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MONDAY 25 SEPTEMBER 2000
THE HEARING RESUMED AT 10.30 AM

CHAIR: Before moving to Mr Kirton's submission, we deal with this issue about whether or not there is a legal question referred to the High Court. Mr Murray, do you want to be heard first?

MR MURRAY: Madam Chair, I think it might work better if my friend, Mr Hindle, goes first because he can report the position of Professor Skegg which has changed. I think it's just logical to deal with just facts and then law, so my friend and I have had a talk about that and that will unfold that way.

CHAIR: Mr Hindle?

MR HINDLE: Ma'am I've taken the liberty of preparing a written submission which is both a report as to the position of the researchers as I understood it from the meeting of 21st September and I can say that I have managed to discuss my draft of that report with ? it's accurate. It also contains a further submission concerning Section 74a and whether or not to go to the High Court. If I can just table that, it does refer to a submission that I made at the 11th of September hearing and I'm just conscious that Mrs Barrett and Professor Duggan won't have copies of those submissions.

CHAIR: I don't either.

MR HINDLE: Well I have them for you. I think it probably would be better just to let the committee have an opportunity to read those rather than read them out.

CHAIR: Mr Hindle, I take it that the Ministry is not going to provide the Committee of Inquiry with the information it seeks under the subpoena duces tecum?

MR HINDLE: There's no suggestion of that.

CHAIR: No suggestion of what? Is it or isn't it?

MR HINDLE: You'd have to ask Mr Murray to confirm it but I don't

1 believe that the Ministry is proposing to provide named information from
2 the Screening Register.

3 CHAIR: You've said at paragraph 19, bullet point 3, the rules need to be
4 changed if an independent research audit is to be done and whether it can be
5 achieved from statutory amendment or regulation maybe an issue but the
6 need for change is not. Tell me this. If the audit can be carried out with full
7 access to the necessary information using the powers under Section 47 of
8 the Health & Disability Services Act plus Section 4D of the Committee of
9 Inquiry Act, why is there a need for change?

10 MR HINDLE: Because Ma'am, the problem with using Section 4D of the
11 Committee of Inquiry Act is that ultimately it requires the information to be
12 made available on compulsion.

13 CHAIR: What's wrong with that?

14 MR HINDLE: That is not something which attracts itself to the research as
15 an appropriate way to deal with epidemiological research. Really more
16 importantly and it seems to me, and I've tried to articulate in that
17 submission, that what's really the problem is not what information is on the
18 Screening Register because it seems clear that the audit could happen
19 without access to that information and we now know names from the Cancer
20 Register. In order for the valuation to be done, in order to even know which
21 slides you have to go and review, you've got to get personal medical
22 records. So there is a question as to whether and to what extent you should
23 do that, absent a woman's consent or indeed in face of a woman's refusal.
24 Those are issues which in my submission it's difficult to impose or give to a
25 researcher because the researcher is then asked to exercise a discretion under
26 the Committee of Inquiry Act as to whether or not to issue a subpoena or to
27 go with the powers of compulsory access under Section 4C. And really the
28 submission or the position that I came to after that was that those are things
29 which need to be debated and resolved and understood transparently within
30 the programme, they are not matters which, should in my submission, be

1 vested in someone who then has to carry the responsibility. Take the case of
2 someone who refuses, does the researcher simply just say too bad or is the
3 researcher to be vested with terms of inquiry powers that simply require that
4 researcher not to even ask for anyone's consent.

5 CHAIR: And is that what I should say to myself? I have the powers or the
6 Committee of Inquiry has the powers to compel evidence, any Court of Law
7 has the powers to compel evidence. It's accepted in the interests of justice
8 that there is a power to compel evidence. The philosophy of whether it is
9 present or not is not for us, it's well beyond our terms of reference, we're
10 hear to find out what the law is and what recommendations we should make
11 because we are faced with a situation where there has been a screening
12 programme in existence 1991, there has not been a complete evaluation of
13 that programme and at the moment, one of the stumbling blocks to that is
14 the legal situation which is unclear. Once that's removed, there may be
15 philosophical disputes, it may be that Professor Skegg wouldn't want to
16 carry out research or studies but he's not the only person in this country.
17 What the concern of the Committee of Inquiry is under its terms of reference
18 is to look at the law and to see whether or not legally an evaluation can be
19 carried out and one way that seems that it can be carried out is using a
20 combination of Section 47 and Section 4D. If legally it can be done,
21 whether the Ministry chooses to do it or not, is another matter. But it is
22 important to know at this point in time whether legally it can be done and if
23 it can't be done, we then need to know whether or not regulations can be
24 done, because we don't even know that at the moment on the state of the
25 law under 74A. And as long as the legal situation remains clouded, there is
26 the likelihood that matters will drift because this issue has been around for
27 some time. My understanding is that Mr Corkill, on behalf of the women
28 affected, had written to the Minister asking that there be an amendment to
29 legislation. I have not yet heard from Counsel from the women affected as
30 to whether or not there has been a precise answer on that. Circumstances at

1 where at the moment, no steps are being taken, it's seems sensible to attempt
2 to use whatever means is available to the Committee of Inquiry to clear up
3 the legal situation. If the Committee were to refer the matter to the High
4 Court, if in between now and any High Court hearing the legal position
5 changed by way of regulations being made or amendment to legislation,
6 then the reference to the High Court could be abandoned. But I can't see
7 why the philosophical issues that you have introduced into your paper are
8 relevant to our inquiry as to whether or not a power exists.

9 MR HINDLE: If I can say first of all, as I indicated the submission, I don't
10 see going to the High Court and dealing with the policy issues as being
11 mutually exclusive. I certainly accepted before, and I say again, that a
12 decision to refer to the High Court and something you have jurisdiction to
13 do and it's not something that would be wrong in an administrative law
14 sense to do but it does seem to me, and I'm not bound to express the
15 opinions I've come to as fairly as I can, that it doesn't answer the real
16 problem. I say that because it needs to be remembered that the issue that
17 would go to the High Court primarily concerns Section 74A and the access
18 to named information of the Screening Register.

19 CHAIR: It could also be the Cancer Register, we may as well include all
20 the questions.

21 MR HINDLE: But you have that information Ma'am, you have it. For the
22 purposes of your inquiry, that's no longer an issue. I appreciate that the
23 Crown Law Office waves some sticks at that ex-post factor and in my
24 submission, the sticks its waved are inappropriate and its opinion on that are
25 simply wrong.

26 CHAIR: There is another issue though and that is this, there is the role of
27 Ethics Committees, we've heard a lot about Ethics Committees. An inquiry
28 which has the powers of Section 47 but 4D is not troubled by Ethics
29 Committees.

30 MR HINDLE: In fact, under the Ethics Committees standards of 1996, the

1 audit study shouldn't be a matter requiring ethical consent anyway. And the
2 position that Professor Skegg took on that in which I submit is correct, is
3 that the law is not wrong, but the way the Ethics Committees are
4 approaching it is wrong. That certainly is an added problem, I accept that.

5 CHAIR: No one could criticise any epidemiologist who had the powers
6 under Section 47 plus 4D if they proceeded exercising those powers without
7 going to an Ethics Committee, I've already heard from Mrs Sholtens that the
8 second limb of the Cox Richardson study, this is not the third limb that
9 we're talking about but the second limb, has also run into problems because
10 of Ethics Committees.

11 MR MURRAY: Ma'am we should clarify that when the opportunity
12 presents and maybe now. In fact, letters have gone out seeking the consent
13 of women and that process is under way, we just double-checked that. So
14 the three limbs of the Cox Richardson Study, the first one on the data on the
15 Screening Register, that's actually been completed and I think the report has
16 to be written up by Professor Cox. If it could be written up in time for this
17 inquiry, that would be considerable benefit of that study. The second limb
18 was some quite creative procedure was used to make sure that consents
19 could be contained.

20 CHAIR: This is what concerns me, the only you could carry out the
21 second limb was adopting a creative procedure to obtain consents.

22 MR MURRAY: Yes and that is underway and it's only the third limb
23 really of Cox Richardson that's now an issue I think in terms of the
24 proceeding of that study.

25 CHAIR: Thank you very much. What Mr Murray has said concerns me
26 because I've heard from experts the impact the need for consent can have on
27 studies in terms of the biasing the study if you don't have sufficient
28 numbers. What I am looking to find out is, is there at the moment in
29 existence a legal mechanism for cutting through the obstacles. I think there
30 is one, whether anyone wants to use it or not is another matter. The use of it

1 has be weighed against the interference it might have on personal privacy
2 against the fact that we have a screening programme that has been in place
3 as long as it has and it has not been evaluated. And we also have to say that
4 if it had been thoroughly evaluated at an earlier stage, would the likelihood
5 of under reporting have been picked up and we have to take into account
6 what the consequences of under reporting can be.

7 MR HINDLE: Yes Ma'am, in the substantive submission that we filed, the
8 long document, the position that my friend and I took on that was that the
9 effectiveness of the screening programme is sufficiently important to
10 warrant access to information. If it's really necessary, even without consent,
11 but that is a controversial issue, that's not...

12 CHAIR: Yes but I'm not interested in debating sociological issues and
13 philosophical issues, that's not our role. I'm looking at the law, I want to
14 know what the law is. If you mix everything up, you end up with a tangled
15 web which ultimately seems to reduce everyone to a state of inertia. I want
16 to separate the issues, there is a legal issue about whether or not the study
17 can go ahead. Certainly there is also a philosophical and sociological issue
18 about should it go ahead if the evidence is obtained under compulsion. But
19 that I think needs to be dealt with separately, as soon as you mix everything
20 up, you get some problem that no one seems to be able to solve. And I think
21 the only way to solve the problem is to pull it apart bit by bit.

22 MR HINDLE: I can't argue that's an available position to take and it
23 struck me that the other underlying issues don't go away but I've tried to
24 articulate that in the submission and I really haven't got much more that I
25 can say about it.

26 CHAIR: I note in paragraph 7 you've conveyed the researcher's concerns
27 about term of reference 3, point is at the end of the day it's the Committee of
28 Inquiry that has to be satisfied as to whether or not there is a systemic issue
29 and if so, of what proportion. Now what you're saying here is you're saying
30 it's generally accepted by parties, persons entitled to be heard, that the

1 answer to term of reference 3 is that the Committee cannot be satisfied
2 Gisborne was an isolated case. Well that may be but it doesn't take it far
3 enough. If it were possible to get some information back from a study
4 before 20 December, we might be in a position to comment not only was it a
5 systemic issue, but to what extent was it a systemic issue. At this present
6 time, we've asked that there be a study carried out in other areas because
7 there was a concern about those other areas. We have no idea now whether
8 there is a concern or not and having matters left as it's suggested they be left
9 in paragraph 7, will not answer the Committee's concerns.

10 MR HINDLE: I don't know that in fact the Committee has asked
11 Professor Skegg to do any particular thing other than to look at the
12 information which is arrived and to provide the preliminary report which it
13 did on the 11th of September or for that hearing.

14 CHAIR: Well that's not so. The Committee issued a subpoena duces
15 tecum, it wanted to get access to all the information. From there, it was
16 prepared to a point Professor Skegg under 4C to investigate further if need
17 be and if he met resistance, to use the 4D powers to subpoena further
18 information, including medical records.

19 MR HINDLE: Yes Ma'am, whilst understanding that that was on the
20 Committee's mind, with respect, that hasn't happened yet. Professor Skegg
21 has issued a report in which he's made some observations, including I'm
22 bound to say one which said that even the four region study couldn't
23 sensibly be resolved. After the legal issues are cleared away, because he
24 would need about six months to deal with that, so uncomfortable as it may
25 be for me to have to say it, it does rather look as though the fact is it cannot
26 be done by the 20th of December.

27 CHAIR: Well who says the 20th of December is written concrete. It may
28 be that the Minister is prepared to accept an interim report from the
29 Committee of Inquiry and leave the systemic issue and the Committee's
30 views, recommendations on whether or not there is a systemic issue and if

1 so, to what extent, open. She may be prepared to accept an interim report,
2 allow us to report on that term of reference 3 in a final form at a later date. I
3 don't know, I haven't pursued it with her but at the same time, I think that
4 the idea has to be contemplated.

5 MR HINDLE: Well that idea cropped up during the course of the 11th
6 September hearing and the position I took was this, that my primary concern
7 at that hearing was that these issues should not be allowed to delay the
8 publication of so much of the report as can be published. Because it seems
9 to me that the most important thing the Committee can do for the women of
10 New Zealand is to report as soon as possible so I took great comfort from
11 that suggestion. That's certainly true but again I'm bound to say that if one
12 was going to consider this study and what is most useful both for the
13 Committee and for health of New Zealand women, I suggest the sensible
14 course is to design the right protocol to check throughout New Zealand. It
15 would be wonderful if the Minister were prepared to leave that possibility
16 open. I think that's caught in my idea of recommending that the Committee
17 reconvene in a year's time but realistically the study that the Committee is
18 contemplating is going to take some time. And one of the first issues that
19 it's going to have to deal with is simply identifying which of the smears
20 should be included in the review. How long the look back period should be,
21 how it should design the reread protocol, it's a very sophisticated exercise.

22 CHAIR: Well if it's going to take six months to look at four regions, then
23 it's obviously going to take a lot longer to look at the rest of the country.
24 You see we've had this already with the Cox Richardson Study where they
25 put forward their proposal which was seen as being too extensive, too
26 expensive, and so there was a focus on the priority areas, even though they
27 haven't been done. It would be ideal to do a Rolls Royce job, most people
28 would like to do that in any field, but sometimes you can't, sometimes you
29 have to be more realistic. At the moment the Committee has focused on
30 four areas. It has chosen those four areas because it has a high incidence of

1 cancer, it wants to know what the situation is in respect of those areas. It
2 may be the information learnt from those areas can give comfort or it may
3 be that extrapolating from that information there is reason to look at the
4 entire country. Equally, there is no reason why the Cox Richardson Study
5 cannot proceed and that I understand is looking at the entire country.

6 MR HINDLE: Without a site review Ma'am.

7 CHAIR: I'm not interested in getting into the nitty gritty of what these
8 studies entail. What I want to know is can they be done, this is the whole
9 problem. We start off with the legal position, they can't be done. Then
10 when you try to clear that away, you find people saying well philosophically
11 it's a difficulty. Then you get down to the structure of the study, I am sure
12 that people could sit around thinking up plenty of reasons which would be
13 another impediment to the study going ahead. The fact is, time passes by,
14 the study doesn't happen. Now whether there is a slide review or not, it
15 seems to me that once part of the study is done, then if a slide review is
16 necessary I would have thought that a responsible epidemiologist would
17 make that very clear to the Ministry that a slide review was necessary.

18 MR HINDLE: Just to go back to the four region suggestion, the danger in
19 my submission of proceeding in that way is that you might just have chosen
20 the only other three regions in New Zealand where there isn't a problem. If
21 you proceed in a selective way such as that, you finish up knowing
22 something about the area of Tairāwhiti, something about the other three
23 areas, but with respect, you're no further ahead in satisfying yourself as to
24 whether or not there's a problem in any of the other nine or ten regions.

25 CHAIR: So that's a good reason for doing nothing?

26 MR HINDLE: No Ma'am, it's a good reason for doing the whole lot and I
27 can't help it that it's a difficult and sophisticated exercise, it is. With
28 respect, I understand a sense of tremendous frustration at this end of the
29 inquiry, at all of the evidence that has gone before about audits not done and
30 evaluations not proceed with, but that doesn't make what needs to be done

1 any less sophisticated. I doesn't reduce the need to do it properly and
2 carefully and it doesn't, with respect, remove the need to consider really
3 how far you are prepared to go against women's consent to get the
4 information you need. As I say, if the Committee wishes to obtain a legal
5 answer from the High Court I own that the Committee has that jurisdiction, I
6 certainly do not think that it would be a wrong decision in terms of
7 administrative law, I'm simply trying to give the Committee my best
8 impression of what's involved in going there. The fear I have is that you
9 could go to the High Court and get an answer which says yes under Section
10 4 or under the Commissions of Inquiry Act, you can have access to
11 information on the Screening Register and that's, with respect, once you've
12 got the Cancer Register data, you can actually bypass the Screening Register
13 altogether. The extent to which the High Court would be willing to embark
14 on a discussion about or make a decision about access to information against
15 consent, is moot. I don't know whether the High Court would be willing to
16 do that.

17 CHAIR: It's not a legal issue.

18 MR HINDLE: But that's the point Ma'am, because you still finish up with
19 that fundamental problem and the thing that emboldens me to take this
20 position is here we have a Committee of Inquiry that has heard more
21 evidence in a focused way about the screening programme than I suspect
22 has ever been put together before, certainly in the case of New Zealand.
23 And you have a unique position to offer the Ministry some observations
24 about those sociological, philosophical issues.

25 CHAIR: The Committee of Inquiry is in no position to do that. We have
26 not heard any evidence on that. It is well outside our terms of reference,
27 unless you can point me to where it fits in and I would like to know what
28 expert evidence have we heard about how one balances private individual
29 privacy against community good.

30 MR HINDLE: Well Ma'am, two observations. The first is that you more

1 than any group of people now understand the needs of the Cervical
2 Screening Programme and the importance of evaluation and audit. I suggest
3 that if I had stood up in any forum a year ago and said that it was necessary
4 in some cases to get personal health records against consent or even in the
5 face of refusal, there isn't anyone much who would have taken me seriously
6 in this country but you have an opportunity to make it clear that there are
7 circumstances when that type of approach is warranted. With respect to the
8 issue of evidence, apart from having heard from Professor Skegg and apart
9 from actually understanding the underlying problem, all I'm suggesting is
10 that you make a recommendation to draw attention to these fundamental
11 issues in a way which is likely to see them advanced at a policy level. You
12 do occupy a unique position of understanding of what's needed to be done.

13 CHAIR: I don't understand at all Mr Hindle. I've no idea about personal
14 privacy, I am not going to embark on attempting to evaluate how important
15 personal privacy is to our society. I might have my personal views but I
16 have no understanding in the context of this inquiry of the importance of
17 personal privacy. I have a understanding of the need for an evaluation
18 because I've heard evidence on that point, however I am sure any High
19 Court judge informed that this was a screening programme that had not had
20 an entire evaluation since its inception where laboratory performance in
21 terms of smear reading had not been thoroughly audited and knowing that
22 there has been underreporting which has resulted in women developing
23 cervical cancer, I am sure that any High Court judge would appreciate
24 immediately the need for an evaluation. You do not have to have sat in this
25 room and listened to all the evidence we have listened to come to that
26 conclusion. Thirdly, as a lawyer, I am very familiar with compelling
27 evidence and in this inquiry, if an order to answer any of the terms of
28 reference I had to compel evidence, I would have discussed it with the
29 Committee and if supported by the other Committee members, I would have
30 issued a subpoena. As far as I'm concerned, the interests of justice in this

1 instance the interests of answering the terms of reference outweigh anything
2 else. Now that approach does not make me a fit person to attempt to
3 evaluate the tension between personal privacy and community good in terms
4 of getting access to medical records without patients' consent. I'm aware
5 that the law allows it in a Court of Law, it's provided that there is a limited
6 protection provided in the Evidence Amendment Act. That is the extent of
7 my knowledge and certainly I would discuss it with the other members as
8 well but I would be surprised if they would see themselves as having
9 specialist knowledge in the area of developing a policy view on what the
10 appropriate balance is between private protection of privacy rights as
11 opposed to the public good in the information being available. I'll just
12 pause as I want to consult. No the preliminary view at the moment is that
13 that would be difficult, we'll police that in any decision we make.

14 MR HINDLE: You do know enough to know that a policy needs to be
15 developed. With respect, you do know enough about this programme now
16 to know that this issue of getting access to women's records without their
17 consent or against their refusal is one that needs to be considered now
18 seriously. I stand by what I said Ma'am and I am also bound to say this,
19 when we were looking at the Tairawhiti audit which was in connection with
20 term of reference 1, Professor Skegg was willing to contemplate the
21 possibility of doing that audit without consent and applied to the Tairawhiti
22 Regional Ethics Committee on that basis because it was important to answer
23 term of reference 1. It was important to that study because of the small
24 numbers involved to have as complete as possible number of participants, in
25 fact all of them ideally. Now that position may not hold when you do the
26 national audit, it may be that there are, and I'm making these numbers up,
27 that there are 300 women across the country whose cases you really need to
28 know about and that it would be sufficient for the purpose of doing that
29 evaluation to study 290 of them and to accept that the other 10 have simply
30 refused to give consent to their information, that the outcome of that study

1 may well be just as robust and as important for the screening programme as
2 if you've got the whole sample. And these are issues because they come
3 back to the question of necessity.

4 CHAIR: It's not a matter of necessity. It's not a matter of thinking how
5 will this study be conducted, it's not a matter of personalising it and saying
6 'well Professor Skegg was going to do this in Tairāwhiti but now maybe if
7 he looks further afield, he may not need all this information', it's a matter of
8 trying to untangle a problem which at the moment is being an obstacle to
9 any evaluation of this programme going ahead. And one aspect of this
10 problem is the law and what I want to know before anything else is can a
11 full evaluation getting all the information be carried out at the moment
12 under the existing law or can't it?

13 MR HINDLE: No Ma'am it cannot.

14 CHAIR: It can't, thank you.

15 MR HINDLE: Let's just assume that the High Court says yes. A
16 Commission of Inquiry can have access to everything on the Screening
17 Register and also to personal health information using subpoena powers and
18 Section 4C powers, let's assume that that's the position we get to. The next
19 step is that the Minister is then going to have to consider whether to
20 establish such a committee. Now ask oneself, why would the Minister do
21 that? And the answer would have to be because the Minister is trying to do
22 that to overcome legal obstacles existing in the legislation. The Minister is
23 inherently an animal of policy and it just seems to me to be highly likely that
24 the Minister's response is more likely to be well look rather than use the
25 vehicle of a Commission of Inquiry, let's sort the rules out for the screening
26 programme so that anyone who enrolls on the programme, any woman who
27 comes along and wants to decide whether to opt on or opt off, knows what
28 the position is going to be in relation to her personal medical records in an
29 evaluation or audit. I quite agree with you Ma'am that you can clear the
30 legal way ahead and as I've said, you're entitled to file the case and to argue

1 it and frankly, I think it would succeed but at the end of the day, it seems to
2 me that as a Commission of Inquiry you are entitled to step back and look at
3 what the real issue is and that is the real issue.

4 CHAIR: Well could you show where in the terms of reference this real
5 issue that you say exists presents itself.

6 MR HINDLE: Yes I have to rely on term of reference 7 of course. Any
7 other matter that the Committee considers to be of importance and this with
8 respect Ma'am, is very important.

9 CHAIR: Mr Hindle, my understanding is it's a pressing issue that the
10 medical profession grapple with. That articles are written about this in
11 medical journals, it gets down to the issue of things like population based
12 registers. Do you follow the approach of the Scandinavian countries where
13 Professor Skegg said all information is readily available including the
14 register of the number of abortions. Or do you give a greater protection to
15 personal privacy. It is a major issue and it is not something that the
16 Committee can deal with in an effective way, given the time it has, it's not
17 specifically in its terms of reference and it hasn't even heard information on
18 the issue. If the Committee were to embark on that type of exercise, I am
19 sure every Ethics Committee in this country would want to be heard on the
20 point, I am sure that every Association of Medical Practitioners would want
21 to be heard on the point. We haven't heard anything. It would be arrogant I
22 think if this Committee were to attempt to answer what is a very difficult,
23 philosophical issue for the medical profession and in any event, attempting
24 to speculate as to what the Minister might or might not do, one other
25 speculation is this Committee might very well make recommendations
26 which themselves are ignored. I'm not saying the Minister will, I'm just
27 saying that if one is going to speculate, you might as well look at the whole
28 spectrum of speculation here.

29 MR HINDLE: Well Ma'am, I stand by the submission that this issue falls
30 within term of reference 7, I stand by the submission that it is an important

1 issue and I stand by the submission that it is not necessary for the inquiry to
2 answer the questions but it is well within your terms of reference to identify
3 the issues and to recommend that steps be taken to develop an answer and
4 that's not to prevent anyone from having an input to it but with all due
5 respect, it does seem to me that that has been one of the most important
6 things that has emerged out of this inquiry. I do submit that to concentrate
7 on the legal issues which I understand the reason for doing that is to, as I've
8 said in this submission I ask that it not distract the Committee from dealing
9 in some way with those important issues.

10 CHAIR: Well the point is this. If the Minister has the power to do it at the
11 moment and that's confirmed by the High Court, she can then embark if she
12 wants to on a public consultation about she exercises the power or not. If
13 she doesn't have the power to do it and here is another uncertainty, and if
14 the regulation making power under 74A does not allow the making of
15 regulations, the Minister is dependent on a change of law. That is done by
16 Parliament, that is subject to parliamentary timeframes. So with the greatest
17 will in the world, the Minister cannot guarantee that any change of law
18 would be passed or if so, at what time it would be passed. Meantime, time
19 ticks by. Now in those circumstances, I think the Minister might well be
20 aided by an answer from the High Court which if favourable and says to her
21 yes you can do everything that needs to be done at the moment under the
22 existing legislation using the power under 47, coupled with 4D. In those
23 circumstances, the Minister then has a choice, she either leaves it to the
24 parliamentary timetable, leaves any proposed legislation to the select
25 committee process and however long that might take or she decides to
26 appoint an evaluation team giving them the powers under 47 and 4C, 4D she
27 can choose whatever powers she wants to given them under the
28 Commissions of Inquiry Act, she doesn't have to give them all the powers
29 and the evaluation can go ahead. If she has to wait until legislation is
30 changed, if there were a 12 month delay there, given what you have told me

1 already that a limited study by Professor Skegg would take six months, we
2 are really saying that any more comprehensive study could take 12 months.
3 We're talking about two years away.

4 MR HINDLE: I wonder if I can answer by saying this. Let's assume that
5 we get to the point where the Minister is found to have the powers to
6 exercise under the Commissions of Inquiry Act and it's clear that she could
7 appoint a Committee of Inquiry. For the purpose of accessing Screening
8 Register information and obtaining documents even where the women don't
9 consent or refuse, what would the Committee's recommendation be to the
10 Minister as to how she should exercise that power?

11 CHAIR: No the Committee doesn't need to recommend to the Minister
12 how she exercises that power, the lawyers can do that. What the Committee
13 can recommend is that from everything that it has seen, it considers that an
14 evaluation needs to go ahead promptly.

15 MR HINDLE: I certainly agree with that Ma'am.

16 CHAIR: Now if the law allows information to be obtained by compulsion,
17 I see no reason to shy away from that. If the power is already there, why
18 shy away from using it.

19 MR HINDLE: I think to those of us who are lawyers and come to these
20 sorts of forum, used to compelling people against their wishes to divulge
21 information, it's not a startling proposition as it is to someone who has for
22 example routinely engaged in epidemiological research where a key as I
23 understand it is that you proceed in a cooperative and consultative fashion.
24 All I know is that when Professor Skegg said in his report of the possibility
25 of information might be made available to him on subpoena, he was very
26 reluctant to want to be involved with that. I'm not sure I can take it an
27 awful lot further. At the end of the day, it is a question of approach and
28 philosophy and I have no quibble but that the Committee has the power to
29 go to the High Court and I simply am raising for the Committee's attention
30 what it seems to me to be the underlying issue.

1 CHAIR: Professor Skegg gave evidence before this Committee where in
2 very emotive terms, he asked the rhetorical question 'how many women
3 must die of cancer before something is done'? So if at the end of the day it
4 turns out that an evaluation that could allow underreporting in any other part
5 of the country to be picked up can legally be taken at the present time but
6 Professor Skegg has his own concerns regarding sensitivities because the
7 information may be gained under the power of compulsion, he can ask
8 himself that rhetorical question, what does he favour.

9 MR HINDLE: Ma'am at the end of the day, it's an assessment of
10 necessity. It's a question of the situation that the researcher or the Minister
11 finds themselves in and whether or not the necessity to do this outweighs the
12 concerns. I really feel I've taken it as far as I can.

13 PROFESSOR DUGGAN: Mr Hindle, could I ask for some clarification on
14 some things as I see them as a researcher. This whole discussion revolves
15 around terms of reference 3 which is to determine if there's been an
16 unacceptable level of under reporting to satisfy yourselves whether or not
17 this is an isolated case, audit and evidence of the systemic issue for the
18 National Cervical Screening Programme.

19 CHAIR: I don't see it involving term of reference 3 alone, I see it also as
20 involving term of reference 8, term of reference 8 is to make
21 recommendations consistent with 4A of the Health & Disability Services
22 Act. 4A says that the purpose of the Act is to secure for the people of New
23 Zealand the best health and the best care or support for those in need of
24 those services and I think part of achieving the best health and the best care
25 of support for those in need of those services is a service which is subject to
26 regular auditing. I see the exercise, the question of going to the High Court
27 to resolve matters not just so this inquiry gets information it wants to answer
28 term of reference 3, but so that it knows that the Minister of Health can set
29 up other inquiries using the same powers that we have to carry out audits of
30 the screening programme with a view to achieving term of reference 8. I

1 also see it as being relevant to term of reference 6 to consider all relevant
2 proposals that could ameliorate any risks of under reporting of abnormalities
3 and cervical smears. As far as I'm concerned, one of those would be an
4 evaluation study that went ahead and the way to know whether or not such
5 an evaluation study could occur would be to find out first of all can it, under
6 the existing law, be done and that too would be one of the reasons to go to
7 the High court.

8 MR HINDLE: I don't have any quibble with that Ma'am.

9 CHAIR: Yes I just wanted to make that clear to Professor Duggan as well
10 because there is a danger that because this whole issue has sprung up as a
11 result of the subpoena duces tecum, people are getting very focused on the
12 subpoena and term of reference 3 which will assist this inquiry without
13 looking at the bigger picture and the consequential issues which arise about
14 whether or not an audit can be carried out using the powers of a Section 47
15 coupled with Section 4C and D inquiry.

16 MR HINDLE: Professor Duggan, you were asking me about term of
17 reference 3 in particular.

18 PROFESSOR DUGGAN: I'd just rather do the study to be honest but
19 never mind. I think that actually Ms Duffy has answered the question. My
20 question was this approach which is this combination of Section 47 of the
21 Health & Disabilities Act plus Section 4D of the Commission of Inquiry Act
22 to annually conduct this type of review and I think that's what I heard you
23 say.

24 MR HINDLE: Yes that's certainly the suggestion that I've no quibble with
25 the proposition or the fact that as a result of those terms of reference there's
26 jurisdiction to do exactly what's proposed. If you think about it from
27 outside the square, one could say that surely the rules relating to information
28 on the screening programme or information that's necessary for the
29 screening programme should be set outside in the legislation that governs
30 the screening programme. So that someone who comes to it sees

1 transparently what they're committing to or opting out of. That's the policy
2 issue, that goes back into that whole debate.

3 PROFESSOR DUGGAN: I understand that, thanks.

4 CHAIR: One point following on from that is that there's plenty of
5 legislation where access to information is governed by other legislation.
6 You can look at the Inland Revenue Act which has its own secrecy
7 provisions but there are other Acts which are subject to the Privacy Act and
8 the Official Information Act so although what you say would be helpful if
9 the provisions governing access to information were clearly stated in the
10 Health Act, equally we are very familiar with law which is constructed in
11 such a way that provisions allowing access to information reside in other
12 pieces of legislation.

13 MR HINDLE: That's certainly true Ma'am. I suppose one difference here
14 is that unlike the Inland Revenue Department, sadly I don't think you can
15 opt off that. In this particular environment, women make a choice at some
16 point as to whether they want to be involved or not and it does seem to me
17 to make it particularly important that they know what they're making a
18 choice about and what's involved with...

19 CHAIR: Well it also seems important to me that women be aware that up
20 until now those who have chosen to stay on the Register are doing so in an
21 environment where there is no complete audit and evaluation of the
22 screening programme and the reporting particularly the reporting of smear
23 tests. I have not yet heard evidence which would suggest that women are
24 fully aware that they are participating in a programme that is not being
25 audited.

26 MR HINDLE: I couldn't agree more Ma'am and please don't hear
27 anything that I have said to be wanting to delay the audit, wanting to delay
28 the evaluation, those things have to happen because it is absolutely
29 scandalous that they haven't happened to date.

30 CHAIR: Well that's why the Committee is concerned to do everything

1 that it can in a concrete way to remove the obstacles.

2 MR HINDLE: I understand that Ma'am.

3 CHAIR: Mr Murray, before I hear from you, I'll hear from everyone else
4 first. I think it's best if you go last.

5 MS ANDERSON: Yes Ma'am, I have a memorandum here. I should say
6 Ma'am this adds little to what Mr Corkill has already put and I think
7 actually the memorandum speaks for itself. I can say however that we have
8 had no response to the letter to the Minister dated 1st September.

9 CHAIR: One of the concerns that I have had where you talk about
10 paragraph 3 and making regulations, I accept what you say, I accept what
11 Mr Rennie has said, but whether or not regulations can be made to turn on
12 the meaning of the phrase a study of cancer, and again, there are those who
13 can see arguments for reading an audit as a study of cancer, there are
14 arguments to the contrary and unless it were clear to everyone that
15 regulations could be made, indeed until it became clear the Ministry was in
16 the process of making regulations on the basis it believed that an audit did
17 amount to a study of cancer, it's difficult to have any confidence in looking
18 purely at getting around the obstacle 74A creates by saying well make
19 regulations to remove this obstacle because it's by no mean clear that
20 regulations will be effective.

21 MS ANDERSON: Yes Ma'am I would agree that is a concern and would
22 be interested to hear what the Ministry have to say on that particular point.

23 CHAIR: I see with regard to access to clinical records because here, what
24 the Committee is talking about is getting a legal answer on whether or not at
25 the moment it is possible to use a combination of Section 47 of the Health &
26 Disability Services Act and 4C and D of the Commissions of Inquiry Act as
27 powers given to an audit team. I see that your position is that consent ought
28 to be obtained where reasonable and practicable to do so.

29 MS ANDERSON: Yes Ma'am.

30 CHAIR: That is different to saying that the study should go ahead only if

1 consent is given, isn't it?

2 MS ANDERSON: Yes and I think the positions are set out well by the
3 Cancer Society and the Women's Health Action Trust which refers to a
4 method of contacting the woman's doctor and I think that's probably the
5 appropriate way to progress this if there's any difficulties, and certainly our
6 instructions have been that women would be happy for this to go ahead and
7 most would like to give their consent. So I think it is a matter of informing
8 women about it.

9 CHAIR: Yes well that would be something if the High Court said that the
10 powers were available and the Minister did give these powers to the audit
11 team, that would be something that they could do. In other words, rather
12 than move immediately to exercising a power of compulsion, they would
13 have that up their sleeve to use in those circumstances where obtaining
14 consent wasn't reasonable or practicable. This is the way in fact most
15 lawyers operate in the sense that we only use subpoenas when we have to.
16 The other point is that if the powers are being exercised under 47 and 4C
17 and D, although using the Health and Information Code as a guide to how
18 those powers are exercised, if the Code itself does not legally apply, again
19 you avoid the need for Ethics Committees involvement because it's under
20 the Code that researchers are obliged to get Ethics Committees approvals.
21 Then you run into this argument well is it research, is it an audit? Now one
22 way of bypassing the whole event is no one certainly has questioned the
23 ethics of this inquiry and the work it has done is simply to give the power
24 under 47 plus 4C and D and then you avoid the Ethics Committees
25 conundrum.

26 PROFESSOR DUGGAN: Ms Anderson, could I ask you a question
27 because I'm ignorant on these details, I just need some information. If a
28 woman has opted off, it's her expectation that everything about her is private
29 with regard to her screening history, is that right?

30 MS ANDERSON: Ma'am, I can't speak for individual woman, that's the

1 difficulty. We've got different instructions from different women on this...

2 PROFESSOR DUGGAN: Just in general.

3 MS ANDERSON: In general, I would say that there's probably, because
4 they've made a conscious choice to actually remain off the programme and
5 any consequences related to the programme.

6 PROFESSOR DUGGAN: So does a subpoena take precedent over that?

7 MS ANDERSON: I can't answer that question. I can't answer that matter
8 at all for you at the moment.

9 CHAIR: Anyone else wish to be heard? Mrs Marshall?

10 MRS MARSHALL: Firstly Madam Chair, we the Cancer Society also
11 wrote to the Minister of Health in support of counsel for the women affected
12 letter, indicating that we would certainly support a quick fix solution in
13 terms of 74A by way of the current legislation being considered. But
14 obviously we appreciate that there remains a lack of clarity as to whether or
15 not the law needs to be changed or whether regulation alone is required. So
16 we also have not received any response from the Minister so far to that letter
17 and because of the need to clarify whether or not there can be regulation
18 made to 74A or whether the law has to be changed, we would support going
19 to the High Court to get a ruling on that. With regard to the whole issue of
20 the National Evaluation, I think that our understanding of the situation is in
21 fact that the one barrier to this going ahead is the absence of Ethical
22 Committee approval, that there are no other legal barriers to this taking
23 place and as was discussed on Friday, it really boils down to the method by
24 which a woman is made aware of the fact that this is occurring. So as a
25 result, we would not support that in any way the requirement for Ethical
26 Committee approval be waived. We recognise the fact that if a researcher
27 goes to a clinician for the files of a woman, the first thing that that clinician
28 will ask is has there been Ethical Committee approval for this and if there is
29 isn't, there is a likely chance that each clinician who is approached will feel
30 as if he/she has to make that ethical decision themselves.

1 CHAIR: The point is Mrs Marshall that if a High Court answer is that yes
2 under the powers of a Committee of Inquiry under Section 47 coupled with
3 4C and D of the Commissions of Inquiry Act, an inquiry is set up and an
4 inquiry can be set up for any purposes, I will read out the purposes under 47,
5 the Minister or the Director General may from time to time, it doesn't have
6 to be any special incident, appoint one or more persons to conduct an
7 inquiry or investigation into the purchase or provision of health services or
8 disability services or both. In audit of the programme of the Cox
9 Richardson type could be said to, the Minister could appoint Doctors Cox
10 and Richardson coupled with a lawyer to assist them or whatever, to conduct
11 an inquiry into the provision of Health Services namely to inquire into
12 whether or not the screening programme is functioning effectively. So the
13 evaluation would become an inquiry into the provision of that particular
14 health service. Now once that was done, the whole purpose of getting the
15 answers from the High Court is to see whether or not under the existing
16 powers available to a Committee of Inquiry set up in that way, access can be
17 gained to the Screening Register and to clinical records. And of course,
18 there is no need for an Ethics Committee approval in these circumstances, it
19 would bypass that altogether and those carrying out the inquiry may, and I
20 would expect most persons normally would first of all approach clinicians to
21 see if they could get approval, but they would have up their sleeve so to
22 speak the ability to fall back on the powers of compulsion in circumstances
23 where they considered it was imperative to get information but it wasn't
24 practicable to get the consent of the woman concerned.

25 MS ANDERSON: I appreciate those issues. I think that the Society
26 submits that it would be unfortunate to have to take the avenue of
27 compulsion when in fact the barrier, the only barrier as we understand it at
28 this point in time in terms of access to clinical records, is in fact the absence
29 of Ethical Committee approval which really is focused mainly on the issue
30 of whether the Cancer Registry approaches the women or whether the

1 researchers work through clinician.

2 CHAIR: Yes but the point is Ethics Committees are entirely a separate
3 body. Anything that this Committee of Inquiry might say in its report to the
4 Minister has no impact on Ethics Committees directly and this committee
5 hasn't heard enough about Ethics Committees to be able to report in any
6 substantive way on how they work and what changes there ought to be,
7 short of recommending to the Minister that whatever the law is in relating to
8 Ethics Committees that it be changed in such a way that Ethics Committees
9 no longer sit and decide on these matters or grant their approval, it's difficult
10 to see what the Committee of Inquiry can do to influence Ethics
11 Committees. But what it can do is try and find out if legally there is a way
12 at the moment which would allow the evaluation to go ahead without the
13 need for Ethics Committees approval and if there is, then whether or not that
14 way is used is again another a policy issue for the Minister. But at least
15 everyone will know that the study can go ahead without the barrier Ethics
16 Committees present.

17 MS ANDERSON: I think the Society is hopeful that the inquiry can in
18 fact make recommendations on Ethics Committees and in fact has outlined
19 in its Appendix C, Part 2 of its closing submission, it's concerns in this
20 matter. But that sums up the Society's concerns at this point in time.

21 CHAIR: Perhaps you could tell me where and how Ethics Committees
22 relate to the terms of reference the Committee has before it.

23 MS ANDERSON: I think we see that it relates to terms of reference 6 in
24 terms of looking at ways of ameliorating the risk of under reporting in
25 future. Because we are concerned with routinely enabling these sorts of
26 audits to occur and we see the need for Ethical Committee approval if
27 information is being accessed from patient files, therefore we see that there
28 is a need for some recommendations as to how Ethics Committees are
29 constituted and operated. The Society submits that Ethics Committees are
30 important and that their role in these sorts of matters is important but as we

1 submit in our closing submission, there are ways in which the Committees
2 are constituted and operated that need to be addressed.

3 PROFESSOR DUGGAN: Ms Marshall, is it your concern that this avenue
4 that's been discussed here this morning may become the standard and that
5 all audits may somehow follow this avenue in the future and the audit of any
6 Ministry of Health programme and that the ethical approval process will not
7 be considered. Is that the concern of the Cancer Society?

8 MS ANDERSON: It is a concern and it's also a concern echoing
9 Professor Skegg's concern that if this goes ahead in a manner of
10 compulsion, that this might make this sort of audit in future more difficult.
11 It's just weighing up the fact that the barrier is one that we submit is not
12 insurmountable, the barrier is in relationship to the Ethics Committee's
13 decision that the method of approaching women is in their view
14 inappropriate, in our view hinges on that. We submit that this should not be
15 in some way this barrier can be overcome without relying on compulsion.

16 CHAIR: Can you say how it will be overcome?

17 MS ANDERSON: If it is to be overcome quickly, I would hope that
18 perhaps a meeting of the key people that is a meeting of representatives of
19 the Ethics Committees that have been concerned about this issue, that some
20 consumer representatives, I'm aware of the fact that Ms Coney for example
21 on Friday spoke very strongly about her concern that women would want
22 this to go ahead and would feel it's more appropriate if an approach were
23 made through her clinician rather than a letter from the Cancer Registry. If
24 we had people get together in that way for this particular circumstance, I
25 think that we would see that as being one option of possibly avoiding having
26 to resort to compulsion.

27 CHAIR: Mrs Marshall, I've seen a lot of evidence in this inquiry that
28 attempts to resolve other issues by facilitation and consultation and the
29 resolution if it has occurred at all has taken a very long time. The other point
30 is that my recall of the evidence from Professor Evans is that the Ethics

1 Committees are bound by the guidelines that they have published in New
2 Zealand plus the CIOMS Guidelines. Now irrespective of what people
3 might attempt to do around a table, ultimately the impression I get from
4 Professor Evans is that those persons who belong to Ethics Committees will
5 see themselves obliged to adhere to their guidelines and the CIOMS
6 Guidelines. Once you see an audit as research, which is the way Professor
7 Evans saw it, then those guidelines were quite clear about the need for
8 consent and what would happen. I can't see therefore how people with the
9 best will in the world sitting around a table trying to solve a problem can
10 overcome those guidelines. At the end of the day, you have to look at the
11 various legal structures and ethical structures affecting each entity and
12 Ethics Committees have their guidelines and unless there is any
13 authoritative way in which their guidelines can be changed, they're going to
14 act in accordance with those guidelines.

15 MS ANDERSON: We would submit Madam Chair as outlined in our
16 appendix C within our closing submission that in fact the approach that has
17 been recommended is not in fact inconsistent with those guidelines and in
18 fact our closing submission argues that in fact in looking at what this is
19 called observational research, they are in fact what is being recommended is
20 not inconsistent but I appreciate that the concern at the moment is to proceed
21 as quickly as possible.

22 CHAIR: Well it's not just a matter of that. I would be interested in your
23 telling me is this, if the Committee accepted your recommendations and it
24 wrote in the report that it thought that Ethics Committee had wrongly
25 interpreted the KIOM Guidelines, where does it taken the matter in the sense
26 that the Ethics Committee can say so what, we think differently, we have
27 consulted our lawyers, they think differently. What can this Committee do?

28 MS ANDERSON: I think in terms of our recommendations, our
29 recommendations in fact do not address these issues. Our recommendations
30 specifically address the constitution and operation of Ethics Committees.

1 CHAIR: Yes, but getting back to the point, if the Committee were to say
2 that the Ethics Committees had wrongly interpreted the KIOM Guidelines
3 and their own guidelines and that Ethical Committee approval to the extent
4 that it's being required at the moment was unnecessary, what impact do you
5 see that having on Ethics Committees other than a persuasive one?

6 MS ANDERSON: We would not submit that a commentary on the
7 different interpretations is what is required of the inquiry or its findings. We
8 submit that there is a need to look at the constitution and processes of Ethics
9 Committees so we would not submit that the inquiry should in fact comment
10 on interpretation versus another.

11 CHAIR: What evidence do we have on the constitution and processes of
12 Ethics Committees in their entirety?

13 MS ANDERSON: We have some information that was provided by
14 Professor Evans in terms of the fact for example that there are regional
15 Ethics Committees, that there is no National Ethics Committee but that the
16 Regional Committees come together by way of the Chairs of the Ethics
17 Committees. So that our submission is in fact and I think that this matter
18 was discussed in evidence with several witnesses and I think it might have
19 been Ms Coney, Dr Cox, Professor Evans and possibly Professor Skegg as
20 to whether or not it would be advisable to have a National Ethics
21 Committee.

22 CHAIR: Well my recall of I think Professor Skegg's evidence on this
23 point was that if the National Committee comprised the heads of Regional
24 Committees, he didn't think it would take the matter much further.

25 MS ANDERSON: Our submission is in fact that our National Committee
26 should not be comprised of the Chairs of the Ethics Committees because
27 that does not comply in fact with the guidelines for Ethics Committees.

28 CHAIR: But the other point is that the guidelines are general, the Ethics
29 Committees have their guidelines, they have the CIOMS Guidelines whether
30 it's a Regional Committee, whether it's a National Committee. Ultimately

1 there is sufficient discretion of the Committee to reach its own decision, its
2 decisions cannot be influenced so short of saying that the scope of what
3 Ethics Committees inquiries look at should be restricted to exclude audit
4 evaluation exercises, which in fact is not what you advocate anyway. It's
5 difficult to see how the Committee could make any recommendations about
6 Ethics Committees which would ensure that the problems that have been
7 encountered to date are not encountered in the future.

8 MS ANDERSON: One of our recommendations also relates to the role of
9 the HRC Ethics Committee. Again I think Professor Evans made reference
10 to the fact that the HRC Ethics Committee is the Committee to which an
11 applicant can seek a second opinion and I realise that it's probably not in
12 evidence and we may have stepped a little bit beyond in terms of indicating
13 this but we have drawn attention to the fact that it is not impossible for a
14 member of a local Ethics Committee or a Chair of a local Ethics Committee
15 to be also on the Committee of Chairs which is currently seen as a National
16 Group and also be on the HRC Ethics Committee. So it's really looking at
17 these issues relating to Ethics Committees in some way that there's a way to
18 move forward.

19 CHAIR: How are we going to move forward in the sense we're looking
20 here at a substantive decision by a Ethics Committee which has prevented
21 an evaluation study going ahead which I think everyone agrees is essential
22 that it go ahead. How is looking at whether one has a National Body,
23 whether one has an HRC, how it's constituted, how is that going to actually
24 move the issue forward?

25 MS ANDERSON: We would submit that it is still an important issue
26 relating to ongoing monitoring and evaluation of this programme in terms of
27 the current situation, I guess it is a dilemma because we would be concerned
28 if the solution to the current situation would in some way impinge on what
29 happens in future. I think that it refers back to Professor Skegg's concern
30 that if this goes ahead by way of compulsion, that this in fact could impact

1 on future evaluations of this sort. In terms of what happens currently, I'm
2 afraid I have no more really that the Society submits other than to suggest
3 that possibly and I suspect that Ms Coney implied this as well, that if there
4 were some mechanism whereby some of these key players could get
5 together which included a consumer voice because I don't think that has
6 been included so far, that in fact that might be a way forward in terms of the
7 current situation.

8 CHAIR: How, I mean unless everyone suddenly comes up to some
9 brilliant solution which everyone agrees with, how is putting them in the
10 same room, talking about the problem, going to resolve it?

11 MS ANDERSON: I don't know that we could submit that it would
12 necessarily guarantee be resolved in that way but we would hope that there
13 would be at least the opportunity to include the consumer view on this issue.

14 CHAIR: How is that in itself going to ensure that we all know whether or
15 not at the moment there is a legal vehicle which would allow an evaluation
16 of the programme to be carried out.

17 MS ANDERSON: I think our concern in this respect is that obviously the
18 legal issue with regard to 74A is clarified and resolved and if this other
19 matter can be resolved without resorting to compulsion, then we feel that
20 that would be a positive way forward.

21 CHAIR: And if the only choice was no evaluation in the near future or
22 evaluation being carried out using powers of compulsion, what would the
23 Society favour? And I'm talking about an evaluation actually getting off the
24 ground effectively within the next 12 months.

25 MS ANDERSON: I think with regard to that question I would need to
26 really go back to my organisation. I'm not able at this point in time to give
27 a definitive answer to that.

28 CHAIR: Mr Kirton?

29 MR KIRTON: Madam Chair thank you for the opportunity to comment.
30 The view which I've canvassed over the weekend with a number of the

1 women involved in the organisation I represent is very much in favour of the
2 course of action that you have proposed, we must get on with the job, it's a
3 matter of, first and foremost, the safety of the women. That must be the
4 priority. If it's a matter of interpretation of a legal issue, well let's get on
5 and get it done. It should have been done 10 years ago, it should have been
6 done in April, we are now at this stage of the inquiry, I think it's a travesty
7 that it hasn't been done and I appreciate wholly the situation that the inquiry
8 finds itself. As I said, the imperative is the prospect that women's safety is
9 at risk, there is potentially a time bomb ticking away, we are not sure, we
10 are unclear of that, we have as I submit to know an imperative to act
11 immediately. The second aspect I would like to put to you is that the issue
12 in terms of this inquiry must not be shrouded in some sort of imagined legal
13 uncertainty. The authority of this inquiry, its recommendations must not be
14 impeded or any excuse offered to give any party an opportunity to avoid
15 addressing the issue. So that's the second issue. Thirdly, I appreciate your
16 comment and agree with it that we're not here to consider the issues I guess
17 the morality of it, the ethical nature of it. However, I do submit that the
18 Ethics Committees in my view and the view of the people that I'm here to
19 talk for, is that they plainly got it wrong and if you're looking for any other
20 than a legal imperative, I believe you have a moral imperative as well and I
21 will put it later in submission in terms of the CIOMS Guidelines. I think
22 they give adequate and appropriate guidance with regard to what the
23 imperatives in terms of ethical approval for this type of study are. So they
24 are the three grounds Madam Chair that I submit to you, give a very very
25 strong message to proceed immediately and with urgency.

26 CHAIR: Thank you Mr Kirton. We've been going since 10.30 and I see
27 it's 5 past 12, what I suggest is that we break and resume again at 12.20 and
28 that will give you time Mr Murray to take into account submissions made
29 already this morning.

30 MR HINDLE: Ma'am just before we do that, my friend Ms Janes who is

1 listening to the debate has offered a suggestion which maybe I ought to
2 communicate so it can be thought about. The suggestion is this, if one takes
3 the view that it's within your terms of reference to do something like the
4 national evaluation to satisfy yourselves whether this is an isolated case, this
5 Committee could itself use its existing powers under Section 4C to authorise
6 a researcher to go and get information even if that needed to be done
7 compulsory.

8 CHAIR: But the whole point is I don't know that I have the power because
9 I've issued a subpoena duces tecum.

10 MR HINDLE: Let me just go on. Certainly that issue is still moot in
11 relation to Section 74A and the information on the Screening Register but I
12 don't think I've heard anyone suggest that a Committee of Inquiry doesn't
13 have power to compel the production of the personal medical records
14 outside the Screening Register. And so since it seems to be clear that the
15 starting point which we already have which is the named information on the
16 Cancer Register is there, if the Com wanted to pursue it, presumably a
17 further subpoena could issue for the production of all remaining information
18 on this Cancer Register. There would be then a complete list of all women
19 who have contracted cervical cancer and at that point, this Committee could
20 authorise under Section 4C the researchers to get on with the research. I just
21 wanted to communicate that idea because it did seem to me to have some
22 merit to it.

23 CHAIR: I haven't looked in great detail at the proposed research by
24 Doctors Cox and Richardson in terms of coming to any decision as to
25 whether or not that study falls within term of reference 3. In other words,
26 whether or not the planned study by Doctors Cox and Richardson could be
27 seen as a study which would provide evidence on whether or not there was a
28 systemic issue for the programme or if it goes beyond that. Because if it
29 goes beyond that, then we're not here as a Committee of Inquiry to look at
30 the programme generally, we are here to, one of the things we have to do is

1 to determine whether or not there is a systemic issue.

2 MR HINDLE: Maybe it's not helpful to even think about that evaluation
3 plan. The point really is that if the slide review indicated as a result of the
4 preliminary data received and considered by Professor Skegg needs to
5 happen in order to answer term of reference 3, the protocol could be
6 developed and as I say, the existing powers could be used and then it would
7 be up to this Committee to decide the extent to which it needs or is willing
8 to compel them to provide information against their refusal.

9 CHAIR: Well this is an entirely separate issue. It's not an issue which
10 deals with whether or not there is legal power at the moment on an ongoing
11 basis to audit and evaluate the National Screening Programme, it's a
12 question of whether we use powers available to us to answer term of
13 reference 3.

14 MR HINDLE: It just did provide a way through, I mean if speed and
15 urgency is required, it did seem to have some merit because you are here,
16 you've got powers, we can just get on with it.

17 CHAIR: There are concerns because I want to find out legally what the
18 situation is for the future. If we push the issue here, and it seems to me that
19 a full evaluation, given that an evaluation of four regions will take six
20 months, a full evaluation would take much longer, there is no comfort that
21 other evaluations will happen in the future.

22 MR HINDLE: Well it was an idea Ma'am.

23 CHAIR: But I also would need further help from you to point out whether
24 or not this evaluation did fit with term of reference 3 and if not, we'd be
25 then sitting down ...

26 MR HINDLE: Well Ma'am I'm saying we'd design one to do that, that's
27 the point.

28 CHAIR: Well what had been contemplated with the Professor Skegg study
29 that he get the two registers, see if there was an unusual pattern of reporting.
30 For those cases where he had identified an unusual pattern of reporting, he

1 then look further and we wanted to hear from him as to what he needed to
2 look further and once we knew what he needed to look further, we could
3 give him powers under 4C to go out and inquire on our behalf. And if he
4 encountered difficulties in getting access to whatever he needed, and that
5 may include a slide review it may not, it would be whatever he needed, we
6 would use the powers under 4D but everything I've heard from you to date
7 is that the Skegg study is unlikely to go ahead.

8 MR HINDLE: No Ma'am this is where we've got to untangle the labels
9 we've given these studies. The position is that the Cancer Registry
10 information and the anonymised Screening Register information was made
11 available to Professor Skegg who considered it together with Doctors Cox
12 and Associate Professor Paul and the report of the 7th of September suggests
13 a way in which you could look at smears to see what it tells you about
14 reporting in different regions.

15 CHAIR: Well is that happening at the moment?

16 MR HINDLE: No Ma'am because apart from funding issues and other
17 issues, we seemed to have arrived at a point where arguably it's not
18 necessary to have this information to deal with term of reference 3.

19 CHAIR: Who made that decision?

20 MR HINDLE: I understood that my friend had accepted that.

21 CHAIR: At what point was it brought to the Committee to decide whether
22 or not it was unnecessary for the Skegg Study...

23 MR HINDLE: It hasn't been. The reservation that was recorded at the
24 meeting was about doing the study for four regions when their view was that
25 it needed to be done for all regions. What I'm suggesting here is that such a
26 study for all regions could be done under term of reference 3 in the terms of
27 reference using your powers. It is true that you will not have an answer to
28 the Section 74A problem out of doing that because that is a discreet problem
29 that relates to the Screening Register only. But you would be able to
30 facilitate this study in the way that my friend has suggested and as I say, the

1 Committee would then be in a position to make it's own judgements about
2 what is necessary and what should be done to require the release of
3 information where there's women absent or dead or refuse. And that would
4 allow the study to get going as soon as, practically one is going to have to
5 think about the issue of funding but you have existing Commission of
6 Inquiry powers and I haven't heard anything suggested that putting aside the
7 Section 74A issue, that suggests a Committee of Inquiry cannot require
8 compel the production of records. Now I've put aside the question of
9 whether the epidemiologists would be willing to be involved in that but just
10 in terms of providing a way ahead, the point I think my friend makes which
11 I think is right, is that you may actually already have enough powers so we
12 don't need to worry about other Committees or the High Court or anything
13 of that nature.

14 CHAIR: We would still have the problem of 74A.

15 MR HINDLE: That certainly wouldn't be resolved. Of course, the
16 Ministry would have the entire time to sort that out and one of the
17 suggestions I made was for a recommendation that the Committee do
18 reconvene in a year's time which is a realistic timeframe and then you
19 would be able to receive a report to find out exactly what happened in the
20 interim.

21 CHAIR: What if the recommendation isn't accepted?

22 MR HINDLE: Well Ma'am, there comes a point where that's a fear and a
23 risk that is simply inherent in what you doing. You're quite right, the
24 Ministry may simply put the report in the bin. I'm not suggesting that it will
25 do that but at the end of the day, if it does that, there's actually nothing
26 much you can do.

27 CHAIR: Why is there so much resistance to going to the High Court to
28 find out what the legal position is at the moment?

29 MR HINDLE: It doesn't solve the problem Ma'am, that's why.

30 CHAIR: Well it may not solve a problem in terms of whether or not a

1 power is going to be used but at least it will then become clear that it can be
2 done. Whether or not at the end of the day those who can exercise that
3 power choose to exercise it is another matter but at least we will know it can
4 be done.

5 MR HINDLE: Yes well we covered that this morning. I just wanted to
6 add that further idea before my friend Mr Murray stood to speak.

7 CHAIR: Well I think he would like some time to think about that one.

8 MR MURRAY: Just before we break Madam Chair, just a suggestion I
9 have is that my friend, Mrs Sholtens, managed to find the agreement for the
10 Cox Richardson Study to go ahead. My suggestion is that I hand this up, it
11 gets photocopied and we break now and come back at 2 o'clock when we've
12 had a chance to actually see what the Cox Richardson problem is.

13 CHAIR: So you would like until 2 o'clock would you?

14 MR MURRAY: Yes I've only had a chance to quickly skim this on the
15 plane up but I think it might help us just with particularly some of the ideas
16 that are coming out, if we know what's contracted at the moment, the
17 likelihood of it going ahead anyway that just might cut through this. My
18 friend, Mrs Sholtens has a clean copy that she could make (inaudible).

19 PROFESSOR DUGGAN: We can get this copies right away.

20 MR MURRAY: Yes if the Registrar can photocopy them, they can be
21 made available and read over the lunch break.

22 PROFESSOR DUGGAN: This document that you have in your hand
23 relates to the three limbs of the Cox Richardson Study?

24 MR MURRAY: Yes this is the contract for the three of them.

25 PROFESSOR DUGGAN: It's a very small looking contract.

26 MR MURRAY: Well there's a protocol somewhere too. There's three
27 limbs, one's done, the other's being done and the third one we're talking
28 about here.

29 CHAIR: You better think about Mr Hindle's suggestion too which seems
30 to be that we embrace this study as part of our inquiry.

1 MR MURRAY: I don't think we need to. There's a lot of work going on
2 actually implementing the third limb as well. One of the things about this
3 inquiry is of course the issues become clarified, everyone reassesses their
4 position, I think Ethics Committees are looking at issues too and I can't
5 speak for them but the Ministry has been involved in a plan of attack, if I
6 can put it that way, so that the third limb of the Cox Richardson Study can
7 go ahead. One of the problems I think are some of us are making these
8 statements from the bar and I appreciate the difficulty the inquiry is in
9 because unless you've got an affidavit from somebody, you're not going to
10 get the confidence that we're getting there. Let's make progress that we can
11 and I think this contract and the protocol might be at least...

12 CHAIR: We'd like to have the protocol too and we will adjourn until 2pm.

13 PROFESSOR DUGGAN: I've been struggling with one issue all of last
14 week and perhaps you can clarify it for me when we come back at 2 o'clock.
15 Under terms of reference 3 when it says the systemic issue for the National
16 Cervical Screening Programme I really would need to find who is on the
17 programme.

18 MR HINDLE: I think you might have to help me with that a little more.

19 PROFESSOR DUGGAN: I think this is very important.

20 CHAIR: Yes I think actually Dr Duggan is right because when Ms Coney
21 was making her submission, she talked about the programme being
22 something other than the Register, there is the Register and of course
23 women choose to be on it or not but overall, we have a Cervical Screening
24 Programme which is really aimed at reducing the incidence of cervical
25 cancer by encouraging women to participate in the programme. Now in
26 some ways you could say well whatever publicity there is around, the
27 programme and education, even if a woman chooses not to be on the
28 Register, if she goes to her doctor and has screening every three years and
29 she might even have it every year, is that part of the programme? Is the
30 programme the Register, or is the programme a concept developed by the

1 Ministry of Health to reduce the incidence of cervical cancer?

2 MR MURRAY: That's when I started from with this inquiry. That was
3 the first question that was in my mind, what is the programme and I will
4 reflect on what answer to give...

5 CHAIR: Hopefully, if it was first in your mind at the very beginning, you
6 would have lead lots of evidence on the point.

7 MR MURRAY: I think we did but we focused on I think we indicated that
8 the terms of reference did not seem to be asking us to conduct a review of
9 the whole programme. In other words, every step of the screening pathway.

10 CHAIR: I agree with that.

11 MR MURRAY: So where we're at in my submission is that we're focused
12 on the narrow issue of Dr Bottrill and Gisborne and if that leads you into
13 systemic issues, you come out from there and say 'right, there are issues that
14 come out of Gisborne that we need to address for the programme overall'.
15 There is then a question of what if it's a smear taking, it's the taking of the
16 smear that could be a problem. Do the terms of reference mean we go into
17 that or do we leave that aside because the terms of reference are focusing on
18 laboratory smear reading?

19 CHAIR: My view would be that term of reference 3 starts off if we
20 determine there has been an unacceptable level of under reporting. We then
21 have to satisfy ourselves if the unacceptable level of under reporting was an
22 isolated case, or evidence of an systemic issue, so I think that any systemic
23 issue that flowed from under reporting or could be attributed to under
24 reporting would be for us to look at. Now if it turned out for example that
25 we concluded that the unacceptable level of under reporting here had all
26 flowed from bad smear taking, well then we might launch into making
27 comments about smear taking as a systemic issue. But if the unacceptable
28 level of under reporting is attributed to laboratory reporting of smear tests,
29 the question then would be well is it just isolated, just it did happen in
30 Gisborne or is there evidence of a systemic issue?

1 MR MURRAY: With respect, I believe that is the correct way to approach
2 the terms of reference. They start from a very narrow base and they open
3 out and seem to be concerned to make sure you're not constrained if you
4 found something like that, where it says to comment on any other issue the
5 inquiry believes to be of particular relevant, it obviously would be unusual if
6 the inquiry thought 'oh well, we found a lot of systemic issues unrelating to
7 smear reading but we're just not reporting those. I have no difficulty with
8 that, that's like a funnel, you start with the small points and you lead out and
9 there's a judgement call as to how far you go depending on how serious the
10 issues are that you discover. I don't think I've really addressed Professor
11 Duggan's point.

12 PROFESSOR DUGGAN: I'm very concerned about this because term of
13 reference 3 is the only one that actually mentions the screening programme.
14 I asked Ms Sholtens, I forget what day last week, who is in the programme
15 and her answer to me was 'women on the Register'. Ms Coney had a
16 different answer. Her answer was that any woman who has had a smear is
17 in the programme so by her definition, all women who have never had a
18 smear, are not on the programme. So that if you're doing an audit of the
19 screening histories and management of women with invasive cervical cancer
20 which is what the Cox & Richardson, one of the limbs of the three limb
21 study is you have to include I think the women all of the women who got
22 invasive cervical cancer and the only women not of interest to the
23 programme are those who have never had a pap smear.

24 MR MURRAY: I think that must be right and that is why you probably
25 need to make a distinction when we're talking about these studies if I can try
26 and use a neutral term.

27 PROFESSOR DUGGAN: Project is a good word.

28 MR MURRAY: Yes, we need to think well are we studying cervical
29 cancer in which you case you go to the Cancer Registry and see what has
30 happened or is the focus becoming more down to the performance of the

1 National Cervical Screening Programme which means you then go into a
2 subset of women who are on the Register. There will always be those two
3 groups of women...

4 CHAIR: Wouldn't it overall if you were doing a full evaluation be both?
5 Because the programme costs you money and indeed the European
6 guidelines have a way of getting information so you can do a cost benefit
7 analysis. You can say well this is how much money we save in health terms
8 by having a programme. But first of all, you would want to make sure what
9 is the incidence of cervical cancer, is it being reduced or not, what is the
10 impact in New Zealand and in that sense, you would want to look at all
11 women, those who have been screened, those who hadn't. But equally you
12 would want to make some assessment of whether the programme was
13 working because ultimately you would have to say what is the point of
14 spending the health dollars on a programme that is not effective.

15 MR MURRAY: And that is what the Cox Richardson Study as I
16 understand it just having quickly looked at it, actually does. It doesn't focus
17 on just the women on the screening programme, it focuses on the women
18 who had developed cervical cancer.

19 CHAIR: Well we have to look at whether or not the under reporting is a
20 systemic issue for the National Screening Programme. If you are thinking
21 broadly, you could say well is the under reporting evidence of a systemic
22 issue for provision of health services and just it take back to laboratories and
23 say well why aren't laboratories reading smears properly for anyone. But
24 it's looking at the systemic issue for the programme which to me had
25 seemed to be an issue therefore of well if we have a programme, if there has
26 been an unacceptable level of under reporting, how does that interface with
27 the programme? In other words, one would expect a well functioning
28 programme to identify under reporting at an unacceptable level. Or even to
29 prevent under reporting at an unacceptable level because of the checks and
30 balances the programme put in place. So if you have a combination of a

1 programme plus an unacceptable level of under reporting, you then have to
2 say well how did that come about, what relationship to the systems within
3 the programme does this level of unacceptable of under reporting have.
4 That's as I've seen it.

5 MR MURRAY: It's actually quite complex. The analysis for term of
6 reference 3 requires some real thought because there are a number of
7 distinctions to be drawn, I think this is just one of them.

8 CHAIR: Is this why I haven't had the assistance of your submission on
9 that yet.

10 MR MURRAY: They're a work in progress Madam Chair.

11 CHAIR: Well the point is really fundamentally the terms of reference are
12 our jurisdiction so really the first thing anyone has to say about anything
13 should be what is our jurisdiction. What is the correct interpretation of the
14 terms of reference? And if there are varying interpretations put forward, one
15 of the first things the Committee has going to have to do is make an
16 interpretation of the terms of reference, decide which interpretation it prefers
17 if there are competing interpretations and if it gets it wrong, it will be
18 subject to review.

19 MR MURRAY: Just very quickly on Professor Duggan's point, I believe
20 that a comment was made earlier that in fact women who are not on the
21 screening programme participating in the sense of not being on the Register
22 may nevertheless be beneficiaries of an effective National Cervical
23 Screening Programme because the monitoring and auditing done of
24 laboratories for example would pick up under reporting if it's done well
25 hopefully. And so the value to the women who have never been on the
26 Register is that simply that laboratory will be detected and the fact that their
27 smears were being read at that laboratory and the problem is resolved, is an
28 advantage.

29 PROFESSOR DUGGAN: Yes we had that discussion last week because I
30 had some concerns with regard to the creation of a two chair laboratory

1 system. One for women on the programme as the finders being on the
2 Register, and another for women who were not on the programme. And that
3 this whole issue of minimum volumes wouldn't apply to laboratories who
4 were not serving women who weren't on the programme.

5 MR MURRAY: Yes then I came back and said that that distinction is not
6 drawn by the Health Funding Authority, they regard these standards as
7 having to be implemented and it's not for laboratories to say well I'm sorry
8 this is a smear that we're reading for a woman who has opted off the
9 programme. The laboratories can't opt out of complying with the standards.

10 CHAIR: There is actually a real danger of talking about opting out of the
11 programme. You don't opt out of the programme, you opt off the Register
12 and the Register is not the programme and in fact, the programme can be
13 seen as a more organised vehicle for smear testing in New Zealand because
14 if you didn't have the programme, you would have a situation where smear
15 testing happened in an opportunistic fashion with individual doctors. Some
16 might promote it, some wouldn't, it would be very adhoc, those smears
17 would be sent to laboratories, read because laboratories in New Zealand are
18 funded by Government, the smear test reading of them would be funded.
19 But everything would be lazire fare and it would depend on individual
20 patients, individual practitioners, the way things were managed. As it is, we
21 have a programme which is attempting to now put in place standards for
22 laboratories, reading cytology in terms of accreditation and in terms of
23 minimum numbers, also public education about having smears, setting up
24 smear taking in the sense that there are well women clinics etc. So what it
25 really means is the delivery of cervical smear reading in a more organised
26 fashion and part of that organised fashion is the opportunity for women to be
27 on a Register unless they choose to opt off it.

28 MR MURRAY: I think I better stop talking and thinking on my feet
29 because Mrs Sholtens actually knows more about this than I do.

30 CHAIR: Obviously this whole issue of the Register, the programme has a

1 big impact because it actually effects how you interpret the terms of
2 reference so we do need to hear from you on that and others may comment
3 because so far, the submissions have attempted to address the substantive
4 issues before us, they have not attempted to address the jurisdictional issues
5 in the sense they have not gone into any detail into how the terms of
6 reference should be read.

7 MR MURRAY: We have approached term of reference 3 and thought we
8 can do this once over lightly and it won't be of much value but with the time
9 that we had before this hearing started, we suddenly realised there was some
10 actually quite deep jurisdictional issues in that term of reference and
11 therefore we paused and came to the inquiry, not I must say to keep our
12 powder dry we just didn't have the time to do what we thought was required
13 there. Having said that, I must say Ms Marshall from the Cancer Society
14 has done an impressive job which is left us feeling how are we going to beat
15 that.

16 CHAIR: We'll adjourn until 2pm.

17 PROFESSOR DUGGAN: I was just wondering if we were going to get
18 those protocols while we are waiting.

19 MR MURRAY: Yes we'll locate them and get them copied.

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21 **INQUIRY ADJOURNS UNTIL 2PM**

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INQUIRY RESUMES AT 2PM

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CHAIR: The invitation to counsel at the first session to remove jackets without permission is still in place so anyone who wants to take their jacket off, can. Yes Mr Murray?

MR MURRAY: Madam Chair I've done a short memorandum which is just being handed out and I've circulated that memorandum. There's one or two errors in it I would just like to correct before we go any further. It's paragraph 2, the date should be the 4th of August and paragraph 4, there's a reference to the Evidence Amendment Act which is the 1980 Act and in paragraph 6, right at the top of page 3, the Director General cannot and cross out the words 'claim the benefit' and put instead the word 'invoke' because it's not really the Director General's interest we're talking about here, it's the Director General just acting on advice as she understands the law. And it's a relatively short memorandum, I'm happy to just speak to it or just pause for a moment while the panel reads it.

CHAIR: While that's happening, I'll just query whether the letter that came in from the Minister over the lunch hour has been distributed.

MR MURRAY: I've got a copy.

CHAIR: I think I have to distribute it to everyone now because of the issue we're dealing with in the contents of the letter. If I could have a copy, I don't have one with me. Firstly Mr Murray, I'll just deal with the letter from the Minister, the Committee of Inquiry has seen fit to release to parties appearing before the Committee and to make public a letter it received from the Minister of Health during the course of the luncheon break. It has done this because since 10.30 this morning, we have been sitting to determine this issue of whether or not we should refer certain legal questions to the high Court for resolution. The Minister's letter raises questions about the High Court ruling and in her letter she says that at this point, for the purpose of the inquiry reporting to me, I do not consider that a ruling from the High

1 Court is necessary. Now once the Committee of Inquiry was set up with its
2 terms of reference and once it was given the powers under the Commissions
3 of Inquiry Act including a Section 10 power, it was then a matter for the
4 Committee to decide whether or not to use that power. The Minister is free
5 to have counsel appear before the Committee and to make submissions on
6 the question but those submissions should be made publicly. There is the
7 concern that a letter such as this written privately to the Chair of the
8 Committee could be seen and I do not wish to say the Minister was
9 attempting to influence the Committee, but it could have that appearance
10 and in order to preserve the Committee's decision making from any later
11 allegations of bias or pre-determination on the grounds that there is the
12 appearance that it has been influenced by the Minister, I have considered
13 and I've taken into account the views of the other Committee members that
14 this letter should be made public and anyone who wishes to make
15 submissions on what the Minister has said in the letter, is welcome to do so.
16 I will emphasise that the Committee sees the decision at this point as to
17 whether or not it refers questions to the High Court for resolution as one for
18 it to decide on the basis of the evidence that is heard to date and the
19 submissions made to it in this inquiry. Now Mr Murray, I've read your
20 submission.

21 MR MURRAY: Perhaps if I just speak to it briefly and then the panel
22 might have questions for me. I'm conscious that I was on my feet for
23 almost a couple of hours on the 11th of September with submission and
24 they're were not that many people at present at that hearing so are my
25 submissions are a development of the thinking that's gone into the subject
26 since that 11 September hearing. I suppose the fundamental point that's
27 made in this submission is that we are drawing a distinction, or at least the
28 Ministry is drawing a distinction between where the inquiry started off with
29 the subpoena which was to obtain evidence for terms of reference 3 and in
30 that area, clearly the inquiry has issued a subpoena, it hasn't got all the

1 information it wanted. It's got a lot of it but there's that residual issue about
2 Section 74A of the Health Act and the Screening Register information
3 relating to identifiable women, it hasn't been handed over. So if the inquiry
4 is still to pursue what I call a four region study, then of course one can
5 understand the inquiry's duty to take questions of evidence as far as possible
6 and if it hasn't got the evidence it wants, of course it's entitled to look at
7 how to get the evidence and the inquiry panel itself has referred to Douglas
8 & Pindling. So one can understand where we started out from but as I
9 apprehend, the thinking has evolved to the point where apart from the
10 inquiry's wish to get evidence, it may also have legal issues that it wants
11 determined which will assist with answering its terms of reference. And the
12 submission really goes on to make the point that it is important that we draw
13 the distinction because once we go over to additional questions of law, we
14 then have to make another distinction and that is the responsibilities of the
15 inquiry to answer the terms of reference in responsibilities of the
16 Government to make sure that the screening programme is evaluated and I
17 think where the Ministry position is much the same as the counsel assisting
18 the inquiry because we are essentially identifying that there are a number of
19 legal issues and that we would be greatly assisted as a Ministry in having the
20 inquiry's report both on the factual problems and the legal problems but that
21 then passes the responsibility firmly over to the Ministry and the
22 Government to make sure that the concerns that have been identified in this
23 inquiry are actually resolved. What we therefore need to do in my
24 submission is to go back to the subpoena issues which are identifiable and
25 manageable in terms of the ordinary way that we're all used to dealing with
26 summonses and the need for information. So if I could just deal with that
27 part of the Ministry's position first. We've basically come to the view that
28 the Ministry will facilitate a four region study if the inquiry panel thinks that
29 that study should be done, well then the Ministry has the information from
30 both Registers and it will make sure that the four regions become the focus

1 of a protocol which meets the requirements of the scientific validity.

2 CHAIR: Tell me this, once you've done the information matching and if
3 you've identified women who should be looked into further, are you going
4 to make those names available to the Committee of Inquiry because the next
5 stage in the process would be to appoint Professor Skegg with powers under
6 4C and if he ran into difficulties in getting extra information using again the
7 4D powers to get that information, so that he could then move into looking
8 at clinical records and laboratory slides.

9 MR MURRAY: No first of all. As far as Professor Skegg is concerned as
10 my learned friend has made clear in fact, Professor Skegg will not be
11 available to do much work on this because he has other commitments and as
12 I understand it, any work would be devolved to Dr Cox so that's the first
13 point. The second point is that there is a question then about whether Dr
14 Cox simply designs the scientific protocol and then the Ministry does the
15 study or whether Dr Cox does a lot more of that actually works on
16 implementing the protocol. But in other event, the whole approach is that
17 the Screening Register and the Cancer Register information will be used to
18 identify the women and they would then be approached for their consent to
19 do the clinical audit that is required and that evidence would then be brought
20 back to the inquiry. Professor Skegg in his report indicated that although
21 some women may not consent of course, that would not undermine the
22 validity of the work that is done.

23 CHAIR: Yes because we could use the 4C power authorising, under that
24 power, authorise any person to inspect and examine any papers, documents,
25 record or things and require any person to produce for examination any
26 papers, records or things in that person's possession or under that person's
27 control. So if there were a difficulty in getting consent and information was
28 seen as being necessary, it could be obtained under that power.

29 MR MURRAY: Yes we could come back to the inquiry so there's a fall
30 back position if you like.

1 CHAIR: The point is, the Committee of Inquiry wanted this information.
2 The Committee of Inquiry of course has been set up with a pathologist, Dr
3 Duggan has certain views on the information she would require from a study
4 and therefore, we would want to ensure whereas before with the intention of
5 Professor Skegg doing the inquiring, the subpoena to get access to the
6 Cancer Register and the Screening Register was simply the first step in a
7 process. If the four region study were to be carried out given that it was
8 given out for the inquiry and at the inquiry's direction, the inquiry would
9 want to have influence in how it was carried out, and the protocols.

10 MR MURRAY: Yes and I think there's quite a bit of work that would
11 have to be done there. I know that if there was a question of issuing
12 subpoenas, that would have to be discussed with the inquiry's expert,
13 whether it is Professor Skegg or focusing now on Dr Cox. I think the way
14 the Ministry would look at it is that it's important that the inquiry has
15 confidence in the person that's designing the protocol. And if it's Dr Cox,
16 then he would have to work through counsel assisting to make sure that
17 before the study is actually implemented, everyone is happy with the
18 protocol and how it will be fulfilled. For all I know, he may have concerns
19 if the inquiry said don't you worry, we'll issue subpoenas if we need to. But
20 that's one of the points the Ministry doesn't have a position on that point
21 because it would be the inquiry's, it would be done as a way of seeking
22 evidence for the inquiry.

23 CHAIR: And ultimately if the inquiry sees it necessary to issue a
24 subpoena, it's a decision to be made by the inquiry.

25 MR MURRAY: Yes it is. So having said that, I wasn't at the meeting last
26 Thursday but my friend Mr Hindle was and I think there was a number of
27 things happening. First of all, if it seems that it is not actually necessary to
28 have that study done in a strict sense, I gather Professor Skegg is looking
29 more to the value of the National Evaluation and in that regard a limited
30 slide review is now being considered as an additional to the evaluation.

1 CHAIR: Yes well the point is that there seems to be a willingness by
2 people to assume the role of the Committee of Inquiry. At the end of the
3 day, whether the four region study goes ahead or not or is seen as being
4 necessary, is a decision for the Committee of Inquiry not for anyone else.
5 At the moment, I've discussed this with the other Committee members the
6 Committee of Inquiry considers that it is necessary to have the clinical audit
7 of the four regions carried out. And the reason is we've now had the
8 opportunity to discuss the issue after this morning's discussions, we've also
9 read through the agreement and the protocol for the Cox Richardson Study
10 and this wasn't before use before, we haven't had the opportunity to
11 question Dr Cox about it but there are some omissions there which Dr
12 Duggan can raise with you which are of concern. Equally it seems to be a
13 national study which is going to take some time and if the four region study
14 takes six months, it would mean asking the Minister to accept an interim
15 report which involved a wait of about three months time. She may consider
16 that reasonable, she may not, she may refuse to accept that. I think that to
17 go beyond that would be asking too much. It is better to have something
18 soon than rather than the whole lot at some later date which we have no idea
19 when it will be.

20 MR MURRAY: Yes I think that so far as the National Study is concerned,
21 my understanding is that considerable efforts are now being made to find a
22 way through, practical ways of actually fulfilling the third limb of the study
23 but that's not for the purposes of bringing that back to the inquiry, there will
24 be months of work in completing that third limb of the Cox Richardson
25 Study. So I should just say that I understand that the protocol for that third
26 limb of the study is being looked at with a view to adding a smear rereading
27 and also with a review to resubmitting an application for Ethics Committee
28 approval on a different basis and there is some indications that a different
29 way of structuring it would actually be a more productive way to get it
30 through the Ethics Committee approval. The Ministry has been a party to

1 those discussions so there seems to be a lot of goodwill by everyone now
2 that some of these issues have come to the surface.

3 CHAIR: I think history shows that there has been a lot of goodwill in
4 every step along the way with attempting to do something with the
5 Screening Programme and there was a lot of goodwill towards getting
6 TELARC accreditation but goodwill doesn't seem to expedite matters.

7 MR MURRAY: No, we'll see. In any event, it's obviously for the inquiry
8 to decide whether it carries on pursuing the four region study but if the
9 Ministry's position is accepted, that of course means the study can be done
10 at least on the face of it without the names of the women on the Screening
11 Register being disclosed to the inquiries so that the summons wouldn't need
12 to be complied with and so that that reason for going to the High Court falls
13 away and the only thing about that of course is that we would actually have
14 to make sure that Dr Cox produces the protocol, that the inquiry's happy
15 with the protocol and that we get a reasonable timeframe around that work
16 so that the Minister could be informed on some accurate basis about when it
17 would come back to the inquiry.

18 CHAIR: You probably haven't spoken to Dr Cox so you won't know but
19 one thing though is it strikes me is that unless that four region study were to
20 bypass the Screening Register entirely and just look at the Cancer Register
21 and then use that to identify, I know women with some abnormality, the
22 minute that you look at the Screening Register and use that information at
23 some point in time when the women, if women are identified indirectly there
24 could be a breach of 74A in the sense that the women are going to be
25 identified, women on the Screening Register are going to be identified.

26 MR MURRAY: They'll be approached just to make sure that this work is
27 done with their consent.

28 CHAIR: What if they don't consent?

29 MR MURRAY: To that extent they won't be included in the work.

30 CHAIR: And how then we will know whether or not there is a systemic

1 problem?

2 MR MURRAY: Well I can only take Professor Skegg's report at face
3 value and he indicates that with that limited study, the premises for it would
4 not be undermined by some women withholding consent.

5 CHAIR: Well the problem we get into is Professor Skegg hasn't appeared
6 before us, we haven't had the opportunity to question him, Dr Duggan
7 particularly hasn't had the opportunity to question him. We've heard plenty
8 of evidence before about a concern of biasing studies, it would be a fruitless
9 exercise to appoint someone to carry out the four region exercise and then
10 find it falls flat on its face because it doesn't cover enough people.

11 MR MURRAY: I suppose my position for the Ministry is really that we're
12 here to facilitate that study and whatever needs to be done, we're happy to
13 pursue it and in that regard I suppose the inquiry itself has the principal
14 incentive to make sure it's all set up properly and counsel assisting has
15 direct communication with Dr Cox. And I know the Ministry is in touch
16 with Dr Cox as well. So if there is solutions to all these things I'm sure they
17 can be brought back to the inquiry in an affidavit if necessary. Otherwise I
18 gather Dr Cox has already done a draft protocol so people are ready to
19 implement things but really we're in the inquiry's hands on that..

20 CHAIR: Dr Duggan has questioned whether the national study couldn't
21 use the four regions as a priority and report on those as a priority but that
22 might be confusing matters more by blending two studies.

23 MR MURRAY: My quick reading of the protocol, it seems to be an
24 extremely value study or evaluation for all sorts of purposes and I'm just a
25 lay person but when you look at it, it seems to be very valuable but it needs
26 to go further.

27 CHAIR: But Dr Duggan thinks it doesn't allow for the discovery for under
28 reporting.

29 MR MURRAY: No that's my point. Educated as we are now by the expert
30 evidence that we've heard at this inquiry, and this is just purely an

1 assessment that I made from my quick reading of it, is that it was by no
2 means clear how you would establish the false negatives rate and that's why
3 there is now a smear reading exercise being looked at to incorporate within
4 the work and I'm not able to say whether that would resolve the problem but
5 Professor Duggan may well be able to.

6 PROFESSOR DUGGAN: Well you worry Mr Murray because you used a
7 word limited smear reading and I don't know what that means, perhaps you
8 could tell me. You did tell me last week but this is another week.

9 MR MURRAY: It's exactly the point that you take the four region study
10 as Professor Skegg put forward in his report and you say let's build that into
11 the national evaluation for all regions. Now I just cannot join the debate on
12 whether from an epidemiological point of view that is sound or not. All I
13 am doing is saying that it seemed to be sound to Professor Skegg.

14 PROFESSOR DUGGAN: I note on page 9 of the protocol for the audit of
15 the National Screening Programme that it says we are investigating the
16 feasibility of a slide review for these women with invasive cancer, it is
17 hoped that the investigation will lead to a systematic nationwide
18 pathological review of previous cervical cytology for women who
19 developed invasive cervical cancer as part of the recognised medical audit
20 process and the ongoing manner. The investigation team will advise the
21 Ministry of Health about how that can be achieved. So are you now
22 indicating that the pathology review is going to be part of this protocol, it is
23 an amendment to this protocol?

24 MR MURRAY: Yes that is my understanding. I hesitate to get too far
25 into this territory, I don't just want to anticipate things that the experts like
26 Dr Cox and Professor Skegg may know but have not articulated and I don't
27 think it would be fair to them for a lawyer to get into that. I think I can say
28 though they have been in direct communication with the Ministry and I
29 think that these are the topics that are being discussed. The point that I
30 would like to emphasise is that there is a will to achieve the outcome that we

1 will desire, it's just how we get there. One of the points about the four
2 region study as opposed to the national study is that we're really talking
3 about Dr Cox and if he is to go off and study four regions, that's likely to
4 delay him implementing his national evaluation. So there is just a practical
5 issue there that the inquiry could consider where you emphasise this is quite
6 a difficult issue but I think in my submission it comes down to do you want
7 to get evidence to be brought back to this inquiry as quickly as possible, in
8 which case you say Dr Cox let's see your protocol, if we approve it and you
9 give us a date or the Ministry gives us a date, the inquiry might decide to
10 pursue that. Alternatively the inquiry might see the value of the national
11 evaluation continuing from here on if we can now cut through some of these
12 problems and although that would not be brought back to the inquiry, it
13 obviously would achieve the outcome that we all want. I'm not trying to
14 influence the inquiry, the Ministry has given me instructions to make sure
15 that I happens and that it's done on the advice of experts and if the experts
16 can't give advice within New Zealand, the Ministry will engage other
17 experts. So there is a very strong incentive to cut through this from a
18 practical point of view and from a legal point of view.

19 PROFESSOR DUGGAN: There are hurdles in the national protocol and
20 the slide review is just one of them. There are others that have already been
21 mentioned and I note that the start date of the study was July 1st of 2000.

22 MR MURRAY: That's the clinical audit part of the process.

23 PROFESSOR DUGGAN: And everything is to be complete within 12
24 months, it was to June of 2001. Is that a realistic timeframe given the
25 hurdles that have been identified and the amendment now which is the
26 addition of a slide review? So my concern is I don't think that timeframe is
27 realistic and then the inquiry is left in this position of things are delayed
28 even further.

29 MR MURRAY: Could I just make a brief submission on term of reference
30 3 because I do think that it depends on how one approaches this systemic

1 issue. It's got in there 'satisfy yourselves whether or not this was an isolated
2 case' and in my submission we may be focusing on that too much. The
3 substantive part of that term of reference is whether there's evidence of a
4 systemic issue for the National Cervical Screening Programme. I for one
5 would feel comfortable with advancing the submission that we shouldn't set
6 the threshold for going into systemic issues too high and the reality is there
7 have been a number of systemic issues identified, particularly during the
8 early part of the programme. If one takes a constructive approach to this
9 term of reference, one does two things, one looks at Dr Bottrill and said well
10 that situation, the Gisborne Laboratories situation clearly raised systemic
11 issues that went beyond that laboratory and the inquiry has a mountain of
12 evidence that we're all trying to assess and that could be written up on that.
13 We then have the HFA's National Laboratory Review which was done and
14 that showed up some systemic issues as well. So that if one takes a
15 constructive approach to term of reference 3, it may well be that we should
16 not worry too much about what the four region study would show, we
17 should just set the threshold for systemic analysis at a low point. If the
18 inquiry does not feel satisfied that Dr Bottrill is an isolated case and there's
19 some basis for that, at least historically, then one goes into writing a report
20 about systemic issues relating to the programme which would seem to have
21 considerable value and in my submission, one then comes into another
22 distinction that has to be drawn. That is systemic issues for the programme
23 historically and systemic issues for the programme today and it may well be
24 that Dr Bottrill and Gisborne Laboratories Ltd issues show quite serious
25 systemic issues at the early stage of the programme. But that in the year
26 2000, many of those systemic issues have been overcome and others will
27 shortly be overcome when the HFA, Dr Peter's work, is implemented and
28 that seems to fit comfortably with the terms of reference that follow after
29 term of reference 3. Clearly we shouldn't be stuck in a timewarp here, we
30 had a historical situation which a lot of evidence has had to address but we

1 also have to assess the current position and this is normally the purpose of
2 systemic analysis. What happened back then to make sure any risks are
3 identified now and are resolved for the future, so its past, present and future.
4 I believe the terms of reference intend to pick up that and they pivot around
5 term of reference 3 and I'm saying my submission is that let's not get hung
6 up on the pivot lets actually get into the systemic issues because then we can
7 address whether there is current risk.

8 CHAIR: That's saying well let's focus on the systemic issues known to us
9 now. There could be a raft of systemic issues out there, there could be real
10 systemic issues shown up by the Northland situation, we don't know. A
11 survey of Northland might show that the screening reporting there is
12 working fine there, it may not, we simply don't know. Certainly we've
13 heard enough evidence to be able to comment on systemic issues in relation
14 to the way the programme was set up, the way it ran which might provide
15 some explanation for why an unacceptable level of under reporting
16 occurred. The fact is that it may be going on, it may be happening
17 elsewhere in New Zealand, it may have happened elsewhere in New
18 Zealand and we have the opportunity to find out. We can call it quits now
19 and deal with what we've got or given the amount of knowledge we have
20 acquired about this topic, given the information we have and given we have
21 a report date in 20 December, we can, as I said in Douglas & Pindling, be
22 vigilant and attempt to find out as much as possible and to identify as many
23 systemic issues as possible.

24 MR MURRAY: Well I don't want to take up too much time on this
25 because I believe my duty is to explain the Ministry's position, make
26 submissions that clarify issues if I can, I think to round off this first half of
27 my submission though we come down to the question of whether the inquiry
28 wants to do the four region study and if so, whether it wants to go to the
29 High Court and get information that is being withheld at present or whether
30 it agrees that we don't need to do that because the Ministry will do the

1 study. So then I would move on to the additional questions of law. And
2 really there I don't think I have much to add to the analysis that my friends
3 counsel assisting have advanced, I just say that if one was to argue for a
4 wide interpretation of Section 74A that may cut across and give us an
5 answer that says there is a wide regulation making power.

6 CHAIR: If I could just ask you to go to paragraph 10 of your submission,
7 you've said it's important to distinguish between the inquiry's responsibility
8 to inquire and report on the Ministry 's responsibility to evaluate. One of
9 the benefits of having the High Court determine whether or not you could
10 get access to information which 74A at present prohibits you doing so,
11 utilising the Committee of Inquiry powers, I'll use that phrase Committee of
12 Inquiry as a catch all to cover section 47 and 4C and D. It seems to me is to
13 answer term of reference, really I started with 8 because if you can carry out
14 an evaluation exercise using those powers, it's going to be for the benefit of
15 health services. It's not therefore saying the inquiry is seeing that the
16 evaluation is done, it's the inquiry attempting to find out whether or not at
17 the moment there is any legal impediment to a full evaluation being done.
18 The next point is when you look at term of reference 4 identifying changes
19 already made to legislation, it would be necessary to say well what is the
20 legislation at the moment. Is it legally possible to carry out an evaluation
21 and the answer from the High Court on the Committee of Inquiry powers
22 would answer that, then to look at other changes that would ameliorate risks
23 of under reporting. Now if the High Court says no you cannot use the
24 current Committee of Inquiry powers to get access to 74a material, that
25 would be a very clear statement and the Inquiry could then say you need to
26 change the law. And also given that the questions contemplated, involve
27 asking the High Court to rule on whether or not an evaluation is a study of
28 cancer, you would also know whether or not the proposals to ameliorate risk
29 of under reporting would be by regulation or whether you would need
30 primary legislation. So as I see it, it is not really a matter of the inquiry in a

1 sense forcing the evaluation but rather reporting to the Minister on the
2 current state of the law in terms of whether or not it allows an evaluation
3 exercise to be carried out. I've become very concerned having read the
4 agreement for services, this is a document entered into by the Crown and by
5 the University of Otago, its an agreement signed on 13th of May 1999, I
6 would have thought that both parties would have received legal advice.
7 When I look at the document the schedule to it sets out the services to be
8 provided under the agreement. At page 4, under methods, in the first
9 paragraph you will see there it is said that in an audit is a routine feature of
10 organised cervical screening programmes. The document then goes on 'in
11 New Zealand except for the special circumstances of the Cartwright Inquiry,
12 only two small studies have ever been done involving systematic review of
13 the cervical screening histories of women with invasive cervical cancer.
14 First one was by McLean and others in 1985, the second by Ratima and
15 others in 1993. McLean reviewed the screening history of 18 women who
16 had cervical cancer using medical records, Ratima obtained the screening
17 history of 46 Maori women with invasive cervical cancer diagnosed
18 between May 1989 and April 1991. So in a sense this document signed by
19 the Crown shows what little work has been done to date on this issue and it
20 seems that the work that has been done, the two small studies were done by
21 independent researchers. I just referred to this because it confirms that there
22 has been no thorough evaluation of this part of the programme. The next
23 point though is in the third paragraph down, the document says that women
24 with recent or new diagnosis of invasive cervical cancer may be identified
25 from the New Zealand Cancer Registry. It then says the registration of
26 cancer diagnoses is compulsive under the Cancer Registry Act. Then it says
27 this Act also sets guidelines for the release of data for research, ethical
28 approval for the approach outlined below would be required. Now I've
29 looked at the Cancer Registry Act, I haven't seen that, I don't know whether
30 I'm missing something or whether the parties who drafted this document are

1 missing something. Now you might like to address me on that point.

2 MR MURRAY: Well Madam Chair, I think this may be an inevitability of
3 where we're going and so if I can clarify some issues on the way, I will.
4 Just on that one, I think that it is important to distinguish between difficult
5 issues where a High Court judgement would be authoritative and issues
6 where actually with a bit of application of counsel, one can see a way
7 through. In the memorandum I just simply bracketed off the issues relating
8 to the Privacy act and Official Information Act as they apply to the Cancer
9 Registry because I think the ombudsman's ruling and your own writing on
10 that topic shouldn't leave us uninformed about what the law is.

11 CHAIR: One of the reasons why I keep harping back to the High Court
12 though is the Ministry has legal advisors and I'm am just dumbstruck at how
13 in a legal document for an evaluation when the document itself recognises
14 that there has not been a thorough systematic evaluation of cervical
15 screening histories for women with invasive cancer, that written into this
16 document could be something that is legally incorrect that has created one of
17 the major barriers to the audit being carried out. It's not a situation which as
18 I thought before that Dr Cox had applied for Ethics Committee approval, it's
19 a situation where the contract the Crown has entered into with Otago
20 University specifically contemplates Ethics Committee approval for getting
21 access to the Cancer Registry.

22 MR MURRAY: I think the agreement represents the Crown and the
23 researchers as coming together and just how that got in there of course I
24 don't know but it may well be the researcher's protocol and how they wish
25 to proceed. And the Ministry agreed to contract with them on that basis.

26 CHAIR: Well it's one thing for researchers to say we don't want to
27 proceed without Ethics Committee approval and that can be written into a
28 contract but to state it as if it is the law is quite misleading.

29 MR MURRAY: But in any event Madam Chair those are my submissions.

30 CHAIR: I want to ask you some more about this document because at the

1 end of the day whether or not these legal issues are resolved by the
2 Committee or whether we refer it to the High Court, depends really on the
3 degree of confidence we have and whether or not the Ministry fully
4 appreciates what the law is and is willing to listen to what we say the law is
5 or whether it needs a clear, strong indication from a body such as the High
6 Court which it will not be able to contradict. Because under Section 10 the
7 ruling of the High Court (inaudible). Now page 7, it is written into the
8 document again the second paragraph from the bottom, it is said subject to
9 Ethics Committee approval, a random sample of 300 women with HSI or
10 HSIL cytological lesions identified using the National Cervical Screening
11 Register would be surveyed. This incorporates the needs for Ethics
12 Committee approval and it incorporates using information from the
13 Screening Registers about identifiable women, which can't be done because
14 of 74A. So there is that problem with it. I then saw when I looked at the
15 protocol...

16 MR MURRAY: I think Madam Chair I just interpolate that these
17 documents of course were signed some time ago. One in May 99 and one in
18 December 99 and I understand that things have moved on and to be fair to
19 the inquiry of course the evidence about the detail of that has not all been
20 brought before the inquiry so I can't say whether some of these things have
21 been resolved but I understand they either have been or they're about to be.

22 CHAIR: Let me just say this, page 14 I discover under a title Problem
23 Anticipated, it says access to medical records may be denied where the
24 management of abnormalities has not been satisfactory. However advice
25 will be sought from Mr Ron Jones a gynaecologist at National Women's
26 Hospital who is an advisor to the investigation on how this may be best
27 overcome.

28 MR MURRAY: Yes I think that is Dr Cox's protocol.

29 CHAIR: Yes well I would have thought that if there was difficulty in
30 getting access to medical records because the clinicians were concerned that

1 their management of abnormalities was not satisfactory the best person to
2 tell you how to get information would be a lawyer rather than a
3 gynaecologist.

4 MR MURRAY: Also there's that provision in part 6 of the Medical
5 Practitioners Act which could be used.

6 CHAIR: Yes well that's referred to down the bottom and when I saw that
7 again, I thought that well if they're worried about these sort of problems,
8 again it brought home to me that if the Committee of Inquiry powers were
9 used you could cut right through to that, you could access to the
10 information. The other benefit of using Committee of Inquiry powers is that
11 so long as they're exercised in good faith, those who exercise them have an
12 immunity. So anyone who writes up a report, if in the course of that report
13 they are by acting in good faith are critical of anyone's management of any
14 patient they are protected, you don't have to worry about any litigation
15 flowing on from that. I mention these things because it just seemed to me
16 that the whole basis of this protocol in terms of the legal position had not
17 been clearly thought out at all.

18 MR MURRAY: Yes my friend Mrs Sholtens points out that some of the
19 issues that you have identified in here that resulted in legal opinions being
20 obtained so we've moved on I think quite a bit. What we should have done
21 I think, and my apologies that we didn't get this produced, when Ms Glackin
22 gave evidence right at the end of the inquiry, we put in the time sequence
23 Mrs Sholtens took. The panel may have taken Ms Glackin through the time
24 sequence and she referred to these documents and so probably we should
25 give them Glackin exhibit numbers just so we now know what we are
26 talking about.

27 CHAIR: Is everyone happy for them to be admitted by consent?

28 MR MURRAY: I think they are two separate documents so the agreement
29 is the first one in time and the protocol followed it in December so they
30 could be given the next two Glackin exhibit numbers in sequence.

1 TRACEY: So therefore the agreement will be JMG/MOH/108 so the
2 agreement is Glackin 108. The protocol will be JMG/MOH/109 so the
3 protocol becomes Glackin 109.

4 MR MURRAY: I think where we then end up Madam Chair in my
5 submission is that these things come down to a fine call and I think that why
6 counsel assisting and counsel for the Ministry and the HFA are making the
7 submissions that we are, is that some of these problems are more
8 fundamental in a High Court judgement. We accept that there is some value
9 particularly if the judgement came out one way, we'd save a month or two.
10 I think the concern is that the judgement may not come out in a way that
11 gives us the green light or may come out in a way that is an orange light and
12 the Ministry is therefore taking the stance that it should just go straight to
13 the Section 74 issues and deal with the policy issues in legislative reform.
14 It's not like a situation where we have private parties who are in a dilemma
15 and therefore the only way out is for a High Court judgement. Where we
16 are dealing with a Government, the government would not normally look to
17 litigation as a basis for law reform and if I can say on behalf of the Ministry,
18 the need for law reform is accepted, the inquiry's expertise on the basis of
19 the evidence and the legal expertise it has will be very valuable and the
20 outcome I am sure will be the one everyone wants. At the end of the day, it
21 is for the inquiry to determine whether it wishes to state a case or not.

22 CHAIR: Just help me here, you said that you accept there is a need for law
23 reform. It seems to me that if the Committee of Inquiry powers are
24 available to an evaluation audit team, there is no need for law reform
25 because they could be used. Now the fact that you have the power to
26 compel evidence doesn't mean you do it. This inquiry has issued two
27 subpoenas in all the time that it has sat, there is no need for an evaluation
28 team which has the powers of a Committee of Inquiry to go straight to
29 wielding what can be a blunt weapon. A protocol can be drawn up which
30 attempts to get the consent of women and if it gets the consent of a number

1 of women but not some, as long as it won't bias the study, it could go ahead
2 in that way. But it would have behind it the power to get that information if
3 need be. If the law allows for that situation at the moment it seems to me
4 that there is no need for law reform.

5 MR MURRAY: Two points, one is that Section 47 is about to disappear
6 so that we need to take account of the fact that there is law change anyway
7 and I for one don't know whether Section 47 will be re-enacted in a
8 different guise or not. I don't have the bill with me and whatever is in the
9 bill is subject to select Committee deliberations anyway. Secondly, I think
10 the Ministry has to be mindful to the concerns of using coercive powers to
11 obtain confidential medical information from women. Certainly there is a
12 balance to be struck and I know the inquiry is suggesting that that debate
13 can be had prior to the powers being exercised. But the Ministry has a real
14 concern not to use coercive powers when a statute properly informed by
15 people such as Ms Coney and the Cancer Society will strike the balance.
16 And there is a real danger of leaving our small band of expert advisors in a
17 difficulty if we're looking to them to exercise coercive powers to get
18 information. So that I know that the Ministry's position is not to persuade
19 you to go down the High Court route if that is the driving concern.

20 CHAIR: In order to overcome the problem 74A currently presents, you
21 would need to put in place a law change which removed the protection
22 either completely or in some way so that the overall impact would be much
23 the same as the exercise of a coercive power. In the sense that whether you
24 would use coercive power to access information or whether you remove the
25 legal protection making that information inaccessible, the outcome is still
26 the same, the information becomes accessible.

27 MR MURRAY: The inquiry itself has suggested a way through that, it's a
28 combination of things. Section 74 seems to have emphasised
29 confidentiality. In 1993 it seems the post Cartwright principles were
30 foremost in everyone's mind, confidentiality was part of the bargain for

1 persuading people to go on the Register. I think now we're realising that
2 confidentiality may have been taken too far, the women who sign up to the
3 programme from now on or from when legislative reform can be put in
4 place, probably need to realise that with all the information that is given out,
5 that they sign up with the knowledge that evaluations of the programme are
6 part in parcel of the value of the programme. So you tackle it at the front
7 with educating women about the programme in the legislative machinery
8 that you have in place. And you tackle it at the other end by making sure
9 that the powers reflect the promises and in my submission, its that balancing
10 that has to be done by legislation and that a court is not equipped to do that.
11 We're just most reluctant to get into the legalities first, we'd rather get into
12 that informed policy debate and get the outcome right.

13 CHAIR: You say that you think the fundamental policy issue should be
14 addressed before legal clarity can be sought. The solution I suggest is that
15 you find out where you stand legally and then you address the policy issue.
16 In other words, you find out if you have the power or not, then you decide
17 whether or not you want to use it. And it seems to me for example, whether
18 or not the High Court finds you have that power, if you have it, you actually
19 have it. Not only do you have it, but just thinking in an imaginative way we
20 now know that there has been no evaluation study, there has been an attempt
21 to get one going for some time. If someone like Mr Kirton's trust were to
22 go along to the High Court with an affidavit setting out the past history and
23 saying there is the power to make this evaluation team a Committee of
24 Inquiry under Section 47, that way it would get access to information which
25 would allow a much needed evaluation to go ahead. We have asked the
26 Minister to do it, she has refused to exercise her statutory powers in this
27 way, she is acting unreasonably, please set her decision aside and make a
28 declaration that she should exercise her powers to set up a Ministerial
29 inquiry. Now if that should happen to you and I am just painting a scenario,
30 and if the law is as I think it is that you can Committee of Inquiry powers

1 now to get the evaluation study, that is how the Court will see the matter.
2 Whether it decides the Minister is acting unreasonably or not is another
3 matter but what I am saying is that by not going to Court and not getting an
4 answer, doesn't mean the law doesn't exist, the law is always there, it's just
5 the High Court judgement throws light on it because at the moment, it isn't
6 illuminated for us.

7 MR MURRAY: The study may well go ahead and make all this irrelevant
8 in the next few weeks and I am not unsympathetic to the inquiry's position
9 because the inquiry doesn't know what work is being done outside the
10 inquiry. So we run into this timing issue - do we go out and brief evidence
11 and bring it into the inquiry or do we try and persuade the inquiry that it is
12 being done and we'd be grateful to just get on with the inquiry work and get
13 the report. That's a judgement call, at the end of the day, the inquiry panel
14 has to make.

15 CHAIR: Mr Corkill made the point, he said he wanted to see hard
16 evidence that there had been a change today. If the inquiry were to refer the
17 matter to the High Court obviously I'd think it would probably take three to
18 four weeks to get a High Court hearing. Now it may be by the time the
19 matter comes on to be heard just as many cases settle at the courtroom door
20 the Ministry could at that point be able to point to significant changes in
21 terms of proposed regulations being drawn up because it has formed a clear
22 view that an evaluation is a study of cancer. It may well have prepared a bill
23 to change 74A, I don't know what else it may have done. The new bill to
24 cover the new health restructuring may suddenly contain a provision which
25 will tidy this matter up but if it seemed that there was a move in that
26 direction that made any decision by the High Court redundant then the
27 application could be abandoned, there is no point in going off to the High
28 Court to have it rule on the current affect of 47 coupled with 4C and D of
29 the Commissions of Inquiry Act if there is legislative change about to
30 happen. But at the moment there isn't anything, you haven't produced a bill

1 for example which shows there is going to be change. All there is talk about
2 is the need to debate what seems to be a very difficult, philosophical issue
3 and it's one thing to debate a philosophical issue when you don't know the
4 law. I think often philosophical issues are more readily understood when
5 you've got as much certainty as you can around you and in that sense the
6 philosophical issues might be better understood if you know what the law is.
7 So if you know that you can go ahead and do something such as carrying out
8 an evaluation without getting consent, if consent is not available and the
9 study is essential for the health of the women in New Zealand, you are in a
10 better position to decide what the moral imperative is. Do you still hold out
11 to protect the individual's privacy or do you say this matter is so important
12 for the health of the women of New Zealand that we do have a coercive
13 power and although the exercise of coercive powers and principle are
14 repugnant to us, it is so important here to avoid more women dying of
15 cancer that we will exercise the coercive power. They are the sort of moral
16 arguments you can have with yourself if you know you have got a coercive
17 power. At the moment you don't even know whether you have it or not.

18 MR MURRAY: I think all of us have probably taken it to the point where
19 the inquiry has to just make a call on this and I feel that I've put the
20 Ministry's position, I've tried to clarify some issues.

21 CHAIR: Dr Duggan was actually just saying she would like to see a draft
22 protocol for the four regions.

23 MR MURRAY: So would we.

24 CHAIR: You haven't seen one?

25 MR MURRAY: No.

26 PROFESSOR DUGGAN: You just mentioned it.

27 MR MURRAY: Dr Cox said he had one, a virtual protocol as far as we're
28 concerned. I wasn't at the meeting and my friend, Mr Hindle, can probably
29 present Dr Cox's position more fairly than I can. All I know is that some
30 work had been done on one but it wasn't tabled at the meeting and I think

1 my friend can clarify it beyond that.

2 CHAIR: Thank you very much Mr Murray. You don't want to be heard
3 on anything else I take it?

4 MR MURRAY: Yes I understand he told the Ministry that a draft protocol
5 had been prepared and would be circulated before the Thursday meeting but
6 we didn't see it at the meeting is my understanding. Mr Hindle may have
7 seen it, I don't know.

8 CHAIR: Well the Committee would like to express its appreciation to you
9 and Mrs Sholtens for bringing these documents forward and for the
10 assistance you've given us. Ms Gibson we haven't heard from you, do you
11 have any submissions?

12 MS GIBSON: Thank you Ma'am for the opportunity, no I have no
13 submissions in this matter and others have covered it far more accurately
14 than I could.

15 CHAIR: In terms of the Minister's letter that has been circulated, does
16 anyone have any comment to make on that? Yes Mrs Marshall?

17 MRS MARSHALL: I don't have a comment on that but when it's
18 appropriate, I do have a response to the question that was posed to me this
19 morning. I have taken instruction on the matter that you raised this morning
20 with regard to the National Audit. The Cancer Society's position is that in
21 light of the absence of evaluation of the programme during the past ten
22 years, the Cancer Society would support a national audit based on the case
23 notes and slides which does not require consent of individual women. At
24 the same time, the Society would support the need for public debate as soon
25 as possible regarding a way in which such audits are to be undertaken in
26 future.

27 CHAIR: Thank you Mrs Marshall. We will reserve our decision, what we
28 will do is retire now. I don't want to waste time but I also think this is a
29 very important issue and people should get an answer as soon as possible so
30 it's best that we discuss the matter now. If we are able to be back by 4/4.15,

1 we'll give you word through the Registrar otherwise we'll adjourn until
2 tomorrow morning. Mr Kirton, I hope you're not going to be too
3 inconvenienced, I'm aware that you haven't completed your submissions.

4 MR KIRTON: I'm greatly relieved Madam Chair.

5 CHAIR: Very well, we'll adjourn.

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INQUIRY RETIRES UNTIL 10.00 AM

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TUESDAY 26 SEPTEMBER 2000

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