



HOUSE OF REPRESENTATIVES

STANDING COMMITTEE ON LEGAL AND CONSTITUTIONAL AFFAIRS

Reference: Treatment of census forms

PERTH

Monday, 8 September 1997

OFFICIAL HANSARD REPORT

CANBERRA

HOUSE OF REPRESENTATIVES
STANDING COMMITTEE ON LEGAL AND CONSTITUTIONAL AFFAIRS

Members

Mr Andrews (Chair)

Mr Barresi	Mr Randall
Mrs Elizabeth Grace	Mr Sinclair
Mr Hatton	Dr Southcott
Mr Kerr	Mr Tony Smith
Mr McClelland	Mr Kelvin Thomson
Mr Melham	Mrs Vale
Mr Mr Mutch	

Matter referred to the committee for inquiry into and report on:

The treatment of forms from future population censuses.

The inquiry will examine the issues surrounding the destruction or retention of census forms. It will focus on whether the current practice of destroying census forms after processing should continue or whether they should be retained for medical, social and genealogical research.

WITNESSES

FRANCIS, Mrs Sarah Teresa, Registrar Coordinator, Familial Adenomatous Polyposis Registry, c/- Cancer Foundation of Western Australia Inc., 334 Rokeby Road, Subiaco, Western Australia 6008	74
JARVIE, Mrs Diane, President, Rockingham Branch, Western Australian Genealogical Society Inc., PO Box 881, Rockingham, Western Australia 6968	86
PENN, Mr Malcolm Richard, Senior Policy Officer, Legislation, Ministry of Justice, Level 16, Westralia Square, 141 St Georges Terrace, Perth, Western Australia 6000	102
PINNELL, Mr Martin, President, Western Australian Genealogical Society Inc., 6/48 May Street, Bayswater, Western Australia	86
RICE, Mr John Calvin, 1 Myunda Drive, Wanneroo, Western Australia 6065	96
THOMPSON, Mr Allan Ledger, Director, Legislation, Ministry of Justice, 16th Floor, Westralia Square, 141 St Georges Terrace, Perth, Western Australia 6000	102

HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON LEGAL AND CONSTITUTIONAL
AFFAIRS

Treatment of census forms

PERTH

Monday, 8 September 1997

Present

Mr Andrews (Chair)

Mr McClelland

Mr Randall

Mr Mutch

The committee met at 9.11 a.m.

Mr Andrews took the chair.

FRANCIS, Mrs Sarah Teresa, Registrar Coordinator, Familial Adenomatous Polyposis Registry, c/- Cancer Foundation of Western Australia Inc., 334 Rokeby Road, Subiaco, Western Australia 6008

CHAIR—I declare open this public hearing of the committee's inquiry into the treatment of census forms. I welcome witnesses, any members of the public and others who might be attending this meeting of the committee. The subject of this inquiry is whether the current practice of destroying name-identified forms after the data is collected from them should continue. On Tuesday and Thursday of last week we held the first two public hearings for the inquiry. We look forward to hearing and following up some of the issues that were raised in those hearings here in Perth today.

I would like to welcome Mrs Sarah Francis, who is our first witness today. Although the committee does not require you to give evidence under oath, I should advise you that the hearings are legal proceedings of the parliament and warrant the same respect as proceedings of the House itself. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. We have received your submission No. 50 of 28 May. Would you like to make some brief opening remarks?

Mrs Francis—Yes. I was quite surprised at being asked to attend this meeting. When I really looked at what use a census could be to the registry, I looked in great detail. The registry contacts families and family members at risk of a life threatening condition. It often takes many months to contact family members, especially if members are deceased or in another state. What I came to answer questions on is why we would use a census. I can state examples, if you want me to do so.

CHAIR—Can you elaborate on what you do currently where somebody is detected as having the disease and it is deemed necessary to contact other family members. What process do you follow? What existing data is used for that purpose?

Mrs Francis—Depending on who notifies me—assuming it is a doctor—I am asked to contact the person that has the condition, if they are alive. I can then put a family tree together. Obviously the patient is happy for me to do that. I then contact family members, telling them that I have the permission of the family member. It can be difficult where members in other states do not wish contact. Initially, ethically, because it is life threatening and we could be sued for withholding information, we must give information if possible via their doctor; if not, through personal contact. It is up to them to then accept what we offer and follow it through.

Normally we arrange screening after diagnosis. If we are sure that they have this condition, we then screen the children or the siblings, and then it is determined. Now we have a genetic test that helps some families. Where we do not have a genetic test, yearly examination has to be undertaken. There is yearly follow-up. If, say, a parent dies, we have the children on record and we follow them up. And that is really important.

I was notified that a mother had died. It took me nine years to contact two children. There were no names, no dates of birth—nothing. I was told that they had gone to Melbourne, but I kept it on the books. Eventually, via a family priest, I found that they had returned to the same parish and managed to contact them. I was told that there were two children—there were actually three. The third one developed the condition, but we followed this lass up. It was very important. She has the disease, and she now has a child.

The other two children we were able to do genetic testing on. They do not have the condition. But it took nine years for me to do that. That is of value.

The follow-up then is that the registry keeps in contact with them. They either come to the registry or we notify them and their doctor that they are due to be checked, and then we send results—all with permission of the patients. If another doctor rings the registry and wants information on any family member, it is only with their written permission that that is given. Ethically we are very careful.

CHAIR—You will have to excuse my ignorance about the condition: is this a genetic defect?

Mrs Francis—It is a type of hereditary bowel cancer. It is autosomal dominant; it will not miss a generation. It starts usually with polyps in the rectum. If left untreated they turn to cancer. There is no question of that.

CHAIR—Just on that, if it is detected early enough there is treatment which is preventive in nature?

Mrs Francis—Yes, removal of the bowel.

CHAIR—Just so that I understand this, the purpose of the follow-up is primarily to locate a person in order to—

Mrs Francis—Prevent cancer.

CHAIR—undertake whatever screening is necessary to prevent cancer occurring.

Mrs Francis—That is right.

CHAIR—What is the success rate of prevention if you get someone at the early stage?

Mrs Francis—Very high. The bowel is removed, so the polyps cannot exist in that area. A rectal stump is left and that has to be checked regularly. There are new surgical procedures where sometimes the rectum is also removed and an internal pouch is fashioned so that normal bowel movements occur. But it does not mean that they are not at risk of getting bowel cancer, as is the man in the street. For those with this genetic condition the risk factor is there. A lot of counselling goes on with family members from me and other genetic counsellors as well.

CHAIR—Your argument is that if there were access to census records, which are taken every five years, that would make the task of searching out and contacting family members easier than it is now.

Mrs Francis—It would, because often people travel. People in de facto relationships take children all over the state and to other states. People die; people move. I have access to all hospital records. There are no dates of birth on the census. That would be great, but we do not have it. Just knowing whether a house housed one, two, three or five children in a certain area would be helpful to me, yes.

CHAIR—Just one final question from me before some of my colleagues ask questions. No doubt they have some. Are your activities—the establishment of the registry here in Perth—governed by laws or regulations made in Western Australia?

Mrs Francis—Yes. Also, it comes under a national body of the Leeds Castle Polyposis Group, which is an international body that sets protocols for the registries.

CHAIR—Just so I am clear, is there a specific law in Western Australia, a specific piece of legislation that relates to this?

Mrs Francis—I do not know it as a law. Our ethics come under the NH&MRC.

Mr McCLELLAND—I understand that some countries—the chairman can help me out here—for instance, the United States, retain census records but that they are kept confidential for the average life span—about 72 years in the US and 100 years in the United Kingdom. Would that time restriction on access prevent you from fulfilling—

Mrs Francis—Of course, because this condition happens in a few years. Any access I have to medical records is confidential. I sign forms obviously that cover that. None of that information is given to anyone else. It is purely to allow me to contact people. But if it was held like that, those people would be dead. So would I, probably.

Mr McCLELLAND—Yes.

Mr RANDALL—Could I pursue that line. You are obviously talking about one particular condition. Do you know of other related cancer types in respect of which these records would be helpful?

Mrs Francis—I have not spoken to the new breast cancer registry. I feel they probably have a similar situation there. What is happening is that there is what they call hereditary non-polyposis colon cancer. Instead of the small area that I cover, where families follow on as an autosomal dominant, this covers huge numbers of families, where often cancer occurs in three generations at an early age, and many cancers are in that family. There is the gene, and some families know they have got this cancer.

There is a request for funding to cover this new registry that we are hoping to start. It has started internationally in many countries, and in other states here. In the past, cancer foundations have funded them, but they need government funding because it is going to be huge.

Registrars, looking at people slotting into that criteria, have to do a lot of work before they can contact family members to say, ‘You fall into this criteria.’ That means getting a lot of information, and I feel sure that they would be perhaps looking to access that if it was possible.

Mr RANDALL—Mrs Francis, you have mentioned breast cancer, which is very topical. I might suggest to the chairman and the secretariat that somebody with some expertise in that area come before the committee. You are an expert in your area of cancer and perhaps we could have some expert follow-up in

this area.

Mrs Francis—It could well be that the Director of the Cancer Foundation would be a person to suggest that to—I do not know—because of the many cancers that they perhaps look at. But I do know that a breast cancer registry has started.

Mr RANDALL—And how about something like prostate cancer?

Mrs Francis—Exactly. You have got conditions like Huntington's disease, but that is not a cancer—that is a long-term genetic condition.

Mr RANDALL—So tracing the passing on of this genetic condition would be made much easier if you had access to the census records. When you contact these people eventually, through your long process, do they seem to be offended that you have tracked them down?

Mrs Francis—Rarely. Most are grateful—stunned, often, because they have no idea that they are at risk—and usually they will go to their doctor. Examinations or genetic testing are arranged. There is relief if they do not have the condition and, if they do, they know that we are preventing cancer by them following through with treatment. Occasionally, you get someone that just says, 'I don't want to know and I won't inform my children.' We then explain the risk of us being sued by not informing the children, and they will be informed at an adult age. There is usually no complaint there. But if someone chooses not to take it through, that is their right.

Mr RANDALL—I find what you are saying very interesting, actually.

Mrs Francis—Obviously, I have had situations where we have been trying to trace children in adoptive cases. It took me 10 years with the Brisbane adoptive services, where I had a birth mother whose father developed cancer. She had polyposis and developed cancer because it was not caught in time, and she had a child adopted at birth. It was vital that we contact the adoptive parents to let them know of the risk factor. Because the laws were different in Queensland at the time, I just kept getting brick walls. In the end they said, 'Oh, we'll let the family know.' I said, 'Well, we need the gastroenterologist to know. Can I contact him?' They said, 'Oh, the gastroenterologist said he will see her again in five years time,' and I said, 'That's too long. It's too late.'

I had a lot of problems there. Eventually I sent a letter, saying that they could be sued if this girl developed cancer and they knowingly knew the situation. All bars were lifted. We found that this girl is now being tested. The birth mother has developed another cancer, so this girl is at a very great risk. She is very relieved. So is the adoptive mother, whose father died of bowel cancer; of course, we did not know there was a factor there as there has been no problem with the family.

Mr RANDALL—Good. I want to make an observation and then ask a question. You are confirming that time is of the essence.

Mrs Francis—Yes.

Mr RANDALL—And that access to these records would help you with that. There has been some criticism by the Bureau of Statistics that people would not be as involved if they knew that the records were going to be retained. As a result, you would not get as good a survey sample, and the system would in some way be diluted, corrupted, downgraded. Do you think your stance on this could be sold well enough so that this did not happen?

Mrs Francis—I cannot see a problem as long as people understand that no information has been given to anyone. We do not have personal information; it is just relating to the sex. We do not even have the date of birth. It is just that we want to contact people to give them information regarding a life-threatening condition. I cannot see their problem. I realise people do have problems and have a ‘Big Brother is watching you’ attitude, but I wonder how many people really think about the census in that light.

Mr RANDALL—As a personal thing, you think it could be sold well enough so that it did not cause that problem?

Mrs Francis—I think so. I do not see why not. I think people could get together and put it together as a package that would be acceptable.

Mr MUTCH—Mrs Francis, have you made any submissions in the past to either the Australian Bureau of Statistics or the Australian Archives, putting forward your concerns about the need to retain census information for your research?

Mrs Francis—No, we have not. We were approached by the Genealogical Society because I had spoken to them—this was Mr and Mrs Croker, as you know—and then was made aware of the problems surrounding the census. That was really the first time it was brought to my attention.

Mr MUTCH—That is for this inquiry or for the last census?

Mrs Francis—For this inquiry.

Mr MUTCH—So you had never been approached before at all?

Mrs Francis—No. I might say that in other states they do not all have the same access to electoral rolls that I do. Again, the census would be of use.

Mr RANDALL—When you talk about the electoral rolls, do you mean the state-based electoral roll or the AEC’s records?

Mrs Francis—The state.

Mr RANDALL—Because there are two different rolls. There is a state-based one and there is the federal one from the Australian Electoral Commission.

Mrs Francis—Other states’ registrars do not always run things as the WA registrar does and they

may not always have the access to a state electoral roll, from a registrar's working point of view, whereas if they want information from the census they probably would be able to get it more easily.

Mr McCLELLAND—Just on that issue: you say you have in Western Australia greater ease of access to the electoral roll; is that because state legislation enables you to access it for your tracing and research?

Mrs Francis—Yes. I can do that through the hospital. It can be linked up. I have a letter from the health department giving me access to records, which I have had since I started my job in 1985. I have never had a problem trying to contact through the electoral records, which is often done through Sir Charles Gairdner Hospital, where my office is, although I do not work for the hospital.

Mr McCLELLAND—And they can do a computer search, can they?

Mrs Francis—Yes. This really saves me a lot of time.

Mr McCLELLAND—Just balancing the two different options, if there was that same access to the federal electoral roll, would you still need the census forms?

Mrs Francis—If I have a name, it is helpful. With the census, on a computer you can pull up a name, aliases, family members. I am looking for children who have gone missing, and I have got nothing.

Mr McCLELLAND—So that is the advantage of the census over the electoral roll, is it?

Mrs Francis—Yes.

Mr McCLELLAND—Because the census form would say how many children are in that family.

Mrs Francis—Also, many people are not on the electoral roll. They move, and until the next election comes up, they do not re-enrol. I know from people I have talked to that they are not on the electoral roll. In a matter of, say, five years, when you might be needing to contact someone, an election may come up and they may re-enrol, then I have got to try to find that.

Mr McCLELLAND—So the electoral roll would be second-best, but not best?

Mrs Francis—Yes, I think so. It is great, but it would be second-best if we had the census information.

Mr MUTCH—Are you able in any way to access the Medicare card? We have all got a Medicare card. Is there any access to those cards for research purposes?

Mrs Francis—I have not thought of that. I do not know whether that would be stepping on toes, but I could try. I really do not know. I can certainly look at that and see if it would be accessible.

Mr MUTCH—Obviously, they would not be long-term records, they would be current records, and you need to construct a family tree, really, don't you? That was the other question: with the new facility to take a genetic fingerprint of a person, do you foresee a time when you will not need to do family history research in order to detect genetic problems?

Mrs Francis—I do not know. It is going to be a long time, I think, before it gets to that stage. There is a lot of expense involved in that, and you have got to get people complying as well.

Mr MUTCH—It might cause its own privacy problems in the future.

Mrs Francis—That is right. There are a lot of ethics involved in that, too, and it is very early days now. Things are happening very quickly in genetics but, again, there is a lot going on there.

Mr MUTCH—Are you aware of the field of epidemiological research?

Mrs Francis—Yes.

Mr MUTCH—How does that relate to what you are involved in?

Mrs Francis—On our advisory committee we have an epidemiologist and we are looking at statistics. She helps me. We worked together in setting up the registry.

Mr MUTCH—What exactly is epidemiology?

Mrs Francis—They collect numbers, mainly of medical conditions, in areas. If, say, you have a certain disease cropping up in a certain area, then they are looking at the sex, age, and everything else involved, to draw a picture of what needs to be done. It is a little bit like when they were looking at children with spina bifida and finding that the mothers needed the folic acid. A lot of that would have been through epidemiology and the research done on that—the numbers in the areas. That is just touching on it.

Mr McCLELLAND—I suppose there is a side issue, and perhaps that is not a bad thought—if the Health Insurance Commission, for instance, had the capability and/or willingness to receive a representation from you or your organisation indicating that you believed there was the presence of this condition in families, and then the Health Insurance Commission had the capacity to contact those people to inform them of the communication you received. But I suppose the problem there is that the Health Insurance Commission may be writing to every Smith in the country as opposed to narrowing it down to the family of Alfred Smith.

Mrs Francis—The people involved.

Mr McCLELLAND—You would need to do a bit more finetuning, I suppose, before the Health Insurance Commission fired off correspondence to specific people.

Mrs Francis—When you are looking at health insurance, covering what?

Mr McCLELLAND—The Health Insurance Commission supervises Medicare. I have on my family's Medicare card, for instance, myself, my wife and my three children. So the names would be there, but I suppose it would be difficult, if not impossible, for the Health Insurance Commission to know that I am a descendant of any particular person. Or would it be of some use to you to be able to go through the Health Insurance Commission?

Mrs Francis—I am not sure ethically how that would go. Do you mean that I could contact the Health Insurance Commission for that information? Are you looking at it from that point of view?

Mr McCLELLAND—I do not know whether you can or not, but would that be of use to you? The Health Insurance Commission certainly has a register of people's names and addresses.

Mrs Francis—But we would not be informing them that this family had that condition, so how would they know?

Mr McCLELLAND—You would have to give input to the Health Insurance Commission which they in turn related to the family, as a sort of go-between.

Mrs Francis—I think that would have to go before an advisory committee to decide on something like that, as to whether it would be appropriate. I could see it being useful, but it might also have problems. So that would have to be discussed, off the top of my head. I think anything that would give us access to—

Mr McCLELLAND—The advantage of that over an electoral roll, for instance, would be that it would have the number of children in a particular family.

Mrs Francis—Then I could not imagine there being a problem, but it would certainly have to be discussed—us giving information.

CHAIR—How do you actually make the contact now? Say, for example, Mrs Smith has developed this cancer because of the genetic link, and therefore there is a probability that her children will have it. Assuming you can identify her children from other sources, whether the electoral roll or whatever, what do you actually do in terms of contacting them? Who makes the contact? How is the contact made?

Mrs Francis—If Mrs Smith has given me permission, then I personally contact them. Sometimes they already know that their mother has a life-threatening condition and what the registry is all about. I would ask them if they would like to visit me in my office for the information and to draw the family tree, and if they would like me to send literature explaining the condition and its options, and what we do as a registry, and explaining about blood tests and everything else. Usually I say I will ring in a few days, and they will either ring me, being very interested and wanting to get in straightaway, or they will think about it. They know that they can bring in children, partners, anyone else, as a group, separately. That is how we take it. Usually I ask for their doctor's name and permission to contact their doctors to let them know what is happening.

CHAIR—This person gets a letter or a phone call cold?

Mrs Francis—I have found in the past that a letter can be frightening or confusing, so usually I ring them personally and I then say that I will be sending the written literature, and then they can ask any questions about that, and they can ring me at any time.

CHAIR—And if Mrs Smith had not given permission to make contact with her children?

Mrs Francis—Depending on the ages of the children—

CHAIR—Let us assume they are adults.

Mrs Francis—Then I can do it through her doctor, who can ask me to contact them, which is usually what they do. Usually most mothers want you to, but sometimes if there is a family problem they will say, ‘Don’t tell them that I said it, do it through the doctor.’ So we try to be very tactful.

CHAIR—But, again, you make a phone contact with the children.

Mrs Francis—Yes, usually phone.

CHAIR—Relying on the permission of the doctor.

Mrs Francis—Yes. I also let them know that I have had permission, and I get written permission where possible. Also, there is a form which the adult children sign to say that they want registry contact. We have a lot of forms for confidentiality as well. But initially there are many ways of doing it.

CHAIR—What is the incidence of this particular cancer?

Mrs Francis—The disease was about one in 1,000. I think it is now about 10 in 1,000. I do not have the actual numbers in front of me.

Mr McCLELLAND—It is quite common.

Mrs Francis—But what is happening now is, with genetic testing, we are finding out earlier. Before we had to wait until polyps developed.

CHAIR—Is the increase from one to 10 in 1,000 as a result of better diagnosis?

Mrs Francis—Yes. Originally, the parents came in with a full-blown bowel cancer and with masses of polyps, and often they died. In looking at records, we find that families would say that the mother died of pneumonia. When I actually look at the pathology, which is what I have to do, we found that pneumonia was just by the by. People did not like to say the words ‘bowel cancer’. We now are more educated, I think.

Mr MUTCH—With respect to your contacts overseas, do you have relations with other organisations in, for instance, the UK?

Mrs Francis—Yes. I have just returned from Holland, from an international conference which is held every year. There is one in England, as it started in England, and then every second year it is in another country. In 1999 it is being held in Melbourne. I contact other registrars, clinicians and gastroenterologists. I presented a poster in Holland. We present papers in Australia. We are up to date with all the latest research that is going on for preventative measures.

Mr MUTCH—Could you say that there are cases from the UK, for instance, where they do keep the census and where the census data has been used?

Mrs Francis—I actually, because I was asked about this, sent over to St Marks Registry in London to find this out, but I have not had any response to that yet. They are very slow in getting back to us.

CHAIR—Could I ask, if you do get a response from St Marks, if you could forward it to the committee, because it would be of some interest to us.

Mrs Francis—Certainly. Is it worth me contacting other registries over there as well, or in other countries? Or are you already aware of it in other countries?

CHAIR—No, we are not. If that is not too much of a burden, it would be of interest to us.

Mrs Francis—No. I would be quite interested myself just to see if they are using it as such. Is there a deadline for this?

CHAIR—If we got it by the end of the year, that would be sufficient.

Mrs Francis—If I get it by the end of the year, you are very welcome to it.

CHAIR—Mrs Francis, thank you very much for your submission and also for attending today and discussing the matter with us.

Mrs Francis—Thank you.

[9.44 a.m.]

JARVIE, Mrs Diane, President, Rockingham Branch, Western Australian Genealogical Society Inc., PO Box 881, Rockingham, Western Australia 6968

PINNELL, Mr Martin, President, Western Australian Genealogical Society Inc., 6/48 May Street, Bayswater, Western Australia

CHAIR—I welcome Diane Jarvie and Martin Pinnell from the Rockingham branch of the Western Australian Genealogical Society Inc. Do you have any comment to make in relation to the capacity in which you appear?

Mrs Jarvie—I am here to support a submission that was put to the committee on behalf of the Rockingham branch of the society.

Mr Pinnell—I came here in order to support Diane Jarvie, my colleague, and to give any assistance which may be required.

CHAIR—Thank you. Although the committee does not require you to give evidence under oath, I should advise you that the hearings are legal proceedings of the parliament and warrant the same respect as proceedings of the House itself. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of parliament. We are in receipt of your submission of 10 July of this year. Would you like to make some brief opening remarks.

Mrs Jarvie—Yes. I, along with other genealogists and family historians, am very anxious to see the retention of the Australian census to give people like me the sort of resources that are available in records from other countries such as the UK, Canada, USA, Sweden, Greece—quite a number of European countries. Not only does it help us to track our families for hobby purposes but most of us are very interested in the other genetic consequences of tracing our ancestors.

I did not, unfortunately, hear the full discussion with the previous lady, but our Rockingham branch of the society is actually involved in a project called 'Relative Health' which is all about looking at genetic connections between ancestors and current-day people. We are trying to collect a lot of data from death certificates and so on. It makes it a lot more difficult in Australia, and will indeed in the future for any of these sorts of projects, if we cannot pinpoint certain people in certain places at certain times. That is why I am here.

CHAIR—Thank you. In your submission you indicate certain information which is contained in the census data which you believe should be retained. Can you tell us why that information is the information you believe should be retained and, for example, not other information on the census return or, for that matter, the entire census return?

Mrs Jarvie—I suppose one of my concerns would be for asking for too much. In a situation where the statisticians have decided that we cannot have anything at all, I think at this point to ask for anything

other than the sorts of information that family historians can use would be a bit stupid. Therefore, my particular request is that we keep the kind of information that genealogists are quite accustomed to in other records overseas, and that is the name of a person, their household address, their age, their gender, their marital status, the relationship to other people in the households, the birthplace—and quite a key issue with genealogists, I can assure you, is having the birthplace on the census—the birthplace of parents, the internal migration of those people so we can see where they have been, and the occupation of the people.

I feel that that is quite in keeping with other countries' record retention processes. I feel that it is not asking too much. Most of those records are available in other places, although I have to say that those other places records may not be kept. Otherwise you are going to turn around and say, 'Well, if you have got all those other records, why do you need these?' I do not think there is necessarily any statutory regulation for other records that contain this information to be kept. We may find in 100 years time that you have got some of this stuff in the motor vehicle licensing section, but did they keep the records for 100 years? That is the point. I feel that the census is a national record, and if you do indeed make some kind of legislation for the retention of it we are at least safe in having one national record available for future generations.

CHAIR—If we were to keep the material for 100 years, though, would there not be a powerful argument from general historians to say, 'Why shouldn't we keep details about, for example, income levels of people?' Would that not be of some significance to know? If this material had been kept from the 1890s, for example, would it not be interesting to know the income levels of, say, Perth and compare East Perth with Claremont and other parts of the city?

Mrs Jarvie—It may well be an argument of an historian, but it is not my argument. I am a genealogist and this is the only bit that I particularly want to talk about. So let the historians argue that bit. I am not here to argue on their behalf.

CHAIR—Fine.

Mrs Jarvie—I think I have made a point that I am not here either to argue for medical science or geneticists or anybody that wants to know who has got a particular illness or a disability. That is not of interest to us or to our branch. I should not say all genealogists, but this branch put in this submission and we are not interested in anything other than those things I have stated in the submission. It is really a pinpointing kind of process. It is finding this person in a certain place at a certain time so that we can go and look at other places for the fill-ins, if you want to put it that way.

Mr McCLELLAND—The Bureau of Statistics and Treasury are concerned that retaining the forms may weaken or diminish the quality of the material they get. I suppose it is, just from experience, possible to anticipate why people would be apprehensive of having their income disclosed, for instance. It may be inconsistent with what they have put on their actual tax return, for instance. Would it be of any use to you if there was an election provision whereby the people could elect either to have or to not have their information retained? In other words, would that be an acceptable compromise result to ease the Treasury's concerns and, at the same time, give you access to some, but probably not all, census forms?

Mrs Jarvie—Once again, I personally am not interested in the income levels. I would challenge the

Australian Statistician to give me a level of accuracy of census information that is taken thus far. If you have not kept the census to date and you have not kept personal information to date, and therefore you have nothing else to measure it against, how do you know to date whether that information is accurate or not? My point is that the more you allow to be retained, I agree, the less accurate those personal details will become. That is why income does not bother me at all, because if you have got a few jobs on the side and you are claiming social security then nobody is going to faithfully record that.

However, we are only asking for those things that are not a challenge to people in terms of veracity. We are only asking for the things that people almost unconsciously give without even thinking about it. 'What is your name?' Sure. For 98 per cent of the population nobody is going to lie about that. If they do, then we assume that they are lying about almost everything else.

So, once again, I am not interested in any kind of provisions or electives or whatever about income and illnesses and all those sorts of things. We only want those 10 or 11 things that I have put forward, and I do not think there is a problem about privacy issues with those things. I think you are talking two things here: you are talking privacy issues and you are talking reliability of data.

Mr McCLELLAND—Although I could imagine, for instance, an absconding parent who does not want to pay child maintenance not wanting the information to be known at all. That would apply to even the information that would be desirable for the purposes of your research.

Mrs Jarvie—Yes. Certainly I am not quibbling about that. If you have looked at as many censuses as I have in Britain, you will find that all the ladies usually tell lies about their age, and so do the men if they happen to be younger than their wives. That is a human condition. We are not talking about those sorts of little eccentricities, if you like. We are talking about a national census whose aim and objective is to measure the population on a particular night every five years or every 10 years or whatever. If one worried about the odd fib about one's age or alias or whatever, then you obviously would not bother to do a census population measure at all.

So let us not talk about the few absconders or the few people that fib about their income or anything. Let us talk about 95 per cent of the population. I was a census collector last year, and I have to tell you that the goodwill was incredible. I was expecting to get bitten by dogs and belted up by irate absconders and so on, and I found the goodwill to be incredible.

CHAIR—One of the arguments that is put by the Bureau of Statistics is that if people know that this information is going to be retained then that goodwill will dissipate.

Mrs Jarvie—How does he know that?

Mr RANDALL—He surveyed it.

Mrs Jarvie—Did he? Okay.

CHAIR—He surveyed people. But my question is to you in your capacity now as a census collector

and without your disclosing anything which you are legally bound not to disclose: can you tell us what your experience was? For example, how many districts or households did you cover? Can you recall, for example, how many people raised with you what might be broadly regarded as privacy concerns?

Mrs Jarvie—I covered around 250 households. I was asked to put the information in between about three and half a dozen gold envelopes, which means that they are sealed, and that is it, and the group leader or whatever cannot get at them. There was no comment except, ‘May I have a gold envelope?’ So they obviously had heard the education process.

I had debates with two people—schoolteachers, I think—on their doorstep about what the information was going to be used for and their concerns. It was a good-natured debate. They did not shoot the messenger, is what I am trying to say. So I had two people debate the issues. Up to about half a dozen people used the gold envelopes. I might say at least two of the gold envelopes were used because I asked them if they would like to because I knew the people, so I said, ‘Would you like to put that in the gold envelope?’ which they did.

Mr McCLELLAND—What is a gold envelope?

Mrs Jarvie—When you are a collector you just collect the forms as they are, and there is a process later on where you have to count the number of males and the number of females in the house; therefore, the group leader needs to have the forms available to go through that process. If you do not want anybody counting anything off the form, you put it in a gold envelope and it gets sent off to the big building in Canberra or wherever they go—to George Nichols or whatever. I met George a couple of weeks ago and had a go at him, because he is the man who signs the order to have it pulped, so I am being a bit facetious.

Mr MUTCH—With respect to the gold envelopes, were there any instructions given to you by the ABS as to proffering them or suggestions to you that you should in fact proffer them to people you knew personally?

Mrs Jarvie—I just cannot remember now, to tell you the truth. We had a training course and we had a very good manual, a very extensive manual. I think it was my own response to seeing somebody I knew on the doorstep probably, although it might have been in the instructions, but my personal response was, ‘Would you like to put it in a gold envelope because then I can’t look at it any more?’

Mr MUTCH—You have only done this job once, have you?

Mrs Jarvie—Yes, that is right.

Mr MUTCH—So you could not compare with previous years.

Mrs Jarvie—No. I have got no comparison.

Mr MUTCH—In your view then, would most people be aware, even at the time of the census collection, that the forms were to be destroyed?

Mrs Jarvie—No, absolutely not. Just for an example, I run a TAFE course in genealogy for beginners, so I am looking at a target audience of people who are interested in genealogy and family history, and on Tuesday this week it was ‘census day’. That was the lesson. We were going through the census. I can tell you that I rushed through the Australian bit very quickly. All I had to say is, ‘Well, I’m sorry, folks, since 1911 we haven’t got any more.’ They were surprised. I have a friend here who was in the class with me, and she will testify to that. There was shock in the class that the Australian census was pulped. I said, ‘It is being pulped at this very moment.’

Mr McCLELLAND—So you are convinced most people believe that they are retained?

Mrs Jarvie—Yes. They may think people do not pinpoint them personally, but they certainly think the information is kept, in my experience. There is a significant advertising program to tell them that their life will not be looked into, but I do not believe that it filters through to them that the forms will actually be pulped and destroyed and never available for anybody for any reason again. I do not think that is something the Statistician does educate very well about. Maybe that is part of the point. Maybe in confirming that personal details will not be used they should also say that this information, nonetheless, is very useful for future generations. Maybe there should be a survey about this whole issue of an embargo period.

Mr MUTCH—I have a question about the periodic need for census for your family history research purposes: would one in every five years be required, or would you need one every 10 years, every second census?

Mrs Jarvie—We want all we can get, quite frankly.

Mr MUTCH—What would be a suitable compromise? Is it based on a generational need?

Mrs Jarvie—Most of us, because we are accustomed to using the British census, which is held every 10 years, would have been entirely happy if we had an Australian census based on the same thing. The fact that you take it every five years would be even more useful to us, frankly.

Mr MUTCH—If there was a compromise and there was a box on the front page of the census, saying, ‘Tick here if you are happy for your form to be kept’ as part of even a federation project or something like that, would that be of any use to you? Firstly, how many people do you think would tick the box? Secondly, would that be of some use to you as family historians?

Mrs Jarvie—I think it is better than nothing, but frankly, I wonder whether people really understand the need behind a ticked box kind of concept; whether they would understand the need for or the importance of it.

Mr McCLELLAND—What about, for instance, in the year 2001 census, which will be very significant, being held at the turn of the century, if there was such a question on the form, ‘Do you have any objection to this census form being retained for historical purposes to be released in 75 years time?’.

Mrs Jarvie—That is different. In that year I think you would suck them all in!

Mr McCLELLAND—That may give a balanced account as to how much objection there is in the community.

Mrs Jarvie—Yes. Which is the next one?

Mr McCLELLAND—That will be—

Mrs Jarvie—That will be it, yes. Maybe that is something you have to go through. Maybe the next one is the trial one or the ‘let’s see about it’ one.

Mr McCLELLAND—It is not a bad opportunity in that sense, is it?

Mrs Jarvie—No, that is right. It has a lot of focus that year, so if you are going to do it at all, then that probably would be the most successful feedback that you would get.

CHAIR—Presumably, you would prefer an opting-out system rather than an opting-in system; that is, you tick the box if you do not want it kept, rather than ticking the box if you want it kept.

Mrs Jarvie—I would go for broke and say that these are the questions—

CHAIR—Yes, I understand that, but if that is not possible—

Mrs Jarvie—All right, fall-back position.

CHAIR—If it is a choice between opting in or opting out, would I be right in assuming that you would prefer a system where the information would be retained unless people opted out?

Mrs Jarvie—Yes; certainly, the positive rather than the negative. Going back to the question about whether five years is better than 10, because of people’s mobility now, my husband always says that after five years you need a new house, a new wife, a new job and a new everything else, and five years frequently seems to be a landmark for people. It is a biorhythm thing or something, and people do change things every five years. So maybe five years is better than 10.

CHAIR—If that comes to pass, genealogy will be the least of our problems!

Mr McCLELLAND—He has not acted on any of this advice, I take it?

Mrs Jarvie—Not the second time around, anyway!

Mr RANDALL—Mr Pinnell, we will do something for the equality of the sexes here and ask you a question, if you do not mind. You seem to be somebody who might have some understanding of the British

system. I know Mrs Jarvie said that she did also, and it has been said by Mrs Jarvie that she has operated from the British records. I do not know whether you have any knowledge of records from, say, New Zealand, Canada or other countries, but the Bureau of Statistics tells us that our statistical gathering is far better because it is able to be destroyed and you are able to convince the public that it will not stay around. Can you tell me, by way of comparison, if you can, if you have operated in other systems, the difference between the quality of statistical information from those countries that do retain their records and the Australian system?

Mr Pinnell—I am probably not qualified to comment on analysis of current censuses because my interest in the matter has been using 100-year-old or more—150-year-old—census material. But I certainly believe that the material produced by the ABS is excellent.

Mr RANDALL—Maybe we had better ask Mrs Jarvie, then, as you are operating in a more current era: you said you have used the British information. Is that correct?

Mrs Jarvie—Yes, the embargoed information, so we can only use until 1891. Once again, I do not know the questions on the current form.

Mr RANDALL—Do you know about the situation anywhere else in the world?

Mrs Jarvie—No. I have here, which I would like to table for the committee, if they find it useful, a list of census dates, when it was begun in other countries, and some of the kind of information about it, whether the information is available or not. That might be useful to you. I use it in my class, actually.

Mr RANDALL—Can I just pursue this, though? Have you used statistical census-gathered information from other countries?

Mrs Jarvie—Only from Britain—England, Wales and Scotland.

Mr RANDALL—How have you found the quality of that information?

Mrs Jarvie—The quality varies in a number of aspects. The 1841 census, which was the first national census in Britain, has less information available than in 1851 onwards. We do only see the first page of the census, which basically has similar information to that which we are asking for, which is the name of the householder, the other people in the household and their relationship to him or her, ages, marital status, addresses, occupation, country or place of birth, and so on. There is nothing more available to us, at least between 1841 and 1891, than the bare bones of the things that we are actually asking for. Once again, even though the British census information is available to us, I do not believe that anything other than those basic questions is available. There is no information on income, illness, those sorts of things.

Mr RANDALL—But how is the accuracy of the information?

Mrs Jarvie—Darned if I know.

Mr RANDALL—The information you are using to try to put your data together.

Mrs Jarvie—You mean in the piece that we do get?

Mr RANDALL—Yes, that you get.

Mrs Jarvie—It varies. As I said earlier, if you worked your way through every 10 years, let us assume that you have got a family which you have picked up in 1841 and you have found them every 10 years throughout, first of all you will find age discrepancies, because the 1841 census tended to round down the age of adults—rounded it down to a five-year period. Once you get into 1851, you have got a different age to start with from the previous census. After that, it varies. I have some people who were 21, 31, 41, 51 and so on through the system, and then I have others who vary by a year or whatever, but you have got to remember the thing about the birth date. People say, ‘I am nearly 23,’ or ‘I’ve just passed being 23.’ You are likely to be out by a year in the actual age.

I find that, in ages, they are remarkably consistent each 10-year period. In occupation, they use different terms. All of mine are agricultural labourers, so you get things like farm labourer, agricultural labourer, labourer, but generally you have got the drift. Obviously, if they move, you have got different addresses. The only thing you can pick on, I would suspect, to measure the accuracy of the British census material, inasmuch as the questions we get, which is basically only about 10 questions answered, is probably the age. That is the only thing that you can fix as a measure of accuracy. What else can you fix? The address may be variable, the occupation may be variable. The birth place is a fixed point, and that is pretty accurate. With my ancestors, generally speaking, the information is fairly accurate, moving from one period to another. They might have lied every year for 50 years!

CHAIR—I see in the exhibit that Finland has been taking a census every year since 1634. Was there anything else you wanted to add, Mr Pinnell?

Mr Pinnell—May I make one brief point? A primary source of information for people trying to research their families is going to be the civil registration of births, marriages and deaths, but those records are not 100 per cent accurate. There are holes in the net, such as a child being born at sea or born interstate. Because of that, people researching family history have to look at secondary records.

A week ago I was invited by the public records office here in Perth to help them index the records of vaccination, because those records tell you the name of the child, the date of birth of the child, and the father’s name. Very occasionally that information will fill a hole which somebody has not been able to fill through the primary records. If vaccination records are able to do that, how much more would census records help people in 100 years time?

CHAIR—Can I thank you for your submission and also for coming here today and discussing the matter with us. It has been most useful.

Resolved (on motion by Mr Mutch):

That the exhibit list of census dates provided by Diane Jarvie be accepted as an exhibit to the inquiry.

[10.47 a.m.]

RICE, Mr John Calvin, 1 Myunda Drive, Wanneroo, Western Australia 6065

CHAIR—I welcome Mr John Rice. In what capacity are you appearing before the committee?

Mr Rice—I am appearing as a private individual.

CHAIR—Thank you. Although the committee does not require you to give evidence under oath, I should advise you that the hearings are legal proceedings of the parliament and warrant the same respect as proceedings of the House itself. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. We are in receipt of your submission to the committee. Would you care to make some brief opening remarks.

Mr Rice—Thank you, Mr Chairman. I made this submission in response to an advertisement in the newspaper. I was not going to come along to give oral testimony but some members of your staff asked me so nicely. I simply believe that retention of name-identified forms is a threat to the values of a free society. I do not believe that we should ever concede that the government has a right to know everything. I do not believe that other people, such as researchers of various kinds or students, should be able to use the government to compel us. If somebody else gets a hot flush of curiosity, I really do not think that the rest of us should be compelled to answer questions by force of law.

I have done some research myself. I have written a local government history and I have a biography of Senator E.B. Johnston in manuscript to be published when I get around to doing the proofreading. Most of this argument has been conceived in terms of privacy, but it seems that privacy is what is left over when other people have satisfied their curiosity. There is a complete lack of any principle expounded for it. The Bureau of Statistics really is only concerned about the accuracy of its statistics, whereas there is no principle of respect. That is why I use the term ‘decent respect for people’, because some of the questions people would like to ask amount to insolence.

In this I express considerable scepticism over the use of census forms for medical research. Some may differ but with the rate of illegitimate births at the moment I am inclined to think that nobody really knows who their ancestors were a few generations back. I am very sceptical about the use of census forms in research. For one thing, the census is fairly inaccurate. I do not think the ABS wants to admit it but a lot of people are functionally illiterate, a lot of people are mischievous and will not answer correctly, and the more questions you have that are intrusive and silly, the more people will simply not bother to answer them accurately. If census forms were confined to a few basic items I think people would be far more willing to answer the census.

Over the years census forms have become longer and longer. At one time all they wanted was your name, address and occupation, but now they ask all sorts of questions. The one in 1976 was outrageous. Although individual questions, taken by themselves, may seem perfectly innocent, the overall effect is to pry into the entire affairs of people. I would rather see the bounds of these questions drawn well within the limits of propriety than on the other side of it.

I have, as I said, done history research myself. I think we need to maintain self-denying ordinance here. We have to have respect for people and not inquire too much into their personal affairs, no matter how much it may cost us in lost information. I think that mainly sums up what I have put in my written submission.

CHAIR—You have taken your concept of decent respect from the American Declaration of Independence. Is there not some irony in the fact that the United States maintains its census data and makes it available after 72 years?

Mr Rice—Yes, I would say there would be. I cannot remember ever doing a census in the States. I cannot remember whether I was there when one was done.

CHAIR—I have often got the impression that the American concern for the individual and for privacy, if I can use that expression, is probably even greater than in Australia. I just wonder, if that is the case, why the United States Census Bureau does not seem to have any difficulty in terms of maintaining the data and then subsequently releasing it.

Mr Rice—I really do not know how to answer that. Perhaps they have just gotten used to it. But you are quite right that in America there is greater concern for privacy or individual liberty; sometimes to a silly extent, like resisting compulsory seat belts. But it is part of human affairs that sometimes people will accent some aspects more than others.

CHAIR—You described the 1976 census as outrageous. Can you elaborate on that?

Mr Rice—I have not seen the form for over 20 years, but I remember at the time when the census under the Whitlam government was being designed, the questions were extremely long, and when the Fraser Liberal government came in they cut it back, but they did not cut it back enough. The Australia Bureau of Statistics itself admits that there was a lot of resistance to that census because people thought the questions were too intrusive.

Mr McCLELLAND—Would your concerns regarding the intrusion into people's privacy or, to frame it another way, the need to have appropriate respect for people's decency, be relieved if there was an opting out provision; that anyone who completed a census could opt out of having the information retained?

Mr Rice—Do you mean retained, or not to answer the question?

Mr RANDALL—Opting in or opting out.

Mr Rice—Of retaining?

Mr McCLELLAND—Yes.

Mr Rice—That would be a step in the right direction.

Mr McCLELLAND—You have expressed some disquiet as to the significance of medical research or tracking of inherited diseases. We have, in fact, heard evidence earlier this morning that it would be useful, for instance, in bowel cancers that emerge very early in people's lives, if it could be found out where their children have moved on to. There is essential information—obviously a person's income would not be relevant to that. But there seems to be some utility in the information being kept. If that utility could be balanced against someone being able to preserve their right of privacy by simply ticking 'I object to this information being retained', do you think that might strike an appropriate balance?

Mr Rice—I do not claim to be an expert on medical research but the census being held every five years would not be the most reliable way to track people down if they are moving. The opting-out provision would be an improvement on retaining information for anyone's inspection. We have all been to social functions where someone you know who knows a little bit about your personal affairs starts talking about them in public. It is embarrassing. They start asking you personal questions that you really do not want to answer, and you do not want to tell them to shut up. This sort of thing happens. Many of these researchers, especially in the social sciences, are just like that. They just have no respect, no shame. There is no limit to what they—

CHAIR—Is that not ameliorated, though, by the fact that the period of release might be 70 or 80 or 100 years? Does the principle of decent respect have the same weight when we are talking about or referring to information about the deceased rather than information about those who are still alive?

Mr Rice—Perhaps there is less practical importance, one might say. On the other hand, who trusts the government to keep it for 80 or 100 years? I do not, not for one minute. Once you concede the principle of retention, then, of course, the government will be under increasing pressure to allow other researchers, for one good reason or another, to have a look at those things. Mr McLennan from the Bureau of Statistics made a speech about it, saying that if you retain them then people will be worried and it will reduce the accuracy and the willingness of people to make this information available to the census.

Already people do not particularly like to hand a census form over to the collector or to send it to the bureau. I certainly do not. I make a point of giving them a hard time, to the last possible minute. The harder it is for them, the less likely they will be to ask more intrusive questions, if the cost administratively is difficult.

Mr RANDALL—I just want to tease out further your general statement that you thought the medical research side of things was a bit fallacious. We need to further investigate this, but it appears that even other cancers, like breast cancer, could be tracked through hereditary lines. If we were to save just one life, or several lives, would it not be worth forgoing some of the considerations that you are concerned about? We live in an age of information, computers, and storing knowledge.

Mr Rice—On the question of saving one life, I think society does lots of things that allow lives to be lost—road risks and letting criminals out of prison who have committed armed crime. There are lots of questions like that. I personally think that, when it comes to tracing genetic background, the best thing is to go around and ask the family, look in the family *Bible* or research their background. I think the census is a rather indirect way of researching family history.

Mr RANDALL—The Muslims might not have a family bible.

Mr Rice—Well, something like that.

Mr RANDALL—You are talking about being intrusive. Given the fact that you give people a hard time, going around and speaking to families might be harder to do than collecting information in the census form.

Mr Rice—I think in a case of disease they would be more willing to cooperate than just filling out forms.

Mr MUTCH—Mr Rice, you say that, because of your view, you are a rare bird when it comes to historians. I wanted to ask you about the AGB McNair report. I tend to agree with you, I was surprised that 63 per cent disagreed with the statement that governments can be trusted to honour guarantees. From my reading of the McNair survey, I thought it might have been higher. How did you get hold of a copy of that survey? Did we provide you with that?

Mr Rice—No, it was sent to me. I got it from Senator Campbell actually, whom I know. I am active in the Liberal Party. I met him at a party meeting. I told him I wanted to make a submission to this, so he gave me copy of it.

Mr MUTCH—Did you read that survey yourself?

Mr Rice—Yes.

Mr MUTCH—And the questions?

Mr Rice—Not the questions. I just got the summary of it. That is all.

Mr MUTCH—The summary of the results?

Mr Rice—Just the summary of the results.

Mr MUTCH—You have not had a chance to read the questions that were asked in that survey?—

Mr Rice—Not the report itself, no.

Mr MUTCH—so you could have an opinion as to the efficacy of that survey?

Mr Rice—No, I would not.

Mr MUTCH—I was interested to see how you got the copy.

Mr Rice—All I had was one or two pages of the summary.

Mr MUTCH—Could you please provide us with a copy of the summary that you have been provided with?

Mr Rice—It is here somewhere.

CHAIR—Perhaps later when we have finished.

Mr MUTCH—I would also like to note your comment, ‘Most politicians, despite public cynicism, do sincerely work for the public interest.’ I thank you for that observation. In your experience have you seen any major concerns in the United States—unauthorised access or anything of that nature—with their census retention?

Mr Rice—My experience of the States is not very great. I left when I was 16 and I have only been back for 3½ years since 1960. I cannot answer that.

CHAIR—Thank you very much, Mr Rice, for your submission, and also for coming and discussing it with us today.

[11.14 a.m.]

PENN, Mr Malcolm Richard, Senior Policy Officer, Legislation, Ministry of Justice, Level 16, Westralia Square, 141 St Georges Terrace, Perth, Western Australia 6000

THOMPSON, Mr Allan Ledger, Director, Legislation, Ministry of Justice, 16th Floor, Westralia Square, 141 St Georges Terrace, Perth, Western Australia 6000

CHAIR—I welcome Mr Thompson and Mr Penn. At the outset, we thank you for coming over earlier than you had originally planned. In what capacity do you appear today?

Mr Thompson—I am appearing on behalf of the Ministry of Justice, but in relation to the short submission which I believe has been provided to the committee, tendered by the Attorney-General, the Hon. Peter Foss, QC, MLC.

CHAIR—Although the committee does not require you to give evidence under oath, I should advise you that the hearings are legal proceedings of the parliament and warrant the same respect as proceedings of the House itself. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament.

We thank you for the copy of the submission from the Attorney-General. Can I perhaps take up some matters in it. Is it fair to say, on reading the submission, that the Attorney is not adamant one way or the other, but is merely raising some concerns if the data was to be collected and retained?

Mr Thompson—The background to the submission that we put in is that in this state we do not have a privacy legislation regime. As with other jurisdictions, of course, we have many statutes that have secrecy and confidentiality type provisions. But in the absence of privacy legislation there really is not a legislative framework against which we could really cast comments. Additionally, within the government's current policy there is not any firm commitment to a privacy regime. That said, the Attorney-General has responsibility in this area, both in privacy policy and in FOI. Over the last couple of years quite a bit of work has been undertaken in that area. It is against that backdrop of there being neither a firm policy prescription nor legislation that these comments have been tendered.

Reduced to basics, I suppose what we are saying here is that there is certainly some general sympathy to the position that is enunciated through the Commonwealth Privacy Act in relation to the broad principles therein. They, in turn, are reflected in some work that has been undertaken in this state in both data matching and in an administrative approach to information privacy principles. The Attorney-General is here saying that, against that backdrop of generally being supportive of the sorts of principles in the Commonwealth legislation, there are some particular concerns which he would like to draw to your attention.

The particular concern really relates to the Commonwealth information privacy principle No. 1, which in very broad terms states that information should only be used for the purposes for which it was collected. In empathy with that principle, the Attorney is not enunciating a firm view—as you put it, either yes or no—but in the event that the information is retained, either people should be told, firstly, up-front that it is going to

be used for particular purposes; or as a fall-back position, in the event that we are not able to isolate the particular uses to which it may be put, it may be put to some uses—for example, medical or health research—alerting individuals as they fill in these forms to the fact that the information may be used for those purposes.

CHAIR—Are those privacy considerations ameliorated in circumstances where the name-identifying information is not subject to any form of release until a certain period of time, say 80 or 100 years, when the life expectancy of all but a very few people would be expected to have passed?

Mr Thompson—No, not at all. I do not think that is implicit in what is said here. In the case of medical research, I am aware, for example, of work that is currently going on within the portfolio of the Minister for Health through my own involvement in that work. We are currently grappling with a number of issues relating to the confidentiality of health and medical research. I see the conduct of epidemiological research as being one of the possible underpinnings to your inquiry here. I certainly think that research is based upon being able to access, capture and use that data now, rather than simply waiting for all of the data subjects, in your terms, to have passed on.

In those instances, the issues are much more that, if the data is collected and is to be used, for example, for health or medical type research, we either should flag on the census forms that it is going to be used either for particular health projects—which I appreciate you may not be in a position to do—or, alternatively, we should flag that it may well be used for a range of epidemiological health and medical research type projects.

At the time of the conduct of those projects the researchers will need to jump through, I suppose in crude terms, a number of hoops. Those hoops might include, for example, the fact that any such research should be authorised by an institutional ethics committee, that it should be undertaken, say, in a manner consistent with National Health and Medical Research Council standards. It might, for example, be subject to some sort of audit process so you can actually provide some assurance back to the community that the research was in fact undertaken consistent with those principles. If it is, then that is what would provide the certainty to the public that the confidentiality and privacy considerations have been properly protected.

CHAIR—I am not sure whether you can answer this question or not, Mr Thompson, but there is a lot of data relating to people's health and medical circumstances which is currently kept. Some of that is routinely taken, not necessarily in circumstances where people even give their consent. I am thinking, for example, of the peri-natal statistics which are kept throughout the country. Is data like that name identifying or are the name identifying aspects of it removed?

Mr Thompson—As I understand it—and I make these observations more on the strength of the fact that I have been representing the Ministry of Justice on a health department working party—oftentimes the conduct of the health, medical and epidemiological research would dictate that name identified data be used. That is why I made the comment that where that is the case, clearly if you are in a position to be able to obtain the consent of the data subjects, well and good. I do accept, though, that there are probably two qualifiers to that. Oftentimes you are not in a position to obtain the consent of the individual data subjects if in fact you are looking at either some very large either data set or the entire population. Oftentimes it is data

that has already been captured, so ex post you cannot actually go back.

There is another consideration there too. Oftentimes, if you seek to obtain the consent of the data subject, that may, for particular forms of research, seek to actually bias the conduct of that research. In the course of our deliberations we were spoken to by a Dr Fiona Stanley from, I think, the Child Health Institute.

CHAIR—Western Australian Child Health Institute, yes.

Mr Thompson—A comment she made that stuck in my mind very firmly was along the lines that poorly conducted research is both unethical in itself and leads to the wrong public health policy responses. So accepting that that is a truism—and I would have no problem with that—where name identified data is used and the consent of the data subjects cannot be obtained, I think it is critically important that the broader society is going to be assured that every possible safeguard is built in there in relation to their confidentiality and privacy.

CHAIR—If there was a scheme in place where privacy principles were constructed, held forth, that there was a mechanism by which people have to—to use your expression—‘jump through hoops’, that there was no access to such information without first putting a proposal to an institutional ethics committee, et cetera, are you suggesting that the public benefit that would flow from the access to the name identifying data for the purposes of medical research would outweigh the detriment of retaining name identifying census data?

Mr Thompson—In this whole area what we are constantly seeking to do is to strive to achieve that balance between the privacy concerns of the individual and some broader, societal good that may at times come from trading off the right of the individual privacy for the benefit that will flow to the community from properly undertaken, ethically undertaken, research. Those considerations are inarguably out there in the community these days. Those decisions are already being taken by institutional ethics committees in relation to the conduct of health and medical research right across the country.

In the context of this particular inquiry I would say what we are seeking to do by putting it to this committee that you advise the individual members of the public, on the census form, that their information in fact may be used for these sorts of purposes is really, I suppose, adding an element to the community debate, to community education, in the way in which decisions are made by government in trying to seek to balance out those two broad thrusts: the individual right to privacy and some notion of community good.

Mr McCLELLAND—Do you think it would be useful to almost divide the census into perhaps three parts? The first part would be where you have the essential data which could be useful for medical purposes, such as name and the number of children and so forth, perhaps in one colour. Then you would move into the second part, which is information that would not be retained such as financial information, how much you earn a year, that sort of thing. Then perhaps a third part yet again—whether it is a different colour or what have you—of information which is not compulsory to complete, such as Mr Mutch was discussing earlier. It is not compulsory, as I understand it, to specify what religion you are, and things of that nature. The part to be retained would contain the essential name and children sort of information.

From the thrust of your response I think it is important to be up-front with people at all times. It is a

long-winded question, but it is in two parts. The question I essentially ask is: would it be useful to divide the census form up in the manner that I have postulated? Secondly, in any event, do you think it is important that people at all times be advised why you would be retaining the information?

Mr Thompson—I will perhaps answer part of that question, and I will ask Mr Penn to make a comment on the types of information we think that possibly people could opt out of. Not speaking either as a medical researcher or on behalf of the Minister for Health, I could not really specify what aspects of the census might in fact have relevance to the conduct of that sort of research. For all I know, that may well include a range of socioeconomic data, including income and education. I just would not know. I suppose my partial answer to that would be to say that the type of information that would be warranted or required for epidemiological type research would be what the researcher would indicate is needed to answer that question.

It may in fact be that all sorts of information sets would be required for that research to be conducted properly. By ‘properly’ I mean both ethically and to appropriate scientific standards. But there may well be some opportunity for individuals to opt out in relation to some of the information requested on the census form. I will just ask Mr Penn to make some comment on that.

Mr Penn—The critical issue, looking through some of the submissions that other agencies and organisations have also put to your inquiry, is in relation to genealogical research. This may be an area where the public should be given the option to opt into a system where personal, name identified information was kept for genealogical reasons. So it would not necessarily be a case that it would always be kept unless people made a decision that they did not want it kept. It would be something that they would be opting into, so they would have to consciously consider it.

Maybe that needs to be specified in the information that is handed out when the census forms are distributed, first of all, as Mr Thompson has pointed out, in terms of the use of information for health and medical research, but also the other part where people can be given the opportunity to have their information retained for genealogical research. That is probably something that needs to be considered as part of the structure of the census form and also the information as presented to the public as to background: initially why the census information is being collected over time, what it is generally used for and then also those issues of health and medical research, and the opting in for genealogical research as well.

Mr Thompson—Possibly that comment on opting in might equally apply to that broad area of social research. If I have some, possibly minimal, understanding as to what constitutes health and medical research—and I have some lesser understanding of what genealogical research is, and some lesser understanding again as to what might be intended to be captured by that term ‘social research’—it is critically important that at the time the data is being captured on the census form people are given a very real understanding of the types of uses to which either all of the data or some aspects of it might be put.

The distinction, for example, that I might seek to draw—and forgive me if I am wrong; I hope I am neither wrong nor misleading—is that I would assume that for the conduct of most genealogical type research people would not be required to go through the same sorts of ethical hoops that, say, a medical researcher is, even today, required to go through in terms of institutional ethics committee approvals for research and the conduct of that research according to documented standards. I do not really know to what standards

genealogists might work, and therefore I am not really able to make any informed comment on what protections can be assured to individuals.

CHAIR—The distinction, though, it seems to me, is that for the genealogical research the data which is available is only data which is at least a lifetime old. If you take Australia, I think there is some census data from New South Wales which is available from the end of last century and early this century but, if you look at, say, the United States and the United Kingdom, in the United States it is 72 years and in the United Kingdom it is 100 years before people can have access to it.

That is in one category, if you like, for which the protection is a time period, whereas what we have been discussing with you is more immediate use of material for epidemiological and other medical research uses, for which 100 years is probably useless. It may be of some medical historical value, but it is not going to do much to help improve the health standards of the population in the shorter term.

Mr Thompson—It might be fair to say that when the Attorney-General sought our advice as to whether or not there were some particular comments that he could put before this committee, our launching point in advising him that there was, was the thread in your paper that indicated that—I am sorry if this is very crudely stated—there might be good reasons in the future for collecting this data, or that it might get collected as a year 2001 project. If that is the sort of view, then you are talking about the retention of data in the event that you might subsequently think of some sort of use for it.

What we are saying is that that is really no reason for the retention of the data—the fact that there might be a use for it in the future. Such uses might be thought to be a good thing for some people and very threatening to others. That is why, using that as the entry point, we made the comment that, if it is to be retained, then the argument in favour of its retention is that we are, here and now, able to provide some sound reasons to society as to why that ought to be the case. If sound arguments can be made out in the range of areas that you have discussed here—genealogical, broader social policy, epidemiological and health-type reasons—then well and good. Let us specify it up-front; let us collect and retain that data. We may well have been reading something into it that may not have been there, but just the notion of collecting it as a project, as a ‘just in case’, we did not think was a good starting point.

Mr RANDALL—I want to clarify a few points. I understand how government departments work, et cetera, and that we are going to take a lot of information from a range of witnesses which we can cross-reference one way or another. Is the position you have arrived at the state Attorney-General’s view? Is it his individual view that you are representing? Is it a policy that you have come to him with? Is it the government’s point of view in terms of the coalition? Can you tell us from what area you have gained the authority to put forward this information.

Mr Thompson—I indicated at the outset that we are operating in something of a policy vacuum in not having privacy legislation and having only a very restricted provision within the existing government platform relating to privacy, that is a very narrow provision that talks about the confidentiality of particular data. It is commercial-in-confidence data arising out of some issues in commerce and trade. I think the concern was that if people were going to be making applications, for example, for government grants from a government agency, they ought to be provided with every assurance that their commercial-in-confidence

information cannot possibly go to any other competitor—or anyone.

There is a very narrow policy provision, but not a broad policy provision in relation to privacy. It is against that backdrop over the last couple of years that we have been required to keep the Attorney-General informed in relation to privacy developments across Australia. For example, in 1996 we provided a detailed privacy information and options paper which I think is called 'Privacy legislation information and options paper'. We have recently provided some advice to the Attorney-General in relation to the Commonwealth government's position that it will not be prescribing the application of privacy principles for the private sector, other than the narrow coverage in credit and other areas which currently exists. We have been keeping the Attorney-General informed of current developments in New South Wales and Victoria in relation to the development of privacy legislation there.

It would be fair to say that what we have, on behalf of the Attorney-General, is a watching brief in relation to privacy generally, but within that, or maybe through that, the ministry has then come to be involved in a number of privacy related developments across government. The work I indicated going on in the Health Department in relation to the confidentiality of medical records and medical research is one. Also, the government currently has a group, I believe, called its information policy committee. It has recently been working on developing a framework for data matching across the state government, and the development of information privacy principles which may well be implemented on an administrative basis across the state government. That is really the context of our providing ongoing advice to the Attorney in this broad area of privacy.

Mr RANDALL—But it is not an individual position of his or the government's at this stage?

Mr Thompson—To the extent that I was advised five minutes before coming down here that the Attorney is going to be signing off to the unsigned submission which I provided, that is the view that he is putting to this committee as the minister responsible for this policy area.

Mr RANDALL—With regard to the privacy paper you talked about, which you are developing, is that freely available?

Mr Thompson—No, it is not. That is an information and options paper to the Attorney-General.

Mr RANDALL—We could not get that under FOI?

Mr Thompson—I do not know. With regard to the other two papers that have been developed through the information policy committee, the data matching one and the one on information privacy principles, I believe the latter is very close to finalisation. I am quite happy to make an inquiry to ascertain whether or not we could provide that to this committee.

Mr RANDALL—I would appreciate that. You said in your submission that retaining the information as a centenary census is no different from retaining it at any other point in time. That is like saying birthdays, Christmas and wedding anniversaries are no different from any other day, too. I would have thought that certain times have special significance, and that the arguments you referred to earlier in your evidence do not

really address that.

Mr Thompson—I would say unarguably that is a date of very particular significance, but that of itself does not provide a rationale for, in a sense, giving up on the generally accepted principle that you use data for the purpose for which it was collected. If, in fact, this were to be a centenary project—and, as I indicated before, I am sure there are very good reasons why it ought to be—then we ought to be up-front about the particular uses to which that data may or will be put, the rationale for that, and in a sense get people to sign off to that by informing them of the use to which it is going to be put.

Mr RANDALL—Finally, do you have any evidence that there is a general public objection to providing information if the records were to be kept?

Mr Thompson—No.

CHAIR—Thank you very much for the minister's submission and also for coming along today and discussing it with us. We found it most interesting.

Mr Thompson—Thank you very much. I will undertake to provide the signed submission and to inform the committee secretariat as soon as we can provide that IPP document to you.

CHAIR—I thank everyone for their attendance here today.

Resolved (on motion by Mr McClelland):

That this committee authorises publication of the evidence given before it at public hearing this day.

Committee adjourned at 11.44 a.m.