

---

## Reply

# The ethics of anonymised HIV testing of pregnant women: a reappraisal

Paquita de Zulueta *Imperial College School of Medicine, London*

---

“Anonymised screening is a research tool to inform policy and practice and individual decision making, but is not a tool to identify those at risk that could directly benefit from intervention.”<sup>1</sup>

The assumption that the information acquired will be used to prioritise health care resources may prove false. A government, after weighing up the costs and benefits, may choose not to adopt appropriate interventions. Or, even if a policy is proposed, (such as universal screening in areas of high prevalence), it may not be adhered to. Even as I write, antenatal clinics that serve populations with the highest concentration of refugees from sub-Saharan Africa, and therefore of those at risk, still do not have a policy of universal screening.

Anonymised screening is a form of non-therapeutic research, and should comply with the Helsinki Declaration on Non-therapeutic Research involving Human Subjects. I have already argued that physicians who undertake anonymised screening have abrogated their duty, as outlined in article one, “... to remain the protector of the life and health of that person on whom biomedical research is being carried out”.<sup>2</sup>

In addition, article four states: “In research on man, the interest of science and society should never take precedence over considerations related to the wellbeing of the subject.”<sup>2</sup>

The desire for an outcome—perfect epidemiological figures—should not override the ethics of the process whereby this is achieved. The research subjects are entitled to have their autonomy respected. For consent to be valid, they must fully understand the procedure for anonymisation, and be made aware of the alternatives, including the benefits of named testing. Anecdotal and empirical evidence suggests that this is not the case. In one study only five per cent of women fully understood the nature of the testing, and a significant proportion believed that they would be informed if the results were positive.<sup>3</sup>

### Standards of implementation of policy

The failure to achieve proper consent does not necessarily reflect “poor standards of implementation”,<sup>1</sup> but accepted standards. Accepted practice since 1992 has been that midwives taking the routine heel-prick samples do not raise the issue of unlinked anonymous testing. In other words, the procedure is done covertly. Information about anonymous screening is available in the antenatal clinics, but no attempt is made to ensure that this has been read or understood (particularly by non-English speaking women) prior to testing.

Professor Pinching suggests that educational strategies for both members of the public and health care professionals will provide the relevant information to all, and encourage women at risk to come forward for testing and treatment. This “request policy” has had poor results and is not recommended.<sup>4</sup> It also assumes that the individuals at risk will be able to make use of the educational material.

I accept that it may be more ethical to perform anonymised testing where universal testing is available, but the contradiction in such a policy is striking. On the one hand, the woman is receiving the strong message that she should accept testing “for the good of her baby”. Yet on the other hand, she is being asked to accept testing whereby she and her baby cannot benefit!

### Widespread misunderstanding of anonymised testing

I would suggest that it is important to explore the possible reasons why a lack of understanding is so prevalent. This may provide further support for the claim that the methods used for anonymised testing are unethical. I would propose the following: when a woman attends an antenatal clinic, she has a reasonable expectation that all tests and procedures will be to benefit her directly, or her child-to-be. This expectation may be further reinforced by the tests being undertaken by a health

care professional (such as the midwife). She may assume that the health care professionals have a duty of care to safeguard her interests. The notion that this may not always be the case, and that a test may be done which cannot benefit her, creates confusion and a justifiable disbelief. One could argue that the policy-makers exploit the inherent trust which people have in their health care professionals in obtaining the blood for anonymised testing.

### The woman's right to choose

At no stage do I suggest that women cannot elect, having been properly informed, to refuse named HIV testing. I accept that for some women the disadvantages of knowing their HIV status may outweigh the advantages, and their wishes should be accepted. I am also strongly against mandatory named testing, which, alas, exists in some countries. I do suggest, however, that it is unethical for health care professionals to encourage women to relinquish their moral (not legal) duties to protect the interests of their unborn children, by denying themselves the opportunity to pivotal information.

### The ethical principles underlying refusal to agree to anonymised testing

It is not surprising that the midwife, an HIV specialist nurse, was surprised when challenged by Frances's objections. Only a tiny percentage (0.1%) of women refuse such testing.<sup>3</sup> The midwife's "greater good" argument is precisely the one given to justify anonymised testing. That this is offensive in the individual situation highlights its inherent ethical flaw. Frances's ethical principles are framed as duties. As a responsible mother she recognises her special duties to her unborn child. She must be given the result of a test that could have a relevance to the future wellbeing of her child. She cannot accept the "unlinkage" of her duty by agreeing to have the results anonymised. She does not, however, have a specific duty to request an HIV test as she is clearly at low risk. By requesting the test, she would place herself in the high-risk group, with the attendant anxiety and stigma. She would also find it hard to justify the use of resources for undertaking the test (as would the doctor).

### The public good versus the individual good

I do not believe that these need necessarily be in conflict. Individuals may share in the same end. If they do not, however, they are being used "merely as a means", to paraphrase Kant. The benefits of allowing the infringement of individual autonomy must be very great, and the harms minimal (for example, with compulsory seat belts). Health care professionals, however, have special moral and legal duties to their patients that they cannot abandon for the greater good. The danger of a crude utilitarian ethic is exemplified by the infamous Tuskegee syphilis study (although it is doubtful that any real "good" was served by withholding information and treatment).

I acknowledge the usefulness of obtaining accurate prevalence figures, and of the figures being used as a national audit tool (which appears to be a more recent justification). But these justifications are insufficient. We now have information on the prevention of vertical transmission that we did not have at the onset of the screening. We have obtained sufficient data to inform policy. The continuation of anonymised screening, particularly without valid, informed consent is, I maintain, ethically unsound.

*Paquita de Zulueta, MBBChir, MA (Cantab), MRCP, MRCGP, MA (London) is a Part-time General Practitioner, and Lecturer at the St Mary's Campus, Imperial College School of Medicine, London.*

### References

- 1 Pinching AJ. Commentary. The ethics of anonymised HIV testing of pregnant women: a reappraisal. *Journal of Medical Ethics* 2000;26:22-4.
- 2 World Medical Association. *Helsinki declaration on non therapeutic research involving human subjects*. Articles 1 and 4, 1996.
- 3 Chrystie IL, Wolfe CDA, Kennedy J, Zander L, Banatvala JE. Voluntary named testing for HIV in a community based antenatal clinic: a pilot study. *British Medical Journal* 1998;318:190.
- 4 Royal College of Paediatrics and Child Health. *Reducing mother to child transmission of HIV infection in the United Kingdom*. London: Royal College of Paediatrics and Child Health, 1998, April.
- 5 Department of Health. *Prevalence of HIV in England and Wales in 1996*. Annual report of the Unlinked Anonymous Prevalence Monitoring Programme, 1996.