatal attendance.



**We recommend that:**

**Further work be undertaken to agree definitions for such indicators and to use the HES maternity tail to develop these data. This should include the development of capability to monitor ethnic differentials in these indicators.**

**Indicators for Use in Other Parts of the CHI process**

Preparation for the CHI Clinical Governance Review and Inspection Process might be further enhanced by the use of the following indicators:

- response times for reporting to CEMACH. Further work is needed to define a threshold standard for response times that would be reasonable.
- Indicators based on midwifery and health visitor staffing were not strongly supported for performance ratings, but given their evident importance to the ability of Trusts to deliver a high standard of care, we recommend CHI reviews their potential use once work already underway within the Department of Health is complete. As the evidence supports the effective targeting of babies at risk of SIDS by health visitors, we recommend prioritising the development of indicators for health visitor coverage as well as data on advice on sleeping position.
- Future developments should encompass investigation of the extent of data collection and of recording on computerised and manual maternity unit and other information systems of the items on antenatal/postnatal care (first attendance for antenatal care with hospital or primary care contact, gestation at antenatal booking, and number of antenatal visits and post-natal care contacts, etc.). This would involve collating evidence from existing audits and surveys (if any) and identifying the scope for primary data collection via such methods to document this information

*October 2003*

## I The Aims, Objectives and Approach Adopted

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We have developed a set of 18 candidate indicators (some preliminary and not further developed) based largely on existing datasets. We have then undertaken an appraisal of each as follows:

- A number have been rejected at the outset primarily because of their non-modifiability at PCT level and these are indicated in Section VII of the report.
- The remaining indicators have each been subjected to appraisal against a number of criteria of suitability for selection. These are:
  - Epidemiological justification
  - Relevance to policy
  - Constructability
  - Technical issues and data availability
  - Is the risk modifiable
  - Is the indicator open to manipulation/perverse interpretation
  - Relevance to specific PCT functions

The criterion ‘epidemiological justification’ might be more accurately interpreted as ‘strength of evidence as risk factor associated with infant deaths and wider infant and maternal health outcomes’. With respect to strength of epidemiological and interventional evidence as a marker of clear social class gradient in infant deaths, this relationship has not clearly been established for all the indicators reviewed. Similarly, the strength of epidemiological evidence on ability to modify locally has not been comprehensively appraised in all cases. Finally, an attempt has been made to assess the vulnerability of each indicator to perverse/manipulative/interpretation in ratings.)

Some tentative consideration has been given to the extent to which each indicator reflects a core PCT responsibility (that is, public health, primary care provision, and health commissioning).

Our conclusions and recommendations are based on the above assessment as well as the suitability of indicators for use in the different aspects of the CHI process. Finally, we have located indicators in two distinctive categories (as shown in summary and conclusions above):

1. Indicators suitable for immediate use.
2. Indicators that would be suitable for use provided improved data collection/quality are built into the performance requirements.

## II Background

The Department of Health's National Health Inequalities Targets relate to life expectancy and infant mortality. The national target for infant mortality is to reduce the gap in infant mortality between manual social groups and the population as a whole.

Analysis of national data for the year 2000 (on the ONS linked file of births and infant deaths) shows that there are around 3,300 infant deaths a year in England and Wales. These deaths consist of:

- *Neonatal deaths* (around 2,300 a year or 69% of all infant deaths). These are babies dying under 28 days of age. Some analyses also distinguish *early neonatal deaths* (around 1,730 a year, 52% of all infant deaths or 75% of all neonatal deaths). These are babies dying under 7 days.
- *Postneonatal deaths* (around 1,000 a year or 31% of all infant deaths). These are babies dying aged 28 days and over but under one year.
- *Infant deaths* comprise both neonatal and postneonatal deaths, that is, the number of deaths of babies under 1 year of age

Neonatal, postneonatal, and infant mortality rates are expressed per 1,000 live births. Other definitions relevant to mortality around birth are the *stillbirth rate* (the number of stillbirths per 1,000 total births [stillbirths and live births] ) and *perinatal mortality rate* (the number of stillbirths plus the number of deaths to babies under 7 days per 1,000 total births).

The contribution of particular causes of death and of the steepness of the social class gradient for those cause groups varies across neonatal and postneonatal deaths. One of the main contributors to neonatal mortality is death associated with prematurity. Major contributors to postneonatal deaths are congenital anomalies, infections, and sudden infant deaths. Several of these causes of death for both neonatal and postneonatal mortality show strong social class gradients, steeper for postneonatal than neonatal deaths. These gradients are seen in prematurity, deaths due to infectious and respiratory diseases, and deaths due to sudden infant death syndrome.

One of the difficulties that PCTs experience in monitoring this target is that infant deaths are relatively rare events at this spatial scale. In 2000, for example, there were only 3,323 infant

deaths in the whole of England and Wales. Within some regions, the numbers at PCT level may be very small indeed. For example, in the South West Region, the number of infant deaths in each PCT varied from 3-18 per year on average (based on 1995-2000 data) or between about 3 and 7 deaths per 1000 live births (SWPHO 2002). Further, the 95% confidence intervals for the lowest rate and the highest rate in this region almost overlap. While the infant mortality rate in the SW Region as a whole is around 1 death/1000 live births below that of England as a whole (just over 6 deaths/1000 live births), these problems of small numbers will affect the majority of PCTs.

A second problem is that the Government target relates to social class differences in infant mortality. It is quite possible, therefore, that some PCTs will have negligible numbers in the most disadvantaged social classes for the purposes of monitoring differences between infant deaths in this group and all infant deaths. Such low counts are subject to the “small numbers” problem, that is, there is a high probability that they could have arisen by chance rather than through processes of systematic variation. Consequently, any rates based on such small counts are inherently unstable at PCT level. One solution to this problem is to combine 5 or 7 years of data to raise the numbers to a statistically valid level. However, such a method masks changes in these rates (a downward trend overall in both stillbirths and infant deaths over recent years but persistent social class differences). Further, there may be attrition from the numerator used in the calculation of social class differences as sole registrations are not assigned a social class. In 2000 10.5% of infant deaths in England & Wales could not be assigned a social class because they were to sole registered mothers. Further, 8.5% of all infant deaths (or 9.5% of those inside marriage and outside marriage jointly registered) were assigned a social class of ‘Other’ (outside the Registrar Generals I-V classification). Finally, for live births, ONS only codes a 10% sample for father’s occupation.

For these reasons PCTs have found it impossible to comment on trends in social class differences in infant mortality, even where the postcode of the infant death is linked to deprivation databases based on linked postcode-Census enumeration district data (such as the Townsend Material Deprivation Index and Carstairs & Morris Index of Deprivation) to make use of all the deaths. To obtain statistically valid data at the *Region* level using the Carstairs and Morris Index of Deprivation (such that the range of the 95% confidence interval does not exceed around one infant death per 1000 live births), public health observatories have had to combine up to 7 years data to obtain valid comparisons between the least deprived and most deprived quintiles.

One solution is to monitor the risk factors for infant mortality since substantially higher counts make this technically feasible at a local level. There are some national datasets that can be exploited to yield information on these factors; in other cases local data collection may need to be strengthened through standardisation of collection practices and data definitions.

### III. The Policy Context

In its priorities and planning framework for 2003-2006 (Department of Health 2002), the Department of Health set out its objective for reducing health inequalities: ‘To reduce inequalities in health outcomes across different groups and areas in the country. Initially the focus is on reducing the gap in infant mortality and life expectancy at birth, and on reducing teenage pregnancies. Six targets were identified, three relating specifically to infant mortality:

- Deliver a one percentage point reduction per year in the proportion of women continuing to smoke throughout pregnancy, focussing especially on smokers from disadvantaged groups as a contribution to the national target to reduce by at least 10% the gap in mortality between “routine and manual” groups and the population as a whole by 2010, starting with children under one year.
- Deliver an increase of 2 percentage points per year in breastfeeding initiation rate, focussing especially on women from disadvantaged groups.
- Achieve agreed local teenage conception reduction targets while reducing the gap in rates between the worst fifth of wards and the average by at least a quarter in line with national targets.

Under *national capacity assumptions* the document highlights improved access to services for disadvantaged groups and areas, particularly: early antenatal service booking; antenatal and child health screening services; sexual health services, and breast/cervical screening; and strengthened primary care services through increased numbers of health professionals and improved facilities in under-served and deprived areas.

In April 2003 the Department of Health published the document *Key NHS Interventions to Support the Achievement of the National Health Inequalities Target* (Department of Health 2003), building on the interventions identified in the *Cross Cutting Review* (Department of Health 2002). Those for Infant mortality were:

- Reducing smoking in pregnancy
- Improving nutrition in women of childbearing age
- Reducing teenage pregnancy
- Increasing breast-feeding initiation and duration rates
- Providing effective ante-natal care (including screening and immunisation) and promoting early ante-natal booking

- Improving the quality of midwifery, obstetric and neonatal services
- Effective education about ways to promote health, e.g. immunisation
- Provision of high quality family support (e.g. through health visitors) including particular efforts to address risk factors for Sudden Infant death



## IV. PCT Performance Assessment: The CHI Approach

The Department of Health (DH) awards 0, 1, 2 or 3 stars for NHS organisations in England informed by three sets of information: key targets, a wider set of indicators that make up the 'balanced scorecard' and, where there is a CHI report, progress in implementing clinical governance. Only CHI reports published between 19 September 2001 and 12 July 2002 have been used for this year's ratings.

CHI's Finsbury rules are the rules for incorporating CHI's clinical governance review (CGR) scores into star ratings. They are:

- § A trust will be zero-star, if it fails the Department of Health's criteria on key targets or CHI's zero-star threshold. For CHI's threshold a trust receives 0 if it is scored five or more Is.
- § For a trust to be eligible for three-star status it needs to pass both DH's criteria on key targets and the balanced scorecard and in its CGR have scored one or more IIIs and no Is.
- § If a trust is borderline two/three star on key targets and the balanced scorecard, it is promoted to three stars if, in its CGR, it scored three or more IIIs and no Is.

However, these rules do not currently apply to all trusts. For 2003, Finsbury rules apply as above to acute, specialist and mental health trusts. For this year's ratings, primary care trusts and ambulance trusts are exempt from the Finsbury rules. Their star ratings currently depend purely on their scores on the performance indicators. The Finsbury Rules will apply to PCTs for the next set of ratings.

While CHI has responsibility for producing performance ratings and indicators, the Department of Health retains responsibility for setting overall priorities and the key targets covered by indicators in the ratings. CHI's responsibility lies in the development of indicators in the balanced scorecard and the methodology used in the ratings but the Government retains responsibility for setting priorities and key NHS targets to be used in the ratings. CHI is responsible for the ratings and their methodology, including how the system of performance ratings and indicators will be further developed for 2004.

With respect to 2004 CHI want the ratings and indicators it publishes to be as valuable as possible to both the health service and the public. In reviewing the system used they are consulting experts in the field and those who work in the NHS and are also looking at what kind of information people who use health services would find most useful. They wish to ensure that patients and those who work in the NHS find the kind of information set out in ratings and indicators useful in understanding where their health services are achieving high standards and where they are failing to deliver.

There are currently 46 performance indicators for PCTs (CHI 2003). Only two relate to pregnancy and infant health: Indicator – Sexual Health – Access to services for early unintended pregnancy; Indicator – Teenage Pregnancy – Conceptions below age 18 (change in rate). These are all in the balanced score card.

## **V. Key National Datasets for Indicator Construction**

Clearly, if useful proxy indicators are to be constructed at PCT level, it will be desirable from the quality viewpoint, for these to be readily understood and interpretable (and, in some cases replicable) by PCTs themselves. This means they must be simple to construct and be based on already collected data or data that is easily collectable. That limits the choice of indicators to those based on 4 or 5 key datasets. It is possible that other data collections can be routinely introduced (such as smoking in pregnancy information) but that will render some of the proposed indicators potential candidates for the future, even if some PCTs are already collecting the data.

### **HES Core Dataset and Maternity Tail**

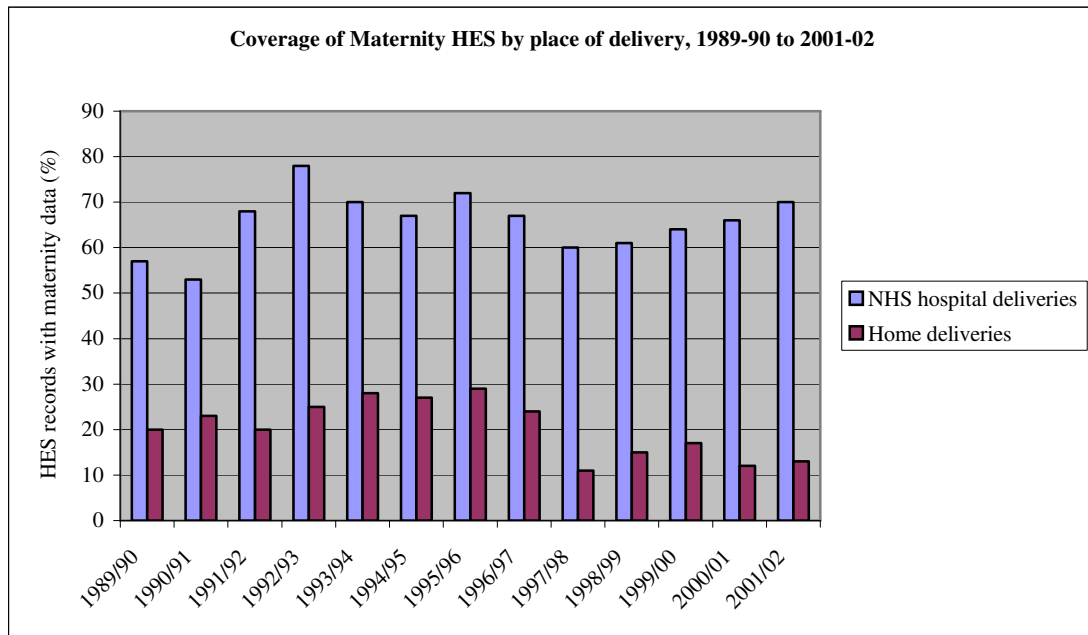
The Department of Health's Hospital Episode Statistics (HES) database contains data about all maternity events – in NHS and other settings - and care given at birth in a special extension to the general core HES record of care for patients admitted to hospital, known as the 'maternity tail' and first implemented in 1989. The maternity tail items are: first antenatal assessment date, total previous pregnancies, delivery place (actual), delivery place (intended), delivery place change reason, gestation length, labour/delivery onset method, delivery method, status of person conducting delivery, anaesthetic given during labour/delivery, number of babies, sex (baby), birth order, live or still birth, birth weight, resuscitation method, birth date (baby), birth date (mother) (see table 1).

These data are sent by trusts either from their Patient Administration Systems to the Department or directly to the Department of Health for those maternity units whose systems are not linked to their hospital's patient system. The core HES record now (2001-02) contains 97% of all NHS hospital deliveries but only 14% of home deliveries. Over the last decade information collected in the maternity tail has been widely recognised to have been incomplete and continues to pose problems across all regions in England (figs. 1 & 2), although there is also evidence that some StHA areas have generated almost complete data (LHO Personal communication). Coverage of NHS hospital deliveries has risen from 66% in 2000-01 to 70% in 2001-02 but coverage of home deliveries has remained low at 12 and 14%, respectively (Government Statistical Service 2002). Across regions the percentage of HES records in 2001-02 with maternity data for NHS deliveries varied from 56% (SW) to 89% (NW).

Table 1. Hospital Episode Statistics: Fields on the HES 'Maternity Tail'

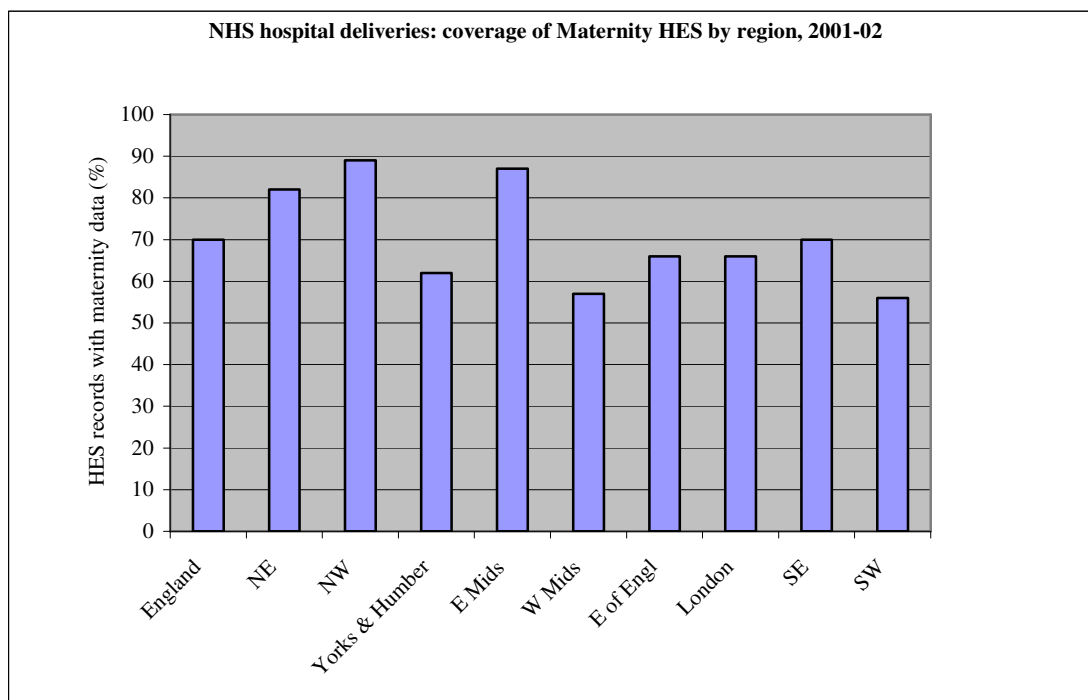
<i>Name of field</i>	<i>Definition</i>
ANASDATE	<i>First Antenatal Assessment Date:</i> Gives the date when a pregnant woman was first assessed & arrangements were made for antenatal care. This is not always the date when delivery arrangements were made.
BIRORDER	<i>Birth Order:</i> If there is a multiple delivery, this gives the position in the sequence of births.
BIRRESUS	<i>Resuscitation method:</i> The method used to get the baby breathing normally. This is not recorded for stillbirths.
BIRSTATE	<i>Live or still birth:</i> Indicates whether the baby was born alive or dead ("stillbirth").
BIRWEIT	<i>Birth weight:</i> The weight of the baby in grammes immediately after birth.
DELCHANGE	<i>Delivery place change reason:</i> If the place of delivery is different, either in type or geographic location, from that originally intended, the reasons for the change are recorded in this field.
DELINTEN	<i>Initial intended delivery place:</i> See DELPLACE for the codes used in this field.
DELMETH	<i>Delivery Method:</i> The method used to deliver a baby which is a Registrable Birth.
DELONSET	<i>Labour/delivery onset method:</i> The methods used to induce (initiate) labour, rather than to accelerate it.
DELPLACE	<i>Delivery place type:</i> Used to classify initial intention and actual place of delivery.
DELPOSAN	<i>Anaesthetic given post delivery:</i> This records the type of anaesthetic/analgesic administered during and after labour and delivery.
DELPREAN	<i>Anaesthetic or analgesic administered before &amp; during labour and delivery.</i>
DELSTAT	<i>Status of person conducting delivery.</i> This is normally the status of the individual who delivers the baby.
DOBBABY	<i>Birth date (baby)</i>
GESTAT	<i>Length of gestation:</i> The WHO definition is to be used measured from the first day of the last menstrual period (LMP) where this is thought to be reliable.
NUMBBABY	<i>Number of babies:</i> The number of registrable babies (live or stillborn) at a particular delivery.
NUMPREG	<i>Total number of previous pregnancies.</i>

Fig. 1. Coverage of Maternity HES by place of delivery, 1989-90 to 2001-02



Source: Government Statistical Service (from HES, ONS)

Fig. 2. Coverage of Maternity HES for NHS hospital deliveries by region, 2001-02



Source: Government Statistical Service (from HES)

## **Confidential Enquiry Datasets**

Data are collected from maternity units via the Confidential Enquiry into Maternal Deaths (a review of individual maternal deaths) and the Confidential Enquiry into Stillbirths and Deaths in Infancy (which reviews samples of events). These were merged as the Confidential Enquiry into Maternal and Child Health (CEMCH) on 1<sup>st</sup> April 2003 and run by the National Institute for Clinical Excellence.

CESDI was established in 1992 and was developed around the pre-existing structure of regional perinatal surveys. It maintains a record of all deaths of babies from 20 weeks gestation to 12 months old. The 14 former English Regions, and offices in Wales and Northern Ireland, operate autonomously from the Central Secretariat. Enquiry cases are reviewed by local multidisciplinary panels of clinicians, undertaken by a network of local clinicians developed by CESDI who undertake this work.

The CESDI Rapid Report Form collects information on each fetus born after 20 weeks of pregnancy (or birthweight .300 grams if weeks not known) including legal abortions and each live birth dying before one year of age. Information on mother includes mother's date of birth/estimated age; ethnic group of mother; parity (number of previous pregnancies of 24 weeks+ only); first day of last menstrual period; early ultrasound; gestation at birth; date & time of delivery/birth; intended place of delivery at booking; actual place of delivery; reason for change between planned and actual place of delivery; number of babies in this pregnancy; birth order this baby; presentation just prior to delivery; and mode of delivery. Information on the baby/infant comprises: sex; birthweight; date & time death was first diagnosed; signs/observations at birth; discharge home after birth or neonatal care; cause of death; extended Wigglesworth classification; fetal & infant classification; obstetric classification; & post-mortem. A field for how the case was defined & date CESDI form completed are also recorded.

## **The Standard Birth Notification Data Set**

A new electronic system of statutory birth notification became operational on 29<sup>th</sup> October 2002 (*see*: <http://www.nhsia.nhs.uk/nn4b/oages/>). This encompasses the statutory requirement to send birth notifications from Maternity to Child Health Departments within 36 hours and is also tied to the issue of the NHS Number for the baby. A birth notification needs to be raised

– and an NHS number issued – for all babies born in England and Wales, including all live births, babies born in NHS- and non-NHS hospitals, home births, births overseen by independent midwives, stillbirths<sup>1</sup>, and other categories of babies (e.g. overseas visitors). This new system changes the processing of data for stillbirths (that is, a baby born on or after 24 weeks gestation, who shows no sign of life after being born). Stillbirths born pre-29<sup>th</sup> October 2002 do not have an NHS Number but all stillbirths over 24 weeks gestational age born on or after this date will have an NHS Number. There is a difference between the requirement of CESDI (Confidential Enquiry into Still Births and Deaths in Infancy, now CEMCH) to record deaths at 20 or more weeks gestation and a stillbirth being defined as notifiable at 24 weeks gestation.

Table 2: Key Fields on the Birth Notification Dataset.

<b>Field Name/Description</b>
<i>Baby's Identification and Birth-Related Information</i>
NHS NUMBER
BIRTH DATE (BABY)
DELIVERY TIME
SEX
LIVE OR STILL BIRTH
BIRTH WEIGHT (GRAMS)
GESTATION LENGTH (WEEKS)
NUMBER OF BIRTHS IN THIS CONFINEMENT
BIRTH ORDER (IF MULTIPLE)
SUSPECTED CONGENITAL ANOMALY (Yes, No or Uncertain - further review required)
ETHNIC CATEGORY (defined by mother)
BABY USUAL ADDRESS
BABY DISCHARGE ADDRESS
<i>Place of Birth Details</i>
ORGANISATION NAME/CODE
DELIVERY PLACE TYPE
<i>Information about the Mother</i>
NHS NUMBER
BIRTH DATE (MOTHER)
<i>Information about Relevant Healthcare Professionals</i>
SURNAME OF NOTIFYING PERSON (usually a midwife)
GP NAME
PRACTICE NAME/ADDRESS
CHILD HEALTH ORGANISATION CODE

Source:

This new electronic system of birth notification is supported by a *standard birth notification dataset* that encompasses the NHS Number for the baby and a set of notification data (data

<sup>1</sup> The RCOG (2003) incorrectly pointed out in evidence to the House of Commons Health Select Committee that this system will not identify stillbirths, a major contributor to perinatal mortality, and may consequently fail to provide evidence upon which to improve antenatal and intrapartum care.

fields such as birth weight, time of birth, etc.: for a full list of data items in the standard birth notification data set, see table 2). The NHS Central Issue System has the responsibility for transmitting the standard birth notification dataset from the maternity unit to the Child Health department, although the standard birth notification dataset can be transmitted electronically directly between maternity and child health.

## **Civil Registration**

Under rules governing the civil registration of births and deaths, births, stillbirths at 24 or more completed weeks of gestation, and deaths must be registered by the next of kin at the local register office. Births must be registered within 6 weeks, stillbirths within 3 months, and deaths within 5 days. The cause of stillbirth or death must be medically certified by a doctor who was present at the death or stillbirth or who examined the dead baby. For live births most of the information recorded is socio-economic in nature. The Office for National Statistics (ONS) maintains anonymised data for statistical analysis and also separate registers of identifiable information for legal reasons.

*Linked Anonymous Births and Deaths file* is an ONS-maintained database that links births and infant deaths at the person level in an anonymous file, going back to 1975 (anon., 2001). It covers stillbirths and infant deaths registered in England and Wales that have been linked to their corresponding birth records (table 3). The major benefit of the linked file is that it is a comprehensive record that is substantially complete. In 2000, for example, 98% of infant deaths were linked to their birth records. Of the 54 records that were not linked, 28 were born outside England & Wales and therefore not registered in England and Wales; a further 26 were not linked because no record of the birth could be found. This high record of linkage is comparable to the rates for earlier years.

The linked file enables the analysis of infant (and perinatal) deaths by risk factors recorded at birth registration, including birthweight, mother's age at birth of child, mother's country of birth, marital (registration) status, parity (within marriage), and father's social class based on his occupation. However, the implementation of the NHS Numbers for Babies Project (in the Birth Notification Dataset) has had adverse effects on two national data collection systems operated by ONS and recorded on the linked file:



Table 3: Fields on the ONS National Linked Infant Mortality File

<b>Field</b>	<b>Details</b>
LIVE BIRTH	
STILL BIRTH	
DEATHS	Date of death enables early neonatal, neonatal, and postneonatal deaths to be identified
BIRTHWEIGHT (grams)	Missing on 1.7% of infant deaths, 2000
GESTATION (weeks) [stillbirths only]	Missing on 6.5% of still-births, 2000
MOTHER'S AGE AT BIRTH OF CHILD	
MOTHER'S COUNTRY OF BIRTH	
MARITAL STATUS	Inside marriage, Outside marriage (joint registration/same address; joint registration/different address; sole registration)
PARITY (inside marriage)	
SOCIAL CLASS	Information on father's occupation is not collected for births outside marriage if the father does not attend the registration of the baby's birth; a 10% sample of live births are coded for father's social class. 8.1% coded 'Other' or father's occupation not stated for infant deaths inside marriage, 2000; 15.5% coded 'Other' or father's occupation not stated for infant deaths outside marriage (joint registration), 2000.
CAUSE OF DEATH	

- (i) Since 1975 birthweights recorded on birth notifications have been passed via child health systems to local registrars of births & deaths and thence to ONS for inclusion on the linked infant mortality file. Since the implementation of 'NHS numbers for babies', many birthweights are not reaching local registrars and, consequently, ONS can no longer study infant mortality for babies in different birthweight groups.
- (ii) Further, because of limitations of the minimum dataset used in 'NHS numbers for babies', information on congenital anomalies is no longer passed to the National Congenital Anomalies System.

[See: Letter, *Re: Maternity Services Sub-Committee – Inquiry into the Provision of Maternity Services*, James Chalmers, Chair, Information Committee, Faculty of Public Health Medicine, d. 12 February 2003]

Child Health Departments also pass on to the registrar of births and deaths details of the birth notification including NHS Number (although this notification and civil registration are independent events, the registrar of births and deaths matches the two sets of data before sending the baby's details to the NHS Central Register).

Registrars of Births have a responsibility to pass on data for stillbirths to the stillbirth register at the NHS Central Register (NHSCR), a separate procedure from passing on data for live births. However, the NHSCR does not pass data for stillbirths on to the National Strategic Tracing Service.

Currently, as part of the process of modernisation, the Government has issued a three month consultation paper concerning the future information that should be collected as part of the registration of births, marriages and deaths:

[www.statistics.gov.uk/registration/whitepaper/default.asp](http://www.statistics.gov.uk/registration/whitepaper/default.asp)

This may lead to changes in the data items collected at birth and death registration (one of the items being considered being ethnicity).

### **National Sentinel Caesarean Section Audit**

The National Sentinel Caesarean Section Audit was a comprehensive exercise that covered 99% of all births. Response rates for organisational surveys ranged from 92% to 100%, for the survey of women's views 84%, and for obstetricians' 77% (at least one consultant responded from each of the participating units). However, the audit was a one-off cross-sectional rather than continuous survey.

### **Child Health Systems**

Community child health departments have a major role in managing babies and young children and their operational systems generate an additional set of records. They receive the standard birth notification data set from maternity units either via the NHS Central Issue System or by direct electronic transfer, add the NHS Number and other information to their Child Health System, and pass on the notification of the birth to the registrar of births and deaths. A range of information may be held on their systems, including the recording of infant feeding methods, but such data are not analysed nationally, with the exception of babies' birthweights (passed to local registrars of births and deaths who pass them on to ONS) and notifiable congenital anomalies (passed to ONS's National Congenital Anomaly System or a local anomalies register).

## VI Assessment Criteria For Candidate Indicators

There are potentially many criteria that could be used to assess candidate indicators. An initial list was carefully considered and those selected are listed below. In the next step the report's authors are collating an appraisal by each individual member of the advisory group and will take their findings into account.

- (1) *The data used for the construction of the indicator needs to be collectable and of high quality.* That would essentially mean that the data item would need to be currently collected in an existing system or that enhancement of an existing system, for example, through record linkage, could readily result in collection. However, criteria for improvement of information systems or of quality/completeness of information collected could, in themselves, be developed as candidate indicators.
- (2) *The sensitivity as a marker of social class differentials in infant deaths.*
- (3) *The risk factors identifiable in candidate indicators should be demonstrably modifiable at PCT level.* This should be interpreted to include the wider public health role of PCTs working in partnership with non NHS agencies.
- (4) *The indicators should, as far as possible, be free from manipulation and perverse interpretations.* The scope for manipulation needs thus to be assessed.
- (5) *The extent to which the indicator reflects core PCT responsibilities (primary care provision, commissioning healthcare, and public health).*
- (6) *National policy relevance*
- (7) *Utility in different parts of the CHI ratings process.*

There is an argument that the second of the above – that the risk factors identifiable in the candidate indicators should be modifiable at PCT levels – should be discretionary. For example, there may be indicators that satisfactorily identify social class differences but are not, in themselves, interpretable in terms of modifiable risks (for example, there are social class gradients in birthweights and length of gestation, although they are not very steep).

There are, in addition, other implicit criteria. Given that the Government's interest is in reducing inequalities in infant mortality, indicators are needed that can be structured on the basis of direct or proxy measures of social class. Proxy indicators need to be relevant to other

Government policies as represented in the national service frameworks (the National Service Framework for Children's Services will include maternity services), guidelines developed by the National Institute of Clinical Excellence, and findings of the joint working parties of the Royal Colleges.

## **VII Initial Rejection of Indicators that are not likely to be Modifiable at PCT level**

### **i. Low birthweight**

At first birthweight might appear as a strong candidate for indicator development. The infant mortality rates for very low birthweight babies (under 1,500 grams) and low birthweight babies (under 2,500 grams) were 100 and 21 times higher than normal birthweight babies (2,500 and over grams), respectively. The infant death rate was 5.5 in 2000 but 211.5 in babies <1500 grams, 25.2 in babies 1500-1999 grams, and 9.1 in babies 2000-2499 grams.

However, the most recently published data, for England and Wales, 1994 (Botting 1997), shows only modest gradients in infant mortality across the social classes (based on the social class of the father, inside marriage) for different birthweight groups. For birthweights <1500 grams, the rate for social class V is higher than for the other classes (I-IV) which show no gradient. For babies of 1500 to 2499 grams there is a stronger social class gradient, the rate of infant deaths per 1000 livebirths (inside marriage) rising from around 14 in social class I to around 18 in social class V. Data tabulated by father's social class for births inside marriage and outside marriage (jointly registered) show that the average birthweight in social class V was 115 grams lighter than in social class 1 for births inside marriage and 130 grams lighter for births outside marriage registered by both parents.

In addition, Scottish data shows an association with socio-economic status. The Scottish Executive (1998) reports that, based on data for 1987-96, the association between deprivation and low birthweight was stronger than that between deprivation and preterm birth which showed differences of 1.7 between the most affluent and most deprived areas (see gestation, below).

However, low birthweight is a complex risk factor that is affected by other risks such as smoking in pregnancy, poor maternal nutrition, etc. It is not readily amenable to modification by PCTs because of its complex character. Nevertheless, it may be still be useful as a means of monitoring social-class differences in a proxy variable if not one that has an explicit relationship with specific intervention strategies. Working definitions (and % of all live births, England & Wales; Scotland) include: low birthweight <2,500 grams (7.6%; 5.4%), very low birthweight <1,500 grams (1.2%; 0.7%), and extremely low birthweight <1,000 grams (0.2%, Scotland).

## Evaluation

Amongst those candidate indicators initially rejected, comment in the consultation was received on only this (by two assessors) and one other (gestational age). One of the assessors felt that low birthweight rates should be reconsidered as they were a major cause of morbidity, showed a strong social class gradient, and were looking more preventable. The other strongly recommended that birthweight (or low birthweight) and gestational age be reconsidered as indicators, since both are correlated with infant mortality and reasonable data are available, adding: ‘...they have only been excluded due to lack of modifiability at PCT level, which...seems an illogical reason for exclusion’.

### **ii. Parity**

The ONS linked births/infant deaths file contains information on parity inside marriage, enabling rates to be calculated for women who have had none, one, two, and 3 or more previous children. Infant mortality rates do not vary significantly across the groups, except the 3 & over group: 5.3 in 0, 3.8 in 1, 4.7 in 2, and 6.7 in 3 & over. Infant deaths in the 3 & over parity group (inside marriage) accounted for only 204 deaths in 2000, just 6.1% of all infant deaths.

Moreover, high parity is not a risk factor that is amenable to modification by PCTs.

### **iii. Mother’s country of birth**

Currently, there is no routine collection of information on ethnic group of mother (or child) at birth registration. However, information is collected on mother’s (and also father’s) country of birth. Mother’s country of birth is now a poor proxy for ethnic group, as a substantial proportion of total fertility in the different ethnic groups is accounted for by women born in the UK rather than migrant women.

The ONS linked file shows that babies of mothers born in Pakistan had an infant mortality rate of 12.2 per 1,000 live births in 2000. This rate was higher than babies of mothers born in any other country and double the overall infant mortality rate (5.5 per 1,000 live births). Rates were also elevated in mothers born in the Mediterranean (9.6) and Caribbean (10.4).

However, in 2000 in England and Wales there were only 165 infant deaths to mothers born in Pakistan (just 5.0% of all infant deaths) and infant deaths represented just 1.2% of all live births to mothers born in Pakistan. The numbers are very substantially smaller for mothers born in the Caribbean and the Mediterranean.

There is some evidence to suggest a social class gradient with respect to country of birth. Using data for 1990-95, Botting (1997) showed that infant mortality by mother's country of birth and social class of father (inside marriage) showed a strong gradient for mothers born in the UK, mothers born in the New Commonwealth (excluding Pakistan and Bangladesh), and mothers born in Pakistan, but almost a reverse gradient (based on very small numbers) for mothers born in Bangladesh. However, factors contributing to these differences are likely to be complex. For example, the higher risk of death due to one particular cause - congenital anomaly - in mothers born in Pakistan may reflect higher birth prevalences of anomalies, differential survival rates, differential uptake of antenatal screening programmes, or some combination of these and other factors.

Moreover, the indicator may be subject to unintended consequences. Although infant mortality rates are higher in women born in Pakistan, we do not know whether this differential extends to the second and subsequent generations. Further, infant deaths amongst these migrant mothers still comprise an extremely small percentage (around 1%) of all such births. Given that the Pakistani population is concentrated in certain parts of the country, the indicator would not be relevant to most PCT populations.

#### **iv. Gestation**

Gestation is available on the ONS linked births/deaths file for stillbirths only and is substantially complete (missing on around 6.5% of records). There are 'gestation length' fields on the Birth Notification Dataset and the HES 'maternity tail'. Scottish data (Scottish Executive 1998) cites data that shows an association between preterm births and socioeconomic status. Rates of preterm births ranged from 4.3% in deocat 1 (most affluent) to 7.2% in deocat 7 (most deprived), even taking account of age as a confounding factor. Scottish evidence shows that decreasing affluence is associated with increased risk of having a small baby on either a gestation or birthweight basis.

Although gestation is not readily amenable to modification by PCTs, the ease with which gestation by social class can be monitored may make it a useful candidate for tracking social

class differences in risk factors for infant mortality. Working definitions (and % of total live births: Scottish data) include: preterm <37 weeks (5.4%), very preterm <32 weeks (0.8%), and extremely preterm <28 weeks (0.2%).

### Evaluation

One of the assessors asked that gestational age be reconsidered as an indicator (see comment under 'birthweight' above).

### **v. Obstetric interventions**

Data for both England and Wales show an increase over recent years in the percentage of births delivered by caesarean section and by vacuum extraction but a decline in the number delivered by forceps. However, instrumental delivery, in itself, does not appear to be a risk factor for infant deaths and professional opinion suggests that it does not present a risk to the baby (although caesarean section can present a risk to the mother).



## VIII. Appraisal of Candidate Indicators

### 1. Indicators of antenatal care

#### (i) Late initiation of antenatal care

*Epidemiological justification:* The justification for including this indicator is the association between gestational age at initiation of antenatal care and outcomes for mothers and babies (although there is not necessarily a causal link). There is no specific randomised controlled trial (RCT) evidence supporting early attendance, but many antenatal screening programmes and other interventions depend on early attendance to be effective.

*Relevance to policy:* The Department of Health has accorded priority to access to antenatal care in a number of recent policy statements on the reduction of health inequalities. Its priorities and planning framework for 2003-2006 (Department of Health 2002) identified improving access to antenatal care for women from disadvantaged groups as part of the plan for reducing health inequalities. Further, the recently published programme for action for tackling health inequalities (Department of Health 2003) identified the improvement of access to maternity services as a key area, focusing on early ante-natal booking and take-up rates for women from low-income backgrounds and black and minority ethnic groups. The National Service Framework (NSF) for children is also likely to reinforce the importance of early attendance for antenatal care.

*Indicator construction:* The literature suggests that the difference between booking (i) in the first trimester or early in the second trimester and (ii) later than this is the important distinction. Many antenatal screening tests (e.g. for sickle cell/thalassaemia trait, ultrasonography for the detection of fetal anomalies, and biochemical screening for neural tube defects and Down's syndrome) take place during this period. UK studies that have used late booking as a measure of attendance have used definitions of 'late' varying from 14 to 20 weeks gestation.

*Suggested definition:* Percentage of women booking for antenatal care before 16 weeks gestation. Numerator: Number of women booking for antenatal care before 16 weeks gestation (=A); Denominator: The total number of maternities (=M). Calculation:  $(A/M)*100$ . It is likely that this indicator would need to be developed for maternities within the area of the

relevant PCT (i.e. on a provider basis), rather than for women resident in the PCT who were maternities.

*Technical issues and data availability:* Indicators need to be simple to construct and to be based on readily available data. Currently, there are no national reporting systems that yield this data. However, there is a variable on the HES 'Maternity Tail' – ANASDATE - *First Antenatal Assessment Date* which gives the date when a pregnant woman was first assessed & arrangements were made for antenatal care (although this is not always the date when delivery arrangements were made). Currently, this data item (along with others on the Maternity Tail) is substantially incomplete, but it is a potential source of such data. Another option would be to introduce a compulsory 'screen' on maternity unit patient administration systems requiring the recording of gestation at booking through an NHS Data Set Change Notice. It is likely that routinely collected data on antenatal care would include gestation at booking, although in some maternity units this may be held as manual records rather than on computer-based systems (the lack of data audits prevents more detailed comment on current practice).

Given possible problems related to current data recording of this item, it may be difficult to construct from manually held records for particular segments of the population of women booking, such as minority ethnic groups, young age groups (<18 years), and women from low-income backgrounds (as measured, for example, by women with unemployed partners, single mothers, or mothers living in areas of deprivation using area-based methods), groups for which there is some evidence of late booking.

*Is the risk modifiable:* There is evidence that the established pattern of antenatal care, including late booking, can be challenged through service interventions.

*Is the indicator open to manipulation:* There is no evidence that it would be open to manipulation or perverse interpretation.

*What PCT responsibilities does it reflect?:* commissioning, provision and public health.

### Evaluation

One assessor argued that there was a need to await definitions of antenatal care in the Royal College of General Practitioners/National Institute of Clinical Excellence report and that indicators based on antenatal care were wide open to misinterpretation. The RCOG/NICE

guidelines are on their second round of consultation and standards have not yet been set. There is substantial documentation on this [*Antenatal Care Guideline. National Collaborating Centre for Women and Children's Health commissioned by the National Institute for Clinical Evidence: Second consultation draft for stakeholder review (16.06.03-14.07.03)*] on the NICE website [<http://www.nice.org.uk/article.asp?a=75962>]. The scoring of the candidate indicators indicated that there was a lack of knowledge about the completeness and quality of the data and, consequently, readiness for inclusion in the 2003/04 CHI ratings and another assessor was unsure of the evidence base.

Clearly, one of the definitional issues that would need to be addressed is whether the antenatal booking interview (which can be in a hospital antenatal clinic or a community setting such as general practice) is more useful than, say, the first attendance with a primary care contact such as a GP or midwife. Differences in the way care is provided may affect when the woman first attended for antenatal care.

Another response indicated that the indicators associated with antenatal care/time of booking and number of visits was “a really good step and would match very well with the NSF proposals” (which are still not yet agreed with Ministers). This assessor strongly supported collecting data on gestation age at booking (with midwife or primary care contact) and described *late* booking as after 16 weeks gestation.

The same assessor also raised the issue of late booking amongst minority ethnic groups: ‘Women from certain ethnic groups are booking later and attending poorly and we need to reach them in our new strategy...it is a cultural thing and can persist in 2/3/4<sup>th</sup> generation women born here’. This very important observation could be addressed by the refinement of this indicator (to capture late initiation of antenatal care by ethnic group. The only practical way that this could be collected is through the HES ‘maternity tail’ (First Antenatal Assessment Date), although the poor completeness of data in this collection and of the ‘ethnos’ variable on the general HES record (in 2000-01 ethnic group was recorded in about 76% of delivery records [Government Statistical Service 2002]) presents barriers in the short term. A recent systematic review of social class and ethnicity factors in attendance for antenatal care in the United Kingdom was undertaken by Rowe & Garcia (2003). Although there was a dearth of good quality evidence on ethnic inequalities in attendance for antenatal care, all four studies reporting on antenatal attendance and ethnicity found that women of Asian origin were more likely to book late for antenatal care than white British women. An analysis of Hospital Episode Statistics by the Department of Health (2003) showed that women from minority ethnic groups (their term is non-white) were twice as likely to “book”

later than 20 weeks gestation, late “bookers” constituting about 8% of the white pregnant population and 17% of the “non-white” pregnant population. Further, a Confidential Enquiry into Maternal Deaths report found that 20% of the women who died “booked” late in their pregnancy (after 20 weeks of gestation), virtually all of whom had multiple indicators of social exclusion and a disproportionate number being members of minority ethnic groups. The reasons for late booking are likely to be complex, including language and other barriers to access, significantly higher mobility amongst some groups (especially the Black African population), and migration during pregnancy.

The development of an inequalities indicator based on late antenatal booking amongst minority ethnic groups would accord with the inequalities delivery priority element in the National Service Framework and the need for early antenatal booking but is currently constrained by lack of data collection.

**(ii) Number of antenatal visits (or number of visits missed)**

*Epidemiological justification:* An alternative measure to late initiation of antenatal care is number of antenatal visits (or number of such visits missed). This variable has been reported in the literature to be inversely associated with delivery of a low birthweight infant, infant admission to a special care baby unit, and perinatal mortality over the 4-14 antenatal visit range (Petrou *et al.*, 2003), although, again, a causal link is not necessarily implied.

*Relevance to policy:* As for (i). Access to antenatal care could be measured by number of antenatal visits rather than late initiation of antenatal care.

*Indicator construction:* Given that there is a standard pattern of routine antenatal care in the UK (consisting, in general terms, of a first antenatal or booking visit at around 12 weeks gestation, followed by monthly visits up to 28 weeks, fortnightly visits up to 36 weeks and weekly visits thereafter), it is acceptable to construct an indicator based on number of antenatal visits. In UK studies the measures of care based on attendance include ‘irregular attendance’ (missing  $\geq 2$  appointments without notification) (Lewis 1982); number of antenatal visits attended ( $<9$  and  $\geq 9$ ) and number of antenatal visits missed ( $\geq 2$  and  $<2$ ) (Arnold 1987); and total number of antenatal visits (defined as any consultation between woman and health professional, in hospital, in community or in woman’s home). Research undertaken by Petrou *et al.* (2003) suggests that the difference between  $<7$  visits and  $\geq 7$  visits may be critical with respect to the selected outcomes used in that study.

*Suggested definition:* Percentage of women having <7 antenatal visits during antenatal care (including all consultations between woman and health professional).

Numerator: Number of women having <7 antenatal visits during antenatal care (as defined above) (=A). Denominator: The total number of maternities (=M). Calculation: (A/M)\*100. It is likely that this indicator would need to be developed for maternities within the area of the relevant PCT (i.e. on a provider basis), rather than for women resident in the PCT who were maternities.

*Technical issues and data availability:* There would be technical issues to resolve, including the definition of an antenatal visit. However, as with (i), the main barrier to using such an indicator is likely to be data availability and quality. Information on the *number* of antenatal visits is likely to be routinely recorded in the woman's maternity case-notes. However, such information may not be recorded on, or readily retrievable from, maternity information databases (whether manual or computerised). In that respect, it may be more difficult to construct (and more amenable to error) than late initiation of antenatal care.

Again, it is likely to be impractical to develop this indicator for particular segments of the population of women booking, unless data collection is successfully introduced via computerised recording on patient information systems.

There is no data item in the Maternity Tail relating to this indicator and it would require a compulsory 'screen' on the maternity unit patient administration system to collect it.

*Is the risk modifiable:* The established pattern of antenatal care, including number of antenatal visits, can be modified through service interventions.

*Is the indicator open to manipulation?:* There is no evidence that it would be open to manipulation or perverse interpretation.

*Which PCT functions?:* Commissioning

### Evaluation

The scoring of the candidate indicators indicated that there was a lack of knowledge about the completeness and quality of the data and, consequently, readiness for inclusion in the 2003/04

CHI ratings and another assessor was unsure of the evidence base. Another assessor's comment that there was a need to await definitions of antenatal care in the Royal College of General Practitioners/National Institute of Clinical Excellence report and that indicators based on antenatal care were wide open to misinterpretation would apply to this candidate, too.

A further comment related to some National Service Framework developments that might impact on this proposed candidate indicator. The indicator has been defined with respect to the *conventional* pattern of antenatal visits (capturing data on women who attend <7 visits). However, as the assessor points out, changes to this are now proposed, the new (currently draft) NICE antenatal care clinical guideline suggesting only 7 visits for women with a previous pregnancy and 10 for primips. The indicator will therefore need to reflect this proposed reduction in suggesting a minimum critical level of antenatal visits.

With respect to the association between the *number* of antenatal visits and outcome, the impact of preterm labour was cited as one way in which this could be distorted: ('If a woman goes into preterm labour she is going to miss antenatal visits which would have taken place in the third trimester, by definition'). Clearly, careful thought needs to be given to how such an indicator could be constructed, including whether visits within a specified period of the pregnancy, e.g. first or first and second trimester, might be more useful and its utility compared with other measures of antenatal care.

### **(iii) Gestational age at first primary care contact for antenatal care**

*Epidemiological justification:* No studies have been identified that report on the association of gestational age at first primary care contact for antenatal care and outcomes for mothers and babies.

*Relevance to policy:* Both in its own right and in so far as gestational age at first primary care contact for antenatal care is likely to be related to late initiation of antenatal care and overall number of antenatal visits, this measure is relevant to Department of Health concerns about access to antenatal care.

*Suggested definition:* Proportion of women registered with general practice whose first primary care contact for antenatal care is <10 weeks gestation. Numerator: Number of women with general practice registration whose first primary care contact for antenatal care is <10 weeks gestation (=A). Denominator: Number of women registered with general practice who

deliver (=M) [it may be impractical to take account of stillbirths and miscarriages].  
Calculation:  $(A/M)*100$ .

*Indicator construction, technical issues, and data availability:* The main barrier to the development of such an indicator is the lack of routinely reported information in primary care trusts on the woman's gestational age at first primary care contact for antenatal care. No studies have been found in the literature that have attempted to operationalise this measure. While it would be reported in the woman's case notes, it is unlikely to be consistently recorded (if at all) on computerised GP databases. It could be made a requirement as part of the new GP contract, although this may take time to achieve.

*Is the risk modifiable:* Gestational age at first primary care contact for antenatal care may be difficult to modify other than through general health education measures.

*Is the indicator open to manipulation?:* There is no evidence that it would be open to manipulation or perverse interpretation.

*Which PCT functions?:* All three.

### Evaluation

The title of this indicator (originally defined as 'gestational age at first contact with general practitioner for antenatal care') has been amended to 'primary care contact' as current policy is to allow women to book with midwives rather than general practitioners. One of the assessors commented that there was a need to await definitions of antenatal care in the Royal College of General Practitioners/National Institute of Clinical Excellence report and that indicators based on antenatal care were wide open to misinterpretation (and that this would apply to this candidate, too). Differences in the way care is provided may affect *when* the woman first attended for antenatal care.

As with the previous antenatal care indicators, the scoring of the candidate indicators indicated that there was a lack of knowledge about the completeness and quality of the data and, consequently, readiness for inclusion in the 2003/04 CHI ratings and another assessor was unsure of the evidence base.

**(iv) Unbooked women**

*Epidemiological justification:* Women falling into this group are likely to experience the same (or stronger) associations with outcomes for mothers and babies as women who initiate their care late or have few antenatal visits.

*Relevance to policy:* As a group who never formally ‘book’, they are clearly relevant to Department of Health policies on access to antenatal care. A recent audit (Beckman & Demilew 2001) showed that almost half of these women had had some contact with antenatal services but had never been formally ‘booked’ for care. Teenagers, single, unsupported women, and unemployed women or women with unemployed partners were over-represented, compared with other women giving birth at the particular hospital.

*Indicator definition:* Proportion of women who deliver who never formally booked.  
Numerator: The number of women who deliver who never formally booked (=A).  
Denominator: The total number of maternities (=M). Calculation:  $(A/M)*100$ .

*Indicator construction, technical issues, and data availability:* The main drawbacks to the use of such a measure are the overall numbers of such women and the difficulty of identifying them in routine datasets. Only about 1% of women giving birth in the United Kingdom fall within this group, that is, without any antenatal care (Hamlyn *et al.*, 2002). By their vary nature (as ‘unbooked’), such women would be difficult to identify in administrative records. However, the data item ‘Booking Status’ on the *Maternity Data Dictionary Version 3.0* contains the category value ‘Unbooked’ (along with ‘Awaiting/scheduled’, ‘Booked’, ‘Booked elsewhere’, ‘Declined booking’, and ‘Mother undecided’).

*Is the risk modifiable:* This risk may be difficult to modify other than through general health education measures.

*Is the indicator open to manipulation?:* There is no evidence that it would be open to manipulation or perverse interpretation.

*Which PCT functions?:*



### Evaluation

The only assessor to comment specifically on this candidate indicator was enthusiastic about its inclusion. However, again, lack of knowledge about data quality and completeness was revealed in the scoring and another assessor was unsure of the evidence base.

#### **(v) Postnatal care contacts**

This indicator is just flagged at this stage as postnatal (as well as antenatal) care also significantly affects the health outcomes for the mother and child. *The Maternity Data Dictionary Version 3.0* includes the Data Item 'Total Number of Contacts', defined as: 'The total number of postnatal contacts with the mother following discharge from an NHS facility, for a six week period. This includes contacts in a domiciliary or clinic setting'. The category value is a positive integer. As with indicator (ii) above, a critical number (cut off) of visits would need to be identified from the evidence base.

### Evaluation

One of the assessors reported the need for a good indicator for postnatal visits and comments may be forthcoming from midwives and other professionals on the post birth National Service Framework group. Another assessor reported that evidence of targeting visits on social classes IV & V would be useful.

## ***2. Maternal behaviour factors in antenatal and postnatal care***

#### **(i) Smoking in pregnancy**

*Epidemiological justification:* Smoking is one of the most important preventable determinants of infant deaths. It appears to have its strongest effect on birthweight. This relationship was examined in the Scottish data for 1987-1996 (Scottish Executive 1998). In a subset of 36,617 singleton deliveries to women aged 25 to 29 years, the rate of low

birthweight babies was 9.8% in current smokers, 4.4% in former smokers, and 4.3% in non-smokers. Similar but less marked differences were reported when deliveries were examined on a gestation basis. The Government's Scientific Committee on Tobacco and Health (SCOTH), which advises Government on smoking and health, stated in its 1998 Report: 'Smoking in pregnancy causes adverse outcomes, notably an increased risk of miscarriage, reduced birthweight and perinatal death'.

*Relevance to policy:* One of the 12 national headline indicators in the Department of Health's programme for action in tackling health inequalities (Department of Health 2003) is: 'Smoking prevalence – manual groups/in pregnancy – prevalence of smoking among people in manual social groups, and among pregnant women'. In addition, the collection of data on smoking in pregnancy is needed to help the Government monitor targets on cessation of smoking in pregnancy. In its White Paper *Smoking Kills* (Department of Health, 1998), the Government set out the target to reduce the percentage of women who smoke during pregnancy from 23% to 15% by 2010, with a fall to 18% by 2005. Currently, progress towards targets on the reduction of smoking in pregnancy are monitored through the Infant Feeding Survey. This is only conducted every five years among women who have recently given birth and, as the data are collected retrospectively, cannot be validated. There is now a requirement to collect data on smoking in pregnancy at the local level for all hospital trusts with pregnant women in their care (NHS Information Authority 2002) but concerns have been expressed about methods of collection. Attention may need to be accorded to methods of local data collection and their accuracy.

*Indicator definition:* (1) Percentage of women smoking before or during pregnancy. Numerator: Number of women smokers before or during pregnancy. Denominator: The total number of maternities. Calculation:  $(A/M)*100$ . (2) Percentage of women continuing to smoke during pregnancy. Numerator: Number of women smoking at delivery (=B). Denominator: The total number of maternities. Calculation:  $(B/M)*100$ . These indicators are compatible with those suggested in the DSC Notice.

*Indicator construction:* There has, until recently, been no central collection of data on smoking in pregnancy. However, the data notice for smoking in pregnancy requires NHS trusts to collect the following data on all pregnant women: 1. Did the patient smoke at all in the 12 months before the start of her pregnancy? (response options: Yes / No / Don't know); Does / did the patient smoke at the time of booking? (Yes / No / Don't Know). 3. Does / did the patient smoke at the time of delivery? (Yes / No / Don't Know). Given that the

implementation date is 1<sup>st</sup> April 2003, there should be 12 months of data by 31<sup>st</sup> March 2004. Where such data have been collected in the past, concern has been expressed and quality and validity. To address such matters additional indicators could be developed to address completeness of the data collected: (3) Percentage of pregnant women whose smoking status before or during pregnancy is unknown; (4) Proportion of pregnant women whose smoking status at the time of delivery is unknown.

*Is the risk modifiable:* As a result of a commitment in *Smoking Kills*, NHS Smoking Cessation Services were rolled out in Health Action Zones in April 1999. These services were extended across the country in April 2000 and include services to help pregnant women to give up smoking. In January 2001 PS(PH) announced a £3 million initiative to bring together all services for pregnant women who want to give up smoking, followed in December 2001 by the announcement of an extra £3 million in funding to help reduce smoking in pregnancy.

*Is the indicator open to manipulation or perverse interpretation?:* There is no evidence that it would be open to manipulation or perverse interpretation. However, given that in some trusts the numbers of those whose smoking status is unknown may be high, indicators will need to take into account information on these women.

*Which PCT functions?:* commissioning, provision and health improvement.

### Evaluation

Assessors felt that smoking in pregnancy was a very important indicator. However, there may be quality issues with respect to the data collected on smoking in pregnancy. With self-reported smoking levels there is no way in routine data collection of validating the mother's account (although, in survey settings, cotinine measurements are sometimes taken). In the 1999 Health Survey for England there were important differences of the magnitude 3-12% between cotinine-adjusted prevalences of tobacco consumption and self reports for all minority ethnic groups (African-Caribbean, Indian, Pakistani, and Bangladeshi) for both males and females, but only minor differences for the Irish and the general population (1-3%) (Erens *et al.*, 2001). For example, only 1% of Bangladeshi women reported smoking cigarettes and 27% consuming some form of tobacco product; however, cotinine-adjusted prevalence suggested that around 38% of these women consumed tobacco. Problems of translation and linguistic equivalence in cross-cultural survey settings may account for some of the difference.

Concern about the accuracy of self-reports in Scottish data on smoking in pregnancy has been reported: Information on smoking behaviour during pregnancy is recorded on the SMR02 national maternity dataset based on self-reported information obtained from mothers at their booking ante-natal visit in the community or hospital. A comparison of data on smoking at booking and at health visitor's first visit shows considerable variation in rates of smoking at both points, a higher rate at booking being consistently reported (Information and Statistics Division 2003).

Consequently, self-reported data collected on smoking in pregnancy could be open to manipulation by those women who may not wish to give up but, for social desirability reasons, conceal their true smoking behaviour. Sample data collected on smoking in pregnancy may need to be periodically validated against results with cotinine and carbon monoxide checks.

However, another assessor reported positive comments on feasibility ('good data coming onstream') and with respect to the reduction of social class inequalities ('good takeup of services by deprived populations'). Indeed, there is now evidence of the effectiveness of smoking cessation services in reducing inequalities (Lowey *et al.*, 2003).

CHI reported that a question on systems in place for collecting information on smoking in pregnancy, and quality of the data in Quarter 4, is included in the provisional list for 2003/04.

## **(ii) Initiation of breast-feeding**

*Epidemiological justification:* The literature reports that mothers who do not breast feed are at a higher risk of pre-menopausal breast cancer and epithelial ovarian cancer compared to mothers who do breast feed. The baby is protected against gastroenteritis and respiratory infection and breastmilk may also prevent otitis media, urinary tract infection, juvenile onset insulin-dependent diabetes mellitus and obesity. With respect to infant mortality, promoting breastfeeding has been said to reduce infections, SIDS, and atopic conditions (McGuire & Anthony 2001).

*Relevance to policy:* The UK Infant Feeding 2000 survey shows that mothers working in higher paid occupations are more likely to breastfeed than those in low income groups (85%

vs. 59%). Increasing the percentage of women who breastfeed is an important part of the UK government's drive to reduce health inequalities in infants.

*Indicator definition:* One or more of the following: (1) The percentage of women adopting the breast as the initial method of feeding recorded within the first six hours of birth. Numerator: Number of women adopting the breast as the initial method of feeding recorded within the first six hours of birth (=A). Denominator: All maternities (=M). Calculation:  $(A/M)*100$ . (2) The percentage of women breast feeding at the time of discharge from the maternity episode. Numerator: The number of women breast feeding at the time of discharge from the maternity episode (=B). Denominator: All maternities (=M). Calculation:  $(B/M)*100$ .

Definitions in (1) & (2) are compatible with the *Maternity Care Data Dictionary Version 3.0*.

(3) The percentage of women who were breastfeeding at the time of discharge from the maternity episode who were still breastfeeding at 6 weeks from discharge. Numerator: The number of women who were breastfeeding at the time of discharge from the maternity episode (=A). Denominator: The percentage of women who were breastfeeding at the time of discharge from the maternity episode who were still breastfeeding at 6 weeks from discharge (=D). Calculation:  $(A/D)*100$ .

*Indicator construction:* There are two possible components (rates) that could be measured: (i) initiation of breastfeeding rates and (ii) duration of breastfeeding rates. In 2000, 71% of new mothers in England and Wales started breastfeeding, demonstrating the practicality of (i). The WHO recommends that, wherever possible, infants should be fed exclusively on breastmilk from birth until six months of age to protect both the child and mother's health. However, at 6 weeks only 42% of new mothers were still breastfeeding, falling to 21% at six months, emphasising the importance of (ii). There would also need to be some clarification of the definition of the term 'breastfeeding', for example, whether or not babies were fed exclusively on breastmilk. Some studies have reported on 'ever breastfed'. Investigators have called for the definitions of breastfeeding, weaning and outcome measures to be standardised, so that data can be compared across studies.

The *Infant Feeding Survey* uses the following definitions: 'breastfed initially': refers to all babies whose mothers put them to the breast, even if this was on one occasion only; 'incidence of breast feeding': refers to the proportion of sampled babies who were breastfed initially; 'prevalence of breastfeeding': refers to the proportion of all sampled babies who were wholly or partially breastfed at specified ages; and 'duration of breast feeding': refers to

the length of time for which breastfeeding continued at all, regardless of when non-breast milk and other drinks or foods were introduced. The evidence on duration of feeding is stronger than that on initiation, but this data is collected at lower levels.

Information on breastfeeding is not centrally reported and is currently probably unavailable locally on a routine basis. There are, however, a number of local data sources that could usefully provide such information, including maternity and child health computer systems and data collected by the health visitors as a part of their caseload profiling (the latter is likely to be available only in some PCTs). Indicators (2) & (3) may be easier to construct as such information is likely to be recorded on computerised maternity unit information systems.

*Is the risk modifiable:* A recent HTA report has reported on the effectiveness of public health interventions to promote the initiation of breastfeeding from systematic review evidence. The investigators report that developing and delivering effective programmes to address this socioeconomic bias 'would result in mothers and infants in low income groups also being able to enjoy the health benefits of breastfeeding'. Although only 71% of new mothers in England and Wales started breastfeeding, around 98% of new mothers in Scandinavia breastfeed.

*Is the indicator open to manipulation or perverse interpretation?:* There is no evidence that it would be open to manipulation or perverse interpretation.

*Which PCT functions?:* All three.

### Evaluation

Assessors also felt that initiation of breast feeding was a very important indicator, although there was also support for having this data matched by social class or deprivation scores (to accord with the inequalities agenda and priorities in the National Service Framework). There was indication in the consultation that tight definitions would be needed and that the indicator would be very open to manipulation (*vide*: '...all the midwife will have to do is put the baby on the breast in delivery suite and say that feeding has been initiated!'). One respondent welcomed the attention to sustained breast feeding as well as uptake.

While the scoring indicated lack of knowledge on completeness and quality of the data to construct the indicator and lack of readiness for inclusion in the 2003/04 CHI ratings, another assessor thought that it was a 'possible' indicator. CHI report that the Department of Health has set up a collection on this that might support the development of indicators on the initiation and duration of breastfeeding in the future. A question on systems in place for collecting this information, and the quality of the data in Quarter 4, is included in the provisional list of indicators for 2003/04.

### ***3. Indicators of data quality and completeness***

There are potentially a number of indicators that could be developed around the completeness and quality of data on maternity care collected at national level. Probably the strongest candidate is incompleteness of the 'maternity tail' data. However, other common problems include the diversity of maternity information systems in use, the lack of common definitions for data items used in maternity datasets, the inadequacy of the routine data collected in relation to childbirth (a paucity of data items on the care of the mother and baby), and response times to national collections (e.g. the CESDI reporting system).

#### **(i) Completeness of the 'maternity tail'**

*Epidemiological justification:* The HES 'maternity tail' contains a number of fields that measure factors associated with adverse outcomes in pregnant women and their babies, including 'first antenatal assessment date', 'birthweight', 'length of gestation', and 'total number of previous pregnancies'.

*Relevance to policy:* The ability of health care organisations to monitor access to maternity services, including late ante-natal booking and low take-up rates for women of young age, those from low-income backgrounds, and black and minority ethnic groups would be currently severely limited by the lack of routinely collected data that is reported. The maternity tail is a potential source of information to address some of these issues, including the initiation of antenatal care.

The drawbacks of the current levels of incompleteness of the HES 'maternity tail' were fully documented in the evidence and report of the Select Committee on Maternity Services.

Moreover, in Scotland data relating to all admissions to maternity units has been collected on a simple and readily completed form (SMR02) that is reported to be 98% complete.

*Indicator construction:* The maternity tail contains a total of 17 data items. Some of these items are more important than others with respect to their measurement of factors associated with outcomes for babies. Also, levels of completeness are likely to vary across these items. The most recent data indicates that only 65.1% of maternity records contain data (as measured by a valid method of delivery in the maternity tail), although this proportion varies between 87.8% (Eastern) and 52.3% (Northern & Yorkshire) across Regional Office Areas. Little is known about the distribution of systematic biases in the recording of items on the 'maternity tail' with respect to: (i) the consistency of recording of the separate data items constituting the 'maternity tail'; (ii) whether the missing data is skewed in some way compared with the data that is recorded, that is, whether recording is *selective* of certain response characteristics.

It would be possible to develop a composite indicator based on completeness of several data items or of a particular data item (such as 'delivery method'), depending on the consistency with which the 'maternity tail' data items are completed across NHS trusts.

*Suggested definition:* Percentage of records with first antenatal visit recorded (or one of the other relevant fields) in the maternity tail. Numerator: Number of records with a valid first antenatal visit recorded (=A). Denominator: All maternity records (=R). Calculation:  $(A/R)*100$ .

*Technical issues and data availability:* The maternity tail is reported by all NHS trusts responsible for maternity inpatient care so there are no data barriers to the construction of such an indicator. Consideration would need to be given to which data fields (or combination of fields) are used in the construction of the indicator.

*Is the 'risk' modifiable:* Although some measures of data completeness and quality on the main HES record have been shown to be difficult to improve (for example, ETHNOS), the fact that some trusts have attained high levels of completeness over a relatively short time scale demonstrates that significant levels of incompleteness on administrative databases are amenable to change in the short term.

*Is the indicator open to manipulation or perverse interpretation?:* There is no evidence that it would be open to manipulation or perverse interpretation.



*Which PCT functions?: Commissioning*

*Evaluation*

There was strong support for this indicator. For example, one assessor stated: ‘Absolutely important to look at completeness of HES and the maternity data tail...such a current problem with massive under-reporting’. CHI, too, felt that the completeness of the maternity tail was ‘potentially a good indicator’, but noted that the inclusion from an inequalities perspective of an indicator on completion of the ethnicity field in the provisional 2003/04 list might preempt a second HES quality indicator.

One of the drawbacks of this indicator is that improvement would largely be in the hands of the acute trust rather than the PCT, although the PCT might be in a position to influence the trust’s behaviour in this regard. Another assessor felt there was only a weak evidence base for the effectiveness of this with respect to the reduction of social class inequalities in infant mortality.

**(ii) Efficiency of computerised maternity information systems**

In the Health Select Committee enquiry into maternity services, much criticism was made of data collection processes and maternity information systems, including the use of non-standard data items in reporting. At the time the NHS Numbers for Babies Project was initiated, not all maternity departments were using computerised information systems. Those that were used a wide range of proprietary systems or those developed in-house. There was wide variability in what information was recorded on the systems and how easy it was to customise reports from the systems. It may be feasible to develop indicators that address some of these issues.

*Evaluation*

Again, improvement would largely be in the hands of the acute trust rather than the PCT, although the PCT might be able to exercise pressure. Also, another assessor felt this indicator was not related to social class inequalities in mortality.

### **(iii) Response times for reporting to CESDI (CEMACH)**

The suggestion has been made of the possibility of using response times for the CESDI (now CEMACH) reporting process, that is, the return of the Rapid Report Form (first instituted in 1993), for use as an indicator.

The current CESDI Regions collect handwritten Rapid Report Form data that is mainly provided by local maternity units that notifies CESDI of deaths of fetuses and babies from 20 weeks gestation to 12 months old. This information is validated by the local Region. Most Regions input the data on to a system developed by the CESDI Secretariat, to whom it is subsequently downloaded.

It may be feasible to develop an indicator that focuses on this process (possibly the differences in response times by trusts) requires further exploration. There is, for example, a field on the Rapid Report Form for date CESDI form completed.

#### *Evaluation*

There is limited evidence on the feasibility of introducing such an indicator and its utility in the CHI process. One of the assessors suggested that it would be possible to undertake but that there was no link with health and another commented similarly ('no evidence that this is related to outcomes of routine care'). However, CHI considered response times for reporting to CEMACH a possibility.

#### ***4. Social and biological factors derived from the linked birth/perinatal & infants deaths file***

##### **(i) Mother: Support Status and/or Parenting Intention.**

There may be only limited (and inconsistently recorded) routinely collected data at booking on mother's 'support status' or 'parenting intention'. However, a proxy could be developed from the anonymous linked file using type of registration, that is, births jointly registered/different addresses and sole registrations.

*Epidemiological justification:* The infant mortality rate was 8.0 for births that were joint registrations/different address and 7.6 for births that were sole registrations, compared with 5.5 for all births, 4.8 for those inside marriage, and 6.6 for those outside marriage.

*Relation to policy:* There are no explicit government policies that are seeking to shift the balance in registration types. However, government policies to reduce teenage conceptions are likely to significantly impact on the proportion of births that are sole registrations.

*Indicator construction:* The *Maternity Care Data Dictionary Version 3.0* lists the Data Item 'Parenting Intention', defined as 'An indication of the mother's parenting intentions for the pregnancy/child(ren). This is normally recorded at booking but may be amended at any time'. The category values are: Child Protection; Father takes legal responsibility; Fostering/adoption planned' Intentions not known; Mother and father take joint legal responsibility; Mother takes legal responsibility; and Surrogate mother. A further data item on the *Maternity Care Data Dictionary Version 3.0* is 'Mother: Support Status', defined as 'The level of potential support available to a mother in relation to her living arrangements'. The category values are: Homeless unsupported; Homeless with partner; In care/fostered; Lives alone/unsupported; Lives with husband/partner; Lives with other friend/relative; Lives with parents; Mother & Baby unit; Prisoner; Psychiatric Unit; and Sheltered accommodation/refuge. There is a *proximate* mapping from 'Mother takes legal responsibility' (on the Parenting Intent data item) and from 'Lives alone/unsupported' (on the Mother: Support Status data item) to 'birth registered/different addresses and sole registrations'.

The ONS anonymous linked births/infant deaths file identifies registration type: 'Inside marriage' and 'Outside marriage', the latter subdivided into 'joint registration/same address', 'joint registration/different address', and 'sole registration'. No missing data is recorded in statistical analyses based on this source. Further, it is based on a comprehensive data source readily available to PCTs.

There are grounds for using a composite indicator: joint registration/different address & sole registration. In 2000 60.5% of all live births in England and Wales were registered inside marriage, 24.7% joint registration/same address, 7.2% joint registration/different address, and 7.6% sole registration. The differences in rates between births inside marriage and joint registration/same address is not substantial, e.g. infant deaths, 4.8 & 5.9 per 1,000 live births, respectively. However, the differences in rates between inside marriage and the other 'outside marriage' categories are much higher, e.g. infant deaths, 8.0 for joint registration/different

address and 7.6 for sole registrations. Moreover, for these two categories of registration, rates are similar across all measures [still birth, perinatal, neonatal, postneonatal, and infant rates]. From the viewpoint of deriving stable rates (based on numbers), there is a strong rationale for combining them. The drawback is that, in 2000 for example, only 20.9% of all infant deaths took place with these types of registration.

*Indicator definition:* Percentage of all live births that were joint registrations/different address and sole registrations (combined). Numerator: Number of live births that were joint registration/different address & sole registrations combined (=A). Denominator: All live births (=B). Calculation: (A/B)/1000B.

[UK value, 2000: 14.7%]

*Is the risk modifiable:* The risk is only indirectly modifiable, in the sense that a significant proportion of these births will be to teenage mothers, the reduction in numbers of whom are amenable to health promotion/education measures.

*Scope for unintended consequences:* The indicator captures only a part of the maternal population at risk of poor support status.

*Which PCT functions?:* health improvement

### Evaluation

One of the assessors considered that the mother's support status and/or parenting intention was not modifiable by any PCT or part of the NHS and another that it was 'not related to NHS services'. CHI felt that, as with mother's age <20, this indicator would mirror trends in the teenage pregnancy indicator. Another assessor commented: 'Sole registrations likely to increase over time, as sociological phenomenon, without implying worsening infant mortality'.

### **(ii) Cause group**

*Epidemiological justification:* The two major causes of neonatal deaths are 'immaturity related conditions' and 'congenital malformations' (together accounting for about 75% of all neonatal deaths). Just under 50% of all post-neonatal deaths are accounted for by two groups:

‘signs, symptoms and ill-defined conditions’ (predominantly SIDS) and ‘congenital anomalies’.

*Relation to policy:* These individual cause groups show strong social class gradients.

*Indicator construction:* The anonymous linked file contains information on cause of death, classifiable into the following *ONS cause groups*: congenital anomalies; antepartum infections; immaturity related conditions; asphyxia, anoxia or trauma (intrapartum); external conditions; infections; other specific conditions; asphyxia, anoxia or trauma (antepartum); remaining antepartum deaths; sudden infant deaths; Other conditions. These causes are comprehensively recorded (but only for deaths) on the linked file.

An indicator based on the incidence or prevalence of some of these conditions (for example, those which show a strong social class gradient) in children aged <1 year (irrespective of outcome) might serve as a proxy for social class differences in infant mortality. There is a lack of epidemiological evidence to support the development of such an indicator, with the notable exception of SIDS. SIDS accounted for 1.6% of all neonatal deaths, 18.1% of all postneonatal deaths, and 6.7% of all infant deaths in England and Wales in 2000. Moreover, there is a strong evidence base for social class relatedness and SIDS is amenable to intervention at PCT level.

However, information may in time be available via the Birth Notification Dataset on congenital anomalies. In 2000 this cause group contributed the second largest number of neonatal deaths (26.3%), after immaturity-related conditions (47.7%), the 1995-2000 data showing a strong social class gradient (Department of Health, 2002a, fig. 4). A similar steep gradient for this cause group is identified using this data to examine postneonatal mortality (Department of Health, 2002a, fig. 5), congenital anomalies contributing 27.2% of postneonatal deaths. Monitoring congenital anomalies by social class for all births may provide a useful proxy for social class differences in infant mortality, although further evidence is required.

For neonatal deaths (occurring in the first 28 days after birth) one of the main contributors (as noted) are deaths associated with prematurity. Prematurity for all births (regardless of outcome) may also have potential as a proxy indicator. The ONS linked file contains information on gestation which could be used in its own right or to derive proxy measures based on gestation by birthweight. ONS’s analysis of immaturity related conditions amongst neonatal deaths demonstrates a strong social class gradient.

*Is the risk modifiable:* The value of these indicators would clearly be their utility as a proxy measure of social class differences in mortality (that is, to monitor trends in social class differences), but – again - dependent on evidence-based findings. With the exception of SIDS , many of these cause groups would not offer modifiable risks at the PCT level. The frequency of some of these events at PCT level might also be too low.

*Scope for unintended consequences:* No specific unintended consequences have been identified.

*Which PCT functions?: commissioning*

### Evaluation

One assessor felt that the process of assigning cause of death in the death certification process was not exact and could be manipulated.

### **(iii) Maternal age (mother's age <20)**

*Epidemiological justification:* Analyses of the ONS linked births/deaths file show that infant mortality rates are raised in women under 20 and 40 & over (8.4 and 6.8, respectively), compared with all deaths (5.5).

*Relation to policy:* One of the final performance indicators for primary care trusts for 2003 is 'Teenage Pregnancy – Conceptions below age 18 (change in rate)'. The Social Exclusion Unit Report on Teenage Pregnancy (1999) set out an action plan with the overall goal of halving the under-18 conception rate by 2010. The NHS Plan also sets an interim target of achieving a 15% reduction in this rate by 2004. The Reducing Health Inequalities section of the Priorities and Planning Framework includes a target to achieve agreed local teenage conception reduction targets while reducing the gap in rates between the worst fifth of wards and the average by at least a quarter in line with national targets.

*Indicator definition:* % births to mothers <20 years at baby's birth. Numerator: Number of live births to mothers aged under 20 years at baby's birth (=A). Denominator: All live births (=B). Calculation: (A/B)/1,000B.

*Indicator construction:* The numerator is available on the ONS births database and in the Birth Notification Dataset, as is the denominator (for a rate of births to mothers <20).

*Is the risk modifiable:* The Social Exclusion Unit Report on Teenage Pregnancy set out an action plan for halving the under-18 conception rate by 2010. The Teenage Pregnancy Strategy seeks to achieve its targets through a wide ranging programme of co-ordinated activity including improved advice and contraceptive services for young people.

*Scope for unintended consequences:* Indicators based on teenage conception rates are widely accepted.

*Which PCT functions?: Health Improvement*

### Evaluation

Although different from the teenage pregnancy indicator, there is clearly substantial overlap. CHI's provisional list for 2003/04 retains the teenage pregnancy indicator (change in rate). Another of the assessors was in favour of using the latter rather than developing an additional indicator.

## **5. Staffing ratios**

### **(i) Midwifery**

*Indicator construction:* A number of possible indicators could be developed.

- (i) Midwifery staffing ratio, that is, the number of WTE midwives per 100 births or the number of WTE midwives per 100 population aged 0-4;
- (ii) *Vacancy rate for midwifery posts*, that is, the difference between the number of WTE midwife posts funded in 2003-04 and the number of WTE midwives in post in 2003-04. Team working in maternity units is heavily dependent on the recruitment and retention of adequate numbers of midwives. This indicator may be subject to unintended consequences in that recruitment may be affected by housing costs.

- (iii) The difference between the current number of births per WTE midwife and the number of WTE midwife posts needed to meet the Birthrate Plus standard\* [\*the National Birthrate Plus Project, based on the Birthrate Plus tool, a Royal College of Midwives/Department of Health funded project. See: Ball J, Washbrook. *Report of the Birthrate Plus Project – Contribution to demand led Midwifery Staffing Model*. 2002].

The Birthrate Plus is a tool for assessing work force requirements in maternity units. Some work has been done for the maternity and neonatal work force group, using Birthrate Plus data for a range of different types of maternity unit. Births per midwife ratio derived from Birthrate Plus are: Level 1 (small DGH) – 28; Level 2 (DGH) – 28; Level 3 (Tertiary) – 31. The Birthrate Plus tool will be able to analyse midwifery staffing requirements of different models of care provision and the ratios cited are suggestive figures from initial data analysis. For midwife-led maternity units with <500 births per year, the number of midwives may be driven by the minimum staffing required to maintain continuous maternal cover independently of how low the number of births. Based on Birthrate Plus data, 27.12 midwives have been taken as required for midwife-led maternity units with 500 births and to provide additional ante-natal and post-natal services for women who live locally but give birth in a hospital. A births per midwife ratio of 35 has been used for home births, with home births assumed to represent 5% of all births.

Thus, to develop satisfactory indicators would first require classification of maternity units by type, then followed by an assessment of difference between actual and recommended ratio.

Some difficulties may arise in deriving such data for individual maternity units (as opposed to NHS trusts). Information on the number of midwifery posts for specific units within trusts is not routinely collected nationally – but may be required in local workforce planning data. Moreover, such information would need to be reported for maternities within the area of the relevant PCT (that is, on a provider basis) rather than for maternities in the resident PCT population, as women giving birth may attend a number of different maternity units.

Data is reported by the Department of Health on the following categories: Registered midwife - Maternity services (N2C) & Registered midwife - Education staff (N2J), Health visitor – Community services (N3H). The latest data is: Department of Health, NHS Hospital and



Community Health Services, Non-Medical Workforce Census. England: 30 September 2001. Standard published tables provide numbers for each of the above codes at the (former) Health Authority level. There is also a table for NHS trusts (including PCTs) that reports an aggregate count for 'Nursing, midwives, and health visitor staff'. It should be possible to disaggregate this aggregate count to yield separate counts for 'Registered midwife – Maternity services' (N2C) and 'Registered midwife – Education staff' (N2J).

**(ii) Health visitors (HV)**

The Community Practitioners and Health Visitors' Association (the health visitors professional group) offers little by way of guidance on recommended staffing levels.

*Epidemiological justification:* The evidence base linking HV staffing levels to infant mortality is slender but there is evidence that focussed HV input can accurately target babies most at risk of SIDS. There is strong evidence which shows that advice on sleeping position can reduce the risk of SIDS and this is a prime responsibility of both midwife and HV shared as part of statutory post partum care in the first 28 days.

*Indicator construction:*

Data is reported by the Department of Health on the category: Health visitor – Community services (N3H). The latest data is: Department of Health, NHS Hospital and Community Health Services, Non-Medical Workforce Census. England: 30 September 2001. Standard published tables provide numbers at the (former) Health Authority level. Given there is also a table for NHS trusts (including PCTs) that reports an aggregate count for 'Nursing, midwives, and health visitor staff', it should be possible to disaggregate this count to yield the number of health visitors at PCT level.

*Suggested definition:* (1) The number of WTE health visitors per 1000 births or (2) The number of WTE health visitors per 1000 population aged 0-4. Vacancy rates could be added if extractable from the local workforce datasets collected by StHAs.

*Scope for Manipulation/Perverse interpretation:*

*PCT functions covered:* Primary care provision, public health. This would be suitable as preparation for the CGR or inspection process..

### **(iii) Consultants**

In addition, there is an RCOG/RCM recommended standard of *40 hours of consultant time dedicated to the labour ward* (which the RCOG [2003] report is unmet by only 16% of units). Better staffing ratios have been reported to be associated with lower caesarean section rates.

### Evaluation

There was generally little support at present for indicators based on staffing ratios. One of the assessors reported her uncertainty about these indicators: ‘...the ratio of 35 birth per midwife ratio for home births is just a suggestion and not really evidence based...Similarly, we have not accepted the RCOG/RCM statement that there should be 40 hours of consultant time dedicated to the labour ward. These are all just figures drawn up by the colleagues...so better not to develop indicators just yet’. It was also clear that a very substantial amount of work on workforce planning and assumptions was under way by the Human Resources Directorate at the NHS Executive that would require consideration and militate against the current development of indicators on staffing (CHI corroborated this view).

Another assessor felt that, for both midwifery and health visitor staffing, there was not much evidence of a close relationship to the outcomes of interest, although evidence of needs-based targeting might be useful. It was also pointed out that midwifery/health visitor staffing was affected not just by the NHS but by other factors as well, e.g. cost of living.

## **6. HES indicators**

The HES general episode record offers scope to develop indicators of care in the baby’s first year of life as this part of the statistical database (as opposed to the maternity tail) is of quality. The difficulty with this approach is that the ONS Linked Infant Mortality File and the HES system are independent and unlinked databases. The recording of the NHS number is incomplete on both records. While there is scope to undertake probabilistic matching using an algorithm based on baby’s date of birth, sex, and postcode, this kind of exercise is time-consuming and difficult to operationalise with respect to confidentiality constraints. This

would rule out the use of the HES database for development of indicators based on record linkage.

However, HES would provide information on babies that die in hospital within the first year of life (that is, hospital case fatalities). These would include: (i) babies born in hospital who are not discharged after birth but die during their hospital spell (that is, babies whose discharge method is 'died in hospital'); (ii) babies who are admitted to hospital after birth and who die during their hospital spell. However, these statistics would exclude babies who die in community settings during their first year of life, some of whom may have had one or more hospital admissions after birth (these babies could only be captured by record linkage). A high proportion of early neonatal deaths are likely to be hospital deaths (hospital case fatalities), but a much lower proportion of postneonatal deaths.

HES indicators based on hospital episode statistics that capture measures of morbidity of the infant during its first year of life (or first three years if the scope is widened to encompass measures of child health in the first years of life) are feasible.

There are a number of possibilities for indicator development:

*(i) Well babies* - A well baby is a baby born in hospital that did not require special care. Well babies are often excluded from HES analyses. However, a simple indicator based on the percentage of hospital births that are identified in HES as 'well babies' is feasible. This is not subject to the major quality deficiencies associated with the 'maternity tail'. Moreover, it could, straightforwardly, be linked via the postcode of residence to a deprivation classification (such as the Townsend Material Deprivation Index), to provide some measure of social class differences in the prevalence of 'well babies'.

The *NHS Data Dictionary & Manual* has the following definition for Well Baby:

"A well baby is a neonate, a baby aged 28 days or less, that has a neonatal level of care classification of 'Normal Care'. Note that a well baby episode can only be a baby's first ever episode, never a second or subsequent episode. These babies will be looked after by their mothers in a maternity neonatal ward and require minimal nursing care or medical advice."

All registrable births, babies born live at any time, are admitted and start a hospital provider spell. During the time in hospital the baby is the responsibility of a healthcare professional, typically either the consultant or a midwife responsible for the mother. When there is a transfer of care, a new consultant episode (hospital provider) or midwife episode will start.

In the past HES advised that the use of diagnosis codes for well babies was required to distinguish them from other records, when ICD-9 was in use. When HES moved to ICD-10 it switched to using Neonatal Level of Care to identify the well babies. HES do not require the diagnosis field for this purpose now, but it does confirm the diagnosis codes given are the correct ones to use.

In conclusion, the following method of coding is valid:

Admission method	82	<i>The birth of a baby in this HEALTH CARE PROVIDER</i>
Source of Admission	79	<i>Babies born in or on the way to hospital</i>
HES record type	33	<i>Finished episode - birth</i>
	31	<i>Annual census/unfinished episode - birth</i>
Neonatal Level of Care	0	<i>Normal Care</i>
Primary Diagnosis	Z37...	<i>Well babies</i>
	Z38...	

This information may be readily extractable as it is part of the KP70 return – Summary of Patient Activity Return – which requires additional information about well babies.

However, the indicator might be subject to unintended consequences &/or perverse interpretation as the proportion of live births that are classified as “well babies” will depend on factors such as the NHS trust’s population and case mix and is not an indicator of quality of care. This would need to be set against the utility of the indicator for monitoring social class differences (proxy measured) in the health of the infant at birth.

(ii) *Babies receiving different levels of augmented care* - From October 1997, HES has recorded details of intensive (high dependency) care, but only where it was delivered in a dedicated intensive care unit. Again, an indicator could be developed around the levels of neonatal care which, if linked to area-based deprivation indices, might provide an appropriate measure for monitoring social class differences in morbidity at the birth of the infant.

The HES field name is *neocare* (Neonatal Level of Care) and the field is available from 1996-97.

The 'neonatal level of care' field contains a code which defines the level of care given to a new born child. The values for this field are:

- 0 Normal care - care given by the mother or mother substitute with medical and neonatal nursing advice if needed
- 1 Special care - care given in a special nursery, transitional care ward or post natal ward, which provides care and treatment exceeding normal routine care. Some aspects of special care can be undertaken by a mother supervised by qualified nursing staff. Special nursing care includes support for and education of the infant's parents.
- 2 Level 2 intensive care (High Dependency intensive care) - care given in an intensive or special care nursery, which provides continuous skilled supervision by qualified and specially trained nursing staff who may care for more babies than in level 1 intensive care. Care includes support for the infant's parents.
- 3 Level 1 intensive care (Maximal intensive care) - care given in an intensive or special care nursery, which provides continuous skilled supervision by qualified and specially trained nursing and medical staff. Care includes support for the infant's parents.
- 8 Not applicable: the episode of care does not involve a neonate at any time.
- 9 Not known: the episode of care involves a neonate and is finished but no data has been entered; this constitutes a validation error. Alternatively the episode involves a neonate but is unfinished, therefore no data need be present.

An indicator could be developed that utilises the three different levels of augmented care (Special care and Level 1 and Level 2 intensive care). However, as with 'well babies' it might be subject to unintended consequences/perverse interpretation, including its misinterpretation as an indicator of quality of neonatal care.

(iv) Another approach would be to develop HES indicators for *all* babies (possibly broken down by age (early neonatal, later neonatal, and postneonatal), based on one or some combination of several measures, such as *intensity* (bed-days), *frequency* (number of hospital admissions) of hospital use, and cause-related hospital admission. These indicators would be measures of morbidity in infancy (irrespective of mortality outcome as this would necessitate record linkage). However, statistical methods need to be used in the development of these indicators to find the measures and associated cut-off points that give the best proxy for infant deaths.

For some of these measures (intensity and frequency of hospital admissions) probabilistic matching would be needed to identify frequent admitters and aggregate bed-days as the HES record is episode- rather than person-based. It may, therefore, have drawbacks with respect to deployment in routine NHS settings. However, an alternative (for monitoring at PCT level) would be to develop crude indicators, such as total number of inpatient episodes per 1000 children aged <1 (or <3), total number of bed-days per 1000 children aged <1 (or <3), episodes and bed-days in particular diagnostic (cause) groups, etc. Again, it would be straightforward to structure these indices by levels of deprivation (as a proxy for social class), to facilitate monitoring of social class differences in morbidity and mortality in the first year(s) of life.

Further development work is required to identify which indicators are likely to be feasible.

### Evaluation

A comprehensive appraisal with supporting publications and other documentation covering child health was submitted by Roddy MacFaul who felt that there should be more emphasis on the whole health care system approach to reduction in infant mortality. In particular, attention needed to be accorded to access to and improved quality of clinical care in both recognition of more severe illness and in its care once recognised. Further, attention to both secondary and tertiary care was required as children are heavy users of hospital services. Reference was made to the improved outcomes in the hospital care of illnesses in recent years, e.g., pneumonia and meningococcal disease and other illnesses, and in trauma management. While CESDI has found failures in both recognition and quality of care, paediatric intensive care is reported as having had better outcomes.

Importantly, this commentator felt it was worth carrying out more work on the likely linkage between hospital use as a proxy for postneonatal mortality. This could be achieved by either using admission rates for all emergency care or for more targeted morbidities – the lower respiratory infection cluster and gastro enteritis (conditional on the resolution of coding problems) – as a measure of community support to mothers and access to primary care. Exploratory research would be needed to investigate the extent to which social class gradients in hospital usage reflect mortality (but this could only be achieved by the use of proxy deprivation measures associated with the postcode of residence).

Some additional comments were reported on these indicators. For the well babies/augmented care indicators, one of the assessors felt that place of care was dependent on staffing and cot

availability and was difficult to define (e.g., with respect to transitional care). Another respondent reported that the majority of admissions for babies requiring augmented care are short stay/low morbidity and that an indicator based on the low birthweight rate would be better. Hospital admissions in infancy was considered to offer promise but with a need to consider the supply side.

CHI felt that cause group, well babies, and babies requiring augmented care were good for monitoring but (as noted in the report) unsuitable for ratings as PCTs could not be held responsible and their inclusion could lead to adverse consequences.

### **Quantitative assessment of candidate indicators**

Assessors in the consultation process were invited to score each of the candidate indicators on 10 criteria (see Note 1 below) using a 0-3 scoring system (see Appendix). Two participants completed scores for all the indicators and a third assessor only three of the criteria for all the indicators (including, additionally, birthweight and gestational age) (table 4). An aggregate standardised score has been calculated, based on the sum of mean scores for the criteria [excluding the pre-scored data items]. The high level of variability in scoring for some of the criteria reflect the difficulty in identifying and prioritising candidate indicators in this context. Both assessors added additional comments to their scoring, some of which have been included in the evaluation of individual indicators. In addition, one of the assessors felt that all of the 18 candidate indicators contributed too small a slice of the pie and ideally would have liked to include a global measure of infant health in the ratings, that is, mortality and low birth weight, as well as one or two of the above, while conceding issues of practicality.

It is, perhaps, reassuring that the standardised mean scores for the 18 indicators identify smoking in pregnancy (17.3), mother's age (18.3), and initiation/duration of breast feeding (13.2) as the lead candidates. All three indicators are in the provisional list of 2003/04 indicators for PCTs in a proxy format. Other indicators that performed well were 'number of antenatal visits' (11.3) and 'Mother: support status and/or parenting intention' (10.1). There was little support for 'babies requiring augmented care' and 'hospital admissions in infancy'.

Table 4: Quantitative Assessment of Candidate Indicators

Indicator & standardised mean score	1	2	3	4	5	6	7	8	9	10
	0-3	0-3	0-4	0-3	0-3	0-3	0-3	0-3	0-3	0-3
Smoking in pregnancy <b>17.3</b>	1+2	1+NK	0+1	2+3+3	3+3+3	0+3	3+3	3+2+3	1+3	1+3
Completion of maternity tail <b>9.3</b>	1+3	NK+NK	1+0	0+1+0	0+1+0	2+3	2+2	2+3+B	1+1	1+1
Response times for report'g to CESDI <b>7.0</b>	NK <sup>1</sup> +NK <sup>1</sup>	NK+NK	1+0	0+0+0	0+0+0	0+3	0+2	2+3+B	0+1	1+1
Mother: Support status &/or parenting intention <b>10.1</b>	3+3	3+3	3+0	2+2+3	2+2+3	0+1	0+1	3+2+1*	0+1	0+1
Cause group <b>9.8</b>	3+3	3+3	4+0	3+1+1	3+1+1	0+2	0+1	0+3+3	0+1	0+1
Mother's age <b>18.3</b>	3+3	3+3	3+4	3+2+3	3+2+3	0+2	3+3	3+3+3	1+2	0+2
Midwifery staffing <b>9.7</b>	3+3	2+2	2+1	0+1+0	0+1+0	1+2	2+2	1+3+B	1+2	0+1
HV staffing <b>10.0</b>	3+3	2+2	2+3	0+1+0	0+1+0	1+2	2+2	1+3+B	1+2	0+1
Well babies <b>5.0</b>	3+3	3+3	1+0	0+0+0	0+0+0	0+2	0+2	0+2+B	0+2	0+1
Babies requiring augmented care <b>6.2</b>	3+3	3+3	1+0	0+2+0	0+2+0	0+2	0+2	0+3+B	0+2	0+1
Hospital admissions in infancy <b>5.0</b>	2+3	3+3	1+0	0+1+0	0+1+0	0+2	0+2	0+2+B	0+2	0+1
Late initiation of antenatal care <b>9.5</b>	1+1	NK+NK	0+0	0+1+0	1+1+0	1+3	1+3	0+3+B	1+3	0+2
Number of antenatal visits <b>11.3</b>	1+1	NK+NK	0+0	0+1+2	1+1+2	1+3	1+3	0+3+3	1+3	0+2
Gestational age at 1 <sup>st</sup> contact with the GP for antenatal care <b>5.5</b>	1+1	NK+NK	0+0	0+0+0	1+0+0	1+2	0+2	0+2+B	0+3	0+1
Unbooked women <b>6.8</b>	1+1	NK+NK	0+0	1+1+0	1+1+0	0+1	0+2	3+2+B	0+3	0+0
Postnatal care contacts <b>7.0</b>	0+1	NK+NK	0+0	0+0+0	0+0+0	0+3	0+2	3+2+B	1+3	0+0
Initiation/duration of breast feeding <b>13.2</b>	1+1	NK+NK	0+1	0+1+1	1+1+1	1+3	3+3	3+3+3	1+3	1+1
Efficiency of computerised maternity information systems <b>8.5</b>	NK+ NK	NK+NK	0+0	0+0+0	0+0+0	-+ 3	1+2	1+3+B	1+2	0+1
Birthweight <sup>†</sup>				3	3			3		
Gestational age <sup>†</sup>				3	3			3		

Standardised mean score is sum of mean weightings.

**Abbreviations:** NK = Not Known / Not Applicable. NK<sup>1</sup> = NK (but possible). B= Blank. 1\* = 'Sole registrations are likely to increase over time, as sociological phenomenon, without implying worsening infant mortality. Scores are linked by the + sign. For scoring system: see appendix. † Added by TK.

**Acknowledgements:** Thanks are due to HC, CM, & TK for completing the scoring. HC provided own scores for criteria 1 & 2 (CM retained authors' scores, the 2nd listed). TK scored criteria 4, 5, & 8 only.

**Note 2:** Criteria:

- 1 How is Data collected?
- 2 Completeness & Quality of Data
- 3 Readiness for Inclusion in 03/04 CHI Ratings
- 4 Epidemiological Evidence of an Association with Infant Mortality
- 5 Epidemiological Evidence of an association with social class differences in Infant Mortality
- 6 Evidence of Modifiability at PCT level
- 7 National Health Policy Relevance
- 8 Level of invulnerability to manipulation
- 9 Relevance to core PCT responsibilities
- 10 Suitability for Use in CHI performance assessment



Detailed comment was received on the scoring system by one appraiser. Acceptable criteria (with comments) were:

- Data collected at PCT level and preferably routinely reported
- Completeness and quality of data
- Readiness for inclusion in 2003/04 ratings process ('desirable, though should not prevent development of better indicators to be available in the future')
- Epidemiological evidence of an association with infant mortality ('this would seem to be *by far* the most important criterion – if there is no evidence that an indicator is correlated with infant mortality, then it should not even be considered')
- Epidemiological evidence of an association with social class differences in infant mortality ('Though it is pretty unclear in the report exactly what this means, I have interpreted it simply as being that the indicator in question should have a social class gradient, similar to that for infant mortality')
- Level of invulnerability to manipulation or wrong interpretation

Those regarded as unacceptable (for the reasons given) were:

- Evidence of modifiability at PCT level ('It is infant mortality that we want to influence, not necessarily the indicator variable. PCTs need to be applying a *multifactorial approach* to reduce infant mortality in their locality, especially among the poorer classes. If they achieve this, then the change should be picked up by measuring the proxy indicator. The indicator itself does not have to be directly changed by the actions of the PCT, it simply has to reflect what is happening with infant mortality. If the indicator is either a risk factor for infant mortality, or an outcome of interest in its own right, then obviously it would be desirable for the PCT to be able to influence it directly, but this is surely a secondary benefit') [appraiser includes 'low birthweight & 'gestational age' amongst indicators, although excluded from the list due to lack of modifiability at PCT level]
- National Health Policy Relevance ('this would be a bonus, but not necessary for an indicator to be a good proxy')
- Relevance to core PCT responsibilities ('this would be a bonus, but not necessary for an indicator to be a good proxy')
- Suitability for use in the CHI performance assessment process ('this would be a bonus, but not necessary for an indicator to be a good proxy')

The assessor suggested a system of differential weightings across the ten indicators, with epidemiological evidence (4 & 5) predominant, followed by criteria 1, 2, 3 & 8, with criteria 6, 7, 9 and 10 given much less importance. The assessor also flagged the requirement for an additional criterion: ‘Is the indicator available by social class groupings?’ (adding ‘Or has it been assumed that all of the indicators considered can be allocated to social class groups by linking to postcode to provide a proxy measure?’).

### **The Commission for Health Improvement’s Position on the Indicators**

#### *(i) PCT indicators for the 2003/04 ratings*

CHI reviewed the list of candidate indicators in the interim report and provided comments on the 11 feasible indicators described, in the context of ratings (as reported in the evaluations listed in the section on the candidates).

In a number of cases some of the proposed PCT candidate indicators had already been considered by CHI and included in the provisional list for the 2003/04 ratings in a provisional form. For example, a question on systems in place for collecting information on smoking in pregnancy, and quality of the data in Quarter 4, is included in the provisional 2003/04 list. Similarly, with respect to initiation/duration of breastfeeding, the Department of Health has set up a collection on this and a question on systems in place for collecting this information, and quality of the data in Quarter 4, is also included in the provisional list for 2003/04. The provisional 2003/04 list also retains the teenage pregnancy indicator (change in rate).

Other indicators relating to infant health on the provisional list for 2003/04 include MMR, a new indicator on child protection (following the Climbié inquiry [the independent, statutory inquiry set up to investigate the circumstances leading to the death of Victoria Climbié & to recommend action to prevent such a tragedy happening again] and CHI’s audit of child protection arrangements in NHS organisations), and retention of the sexual health indicator.

Thus, in summary, the provisional 2003/04 list includes the key determinants that are currently measurable:

- Teenage pregnancy
- Smoking in pregnancy (proxy measure until data becomes available)
- Breastfeeding (proxy measure until data becomes available)
- Immunisation

Indicators relating to antenatal booking and care were not considered for the 2003/04 list because of non-availability of data. CHI concluded that the review of candidate indicators undertaken had been important in that it had demonstrated that there were not, currently, any other really strong indicators that could readily be included in the 2003/04 ratings. Moreover, it acknowledged the limitations of the current, somewhat prescriptive ratings model, which precluded the use of other relevant information.

Also, CHI has raised an important point concerning the relationship between the PCT ratings and deprivation scores for the PCT areas and the need to be sensitive to this in the current absence of deprivation-adjusted scores. Analysis undertaken by CHI showed a negative association between deprivation and the 2003 PCT ratings, deprived PCTs being less likely to achieve 2/3 star ratings. There has been considerable critical comment by PCTs on the extent to which their ratings are affected by deprivation and CHI are reluctant to include indicators that might exacerbate this pattern, unless the ratings model is altered to adjust for deprivation level.

*(ii) Indicators that can inform the clinical governance review (CGR) process*

CHI state that the CGRs thus far have focussed primarily on the systems and processes that NHS organisations have in place to monitor, assure and improve clinical governance, rather than on individual indicators measuring health care and outcomes. However, with the move to inspections based on fewer visit and the greater use of available information and data sources (and of locally available information), CHI indicate that the potential for looking at wider indicator sets is much greater. The report was judged to provide useful information for supporting this function.

## **The measurement of social class and its availability on relevant datasets**

A number of respondents to the consultation queried the availability of measures of social class in the different datasets and whether there were usable proxy measures in its absence. Indeed, one respondent argued that an additional criterion was required in the assessment exercise, namely “Is the indicator available by social class groupings?”.

Of the datasets reviewed, only that for birth registration (and, consequently, ONS’s linked births/infant deaths database) has it consistently recorded in response to a standard question. Moreover, only a 10% sample is coded as this is undertaken manually, although one assessor suggested the scope for expanding this: “...perhaps this (coding) could be at least partially automated with the NSec [Note: the National Statistics Socio-economic Classification (NS-SEC) has been used for all official statistics and surveys since 2001, replacing Social Class based on Occupation (SC, formerly Registrar General’s Social Class) and Socio-economic Groups (SEG)]. The original proposals for Korner said this should be passed to child health systems, so why not now. Otherwise, there are harmonised questions which could be incorporated into computer screens”.

The limitations of occupational coding have been acknowledged in studies of social class differentials in infant mortality which have classified the infants by their parents’ (usually fathers’) sample social class data. In addition to the small sample coded, information on the father’s occupation is not collected for births outside marriage if the father does not attend the registration of the baby’s birth. Further, Botting (1997) has suggested that the mother’s social class might provide a better evaluation of any risk factor compared with that of the child’s father since the mother carries the child during pregnancy and is usually the main carer in early life. However, mother’s occupation at birth registration has only been collected since 1986 and then only on a voluntary basis, many women choosing not to give an occupation at birth registration. Botting (1997) reported that the proportion of women who gave an occupation which could be classified to one of the social classes rose from 31% in 1986 to 57% in 1995. Her analyses of mortality rates by mother’s social class (1991-5) show similar, but smaller, differentials in infant mortality compared to father’s social class, no clear pattern being found for Classes I and IIIM with increasing rates for the remaining classes.

Given the limited availability of social class information, are there proxy measures that can be used? Some investigators have suggested that an individual’s postcode of residence may be useful as a marker of his/her social class. However, empirical investigations suggest only modest associations. A study by Danesh, Gault *et al.* (1999) showed only a moderate

correlation between a postcode aggregate income measure and individual data (0.40, 99% CI 0.39 to 0.42;  $2P < 0.0001$ ). McLoone & Ellaway (1999) reported a correlation between enumeration district income and self-reported income of 0.48 (99% CI 0.44 to 0.52), falling to 0.38 (0.33 to 0.42) at postcode sector level. Further, the correlation between Carstairs scores (a deprivation indicator derived from census data) and self-reported income at enumeration district level was  $-0.44$  ( $-0.48$  to  $-0.39$ ) and  $-0.35$  ( $-0.40$  to  $-0.30$ ) at postcode sector level. Both of these reported associations are of similar magnitude to the correlation reported by Danesh, Gault *et al.* (1999).

Many attempts have been made to present measures of deprivation based on areas of residence as ecological markers of a person's socio-economic position. Ben-Shlomo and Davey Smith (1999) have cautioned that researchers should not attribute small area population characteristics to individuals because such observed association is likely to be influenced by the "ecological fallacy". They note: 'The optimal population size for categorising the contextual nature of areas will depend on the nature of this contextual effect, and this cannot be assumed to be better indexed by aggregate measures for areas with smaller populations'. Other investigators have argued that area-based effects dilute individual measures, thereby underestimating true associations Evans *et al.* (1999).

The main weight of scientific opinion supports distinguishing between individual and area based measures and argues that, where possible, both should be collected and measured. Postcode-based measures are important to test, for example, whether area-based deprivation may affect access to health care services (Ben-Shlomo & Chaturvedi 1994). However, as these authors and other investigators have pointed out, individual and area-based measures appear to have independent effects on health outcomes, possibly resulting from the contextual effects of residing in poor neighbourhoods: 'To measure one and not the other will result in an underestimation of potential effects associated with socio-economic position. Analyses based solely on an area measure of socioeconomic position can be highly misleading, especially if other risk factors are measured at an individual level' (Ben-Shlomo & Davey Smith 1999). The difference in these effects (individual social class and area-based deprivation) have been demonstrated, for example, in the context of inequalities in low birthweight (Pattenden *et al.*, 1999). This study showed that the majority of births to lone mothers and to joint registrants in social classes IV and V would be missed by targeting the most deprived quintile. A high degree of inequality in low birth weight was found according to social class, area deprivation and lone mother status, all three factors being important to show the true extent of inequalities.

Thus, this evidence indicates that where the Department of Health is planning to introduce new proxy indicators of infant mortality or the health of infants based on data that is designed to be prospectively collected by PCTs or other agencies, it is important to build in individual and direct measures of social class rather than relying on postcode based measures. Since postcode of residence is almost universally recorded on all datasets, this provides a link to a range of area based deprivation measures. Relying on such ecological measures alone is unsatisfactory as these cannot be used as a proxy for an individual's social class. Thus, data collections for, say, smoking in pregnancy or initiation/duration of breast-feeding, should be set up to include a *direct* measure of the woman's social class that is ascertained from her, based on her occupational status, and compatible with the National Statistics Socio-economic Classification.

This distinction between area-based measures of deprivation or socio-economic position and individual level measures is clearly important in terms of the presentation of data, as several of the respondents to the consultation emphasised. Where measures of inequalities *within* populations of PCTs is of interest, individual measures of social class or socio-economic position are of primary importance (although area-based measures may also be important to assess *area-based* effects). If the focus is on how individual-level measures of inequalities differ across PCTs, it will clearly be important to use area-based measures of deprivation in the presentation of findings as the least-deprived areas are clearly going to rank highest in health-related measures. One solution may be to report differences across different strata (or, say, quintiles) of deprivation.

## **IX Candidate Indicators: Differentiation of Effect in Neonatal vs Postneonatal Deaths**

In 2000, of all linked deaths on the ONS births/deaths anonymised linked database, 52% were early neonates, 69% were neonatal deaths, and 31% were postneonatal deaths. The social and biological factors on the linked file show different strengths of association with neonatal and postneonatal mortality.

*Birthweight [not recommended]:* The rate of neonatal death amongst live births < 1500 grams was 181.8/1000, compared with 29.7 for postneonatal deaths. There was also a marked differential for birthweights of 1500-1999 grams (16.9 vs. 8.3) and for birthweights not stated (53.1 vs. 4.1).

*Mother's age [recommended]:* Amongst mothers aged <20, the neonatal mortality rate was 5.1/1000, compared with 3.3 for postneonatal mortality. Rates for mothers aged 40 & over were 5.4 and 1.4, respectively, although mothers in this age group contributed only 3.1% of infant deaths.

*Country of birth [not recommended]:* In Pakistani mothers neonatal and postneonatal mortality rates were 8.0 and 4.1, respectively, compared with 3.8 and 1.7 in all countries of birth.

*Type of registration [recommended]:* The neonatal and postneonatal mortality rates were 3.8 and 1.7, respectively, for all live births, 5.3 and 2.7, respectively, for joint registration/different address, and 4.4 and 3.2, respectively, for sole registrations.

*Cause groups [recommended]:* There were some important distinctions between neonatal and postneonatal deaths in terms of contributing causes. Neonatal deaths from congenital anomalies were 1.0/1000, compared with 0.5 amongst neonatal deaths. Deaths from immaturity related conditions were 1.8/1000 in the neonatal group and 0.1 in the postneonatal group. The rate of sudden infant deaths in the neonatal group was 0.1/1000, compared with 0.3 in the postneonatal group.

In choosing indicators, consideration might need to be given to the differential strength of proxies with respect to neonatal vs. postneonatal deaths.

## **X Summary and Conclusions**

This report has reviewed a “first list” of around 18 indicators as candidate social class-sensitive proxies for infant mortality at PCT level. Of the 18 identified, eleven are useable currently without any major data/quality adjustments, although further consideration may need to be given to definitions. A further seven could be implemented with further data quality developments. Some require further development that is outside the scope of this short term project. We have indicated where this is the case. It should also be noted that the proxies we have identified have wider relevance at the local level. They could be added to the basket of local health inequalities indicators that are currently being developed for the Department of Health.

A process of peer review of the candidates against a set of criteria (using a rapid scoring system) has been undertaken and the results of this review process reported. Appraisal responses were received from a total of 9 people, 3 of whom completed the scoring grid. The comments received from CHI on the 10 feasible indicators described in the report [smoking in pregnancy; mother’s age <20; mother: support status and parenting intention; completion of the maternity tail; response times for reporting to CEMACH; midwifery staffing; health visitor staffing; cause group, well babies, and babies requiring augmented care; hospital admissions; and breastfeeding] indicated that some had already been selected in a proxy or different format for inclusion in the provisional list of indicators for 2003/04. A question on systems in place for collecting information on smoking in pregnancy, and quality of data in Quarter 4, is included in the provisional list of PCT indicators for 2003/04. Also, a question on systems in place for collecting information on breastfeeding (for which the Department of Health has set up a collection), and quality of data in Quarter 4, is included in the provisional 2003/04 list. Clearly, data from these collections could support indicators in the future. The provisional list (2003/04) retains the teenage pregnancy indicator (change in rate), removing the need for the candidate on ‘mother’s age <20’ and, probably, the ‘mother: support status and/or parenting intention’ indicator (likely to mirror trends in the teenage pregnancy indicator).

Other indicators which attracted some support from CHI and the appraisers were those relating to antenatal booking and care, although comments about non-availability of data (and low scoring or not known status on the dimensions of data collection and completeness/quality of data in the assessment exercise) indicated major barriers to inclusion in CHI ratings in the near future. Completion of the HES maternity tail was regarded as



potentially a good indicator and response times for reporting to CEMACH a possibility. There was less support for indicators based on midwifery and health visitor staffing and, given a significant programme of work on these within the Department of Health, further progress on development at this stage is likely to be premature. Cause group, well babies, babies requiring augmented care, and hospital admissions were regarded as good for monitoring but unsuitable for ratings as they could lead to adverse/unintended consequences and, for some, are not readily modifiable by PCTs.

## **XI Next Steps and Further Issues for Development**

### **The Final report**

An attempt has been made to derive weightings for each of the candidate indicators from the scores received from three assessors in the peer review process. Also, comments relating to each of the indicators have been presented as an evaluation summary following each.

Tighter definitions of some of the prioritised indicators need to be derived. Some assessment of the prevalence of the specific values for these indicators could be made at PCT level.

### **Further Issues for Development**

A number of issues emerge from this report which merit further development . They include:

- The need to develop methods of appropriate adjustment for indicators - such as our candidate set - that are significantly affected by factors outside the direct control of PCTs (e.g. levels of deprivation, ethnicity etc). This is an important feature of most wider indicators of public health and health inequalities. Such work is already being initiated to support the implementation of the Programme of Action to Tackle Health Inequalities, and there may be scope for joint initiatives.
- The scope for using existing data to support the development of a practical and scientifically relevant proxy for infant mortality will be greatly enhanced by a performance focus on improving the standardisation, quality and completeness of the datasets we already collect. We believe this could be built into the Performance rating system as it already is for Mental Health Trusts. This is particularly the case for the HES maternity data and locally collected maternity datasets. The development of the Children's NSF offers an important opportunity to improve on the current position.
- The National Programme for Action to tackle health inequalities and the preparation of the Children's NSF both place emphasis on the importance of antenatal care. Along with the recent white paper on Genetics, it will be important for NHS data systems to be able to capture early attendance in antenatal care more effectively. The new GP contract offers scope for doing this from a primary care perspective.

- The utility of making a wider local basket of “Infant Health Indicators” available has been flagged by the APHO in its report to the department of Health and merits further exploration.

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## **Appendix 1. Membership of the London Health Observatory's Peer Advisory Group on Maternal and Infant Health**

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Roddy Macfaul, Medical Advisor, Division Child Health Services, Department of Health

Jean Chapple, Consultant in Public Health Medicine, Westminster Primary Care Trust

## **Appendix 2. Appraisal of the Infant Proxy Candidates.**

Eleven criteria have been adapted from discussions in the Advisory Group for this Project. An appraisal process by members of the group was recommended. Members are being invited to **score each candidate indicator from 0-3 against each of the criteria in the Table attached.** Comment is also invited on either the indicators or appraisal process. These findings will be reported in the second stage of this study.

A scoring based on the evidence reviewed is given for Criterion 1 only and members are invited to disagree with this assessment and add their own.

### **Criterion 1: How is data collected?**

The mode of collection of the data for the indicator is important as CHI needs to be able to use data sources that cover all PCTs. In other words, datasets that are both routinely collected and reported for all PCTs in England will score highest. Data collected by maternity services, for example, may cover populations outside the PCT. We have given our assessment for this criterion in the table as the assessment is factual. If you have a different view then rate this criterion yourself too.

0 = Data not collected at all

1 = Data collected by local maternity services/or other service, but not routinely reported

2 = Data collected locally by PCTs but not routinely reported

3 = Data collected and routinely reported

### **Criterion 2: Completeness and Quality of the Data**

0 = Unacceptably poor

1 = Poor

2 = Variable (some good some poor)

3 = Good



### **Criterion 3: Readiness for Inclusion in the 2003/4 CHI Ratings process**

This criterion assesses the readiness for each indicator to be included in the next round of Star Ratings - based on 2003/4 data. It strongly reflects a combination of data availability, completeness, and quality.

0 = Highly unlikely to be ready

1 = A possibility, but more likely to be ready for 2004/5

2 = Likely if standards of achievement incorporate data completeness/quality requirements

3 = Highly likely

= Good

### **Criterion 4: Epidemiological evidence of an Association with Infant Mortality**

0 = None

1 = Weak

2 = Some

3 = Strong

### **Criterion 5: Epidemiological evidence of an association with social class differences in Infant mortality**

0 = None

1 = Weak

2 = Some

3 = Strong

### **Criterion 6: Epidemiological Evidence of an association with Infant morbidity**

0 = None

1 = Weak

2 = Some

3 = Strong

### **Criterion 7: Evidence of Modifiability at PCT level**

This criterion refers to the ability of PCTs to deliver change locally. Such work might, by definition involve working through other agencies.

0 = None

1 = Weak

2 = Some

3 = Strong

#### **Criterion 8: National Health Policy Relevance**

0 = Not relevant

1 = Limited relevance

2 = Some relevance

3 = Highly relevant

#### **Criterion 9: Level of invulnerability to manipulation**

This criterion is intended to give a measure of the extent to which the indicator could be misused and deliberately constructed or interpreted wrongly. A high score is a good outcome.

0 = Highly open to manipulation/misinterpretation

1 = Deliberate manipulation possible

2 = Not very likely to be manipulated

3 = Highly unlikely to be manipulated

#### **Criterion 10: Relevance to core PCT responsibilities**

This refers to the three roles of PCTs:

- Primary care provision
- Secondary and specialist commissioning
- Health Improvement and reducing health inequalities

0 = Not relevant at all

1 = Relevant to one core PCT responsibility

2 = Relevant to two core PCT responsibilities

3 = Relevant to all three core PCT responsibilities

**Criterion 11: suitability for Use in the CHI performance assessment process**

This criterion refers to the suitability of the indicator in informing the different elements of the CHI's structured review process. These together result in the construction of the "Star ratings" for Trusts. It includes building a picture of each Trust based on a mix of defined quantitative indicators (Key individual performance indicators and a "balanced score card" of indicators across a range) together with a more qualitative process of assessment based on the Clinical Governance Review and inspections. The higher the score the more parts of the CHI process the indicator is suited to.

0 = Unsuitable for CHI performance review process

1 = Suitable to inform inspection process only

2 = Suitable to inform at least two elements of the CHI assessment process

3 = Suitable to inform more than two elements of the CHI process