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25th October 1996

Dear David and Fran,

It was productive to be able to go through our study results with you, and we await your deliberations with anticipation. Meanwhile, Huw and I have reflected on some of the issues which were raised and thought it might be useful to write them down.

(i) Thanks to your calculations we reached agreement that 26 samples had run through the full gamut of tests. Of these only one remained consistently negative.

(ii) The indeterminates resulting from the Pasteur kit would have been officially recommended for retesting, though in practice this by no means always occurs. It is possible that some of these would have been declared positive when accompanied by details of their risk group. However, these same samples were consistently negative when tested on the other two kits. This in itself highlights the major inconsistencies between the different test kits on the market.

(iii) A glaring implication of the above is that because the kits are testing only for the concentration of certain antibodies, and because we found an abundance of *indeterminate* concentrations in our tests (and indeed it is demonstrably so at large), the tests cannot indicate the presence of a specific virus. A specific test would depend on such antibodies being associated only with HIV - the presence of "indeterminate HIV" is a nonsense.

(iv) As you know, two of our seven positive people were wrongly diagnosed. This was revealed through seven false positive results out of a sequence of 37 tests.

(v) Fran rightly wondered, during our discussion on the implications of a 0.1% false positivity rate in a test used in a general population where prevalence of infection was around 1 per 1000, why the mathematically predictable merely 50% reliability (1 in 2) was not reflected in *our* tests. There are two points here: (a) this doesn't mean that of all people tested, 50% would come out positive, albeit wrongly so - it means that of those who *do* test positive, 1 in 2 will be wrong. (b) In our tests we found a very comparable rate of wrong diagnosis - 2 in 7 or 1 in 3.5.

(vi) We consider it a bonus that our two wrong results were through two different systems of testing currently in use. The first (Peter Nichols) can be regarded as an average young gay man anxious to discover his status; the second was a targeted sample high in gammaglobulin as suggested by Dr Eleopulos to show the cross-reacting (and thus non-specific) potential of this condition in relation to an HIV test. Although the PHLS claims it weeds out these so-called false positives, we intend to show through the programme that in practice this is not always done, and a significant number of diagnosed people, with the attendant death sentence hanging over their heads, are suffering under a false diagnosis, even from just this point of view (and excluding the thesis of the Perth group of scientists et al, who argue that *all* tests are wrong because HIV has never been isolated and the proteins being tested for are in all of us). Indeed our programme should demand a national recall of all people with an HIV diagnosis in the same way that the errors in mammography and cervical smears were recently dealt with.

(vii) We still believe it would be productive to conduct a final run of high gammaglobulin samples whose patient source can be identified, with the help of Prof. Pamela Riches at the Protein Reference Lab, St George's Hospital, Tooting. We've been surprised and gratified by the support we've received from clinicians who've given us samples, who have all encouraged our research knowing that this has never been done before.

Indeed these are, as you mentioned, tests that no-one who understood their error margins would want to subject themselves to. However, it is currently the case that the tests are in widespread general use despite their tragic shortcomings.

We look forward to hearing from you.

Yours sincerely,

Joan.