Background

"It is difficult to exaggerate the damage that drugs bring to our communities. Our young people are entrapped or enticed into drug misuse, and some become reliant and addicted to these substances. They are subservient to dealers who demand they steal, deal or prostitute themselves to pay their debts and are subject to violence if they do not.” Keith Hellawell (UK Anti-Drugs Co-ordinator in 1999) 1

Drug misuse is an important public health concern about which little information is available at local level. This report provides an overview of drug misuse in pregnancy and was prompted by concerns about an increase in the numbers of drug dependent babies being born in the region. It reports the findings of a study undertaken in the former Northern and Yorkshire NHS Region of England into the prevalence of drug misuse in pregnancy and the response of maternity services.

Summary of main findings:

- During 2001, 28 of 37 maternity units in the region delivered pregnant drug misusers;
- An estimated 9.3 drug misusers per 1000 deliveries used the antenatal services;
- An estimated 7.5 babies per 1000 live births were identified as being born to drug-misusing mothers (ten-times higher than previously documented prevalence);
- 37% of babies born to drug-misusing mothers received pharmacological treatment for withdrawal symptoms, the majority within a special care unit;
- There was large variability between maternity units in service response and adherence to guidelines on service provision for drug misusers;
- There were shortcomings within current maternity information systems.

Action is required nationally and locally to improve:

- Maternity information systems and the quality of data collected in relation to drug misuse;
- The availability and standard of services to drug-misusing mothers.
Introduction

The importance of drug misuse

“Drug misuse” is defined by the Department of Health as “the misuse of all psycho-active drugs, including illicit drugs and non-prescribed preparations, but excluding alcohol and nicotine” \(^1\). Tackling drug misuse and the harm it causes is a key priority area for the Government\(^2\). In April 1998 it published its 10-year strategy *Tackling Drugs to Build a Better Britain* and is committed to providing additional resources to support it\(^4-6\).

Drug misuse cuts across a multitude of areas of public health importance including: social exclusion, health inequalities, the economy, homelessness, education, crime and disorder, community safety, domestic violence, child welfare, communicable disease, and physical and mental health\(^7-22\).

The health effects of drugs

The effects of drug misuse occur at different levels (Box 1).

**Box 1 Different levels at which the effects of drug misuse occur**

- **Society**: increased burden on the economy, public services, criminal justice system
- **Community**: adverse effects on community safety, crime, neighbourhood conditions
- **Family**: increased child neglect, domestic violence, poverty
- **Individual user**: adverse physiological, psychological and behavioural effects (dependence, increased morbidity/mortality, functional impairment, neglect of social roles, violence)
- **Offspring**: physical, emotional and social problems

Drug misuse is associated with unemployment, poverty and social deprivation, health inequalities, domestic abuse and violence, family breakdown and homelessness\(^7-9,14,15\). Drug misusers find themselves caught in a “cycle of entrapment”, the costs of “seeking, buying, and using” drugs leading to poverty, criminal activity and prostitution\(^17,23\).

General health problems associated with drug misuse include a range of physical problems (e.g., infectious diseases, abscesses, thrombosis, respiratory and cardiac problems, dental caries, anaemia and malnutrition). In addition there is an increased risk of dying, mainly through drug overdose, violence, infectious disease (HIV and Hepatitis B and C) and alcohol-related problems\(^16-18,24,25\). The National Treatment Outcomes Research Study (NTORS) found the annual mortality rate of drug misusers recruited into treatment programmes to be 1.2% (six times higher than the age-matched general population)\(^19\).

Drug misusers also suffer a variety of mental health problems, including depression, psychosis and confusional states\(^20-22\).

In women higher rates of hepatitis, eating disorders, self-mutilation, suicide attempts, low self-esteem, physical and sexual violence, and links with commercial sex work have been

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\(^{1}\) Terminology is sometimes controversial. “Drug user” and “drug misuser” are commonly used synonymously. In this paper, in accordance with Department of Health usage, “drug misuse” is preferred: no pejorative overtones are intended.
found. Compared to men, there is a lower uptake of drug treatment services, possibly because of stigmatisation, difficulties over childcare arrangements, and fears over children being removed into care.

**Health effects of drugs in pregnancy**

Problems associated with drug-misusing pregnant women include:

- Presenting late in pregnancy and having little antenatal care;
- A higher incidence of sexual abuse and violence;
- Higher unemployment;
- Higher levels of psychiatric and psychological problems;
- Higher rates of prostitution.

The late antenatal presentation is partly explained by the fact that many drug-misusing women cease to have normal periods. As well as the lack of early pregnancy awareness there is often the false assumption that they are less fertile and therefore need to be less vigilant over contraception.

Several effects on pregnancy and maternal physical health have been identified, including:

- Pre-term delivery;
- Placental abruption;
- Breech presentation;
- Post-partum complications;
- Sexually-transmitted diseases and other infections;
- Inadequate nutrition and anaemia;
- Dental caries;
- More painful parturition and placental insufficiency leading to intrapartum hypoxia and foetal distress;
- Maternal hypertension and pneumothorax (in the case of cocaine).

There are also likely to be detrimental effects on the offspring, though methodological difficulties (small sample sizes, lack of obstetric information, selection bias, multiple confounding of medical and psychosocial factors including the quality of antenatal care, and multifactorial outcomes) have resulted in inconsistent and contradictory findings. However, most drugs are associated with impaired growth of the foetus as well as premature delivery, resulting in low birth weight and increased perinatal mortality.

Use of cocaine in pregnancy is associated with miscarriage, placental abruption, stillbirth and neonatal death, sudden infant death syndrome, less responsive and alert babies, and irritability.

Opiate use is associated with lower birth weight, antepartum haemorrhage and intra-uterine death, postnatal breathing and metabolic problems, and neonatal withdrawal syndrome (sweating, irritability and crying, stiffness and possible convulsions, reduced alertness, poor feeding, malnutrition and dehydration).

Cannabis use may result in a lower birth weight, and a mild withdrawal-type syndrome with tremors, exaggerated reflexes and reduced responsiveness, though no long-term effects have been consistently found.

Drug misuse in pregnancy is associated with several childhood problems, including:
domestic poverty, family breakdown and removal into care, neglect and abuse, maladaptive early learning experiences, and lower levels of academic achievement and social adjustment.\textsuperscript{11,23,36}

\textbf{The extent of drug misuse in the community}

Accurate prevalence data for drug misuse in the community is hard to obtain because of the illicit nature of most drug misuse.\textsuperscript{16,27} There are several sources of information which provide an indication of the extent of drug misuse.

\textit{Regional Drug Misuse Databases}

The Regional Drug Misuse Databases (RDMDs, now part of the National Drug Treatment Monitoring System) collect data voluntarily provided by treatment agencies and general practitioners. The numbers who present for treatment for the first time ever or the first time for six months are reported.\textsuperscript{37}

The number of people receiving treatment has increased over time. Women comprise about one quarter of those receiving treatment and over 90\% are of childbearing age.\textsuperscript{27,38} The relatively low proportion of women in treatment probably reflects uptake of the services rather than real differences in need.\textsuperscript{2,26}

It has been estimated that 118,500 people received treatment from drug misuse agencies and GPs during 2000/01 in England (equivalent to a rate of 2.4 per 1000 population).\textsuperscript{39}

\textit{British Crime Survey}

The British Crime Survey (BCS) is a questionnaire sample of around 10,000 households in England and Wales. Within each household one person is selected at random and interviewed about victimisation and other crime-related topics. The Survey commenced in 1994 and has been repeated in 1996, 1998, 2000 and then annually.

The limitations of the Survey should be recognised: “non-household” drug misusers (e.g., the homeless, students in halls of residence) are not represented, and with self-disclosure there may be a reluctance (despite confidentiality) to provide information.\textsuperscript{40} Nevertheless, the BCS provides valuable information and “is the official monitoring instrument ... in the Government’s anti-drugs strategy”.\textsuperscript{41}

The proportion of all adults aged 16-59 who reported that they had used any drug within the previous year changed little between 1994 and 2000 (9.9\% to 10.7\%), but cocaine use increased significantly from 0.5\% to 1.8\%. In 2000, 44\% of 16-29 year-old women self-reported that they had used drugs in their lifetime (11\% within the last month). For 16-59 year-old women the respective figures are 28\% and 4\%.\textsuperscript{40,41}

The ratio of males to females was 1.4-to-1 with respect to having “ever used drugs”, 1.8-to-1 with respect to usage in the last year, and 2.3-to-1 with respect to usage in the last month.\textsuperscript{41}

\textit{Other surveys and studies}

The former Health Education Authority commissioned several surveys of drug use. In 1996 42\% of 11-35 year-old females admitted to using drugs at some point in their lives, 8\%
within the last month. For males the figures were 52% and 16% respectively\textsuperscript{27,42}. Surveys of school children have shown an increase among 11-15 year-olds in drug usage in the previous month (7% in 1998, 9% in 2000, and 12% in 2001)\textsuperscript{43-45}. Though boys are marginally more likely to have used drugs, the gender proportions are broadly similar\textsuperscript{45}.

Several studies have utilised a capture-recapture methodology (collecting data from several different sources such as treatment agencies, hospitals and courts, identifying the overlap and employing a log-linear regression analysis to estimate the numbers of “unknowns”). 55,800 people in Scotland in 2000 were estimated to be “problematic” drug misusers (defined as using opiates and benzodiazepines), with a prevalence of 1.1% of the population (four times higher than identified in England through the RDMDs), and a male-to-female ratio of 3:1\textsuperscript{46}. A study in two London boroughs in 1994 reported an overall prevalence of drug misuse of 2%-3.6\textsuperscript{47}. Three per cent of 15-49 year-olds in three London health authority areas were estimated to be “problem drug users” (using any illicit drug other than cannabis)\textsuperscript{48}, and 2-4% of 15-44 year-olds in the North West region were estimated to be using opiates and cocaine\textsuperscript{49}. The latter study (by the North West Public Health Observatory) estimated that only one third of users were known to the specialist treatment agencies.

**The extent of the problem in pregnancy**

Little information is available about the size of the problem in pregnancy. Estimates of prevalence in various settings have produced large ranges\textsuperscript{50}. In England and Wales a postal survey of maternity units undertaken in early 1993 estimated the incidence of babies born to drug-misusing women to be 0.81 per 1000 deliveries\textsuperscript{51}.

**Rationale of the Study**

Key roles of Public Health Observatories include\textsuperscript{52}:
- Identifying gaps in health information;
- Carrying out projects to highlight particular health issues;
- Looking ahead to give early warning of public health problems;
- Highlighting areas for action.

Anecdotal evidence from midwives and child protection officers in the former Northern and Yorkshire region suggested that drug misuse in pregnancy was a growing problem. Recent and reliable information about the extent of drug misuse in pregnancy was not available. Therefore the Northern & Yorkshire Public Health Observatory, with the support of the two Local Supervising Authority (LSA) Midwifery Officers, undertook a study to address the information gap.

**Aims of the Study**

The aims of the study were:
- To ascertain the numbers of drug-misusing women using the maternity services, and the numbers of babies born to them;
- To map out current service provision and evaluate maternity units against any available standards.

**Method**

The research area was the former Northern and Yorkshire NHS region (including North Cumbria). Following pilot studies, a questionnaire was sent to the Heads of Midwifery
responsible for each of the 37 maternity units in the region. (Midwives are key health professionals involved in pregnancy, and usually have most contact with pregnant women. The study sought to explore issues for the maternity services, rather than the drug treatment services.) The questionnaire was supplemented by telephone and email communication.

There are no published systematic standards of health care for pregnant drug misusers. In this study several key documents were identified from which 14 standards have been derived\(^2\),16,26,53-55. The derived standards have excluded those already available for general aspects of midwifery practice and blood-borne infections.

**Findings**

All 37 maternity units responded, though not all questions were completed by all units.

**Prevalence information**

**Size and type of units**

At the time of the study (2001) 37 units in the former Northern and Yorkshire Region offered maternity services. The total recorded number of live births across the region for 2001 was 67,293 from 66,674 women who delivered (the difference being due to multiple births outnumbering stillbirths).

The annual number of women delivered (having a live birth or a stillbirth with a gestation of 24 weeks and greater) ranged from 50 (Berwick) to nearly 5,300 (Bradford), with the mean being 1,802 (Figure 1). The eight smallest units were midwife/GP-led low-dependency units.

**Figure 1** Number of deliveries (women delivered) in 2001, for each maternity unit in the former Northern and Yorkshire region

Twenty-nine of the 37 units (responsible for 65,306 deliveries, 98% of the total) had access to a Special Care Baby Unit (SCBU) within the hospital. These units delivered a minimum of 1100 mothers each year. The eight (midwife/GP-led) units which did not have a SCBU
ranged in size from 50 to 653 deliveries each year and none of them knowingly accepted drug misusers for delivery. Just over half the units with a SCBU (15 out of 29) had access to a Neonatal Intensive Care Unit (NICU) within the hospital. These units were responsible for 44,247 deliveries (66% of the total) and tended to be larger than those without a NICU (averaging 2950 per year compared with 1516).

Nine of the 37 units indicated that they would not book drug misusers for delivery. Eight of these were midwife/GP-led units. The ninth (Castle Hill, Cottingham) had over 2000 deliveries in 2001. It provided antenatal care for drug misusers but referred them to nearby Hull for delivery. All the other 28 units delivered pregnant drug misusers, though not all of them had information on how many. The total number of deliveries from these 28 units was 63,180 (95% of the total for the region).

**Numbers of pregnant drug misusers seen in the antenatal period**

Twenty-seven units (responsible for 53,309 deliveries) knew how many drug-misusing women had been seen antenatally during 2001. The range across units was 0 to 74 women. A total of 497 women were seen by these units (equivalent to 9.3 per 1000 deliveries, 95% confidence interval 8.5-10.2 per 1000 deliveries) (Figure 2).

**Figure 2** Number of pregnant drug misusers seen antenatally per 1000 deliveries (women delivered) for each unit in 2001. (Midwife-led units have been excluded.)

**Types of drugs used by women seen antenatally**

Twenty-three units were able to provide information about the types of drugs used by pregnant drug misusers. However, the quality of data was variable: some units were able to identify all drugs used, others only the main drug of abuse.

Heroin and methadone were the commonest substances reported, followed by cannabis, tranquillizers, amphetamines and cocaine.

**Number of pregnant drug misusers delivered**

Twenty-five units (with a total of 48,420 deliveries) knew how many pregnant drug misusers had delivered in 2001. The range across the region was 0 to 60 women, with a total of 384 women being delivered (equivalent to 7.9 per 1000 deliveries, 95% confidence interval 7.2-
8.8 per 1000 deliveries). Figure 3 shows the range of rates across the 17 units which deliver pregnant drug misusers and for which information is available.

**Figure 3**  Number of pregnant drug misusers delivered per 1000 deliveries for each unit (excluding units which did not deliver pregnant drug misusers)

Number of babies born to drug-misusing women

Twenty-six units had information about the numbers of babies born to drug-misusing women. These recorded 365 babies out of a total of 48,321 live births in the units overall, ranging from 0 to 60 babies per unit (an overall rate of 7.5 per 1000 live births, 95% confidence interval 6.8-8.4 per 1000 live births). Figure 4 shows the range of rates across the 18 units which accepted deliveries of pregnant drug misusers and had the information.

**Figure 4**  Number of babies born to drug-misusing women per 1000 live births (excluding units which did not deliver pregnant drug misusers)

Number of suspected drug dependent babies born and drugs involved

Twenty units were able to provide information on the number of babies born suspected of being drug dependent themselves (ranging from 0 to 49 babies). There were 181 such babies out of a total of 32,858 live births in these units (equivalent to 5.5 per 1000 live births, with 95% confidence interval 4.7-6.4). This suggests that nearly three-quarters of
babies born to drug-misusing women are drug dependent. (Figure 5 shows the range of rates for the 12 units which delivered pregnant drug misusers and had the information.)

Figure 5  Number of suspected drug dependent babies born per 1000 live births (excluding units which did not deliver pregnant drug misusers)

The pattern of drugs involved is similar to that recorded for all antenatal drug misusers (Figure 6). The proportion of heroin and cocaine dependency is higher in the babies but does not reach statistical significance (chi-squares of 2.5, p=0.11, and 2.3, p=0.13 respectively). Less cannabis was recorded as being a problem (chi-square 10.0, p=0.002).

Figure 6  Percentage of recorded drugs by class, for women seen antenatally and babies suspected of being drug dependent

Drug dependent babies requiring treatment

Not all babies suspected of being drug-dependent required pharmacological treatment. Thirty units had information about the number of babies who received treatment (21 of them being units which delivered pregnant drug misusers, Figure 7). The range was 0 to 25 babies per unit. In total 139 babies were recorded as receiving treatment out of 50,262 live births in these units. This is an equivalent rate of 2.8 per 1000 live births (95% confidence interval 2.3-3.3). Overall 37% of babies born to pregnant drug-misusing women received pharmacological treatment for withdrawal symptoms.
The majority of babies who received treatment (88%, 122 babies) had the treatment at the maternity unit’s own SCBU or NICU, with 11% (15 babies) being transferred to another hospital and 1% (two babies) being treated alongside the mother in the postnatal ward. The reasons for the transfer of the 15 babies were: (temporary) shortage of capacity (10 babies), the need for more specialised treatment than was available locally (four babies), and the mother’s preference to be closer to home (one baby).

**Summary of prevalence data**

Table 1 (page 11) summarises the information obtained from the study. The estimated prevalence rates are shown schematically in Figure 8.

It is unlikely that the ascertained numbers represent the full extent of the prevalence within the region. Some maternity units admitted that although they saw and delivered drug misusers they did not record the information or were not able to supply the data. Therefore,
Table 1  Extent of data captured, the prevalence rates based on the available data, and projected numbers for the region based on the calculated rates and assuming that a representative sample has been ascertained

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of units for which information is available</th>
<th>Number of deliveries (d) or live births (lb)</th>
<th>Number recorded</th>
<th>Rate per 1000 deliveries/live births</th>
<th>95% confidence interval of rate</th>
<th>Projected numbers *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total for region:</td>
<td>37</td>
<td>66,674 (d) 67,293 (lb)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of women delivered</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of live births</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug-misusing women seen antenatally</td>
<td>27</td>
<td>53,309 (d)</td>
<td>497</td>
<td>9.32</td>
<td>8.52-10.17</td>
<td>621</td>
</tr>
<tr>
<td>Women delivered</td>
<td>25</td>
<td>48,420 (d)</td>
<td>384</td>
<td>7.93</td>
<td>7.16-8.76</td>
<td>529</td>
</tr>
<tr>
<td>Babies born to drug-misusing women</td>
<td>26</td>
<td>48,321 (lb)</td>
<td>365</td>
<td>7.55</td>
<td>6.80-8.37</td>
<td>508</td>
</tr>
<tr>
<td>Suspected drug dependent babies</td>
<td>20</td>
<td>32,858 (lb)</td>
<td>181</td>
<td>5.51</td>
<td>4.74-6.37</td>
<td>371</td>
</tr>
<tr>
<td>Babies receiving treatment</td>
<td>30</td>
<td>50,262 (lb)</td>
<td>139</td>
<td>2.77</td>
<td>2.32-3.26</td>
<td>186</td>
</tr>
<tr>
<td>Treated in own SCBU/NICU</td>
<td>30</td>
<td>50,262 (lb)</td>
<td>122</td>
<td>2.43</td>
<td>2.02-2.90</td>
<td>163</td>
</tr>
<tr>
<td>Treated in SCBU/NICU in another hospital</td>
<td>30</td>
<td>50,262 (lb)</td>
<td>15</td>
<td>0.30</td>
<td>0.17-0.49</td>
<td>20</td>
</tr>
<tr>
<td>Treated on postnatal ward only</td>
<td>30</td>
<td>50,262 (lb)</td>
<td>2</td>
<td>0.04</td>
<td>0.00-0.14</td>
<td>3</td>
</tr>
</tbody>
</table>

* The projected numbers should only be seen as an approximation, or a “best guess”. Caution is especially necessary when the numbers are small since they are estimated from a small number of recorded cases in the first place and are subject to large statistical variation as reflected in the confidence intervals.
the ascertained numbers will be an *underestimate* of the true extent of the problem. A more likely estimate of the actual numbers of women seen and babies born is obtained by assuming that we have information from a *representative sample* of maternity units. The calculated prevalence rates, applied across the whole region, will provide *projected* numbers as shown in the final column of Table 1.

**Service provision**

*Information systems and data collected.*

The maternity units used a variety of different information systems. Eighteen of the units used only a paper-based system, whilst 19 had a computer-based system (the most common being *PROTOS* in seven units). Those units which had a computer-based information system were on average larger than those which had a paper-based system (2253 compared with 1326 deliveries).

Not all of the units were able to provide data on drug misuse. The units which collected data stored it in a variety of forms, including computer database (often separate from the main maternity information system), manual filing systems (often held by the drug liaison midwife) and admission registers. There was no simple relationship between the information system and the collation of information on pregnant drug-misusing women, though the likelihood of collecting information on pregnant drug misusers was higher if the unit had a computer-based system (odds ratio of 7.3, 95% confidence intervals 1.4 to 42.0).

One of the units which said that it collected data on pregnant drug misusers was unable to provide numerical data for this survey; nine units which said that they did not routinely collect the information were able to supply numerical data of relevance through doing a manual search.

*The management setting of babies born to drug-misusing women*

The initial management of newborn babies of drug-misusing mothers varied:
- Baby initially observed on the postnatal ward (10 units);
- Baby transferred immediately to the special care ward (9 units, including 3 without their own SCBU);
- Practice varied according to individual circumstances (14 units).

Subsequent management of the baby, if signs of drug withdrawal became evident and pharmacological treatment was required, almost universally took place in special care (30 units). In three units babies were occasionally kept on the ward according to circumstances (e.g., treated on the ward for withdrawal, but transferred to SCBU if additional medical intervention such as intubation was required).

*Antenatal detection of drug-misusing women*

Of the 34 units which answered the question, 33 (89% of the total) said that all women were specifically asked about their use of drugs at booking. One unit, however, said that it would not directly ask women the question. This unit was a small midwife-led unit (which stated it did not deliver pregnant drug misusers).
Access to specialist expertise

All units could contact drug treatment teams. Twenty-three of the 37 units (62%) said that they had access to a named individual who had specialist expertise in drug misuse or drug dependency problems in pregnancy (Table 2). Nearly all those “specialists” who were midwives undertook the role alongside other midwifery duties.

Table 2   Access to named individual specialist expertise: the different arrangements

<table>
<thead>
<tr>
<th>Number of units</th>
<th>Source of expertise</th>
<th>Who employs them?</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>Drug liaison midwife</td>
<td>Own trust</td>
</tr>
<tr>
<td>2</td>
<td>Drug liaison midwife</td>
<td>Shared with drug services host trust</td>
</tr>
<tr>
<td>3</td>
<td>Drug advisory/addictive behaviours midwife</td>
<td>Drug/alcohol services host trust</td>
</tr>
<tr>
<td>1</td>
<td>Link worker</td>
<td>Drug/alcohol services host trust</td>
</tr>
<tr>
<td>1</td>
<td>Link midwife</td>
<td>Own trust</td>
</tr>
<tr>
<td>1</td>
<td>Drug/alcohol nurse specialist</td>
<td>Own trust</td>
</tr>
<tr>
<td>1</td>
<td>Social worker</td>
<td>Social services</td>
</tr>
<tr>
<td>1</td>
<td>Drug liaison officer</td>
<td>Health authority</td>
</tr>
<tr>
<td>1</td>
<td>Consultant obstetrician</td>
<td>Own trust</td>
</tr>
</tbody>
</table>

Arrangements for pregnant drug misusers

Twenty-eight units (76% of all units) stated that they had special arrangements for pregnant drug misusers, including transferring the care to a consultant-led service, offering additional antenatal visits and utilising specific protocols.

Facilities for detoxification on the ward

Seven units (19%) said that they had facilities for detoxification of pregnant drug misusers in the maternity unit itself. Three other units (8%) said that they would continue to supply methadone, but only if the patient was already on a detoxification programme. One Head of Midwifery commented that she felt detoxification was contraindicated in pregnancy.

Protocols/management guidelines

Eighteen units (49% of all units) had protocols covering the antenatal, intranatal and postnatal periods specific to drug-misusing women. A further unit had an antenatal protocol and two units a postnatal protocol.

Ten units (27%) had neither a specific protocol for drug misusers nor a section on drug misusers within a general protocol. Six of these units accepted pregnant drug misusers for delivery. One unit responded by saying that they “treated all women as individuals, and the majority of maternity care is the same as for non drug-users.”

Fifteen units (41%) had a multi-agency protocol (involving social services and other agencies), with several others stating that a protocol was being developed locally. All but three of the units that had a multi-agency protocol also had specific maternity protocols for drug misusers.

Ten units (27%) indicated that they had specific protocols for referral to drug treatment services.
Planning meetings

Twelve units (32%) (of which 11 delivered drug misusers) said that they always had an antenatal planning meeting, with eight units (22%) saying that they usually did and 15 (41%) that they sometimes did (as circumstances dictated).

Fewer units had a postnatal planning meeting. Of those units which delivered drug misusers, only two units (5% of the total) always had a meeting, with four (11%) saying that they usually did, and 20 (54%) holding one sometimes. One unit said that it never held a postnatal planning meeting.

When planning meetings were held, a wide range of different professionals attended them. However, only eight units (22%), of which seven delivered drug misusers, specifically commented that the mother-to-be would be invited to the meetings.

Referral to child protection services

Seven units (19%) said that they referred all known pregnant drug misusers, and 29 (78%) “some” (e.g., if there were concerns about the home circumstances prior to discharge of the baby).

Follow-up arrangements

Thirty-five units (95%) indicated that special efforts would be made to contact “defaulters” from antenatal care (usually via the community midwife, or else through the GP or drug treatment services). One unit which delivered drug misusers did not answer the question and another did not make special arrangements for follow-up.

Audit

Nine units (24%) said that they had audited their midwifery services for drug misusers, or were in the process of doing so.

Evaluation against standards

Fourteen standards of care were derived from key “official” documents. The standards are specific to drug misuse and do not include standards relating to general aspects of midwifery practice or to HIV/AIDS or Hepatitis. Standards for these are already available, though not necessarily being monitored.

The derived standards are:

1. **Multi-agency policy:**
   There should be a multi-professional and multi-agency policy involving obstetricians, paediatricians, midwives, drug services, general practice and social service representatives.\(^{16,54}\)

2. **Multi-disciplinary care:**
   Management of pregnant drug misusers should be by a multi-disciplinary team, including drug services and social services.\(^{16}\)
3. **Specialist expertise:**
Specialist expertise should be available, with links to drugs services (e.g., a specialist midwife, attached drug dependency staff, or other liaison arrangement)\(^2,26\). (For compliance the unit should have a named individual.)

4. **Booking question:**
All women should be asked about their use of drugs at booking\(^54\).

5. **Specific antenatal protocol:**
There should be antenatal policies/protocols specific to pregnant drug misusers\(^2,54,55\).

6. **Antenatal planning meeting:**
A multi-agency antenatal planning meeting should always take place at around the 32nd week of pregnancy (to assess child protection and other issues)\(^2,16,54\). (A unit that "never", "sometimes" or "occasionally" held meetings was deemed not to comply.)

7. **Involvement of mother:**
The mother-to-be should be invited to attend the planning meetings\(^16,54\).

8. **Antenatal follow-up efforts:**
There should be clear evidence that efforts are made to follow-up defaulters from antenatal care\(^55\).

9. **Specific labour protocol:**
Pain relief in labour needs special consideration (as evidenced by a specific intranatal protocol/policy)\(^16,54\).

10. **Special care facilities:**
Access to "skilled neonatal paediatric care" is essential\(^16\). (This is interpreted as the presence of SCBU facilities in the same hospital.)

11. **Special care not routine:**
Special care should only be administered if the baby’s condition merits it (so as to protect maternal-infant bonding)\(^54\). (To comply, initial management should not be to routinely transfer the baby to SCBU.)

12. **Postnatal planning meeting:**
An (informal) meeting should take place soon after birth to discuss support for the mother\(^16\). (Compliance decided as standard six.)

13. **Child protection meeting not routine:**
Referral to Child Protection services should be considered but never routine (because it will deter drug-misusing women from disclosing/seeking help)\(^16,53,54\). (Compliance only evidenced if meeting held "sometimes", "None" or "always" deemed non-compliant.)

14. **Audit:**
All units should audit the quantity and quality of their services to pregnant drug misusers.
Each of the 28 units delivering pregnant drug misusers was assessed against the standards. The anonymised results are shown in Table 3. No weighting has been applied: some standards could be more important than others. The total column has no quantitative validity but provides an indication of overall compliance.

Table 3  Anonymised comparison of the 28 units which delivered drug misusers against the 14 standards

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<th>UNIT CODE</th>
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The frequency distribution of the number of standards met is shown in Figure 9. The proportion of units complying with each standard is shown in Figure 10.

As would be hoped, units delivering drug misusers all had special care facilities, and all specifically asked about drug use at booking.

The majority of the 28 units (26 units, 93%) made special efforts to follow-up defaulters from antenatal care, and 24 units (86%) had clear evidence of multidisciplinary care involving drug specialist services. However, only 16 units (57%) had a specific antenatal protocol, 17 units (61%) a labour policy, and 12 units (43%) a multi-agency protocol. Nineteen units (68%) had a named individual with specialist expertise linked with the unit.
Only 11 of the 28 units (39%) would routinely hold an antenatal planning meeting, and only seven units (if they held a meeting) indicated that they would invite the mother to attend. Only two units (7%) would routinely hold a postnatal meeting.

Twenty-four units (86%) would hold a child protection case conference only when necessary. Twenty-two units (79%) would aim to keep the baby on the ward with the mother rather than transferring immediately after birth to SCBU.

Nine units (32%) said that they had audited the numbers of drug misusers seen.

Figure 9  Number of units complying with different numbers of standards

![Figure 9](image)

Figure 10  Percentage compliance with each standard

![Figure 10](image)
Comment

Prevalence information

Maternity units were variable with respect to the availability and quality of the numerical information, and a certain amount of “estimation” was necessary (e.g., when data was not available for a full 12-month period). The ascertained numbers will almost certainly underestimate the true extent of the problem. Most units which did not have the numerical information indicated that drug misusers used the services. (North Tees and Hartlepool, areas of high drug misuse, were unable to provide numerical data.)

There could potentially be some double-counting of the antenatal numbers if individuals received antenatal care at more than one unit (for instance at a midwife-led unit and then a larger hospital). This would have the effect of overestimating the prevalence. However, most Heads of Midwifery felt that women would be referred appropriately only to units dealing with drug misusers.

A survey of English and Welsh maternity units in 1993 estimated the incidence of babies born to drug-misusing women to be 0.81 per 1000 deliveries in the country as a whole, and even lower in the former Northern and the former Yorkshire regions (0.19 and 0.22 per 1000 deliveries respectively). The estimated rate in the present study was 7.5 per 1000 live births. This large difference may be due partly to an increase in the number of drug misusers giving birth between 1993 and 2001 and partly to much better identification and ascertainment.

The number of women misusing drugs has increased over the past decade, the number of people entering treatment doubling since 1993. The 1993 survey showed large variation across the regions (0.15 to 5.01 babies per 1000 deliveries). The area with the highest prevalence rate (Mersey) had a similar rate to that found in the present study. The present survey probably benefits from maternity units having better data capture systems than was generally the case in 1993.

The apparent variation in prevalence between the units may be due to differences in data capture and/or in the populations using them. Examination of Regional Drug Misuse Database information suggests there is variation in ascertainment as well as under-reporting (e.g., the low treatment rates in Sunderland compared with neighbouring Gateshead).

Most of the units have recorded lower numbers of deliveries than numbers identified as using the antenatal service. There may be a number of reasons for this: some women stop taking drugs and may no longer be classified as drug misusers by the time they deliver; some may default from care or have an abortion/miscarriage or deliver in a different maternity unit; some may not have delivered within 2001. The mid-year introduction of data collection systems in some units may result in a lead-time between the collection of antenatal information and postnatal information. In addition, information presented in the Confidential Enquiry into Maternal Deaths (CEMD) suggests that only 74% of all pregnancies result in a “maternity” (a live or stillbirth greater than 24 weeks gestation). With drug misusers it is possible (though this is yet to be determined) that the maternity rate is even lower because of a higher legal or spontaneous abortion rate or higher in utero mortality.

One unit recorded more deliveries than numbers seen antenatally. This is because 17 “out of area” drug-misusing women delivered there for a variety of reasons (such as the anticipated requirement for neonatal intervention, or individual preference).
Maternity information systems

Maternity information is important for various reasons: to monitor the health of women and their babies, to monitor the services provided, to audit, monitor and evaluate changes in the provision of care, and to enable women to make informed decisions. This information should be accurate, complete and available. However, studies have shown that maternity information in general is deficient. The variability in quality and quantity of information collected through the current (optional) maternity tail of the Hospital Episode Statistics (HES) (“Korner” datasets) has been highlighted. In addition a national survey in 1997 found that although all the responding trusts collected most of the required HES data, different definitions were used. Only 11% of trusts collected all the Changing Childbirth indicators of success and only 64% of trusts recorded data on a computerised system.

The variety of information systems in use, including casenotes, midwives’ logbooks and various different electronic systems, impairs adequate appraisal of need and provision of services. This is similar to the situation with respect to implementing antenatal screening for Hepatitis B and HIV. Practical problems have been evident with respect to the lack of data systems to record the information and collate the outcomes of screening, resulting in difficulty in monitoring performance.

Evaluation against standards

Though published guidelines have no defined legal position, they play an essential role in quality improvement and clinical governance. The derived standards in this study offer a framework for evaluating maternity services for drug misusers.

Large variations were evident (Figure 9). No unit met all the standards, and one unit (with 1500 deliveries each year) met only four. Of the six lowest scoring units, five were in the Northern part of the region. Of the seven highest scoring units, five were in Yorkshire.

Even units that do not deliver drug misusers should routinely ask women about their use of drugs so that appropriate referral to another unit can be made. It is of concern that one smaller unit failed to do so. Further, it is unclear to what extent even those units which purport to ask women about drug use do in fact accurately identify misusers. There seems to be no consistent approach to ascertainment, yet it is evident that once the importance of drug misuse has been recognised locally, increasing numbers are identified.

Though 86% of units delivering pregnant drug misusers demonstrated multidisciplinary care, only 68% had access to an individual with specialist expertise. Less than half of the units had a multi-agency protocol.

It is clear from the sources of guidance available that an antenatal planning meeting (involving all the different agencies as well as the mother) should always be held to assess the needs of the mother and child-to-be. Only 39% of units delivering pregnant drug misusers routinely held such a meeting (though a further 18% said they would “usually” hold a meeting, and 39% said they would “sometimes as circumstances dictate”).

There is little information with respect to changes over time, but comparisons with the 1993 survey suggest that improvements have been made.

- One of the impediments to pregnant drug misusers receiving health care has been the fear of their children being removed into care. Therefore, formal child protection case conferences should not be convened without good cause for concern.

In 1993,
52% of units in England and Wales automatically convened a case conference whereas in the present study only 14% of units which delivered drug misusers did so;

- Babies should not need to be removed from their mothers at birth and routinely transferred to SCBU\(^4\). Only 11% of units did so in this study compared with 57% in 1993;
- In 1993, less than half the units had access to drug treatment agencies, whereas in this study all units reported that they were able to access a drug treatment team;
- In 1993, 30% of units had a formal referral policy to drug agencies, compared with 39% in Yorkshire in this study, but only 16% in the Northern area.

**Conclusions**

**Information systems**

Information systems across maternity units are diverse, and the means by which information about drug misusers is collected varies. Often information is recorded on risk assessment forms or in the casenotes, but summary information can only be extracted through laborious manual hand searches.

**Service standards**

The widespread variation in services is understandable because of the *ad hoc* way they were developed and the paucity of guidance with respect to organisation. Different service models are possible (such as integration within existing clinics, or dedicated *one-stop clinics*). However, “best practice” cannot be established without outcome data and an evidence base.

Compliance against *agreed* standards should not be optional. Nevertheless, it is clear from this study that the few available guidelines are not always being followed, perhaps because they have not hitherto been systematically collated.

**Recommendations**

*The Department of Health*, through the maternity strand of the *Children’s National Service Framework*\(^6\) should consider:
1. Developing a core dataset of information about pregnant drug misusers, ensuring that maternity and drug misuse-related definitions used in the core dataset are unambiguous so that they can be used consistently;
2. Endorsing the need for standards for maternity services for pregnant drug misusers, and ensuring their development;
3. Establishing performance management arrangements for these standards.

**Regionally:**

4. Systems should be established for the collection of comparative data. In the Northern part of the former Northern and Yorkshire region this would be through the Regional Maternity Survey Office. In the Yorkshire part of the former region this could be through linked regional data collection for CESDI (the Confidential Enquiry into Stillbirths and Deaths in Infancy).

*Strategic Health Authorities* should:
5. Monitor the performance of maternity units against standards when available and take appropriate action as necessary.
**Trusts providing maternity services** should:

6. Implement robust electronically-based information systems in line with the *Information for Health* strategy\(^7\);  
7. Work with PCTs, the Local Supervising Authority Officer and drug treatment agencies to develop a consistent approach to maternity services for drug misusers;  
8. Adopt a nationally/regionally agreed pro-forma for the collection of information;  
9. Agree and adopt the service standards, when available;  
10. Disseminate the standards to all those working with pregnant drug misusers within the trust;  
11. Ensure that all staff working with pregnant drug misusers are properly trained and aware of the need to be sensitive to the particular needs of this group;  
12. Ensure that staff are trained in the use of computers and the collection of agreed information;  
13. Work with Local Supervising Authority Officers to monitor and to improve service standards.

**PCTs** should:  
14. Work with trusts which provide maternity services and with drug treatment agencies to develop appropriate services for pregnant drug misusers;  
15. Endorse the service standards, when available, and encourage their adoption by the trusts;  
16. Facilitate the dissemination of the standards to all those who work with pregnant drug misusers.

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