Consultation on publication of abortion statistics

Submission from Christian Medical Fellowship

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http://consultations.dh.gov.uk/abortion/changes_to_abortion_statistics_consultation

1. Do you make use of the annual abortion statistics publication? If so, for what purpose(s)?

Yes. For epidemiological research purposes, and review of time trends in the data.

2. Which sections of the publication do you find most and least useful? And why?

All of it.

3. How could we improve the publication, both in terms of the format and the inclusion of any additional statistics or information? (Please give reasons).

A. Population linked longitudinal data on ToP's in England is not available. Only cross-sectional data is currently released by DH in their Statistical Bulletin on Abortions. It appears that linkage by NHS number, and any associated research, has been prohibited in England in the past.

   Many terminations of pregnancy commissioned *outside* of the NHS are undertaken without use of the NHS Number. And yet, in contrast, nearly all other procedures commissioned by the NHS require the NHS number to be used for private procedures. **Therefore it is important that every ToP provider should routinely be required to record and link with the patient NHS number.**

   The ToP procedure should be linked to the female's health record, to enable future longitudinal studies of patient safety and outcome. (eg to measure risk of subsequent premature birth, and infertility for a women post abortion) Therefore it should be a requirement to have the NHS number on all ToP referrals and use the same NHS no. on ToP provider records.

   It may be that *licensing* of private clinics could be made to be dependent upon their provision of ToP linkage with NHS numbers, and female subsequent health outcomes in order to ensure the data is collected by private clinics, with accountability for subsequent health events , as well as NHS.

   In Scotland where ToP's are largely undertaken within the NHS, good record linkage is available.

   The availability of linked data using the NHS number linked to the female health record is well overdue for public health reasons. With over 200,000 ToP's per year, in the UK, this data is needed urgently in order to test the UK evidence of sequelae from ToP.

Public health researchers also need to establish evidence for the safety of ToP among all providers in England as well as to be able to assess its sequelae.

Commissioning Consortia must be able to hold providers accountable for their healthcare outcomes.

B. In 2007, the Science and Technology Select Committee recommended that information on fetal disability *'would be enhanced by better collection of data relating to the reasons for abortion beyond 24 weeks for foetal abnormality, and appropriate analysis of such data'*.[1] **However, there are still gaps and limitations in the data collected on fetal disability which need to be resolved**.

Information on late terminations (on grounds E, F and G) **was required** as a result of the 1991 Regulations which sets out the exact format of the notification form. Schedule 2 Information recorded in sections 13 and 14 of the form required under section 14 that:

Over 24 weeks gestation. If the pregnancy was terminated after it had exceeded its 24th week please give below a full statement of the medical condition of the pregnant woman/fetus.(http://www.legislation.gov.uk/uksi/1991/499/schedule/2/made)

However, the 2002 regulations simply list the information that must be recorded and there is **no longer** a requirement for the information that was collected in section 14. The information required on form HSA4 (http://media.dh.gov.uk/network/261/files/2012/05/HSA4-form.pdf) is set out in the Schedule of the Abortion (Amendment)(England) Regulations 2002 and the Abortion (Amendment)(Wales) Regulations 2002:

10. The ground(s) certified for terminating the pregnancy contained in the certificate of opinion given pursuant to section 1(1) of the Act together with the following additional information in the case of—

(a) the ground specified in paragraph (a), whether or not there was a risk to the patient's mental health and if not, her main medical conditions;

(b) the grounds specified in paragraphs (b) and (c), the main medical condition(s) of the patient;

(c) the ground specified in paragraph (d), any foetal abnormalities diagnosed, together with method of diagnosis used, and any other reasons for termination. (http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.legislation.gov.uk/uksi/2002/887/schedule/made)

We therefore recommend that there should be additional written justification for abortions on the grounds of disability after 24 weeks.

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[1] Science and Technology Select Committee, *Op Cit*, page 32, paragraph 82.

C. **The Department of Health abortion statistics for fetal disability are inaccurate and have been shown to be underreported by the National Down Syndrome Cytogenetic Register** (NDSCR)[2].

740 babies aborted with one of the three trisomy conditions, or 51.5% of the NDSCR's total of 1,437, were apparently not reported by the Department of Health. For Down's syndrome 460 out of 942, or 49%, were not reported.

The NDSCR 2010 annual report, published in December 2011, gives an overall total of 'at least' **1,437** abortions of babies with one of the three conditions, Down's syndrome (trisomy 21), Edwards' syndrome (18) and Patau syndrome (13). Furthermore, the NDSCR estimates that a substantial proportion of those babies with trisomy with 'unknown' outcomes were also aborted.

However the Department of Health Abortion Statistics for England and Wales in 2010, published in May 2011, Table 9, shows that in 2010 there were 482 abortions for Down's syndrome, 164 for Edwards syndrome and 51 for Patau's syndrome, giving a total of 'only' **697**.

If the NDSCR statistics are accurate, and there is no reason to doubt them, then this means that **the Department of Health is being notified about less than half of the abortions carried out for trisomy 13, 18 or 21**.

A separate recently published study said that their results showed: '*that approximately 53% of TOPs recorded by EPICure2 are presented in DH abortion statistics for NHS hospitals*' and that '*substantial differences in the numbers of reported [abortions] remain unaccounted for*.'[3]

It is not clear whether this underreporting is due to failure to report or mis-classification of the reason for ToP. Neither is it clear whether this under-reporting extends to other conditions of termination.

We consider that the disparities in the figures are alarming and require both investigation and rectification.

4. What should we do to engage more effectively with users of abortion statistics?

Ask for feedback from users and researchers - nurture research which can promote better public health outcomes for female and baby health.

5. Should the Department of Health's publication focus on figures for England rather than England and Wales? Please explain why.

Both England and Wales should be able to be distinguished because commissioning of ToP is slightly different in England, Wales and Scotland and may have different health outcomes.

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[2] http://www.wolfson.qmul.ac.uk/ndscr/

[3] Draper E, Alfirevic Z, Stacey F, Hennessy E, Costeloe K, for the EPICure Study Group. An investigation into the reporting and management of late terminations of pregnancy (between 22+0 and 26+6 weeks of gestation) within NHS Hospitals in England in 2006: the EPICure preterm cohort study. BJOG 2012;119:710–715.

6. Are there any specific tables in the publication that you would find important to retain coverage for England and Wales tables? If so, why?

All should be retained.

Already budget cuts to the ONS are having immediate effects on the collecting of vital health data. Datasets are vital to providing good public health intelligence to enable monitoring and accountability to be adequately performed within the new PH structures.

7. Do you agree with the proposal to publish information by CCG and LA instead of PCT? Why?*

If GP CCGs are allowed to commission with new population boundaries, much health service activity data will cease to exist, without true accountability and we will not be able to gauge unmet need for health services because we will have numerator data only.

It is essential to marry GP practice information into LA boundaries - with LA populations - to see the year on year health trends.

8. Do you agree with the proposal to adopt CCGs as the primary breakdown, whilst presenting as much information as possible for LAs?

Datasets are vital to providing good public health intelligence to enable monitoring and accountability to be adequately performed within the new PH structures. The key criteria are that information is accurately recorded and that year by year comparisons within regions is easily manageable even allowing for future regional reorganisations. Ideally information gathered should be correct both for CCGs and Las.

9. Do you agree with the proposal to switch from PCT to CCG for the next report? Why?

The key question will be whether this can be accomplished in a way that accuracy and accountability are maintained and that meaningful year by year comparisons can be made. We are very concerned that this reorganisation does not lead to a loss of data. The LA boundaries by 2007 had largely become coterminous throughout most of England with the PCT boundaries so it is important to continue the record of public health data on LA boundaries so that intelligent year on year health comparisons can be made and health outcomes of any changes in commissioning can be measured effectively.