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Introduction

The focus of this submission will be on recommendations for the future of the National Cervical Screening Programme. The five areas we will cover are:
?? Location of the National Cervical Screening Programme
?? Monitoring and evaluation of the NCSP
?? Health consumers' rights
?? Laboratories
?? Implementation of recommendations.

Location of the National Cervical Screening Programme

Health Reforms

1. One of the themes of much of the evidence that has been put before this Inquiry has been the fragmentation and dilution of accountability that has occurred in the National Cervical Screening Programme (NCSP) over the last ten years.

2. A number of witnesses, including the Director of Women's Health Action, expressed concern about the imminent potential for fragmentation that could occur with the establishment of 21 District Health Boards under the New Zealand Public Health and Disability Bill. These Boards will also each have three committees which can have delegated authority.

3. The Inquiry heard evidence about how the Board of the Tairawhiti CHE did not support the local Cervical Screening Programme. The Inquiry has also heard that at times colposcopy waiting lists varied greatly between CHEs/HHSs and that the practice of contracting has led to fragmentation within local programmes where different elements of the programmes have been contracted to different providers eg. health promotion activities separated from the NCSP register.

4. Another theme of this Inquiry has been the widespread lack of understanding about screening programmes that existed even amongst senior officials of the Ministry of Health.

5. It is highly unlikely that the expertise necessary to understand and run screening programmes will exist in all 21 boards and the board's committees. There are only a limited number of public health specialists and epidemiologists in New Zealand. The history of the National Cervical Screening Programme shows that many GPs have consistently misunderstood what successful screening programmes involve. The District Health Board model will enhance the power of GPs. GPs organised into Primary Care Organisations (PCOs) are being seen as the key providers of health prevention programmes.

6. We urge the Committee to recommend:

?? Strong national leadership to steer the screening programmes through this transition into the future

?? That the artificial distinction between personal and public health services be removed by bringing all aspects of the NCSP together under one agency

?? That critical elements of the cervical screening programme remain under national control and are not delegated to District Health Boards

?? That contracts between the Minister of Health and District Health Boards include the requirement that Boards must deliver nationally consistent services that meet the standards set by the National Cervical Screening Programme

?? That the performance of District Health Boards is closely monitored nationally to ensure that deviation from the policy and standards of the National Cervical Screening Programme do not occur.

?? The need for different elements of screening programmes to be brought together wherever possible

?? The need for a cancer control agency as a matter or urgency to provide a nationally consistent programme that can survive the devolution to District Health Boards.

Cancer Control Agency

7. Women's Health Action strongly supports the establishment of a national cancer control agency to provide a systematic and co-ordinated approach to cancer in New Zealand. A Trustee of Women's Health Action is the consumer representative on the Cancer Control Working Party and we took part in the National Cancer Control Workshop in August 1999.

8. We have seen the evidence of Dr Karen Poutasi, Director-General of Health, who states that the Government intends to establish a cancer control agency.

9. At the National Cancer Control Workshop held last year, participants unanimously supported the establishment of a cancer control secretariat involving a consortium of agencies. This followed a presentation to the Workshop by Dr Poutasi in which she made clear that the Ministry did not see the need for this initiative. As a result, Workshop participants were very clear that the agency should not be located within the Ministry of Health or any other government agency.

10. Even if Ministry officials have had a complete change of heart and are now expressing support for cancer control in line with Labour 's election manifesto (which specifically states support for cancer control) we would not find this reassuring. The history of the NCSP and the Ministry's relationship with it requires that the future involvement of the Ministry of Health be treated with caution.

11. We believe it is appropriate for the Ministry of Health to be involved in a cancer control agency as one of a number of agencies. Other agencies that should also be

involved would include the Cancer Society, universities, community and NGO organisations with an interest in cancer and health professional groups whose membership is represented in areas of cancer prevention, treatment and palliative care.

12. The advantages of such an independent agency are to:

?? Provide a central office and focal point for cancer control activities in line with the approach recommended by the WHO
?? Provide stability for cancer control initiatives such as screening programmes
?? Provide a neutral, non-political environment for cancer control that is not subject to the vagaries of political change and prioritisation that occur within government agencies
?? Provide co-ordination of cancer control activities
?? Provide leadership and direction in reducing the burden of cancer in New Zealand
?? Bring together expertise in cancer control activities
?? Provide a national focus on cancer
?? Foster research into cancer
?? Provide a location for the Cancer Registry and other registers that specifically collect cancer data
?? Provide a base for initiatives in cancer control such as the National Cervical Screening Programme and BreastScreen Aotearoa
?? Undertake monitoring and evaluation of programmes and cancer control in New Zealand
?? Develop guidelines and protocols relevant to the spectrum of cancer control activities (including prevention, information, education, screening, diagnostics/detection, treatment, rehabilitation, palliative care)
?? Develop policy and quality standards relevant to the spectrum of cancer control activities.

13. We urge the Committee to recommend, as a matter of urgency, the establishment of an independent cancer control agency, adopting a consortium approach, and, further, to recommend that both the National Cervical Screening Programme and BreastScreen Aotearoa be located within the agency. The agency would hold funding for both the existing screening programmes.

14. In our earlier evidence, Women's Health Action supported the retention and strengthening of the Health Funding Authority Prevention Team led by Dr Julia Peters. It is our view that this team, augmented with expertise in epidemiology and other relevant areas and adequately staffed and resourced, be transferred to the cancer control agency. This does not mean that it needs to be physically transferred from Auckland, and to do so would undoubtedly weaken the existing Prevention Team. We believe that it is essential that the Prevention Team be retained as we think that the National Cervical Screening Programme would have difficulty surviving more changes in key personnel and further restructuring. The programmes would be strengthened by access to a range of expertise and by the collegiality that would be provided by the agency.

15. We also support that there be separate national co-ordinators for cervical and breast screening, rather than the two positions rolled into one as at present.

16. We would also wish to highlight the need for acknowledgement and support for the managers and co-ordinators of the regional programmes of the NCSP. It is probably true to say that this Inquiry has focused largely on national aspects of the programme. It is regrettable that the Inquiry did not hear evidence from the regional programmes as they have provided much of the backbone and cohesion of the programme during the restructuring that has occurred over the last decade. We wish to draw attention to the submission from all the Regional Programmes of the National Cervical Screening Programme, which is contained in the public submissions. This submission contains a great deal of important information for this Inquiry which we will be referring to in this submission.

17. It is of concern that the programme managers feel that the involvement of the HFA personnel in operational aspects of the programme has led to confused lines of authority and communication and has diminished the role of local programmes. They report that this has led to a loss of morale and the apparent dismissal of the institutional knowledge held regionally.

18. We invite the Committee to make recommendations that the HFA improve relationships with programme managers where necessary. The programme needs clear lines of accountability but the expertise and commitment of the regional programme personnel must be supported.

Monitoring and Evaluation of the NCSP

Monitoring

19. This Inquiry has heard that statistical reports were prepared but that these were sometimes extremely late and that they were not prepared annually.

20. We believe that monitoring of the NCSP must be carried out regularly and that reports must be available in a timely fashion.

21. The Breast Screening Programme has an Independent Monitoring Group that prepares three-monthly reports. We urge the Committee to recommend the establishment of such a group for the National Cervical Screening Programme.

22. It is also critical that the HFA or whoever is leading the programme acts on these reports in a speedy fashion and has the authority to require particular actions and ensure that these are carried out. It is no use producing reports if they are not acted on and used for continuous improvement of the programme.

23. There are also a number of areas for improvement in aspects of monitoring that are referred to in the submission of the regional programme managers and these need to be addressed. Regional programme managers play a key role in continuing quality improvement at a regional level.

Evaluation

24. Women's Health Action strongly recommends that the Committee order the complete implementation of the 1997 Draft Evaluation Plan for the National Cervical Screening Programme written by Dr Brian Cox and Dr Ann Richardson. This includes specific sections for Maori and Pacific women. We strongly support the recommendation that Maori women are involved in the evaluation of Maori aspects of the programme and that Pacific women are involved in the Pacific aspects of the programme.

25. We support the complete evaluation as we feel that after more than a decade this is extremely overdue and women need the reassurance that all elements of the programme are working properly. It was clear from the evidence of women affected by the under-reporting in Gisborne that despite having participated in the programme in the recommended manner, the programme had failed the women at a number of points along the screening pathway, not just in laboratory smear-reading. It was also clear that a number of the women did not fully understand the purpose of cervical screening and the meaning of an abnormal smear.

26. For these reasons, Women's Health Action would like to see the evaluation widened to include an evaluation of the informed consent aspects of the screening programme. The significance of informed consent to screening has been highlighted by the Inquiry and the necessity for this would not have been as apparent in 1997 when the draft plan was drawn up. In particular, we would like to see the evaluation include compliance by smear-takers with the requirements of the 'opt off ' legislation.

Ethics Committees

27. Evidence to this Inquiry has revealed a number of problems with how Ethics Committees approach the evaluation needs of the National Cervical Screening Programmes.

28. Regional Ethics Committees have not been well supported since their establishment following the Cartwright Report. In our earlier evidence we detailed a number of concerns about Ethics Committees including the lack of mandatory, nationally-consistent training for committee members, the failure to evaluate their performance and the lack of a National Ethics Committee to provide leadership, direction and advice to the various committees. There are also problematic issues and matters of

national importance that are not appropriate for referral to a regional ethics committee.

29. Decisions of particular Ethics Committees have been criticised during this Inquiry, however, there is a lack of evidence as to how widespread these problems are. We consider the lack of an appropriate national structure and support system for the committees has compromised the work of Ethics Committees and the subsequent problems that have arisen are symptoms of this.

30. We would not wish to see criticism of Ethics Committees lead to their disbandment or to substantial changes being made to their composition. We would not like to see changes made that allowed researchers or those conducting evaluations to avoid gaining ethical review and approval for their projects. In our evidence we did support the need for epidemiological expertise to be represented on the committees.

31. It is our submission that the committees need greater support and development. The committees exist to protect research participants and potential participants and the public interest. It is most important that this role be supported and enhanced.

32. For some time we have also advocated the establishment of an independent National Ethics Committee to hear complaints from researchers or members of the public, review multi-centre trials and other trials of national significance, and to review any ethics matters referred to it (eg ethics of health sector changes, such as the booking system). Meetings of this committee (along with all other ethics committees) should be open to the public as a form of accountability.

33. It is currently not clear where Ethics Committees will be positioned in the reformed health system. The recently introduced New Zealand Public Health and Disability Bill provides for the Minister of Health to establish a National Ethics Committee or to use the Health Research Council Ethics Committee for this purpose. We do not support either of these proposals. Previous experience is that the Minister of Health controlled the National Ethics Committee to its detriment, while the HRC Ethics Committee is too closely tied to the research community.

34. In our evidence we supported the establishment of a National Ethics Committee in the office of the Health and Disability Commissioner and this committee could provide oversight of Regional Ethics Committees. We understand the Commissioner has some concerns about this, with regard to the possibility that he would be seen to be approving research and that at some point he may have to review such a decision. However, similar issues were raised about health advocates when the Health and Disability Commissioner Act was passed and these were resolved within the legislation. We believe it is possible for the ethical review process to be set up and operate effectively under the umbrella of the Office of the Health and Disability Commissioner in such a way as would answer the issues raised by the Commissioner. Situating ethics committees under the Commission's umbrella would be helpful in emphasising the focus on people's rights.

35. We have recently learned that a discussion paper about future placement of ethics committees has been given by the Ministry of Health to ethics committees for comment. Although we have not seen this, we understand this proposes only three locations: committees contracted to the Ministry of Health; sub-committees of the Minister of Health; or contracted to district health boards.

36. We are seriously concerned at the proposal for a contracting structure as this is inappropriate in the ethics area. Ethics committees should fit within a network with national oversight from a National Ethics Committee. There is a need for clear lines of accountability and responsibility and for a model of open scrutiny of performance, regular evaluation and continuous improvement.

37. We are also critical of the failure to include consumer and community groups such as our own in this process so far. A more open process is needed than simply a dialogue among committees. The evidence put before this Inquiry demonstrates the need for more public scrutiny of committees.

38. We ask that the Committee recommends a review of the location of the National Ethics Committee and regional Ethics Committees, and that this review includes the Office of the Health and Disability Commissioner. Such a study to include consultation with community organisations, Maori and Pacific Islands groups, existing Ethics Committees, researchers and other relevant agencies.

39. We ask the Committee to recommend that an evaluation of the performance of Ethics Committees be carried out to help identify areas requiring support. Such an evaluation to include how well committees protect the interests of research participants (and potential participants), the consistency of decision-making nationally, whether research subjects are provided with sufficient information to give informed consent and researchers' experiences with committees. We also ask the Committee to recommend the need for a fully funded nationally consistent training programme for members of Ethics Committees.

Audits

40. This Inquiry has devoted a great deal of attention to the difference between audit and research. To a large degree we believe this distinction is academic, and that most forms of audit and research should be submitted for ethical review. Ethical review should strengthen rather than weaken audit activities. Ethical review provides an independent review of audit activities to ensure that the rights of participants and their health information is protected. It would be regrettable if the current difficulties, some of which are caused by legislative problems, lead to recommendations that researchers do not need to gain ethical approval for their activities.

41. We believe that audits that involve personnel or agencies external to an institution/facility should seek ethical review if it requires access to identified personal health information.

42. We would argue that any external audit that requires contacting patients or looking at medical records obtain ethical scrutiny and approval.

43. We also believe that audits that involve a clinical risk situation always require ethical approval.

44. We agree there is a lack of clarity about when this is required in the National Standard for Ethics Committees and this has previously resulted in institutions taking differing positions with regard to the need for ethical review.

45. For instance, we have been involved in a review of dysplasia cases at National Women's Hospital. This was ordered by Dame Silvia Cartwright in the Report of the Cervical Cancer Inquiry in 1988 but not carried out until recently. In this case, initial work to audit the cases was taken to the Auckland Ethics Committee for approval and this was given. The only people having access to files in this instance were staff of NWH, but there was a possibility that failures of services could have been revealed and women recalled. In this cases, some women have been contacted as part of the review.

46. On the other hand, the NWH Neonatal Intensive Care Unit (NICU) did not seek ethical approval when it carried out an audit of cases of unusual brain lesions (encephaloclastic porencephaly) in babies in NICU. We were critical of this failure at the Cull Inquiry as a situation of risk existed, cases of babies with encephaloclastic porencephaly were added to the study as these occurred, the parents were readily available for consent purposes and the results of the audit were subsequently published in a medical journal.

47. We argued the audit was actually research and that this was confirmed by its subsequent publication.

48. The evidence of Prof Skegg and Dr Cox revealed problems they were experiencing with ethics committees in carrying out audits. We do not think that these difficulties should be used to argue that ethical approval is not required or that the current standard does not require it. We completely support the work which they wish to carry out. The difficulties they are experiencing have complex causes, including, the urgency now surrounding the need for evaluation (these problems could have been resolved many years ago had an evaluation been initiated earlier), ambiguities surrounding access to the Cancer Registry and the NCSP Register, and the understandings and difficulties of ethics committees.

49. We understand that the Gisborne audit and the national evaluation involved looking at personal health information held by a number of agencies. In the case of the NCSP

Register and the Cancer Registry we believe that those auditing the programme should have access to this information without the need for individual consent to be sought, as it is part of the infrastructure that supports the programme and this was a programme evaluation. Women were also told that the programme would be evaluated as part of its quality features. For this reason we do not have a problem with the researchers' knowing the names of the women with cancer or who their smear-taker was. We do not think it is useful or appropriate for the Cancer Registry to write to people. Most people will not know their information is held on the Cancer Registry in the first place, so that this communication will be confusing and possibly worrying.

50. We support the proposal of the researchers that where they wish to contact women that they go to women's GPs and smear-takers in the first instance, as these people are known to the women and are in a better position to judge how to approach individual women.

51. We have difficulty with the concept that researchers can look at personal health information held by GPs without women's knowledge or consent. These records contain a good deal of health information not related to the women's smears or treatment. One way around this, especially in the urgent context of the Gisborne Inquiry, would be for GPs to provide only information relevant to smear tests and cervical cancer, so that extraneous personal information is kept private. Drawbacks of this approach is that it requires smear-takers to be able to judge what is relevant, and that it might allow them to omit information that demonstrates some deficiency in their own or a colleague's management of the case.

52. It has been suggested that as women were told that a purpose of the register was to evaluate and monitor the programme, their decision not to 'opt off' could be taken as general consent to evaluators accessing whatever records they need for evaluation. We do not agree with this approach. The concept of 'general consent' has generally been frowned on in any review of informed consent in New Zealand. It is also not consistent with the Code of Rights or Privacy Act which require that consumers be told who holds information about them, who will access it and for what purposes.

53. When women decide not to 'opt off', they agree to the transfer of their information from laboratories to the NCSP register, not to researchers being able to access records held by GPs, or records held by hospitals who treated them. These records are outside the programme. This approach would also not cover women who have 'opted off' or women who have not had smears since the legislation was passed.

54. We do not support a process which would require women to agree to access of the information held about them on the Cancer Registry (in the event they could have cancer) when they have smear. Tens of thousands of New Zealand women have a smear every year, but only a very small number will have their names entered on the Cancer Registry. It would be a waste of time and effort to inform all women having smears of something only a few will face. We also doubt that GPs would take the

time to discuss this properly and it may have the effect of more women 'opting off' or GP opting them off without discussion. We would also worry about the introduction of a discussion along the lines of 'if you get cancer' with women having a smear, when the programme has been at pains to reinforce that a smear is a test for abnormal cell changes that are not cancer.

55. As we stated in our evidence, we would support legislation, if it is needed, that provided access to the NCSP Register and Cancer Registry and the ability to match information from the two registers for the purposes of the evaluation of the NCSP. We had thought these functions were already covered by previous legislation.

56. In our evidence we emphasised the need for widespread public debate and consultation with women's organisations before finalising a process for facilitating access to information for evaluating the NCSP. We have gathered up various versions of consumer resources used by the NCSP and are providing these to the Inquiry. These are not necessarily complete, but they show that women have consistently been told their information on the register is confidential.

57. This failure to inform women of the uses to which their information might be put, reinforces are argument, that women must now be informed and be given the opportunity to take part in any discussions about change. If this does not occur, and women object to what happens, this would be enormously damaging to the programme. We appreciate the need for a different approach in the short-term to meet the needs of this Committee to address its terms of reference.

58. We would also advocate the need to inform women whose names are entered on the Cancer Registry that this is occuring and what this means. People diagnosed with abnormalities or cancer could be told at the time about what will happen with their information, and informed about the possibility they might be contacted for evaluation purposes at some time in the future. We suspect that the vast majority of women would be happy to know that their experience is used for improvements in the programme.

59. While we appreciate the reluctance to overburden people newly diagnosed with cervical abnormalities or cancer with information, there is a legal obligation under the Privacy Act to inform them, and if written information is provided, this can be read by people at a later date.

60. It is astonishing and unacceptable that this does not already occur. We strongly advocate that the Inquiry Committee recommends

?? A protocol is established for informing people whose information is recorded on the Cancer Registry that this is occuring and who can access it

?? Information resources are developed in English and other languages that can be given to people whose information is passed to the Cancer Registry.

61. There is a need for greater clarity and guidance for those providing health services as to when ethical approval for their activities should be sought.

Health Consumers' Rights

Informed Consent

62. In the past there has been a lack of understanding of the requirement of informed consent to participation in screening programmes. The need to achieve a target of screening coverage has led to what we described in our earlier submission as an 'uptake mentality' where women were 'recruited' to take part and not offered a fully informed choice. One of the lessons of this Inquiry is that screening programmes can cause harm unless they are well organised. This Inquiry highlights the need to ensure women freely choose to take part with full awareness of both the potential benefits as well as the limitations of screening.

63. In our submission we said that we did not believe that informed consent to screening was routinely and adequately gained from women in New Zealand health services. We argued that there was a need for a guideline on informed consent to screening similar to that issued by the General Medical Council in the UK. We described how we had discussed this with the Health and Disability Commissioner and the Ministry of Health and how this matter has been raised this with the Medical Council of New Zealand. The Health Commissioner is considering the question as to how he might facilitate this.

64. As a result of this approach, we were recently invited to contribute to a review of the Medical Council of New Zealand's guidelines on informed consent. In our submission to the Council we asked them to include specific provisions on informed consent to screening. We specifically recommended the approach used by the UK General Medical Council. At this stage we do not know whether they have accepted this.

65. As there is generally not a good understanding of how informed consent to screening differs from normal consent, we believe we may have some difficulty gaining acceptance of the need for specific guidelines. It would be helpful if the Committee were to recommend the need for specific guidelines or regulations on informed consent to screening.

Women's Information Needs

66. The Committee was provided by the HFA with a copy of the report which was prepared by Women's Health Action as an HFA commissioned report for the National Cervical Screening Programme. The report makes a number of recommendations (pages 6-10

[attached]) which we hope that the Committee will support. This report also provided criteria for resources and key messages which are currently being consulted on.

67. The resources for the National Cervical Screening Programme are in the process of being redeveloped. The final set of core national resources will provide consistent, evidence-based information for women about cervical screening and the programme.

68. We would like to stress the need for the programme to adopt an approach that enables consumers to make informed decisions about participation in cervical screening. Resources need to disclose women's risk of cervical cancer, the reduction in risk to be gained through screening, the risks involved in screening and the limitations of screening, including false positives and false negatives. Information given to women to enable them to decide about participation in screening should describe the whole screening pathway.

Consumer representation and consultation

69. The history of the NCSP is one of progressive exclusion of the consumer voice.

70. We argued in our evidence that this marginalisation has had a detrimental effect in that it led to a loss of knowledge among women's groups and diminished their ability to advocate for women's interests. We proposed that women may be prepared to use strategies to hold health services accountable which health professionals and managers are reluctant to use.

71. The perfect example of this was the reluctance of the authors of the 1984 paper to make their concerns public, so that no action ensued until Phillida Bunkle and I took action in 1987.

72. Currently there is one consumer representative on the HFA Advisory Committee on Population-Based Screening Programmes and all members of the group are bound by a confidentiality contract. Women's Health Action currently has a contract with the HFA to establish a Consumer Reference Group in breast and cervical screening to act as a voice for women consumers, provide support and accountability for consumer representatives and make recommendations to the HFA.

73. We ask the Committee to support the following recommendations that we believe would strengthen the consumer voice:

?? There should be at least two consumer representatives on the HFA Advisory Group
?? There should not be a blanket requirement for confidentiality, but this could apply to particular matters where there is a justification for it
?? The principle of including more than one consumer on all advisory committees should be actioned

?? A newsletter for the programme (or cervical and breast combined) should be instituted as a way of informing women's organisations and other interested people about progress in the programmes (The regular NCSP newsletter produced for many years was extremely well received until it was discontinued. This has been identified by women's groups and those working within the NCSP as a real loss as the information provided and the networking generated was welcomed,)
?? The same information could also be available through a programme web site.

Laboratories

74. Currently 17 community laboratories provide cytology services for the National Cervical Screening Programme. The draft NCSP Quality Standards for laboratories require that they read a minimum of 10,000 smears a year. (We understand this number may recently have been raised). A number of cytology laboratories in the programme do not have this volume. This Inquiry has also heard that despite IANZ's accreditation, practices vary in laboratories. Dr Brian Linehan gave evidence that Med Lab Hamilton did not routinely retrieve the women's former smears of Gisborne women when abnormalities were detected.

75. We do not favour the retention of a large number of laboratories providing smear-reading services for the programme. We believe there is a danger that small provincial laboratories will deviate from accepted practice without this being detected. We favour the use of one or a small number of large laboratories to be used in the screening programme. We have not seen any evidence put to this Inquiry that stated that this was undesirable or not possible. We ask the Committee to recommend that the HFA review the community cytology needs of the NCSP with a view to reducing the number of laboratories used to one or a small number.

76. We also favour public ownership of such laboratories. Our reasons are that we have concerns that the competitive orientation of some private laboratories means that they push the boundaries to enhance their competitiveness. Evidence to this Inquiry has demonstrated this. The evidence of Jim Du Rose of the HFA on the Review of Cervical Cytology Practice in New Zealand Community Laboratories provides examples. One community laboratory has a high usage of ThinPrep smears even though this technology has not been studied in the New Zealand environment, and it pushed down the low-grade reporting rate without monitoring whether this was safe and effective. Dr Linehan purchased the assets but not liability of Dr Bottrill's laboratory, so that seems to have justified the practice of not reading Gisborne women's smears against their previous smears.

77. The HFA Review of Cervical Cytology Practice in New Zealand Community Laboratories measured performance against a number of benchmarks. The review did not audit a number of other features of performance, such as the provision of

information to the NCSP regional programmes or performance in responding to the requirements of the programme.

78. The submission from the Regional Programme Managers details a number of problems in existing relationships between laboratories and the NCSP. It notes the variable degree of co-operation that exists between individual laboratories and NCSP local sites. While most are described as good, some laboratories have not co-operated with the NCSP and have disregarded the 1993 amendment to the 1956 Health Act. The impact of this is that NCSP data is incomplete and the programme in some areas is unable to fulfil its back-up function adequately. Missing results mean that women are given incorrect information. They note a lack of monitoring of laboratories' responsibilities and a lack of timely, effective and consistent service from some laboratories which has compromised the ability of the programme to adequately fulfil it's functions. The submission emphasised that the programme can play an important role in assisting laboratories to provide quality services. But some laboratories do not take advantage of this. For example some laboratories do not ask for previous smear histories to assist with smear interpretation, a requirement in the Victoria and British Columbia cervical screening programmes which are both regarded as leaders in the field.

79. The submission also notes that there is no requirement for the programme to be informed of the performance of laboratories in quality assurance programmes. Local programmes state that although the National Cervical Screening Register produces reports comparing labs, these have not been given to local programmes.

80. It states there is currently no official effective pathway for issues of laboratory non-compliance or laboratory data quality concerns to be to be raised by the NCSP and rectified. It says that the effect of inadequate services provided by some laboratories to the NCSP downgrades the ability of regional offices to adhere to national policy and undermines the quality of service the NCSP offers women. The Regional Programme Managers note that many of these issues have been raised nationally. It is not clear whether these are breaches of contractual arrangements with the HFA, and if they are, what steps the HFA has taken to enforce adherence.

81. It is our submission that these problems reinforce our recommendation that there be one or a limited number of cytology laboratories serving the NCSP. The issues of communication and the authority of the programme to require adherence to its requirements must be addressed in the recommendations of the Committee.

Implementation of Committee recommendations

82. The Cartwright Report made a series of very important recommendations for the establishment of the National Cervical Programmes and reforms in ethics and patients

rights. It has proved very difficult to see these implemented, particularly in the form that was put forward by Dame Silvia Cartwright.

83. Women's Health Action (and other individuals and groups) has spent 12 years supporting and advocating for the implementation of the recommendations. There are a number of reasons why this proved difficult and these are outlined in the chapter 'Unfinished Bus iness the Cartwright Report five years' on which is contained in the book which we produced as Exhibit 11 of our evidence. This chapter details three major factors in the problems implementing the Cartwright recommendations:
- ?? Problems in responsibility for implementing inquiries
- ?? Resistance to the Cartwright recommendations
- ?? Political changes, in particular the change of government and National's restructuring plans.

84. This chapter makes a statement that is relevant to this Inquiry:

> '[O]ne of the problems about committees of Inquiry or Royal Commissions which are established by governments to investigate problems is the lack of any formal requirements for action or specified process of implementation. It is up to the politicians and policy makers whether recommendations are implemented, and how they will be implemented. The person or persons who heard the original, submissions and evidence have no ongoing responsibility or power to see that change occurs. Their job is simply to investigate and recommend. This leaves the way open for action not to take place, or for modifications to occur which minimise the impact of changes, or even for re-capture by the people who were the cause of the problem in the first place.'

85. It is essential that this Committee recommends a process for overseeing the implementation of its recommendations and names who is responsible for implementation of specific recommendations.

86. There are a number of options for such follow-up:
- ?? This Committee to reconvene at specific intervals to measure progress in the implementation and to seek submissions from interested parties as to the progress being made.
- ?? An independent monitoring group could be established to oversee the implementation and to report to the Minister of Health on how well this is progressing. Such a group should include cancer control experts, relevant medical professionals and consumer and Maori representation. We support the recommendation of Bruce Corkill, counsel for women affected, that such a group would appropriately be led by Professor David Skegg.
- ?? Timeframes must be set for the implementation of specific recommendations, in particular timeframes for the monitoring and evaluation of the programme and for any studies of particular aspects (e.g. Configuration of cytology laboratories)

?? As recommended in our evidence, there should be a proper process of consultation and public discussion of any proposed legislative changes to enable access to women's information for the purposes of evaluation. This will ensure public support for any new regulations or laws.

Sandra Coney for Women's Health Action Trust, September 2000