

### **2.13 Deputy K.C. Lewis of the Minister for Health and Social Services regarding non-notification to patients of the results of blood sample testing:**

Would the Minister advise Members why it is not intended to advise patients of the results of blood samples taken from them for testing for H.I.V. (Human Immunodeficiency Virus), and Hepatitis C?

#### **Senator S. Syvret (The Minister for Health and Social Services):**

The type of testing we are to embark upon is unlinked, anonymised testing. That means by definition that the samples taken from routine blood samples will be isolated and anonymised so it will not in fact be possible to inform people of positive results for things like H.I.V. or Hep. C precisely because the system is anonymised. There will be no way of tracing back to the individuals concerned any positive results that may arise. The purpose of this testing is to enable the health authorities to get good and sound epidemiological data about the prevalence of these illnesses across society in the relevant age groups. As far as the testing of individuals who may wish themselves to know is concerned, people have always been able to voluntarily ask to be tested themselves and they would be told the results under those circumstances.

#### **2.13.1 Deputy K.C. Lewis:**

While I applaud the initiative of the Health Department in collating this data and I fully appreciate the need for anonymity, data protection and human rights, I cannot help but wonder if we are missing an important opportunity here. Surely if the patients are given a code number they could for instance tap this code into a hospital website or some similar website set up and get a "blood sample okay" message or "seek medical attention" message. I am sure with all the foreign travel that is going on there must be many people who are completely unaware that they may be infected with Hepatitis C or H.I.V. Does the Minister not agree?

#### **Senator S. Syvret:**

Indeed that is our concern, that there may well be a higher prevalence of these illnesses in society than that which we are aware of. But, I have to reiterate it will not be possible to identify back to the individual patient. This methodology of the unlinked, anonymised testing is standard clinical procedure in other western jurisdictions. It is widely used. It has also been passed through the Health and Social Services Ethics Committee for their views of the subject. So, it is standard clinical practice. We are not doing anything unique here. To follow the path that the Deputy suggests would be attempting to test people on an individual basis basically and then informing them of the results when they have not gone through the process of discussing the issue with their G.P. (general practitioner), with the clinicians at the hospital, being counselled about the subject in terms of what the results might mean for them and a whole range of other considerations that need to be taken into account. The position is that the unlinked, anonymised testing will give us a substantial amount of very useful and important health data, which we just do not have at the moment. As far as individuals are concerned if they consider themselves to be at risk - and perhaps even if they do not consider themselves to be at risk - people should go and get tested voluntarily on the basis of these potential illnesses and they will be told the results.

#### **2.13.2 The Connétable of Grouville:**

May I congratulate the Minister on bringing forward this initiative, which in fact was one of the key recommendations of the Dorey drugs inquiry of 2003-2004, but could he assure me that we have funds allocated for this financial year and a planned date for the commencement of the service?

#### **Senator S. Syvret:**

Yes, Sir, we have funds available. We have long wanted to embark upon this and perhaps would have done so earlier had our financial circumstances allowed but yes, we have funds to embark upon this programme and we will certainly be doing so at the earliest possible opportunity.

#### **2.13.3 Deputy P.V.F. Le Claire:**

In other countries when blood samples are taken by hospitals the actual results are appended to the patient's records and a copy of those results are given to the patient. Is that not something that we could be doing in Jersey and what is the reason for the anonymity in respect of people with concern for H.I.V. and Hepatitis C? Is it, because I am not certain, something to do with if they go for a test for H.I.V. or Hepatitis C that they have to tell their insurance company and therefore there is some kind of a risk or something in life insurance if they do this? What is the reason why we cannot get to grips with what is a serious disease because of an anonymity problem?

**Senator S. Syvret:**

We are doing what we can to get to grips with a serious condition and I have to simply reiterate the answer I have already given. These samples will be a small part of a blood sample that may be taken from patients on a normal, routine basis for a wide variety of other tests. Those tests will remain identifiable with the patients for other clinical purposes but for the purpose of trying to identify the incidence of H.I.V. and Hep. C occurrence in our society a small part of the blood sample will be taken away, anonymised and then tested for H.I.V. and Hep. C and this will give us, as I have said, important public health data which will enable us to track and gauge the incidence of these kinds of illnesses in our society. If people want to be tested - and people should be tested and I would encourage people to do so for these and indeed other illnesses - they should go to their doctor and they will receive the appropriate guidance and counselling and be tested and get the results.

**2.13.4 Deputy D.W. Mezbourian:**

Will the Minister advise what provision is being made for patients to refuse to allow for their blood to be tested in this way?

**Senator S. Syvret:**

Yes, Sir, there was an opt-out availability in the policy. People can discuss these issues with their general practitioner or clinicians at the hospital and they can opt out of this testing programme should they so wish.

**2.13.5 Deputy J.A. Martin:**

I think the Minister has explained why the need for anonymity, and it is collecting data. My concern is, if the data collected reveals a very nasty shock for the Island that there are X amount or maybe 1,000 people with either of these diseases how will the Minister deal with this if it is completely anonymous even to the highest people in the hospital who these people are? Because they are diseases that are spread very quickly and that is my concern that if we do find out we have a serious problem what would the Minister then be able to do about it when we do not know who these people are?

**Senator S. Syvret:**

Well, at present if, hypothetically speaking, there were very high incidences of these infections in society at present we just do not know that. With the unlinked, anonymised testing we would be in a hugely more advantageous position of at least knowing about it and I guess then we would have to embark, were the figures severe, on a much more intense programme of public health education to people to convince them to change lifestyles and take appropriate precautions and all of the other things that health authorities generally try to do to encourage people to lead healthy lifestyles.

**The Bailiff:**

Two more supplementaries, Deputy Mezbourian and Deputy Lewis.

**2.13.6 Deputy D.W. Mezbourian:**

In answer to my previous question the Minister stated that patients will have the power to choose to not have their blood tested but I am concerned that unless they are told about these random testings

they will not be able to say that they do not want to have their blood tested. Will it be incumbent upon clinicians and G.P.s to explain about this testing prior to taking samples of blood from patients?

**Senator S. Syvret:**

Yes, Sir, we have involved fully the Island's G.P. community in devising the relevant protocols and methodology and the fact that this testing will take place will be explained to people.

**2.13.7 Deputy K.C. Lewis:**

Further to that I am slightly confused by the Minister's previous answer that people will have an opt-out. If it was completely anonymous would that be absolutely necessarily? Can the Minister also state whether blood donors, et cetera, are screened for these viruses?

**Senator S. Syvret:**

Yes, it is part of the procedure that people who are good enough to donate blood submit to obviously being tested for blood-borne infections. This is standard clinical procedure and has been for a long time. The point of the anonymity is that people will not know - there will be no way of tracing back to individuals - the results of the tests and that is the reason for its anonymity. I hope that people will understand that this is important public health data that we have to accumulate and that we should not shy away from adopting this kind of policy simply because of these kind of concerns. This is standard procedure, standard clinical practice that is now used in many jurisdictions. We are not doing anything new or novel here and the whole approach has been approved by the independent Ethics Committee of Health and Social Services so I can assure the Assembly that this is a good and correct policy to be embarking upon.