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## **Evaluating the effectiveness of a decision aid for prenatal testing of fetal abnormalities in improving women's informed decision-making: results from a cluster randomised trial**

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**Background:** With the development and increasing utilisation of first trimester tests for fetal abnormalities, facilitating women's informed decision making has never been more important. Decision aids are established as effective interventions where health decisions are complex, but their effectiveness in prenatal testing has not been established.

**Aims:** To evaluate the effectiveness of a decision aid, compared to a pamphlet, in improving women's informed decision making.

**Methods:** A cluster randomised controlled trial was conducted in the primary health setting of Victoria. Fifty-five General practitioners were randomised to providing women with a decision aid (intervention) or a pamphlet (control). Primary outcomes of informed choice and decisional conflict were measured at 14 weeks gestation using questionnaire data.

**Results:** Questionnaires returned from 337/467 women provided a response rate of 77% (intervention) and 78% (control). Women in the intervention group were more likely to make an informed choice than women in the control group (adj OR 1.72 95% CI 1.05 to 2.85,  $p = 0.03$ ). A greater proportion of women in the intervention group (68%) had 'good' knowledge compared to the control group (49%) (adjusted OR 2.60 95% CI 1.58 to 4.29,  $p < 0.001$ ). However women in the intervention group were less likely to have positive attitudes to the test (adjusted OR 0.62 95% CI 0.30 to 0.88,  $p = 0.02$ ). Similar proportions of women in both groups had testing. Mean decisional conflict scores were low in both groups (decision aid 1.70; pamphlet 1.64) (adj mean difference 0.49 95% CI 0.18 to 1.35,  $p = 0.17$ ). There was no strong evidence of differences between the trial arms for the measures of depression, anxiety or attitudes to the pregnancy/fetus.

**Conclusion:** Use of a tailored decision aid can facilitate a greater level of informed choice in prenatal genetic testing decisions than a generic pamphlet.

## **Perinatal data validation – can we do it better?**

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**Background:** Midwives submit information about all births in Victoria to the Victorian Perinatal Data Collection Unit (PDCU) under a legislated requirement. Routinely-collected datasets such as this make significant contribution to epidemiological research. It is important that the accuracy of the data is known and that it is optimised. PDCU uses a number of strategies to maximise accuracy, including on-going communication with midwives; having a nominated midwife at each hospital check each form; coding by Health Information Managers at PDCU; logical checks; a query process for forms with ambiguous or missing data; double data entry; range restraints in the database; and data cleaning processes. Completeness of the collection is checked by selected hospitals providing a list of all births at the end of each year. PDCU supplements these processes by conducting occasional validation projects, whereby data submitted on a sample of forms are checked against the original medical records in order to produce an estimate of the accuracy of various items. The last was conducted on 1999 data.

**Methods:** A validation study is currently underway, looking at births in 2003. The methods of the current study differ considerably from previous ones in that this study:

- includes a random 1% sample of records from 2003;
- checks a range of items on the forms, including all forced-response items and a selection of free-text complications/conditions of pregnancy, labour and birth, postnatal and neonatal periods (chosen after expert input);
- draws data from the original handwritten sections of the record (so as to avoid the circularity of checking database-generated reports against database-generated perinatal data forms);
- checks coding, data entry and data processing at PDCU as well as the accuracy of data on the form;
- describes the source of any discrepancy e.g. data entry error, omission from the form, data recorded on form but not in medical record.

Methods of the study will be presented in detail, including differences from previous Victorian validation studies, implications of these differences and power issues.