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## Positive women's views on routine HIV antenatal screening

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A poster presentation from the 2005 [ASHM](#) [1] Australasian Society for HIV Medicine. The peak Australasian organisation representing the medical and health sector in HIV/AIDS and related areas. Conference held in Hobart, Tasmania.

### Positive women's views on routine HIV antenatal screening

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<sup>1</sup>National Association of People Living with HIV/AIDS (NAPWA)

Australian HIV testing policies have always recommended pregnant women be tested on the basis of risk assessment or [clinical](#) [2] Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science. indication. With a low seroprevalence among Australian women, universally offering antenatal HIV testing has not been seen as appropriate or cost-effective. Although some have argued HIV testing be routinely offered, it has never been policy.

HIV positive women have often had very strong opinions on this, for the obvious reason that many women have had direct experience of receiving a positive diagnosis during pregnancy, or have had children while HIV positive. Being diagnosed with HIV while pregnant can be a distressing or traumatic experience, and positive women have drawn attention to how testing policies directly affect women's wellbeing, and the urgent need for appropriate services and approaches.

A recent analysis by Graves et. al. suggested that there may be economic arguments for routinely offering antenatal HIV testing<sup>4</sup>. Some now argue that current policy should be revised.

The National Association of People Living with HIV/AIDS (NAPWA), through its NAPWA Women's Network, has been seeking the views of HIV positive women on this subject, and have contributed directly to this debate.

NAPWA has:

- submitted a Position Summary on Antenatal Screening to the Inter-Governmental Committee on AIDS, Hepatitis and Related Diseases;
- advised the NAPWA Treatments Policy Group in its deliberations on this question;
- contributed to a Victorian review on antenatal testing issues.

There has been a growing recognition among policy-makers that HIV positive women's views in this are not just legitimate, but crucial.

NAPWA retains major concerns about the practical implementation of routine testing in the antenatal setting. There are significant shortcomings in current practice, including serious deficits in support and referral services. Problems include:

- continuing reports of women tested without consent or knowledge;
- worryingly varied levels of clinical knowledge and capacity for risk assessment among GPs, obstetrics specialists and other clinicians;
- at least one recent case in which a newly-diagnosed woman was advised to terminate her pregnancy in the mistaken belief the baby would likely be born HIV positive;
- a lack of clear and identified referral services for clinical or peer support, with availability of appropriate services varying widely;

the absence of national counselling and treatment protocols;

the possibility that women at the highest risk of HIV, or presenting with symptomatic illness late in pregnancy, would continue to be 'missed' under the universal approach.

Accordingly, there are a number of principles NAPWA would like to see reflected in these deliberations.

### **Consultation and inclusion**

HIV positive women need to be consulted as widely as possible, and directly included on working groups which set up to develop, write or implement guidelines or protocols. It is through gaining insight from women who have directly experienced a positive diagnosis in pregnancy, for example, that policymakers can develop acceptable and relevant protocols.

### **A national approach**

Women report the current situation as "ad hoc" and sometimes contradictory. Anecdotally, women's experiences of testing in pregnancy vary greatly between states. Successful and meaningful policies and guidelines need to consider what is best for both the mother and her infant, and should be nationally recognised and followed.

### **Support and referral**

Whether HIV screening is to be routinely or universally offered, or whether the status quo remains, NAPWA places great emphasis on support and referral services. Many women report current services to be patchy, sometimes inadequate or even non-existent. Any move expansion of testing brings the obligation to provide adequate and appropriate support and clinical referral services. This would be an important condition of any support from NAPWA for changing the current arrangements. It may be possible to set up or contract a specific peer referral service that positive women could access in pregnancy for support or advice.

### **Pre and post test information**

Experience of the pre and post test information was extremely variable. Some women reported feeling isolated; not always made aware of the risks and benefits, pros and cons of testing, and some clinicians had a poor knowledge of HIV treatments options and clinical outcomes. It is not uncommon for women to report they are tested without consent or knowledge.

It was suggested that:

- the partners of pregnant women should be involved in discussions and where relevant, offered testing;
- it could be useful to target and improve GP services, particularly those likely to see women at higher risk;
- there might be a set of "gentle questions" which can be used to talk women through HIV risk, and to help them decide whether or not to be tested;
- since some women reported that they felt 'coerced' into testing, pre test information needed to be clear that women are free to decline a test.

### **Shared care**

Screening protocols, training and guidelines should be targeted to all those involved in clinical care, including midwives, GPs and specialist physicians.

### **Hidden costs**

There are still concerns among some women that universally offering entails a potentially high cost for the benefit gained. In practice, such a policy is likely to incur "hidden" or unexpected costs in implementation, and this needs to be taken into account.

<sup>1</sup> Graves N, Walker DG, McDonald AM, Kaldor JM, Ziegler JB. Would universal antenatal screening for HIV

infection be cost-effective in a setting of very low prevalence? Modelling the data for Australia. J Infect Dis. 2004 Jul 1;190(1):166-74

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- [conference presentation](#)
- [Health, Treatments and Research](#)
- [Positive women](#)
- [Positive Women's Network](#)
- [pregnancy and childbirth](#)

### Links:

[1] <http://www.napwa.org.au/glossary/term/382>

[2] <http://www.napwa.org.au/glossary/term/475>