

## REPORT

### BACKGROUND INFORMATION

1. In response to recommendation 46 of the Inquiry Report, the Director General will supply monthly reports to the Minister. This is the fifth of these monthly reports.

### COMMENT

#### **Evaluation of the National Cervical Screening Programme**

2. The National Screening Unit has provided formal feedback to the University of Otago on the Draft Report on the Evaluation of the Follow-up and Treatment of Women with Abnormal Screening Histories (Part 2 of the National Evaluation). The Report will be finalised by 31 October 2001. (Recommendations 1 & 3)
3. The Cancer Audit (Part 3 of the National Evaluation) is progressing into its second phase. The data matching exercise between the NCSP-Register and the Cancer Registry is complete and discussions have commenced with the University of Otago for the work on the next phases of the project. Overall there is some slippage in project timeframes due to time needed to explore the complex issues of confidentiality of audit results. The Cancer Audit will be carried out as an "open audit" and no special confidentiality arrangements for health professionals will be sought. The NSU is meeting with various agencies, including ACC to discuss the processes for informing women of adverse findings from the audit. Further slippage in project timeframes is also likely as a result of the need to apply to regional ethics committees. (Recommendations 1 & 3)
4. The release of the second Independent Monitoring Group's National Cervical Screening Programme quarterly monitoring report (covering the period January 2001 to March 2001) has been delayed due to a data error. The report will now be publicly released in October 2001. (Recommendation 4)
5. The NCSP Statistical Report 1996-98 is still undergoing peer review and is unlikely to be released before November 2001. Planning for the 1999-2000 Statistical Report is underway. (Recommendation 7)
6. The University of Otago has been asked to assist with the correlation of reporting profiles of laboratories, the region in which smear-tests are taken, and regional incidence of cancer. Further discussion with the University on the timeframe for the work is required before a delivery date can be confirmed. (Recommendation 8)

## **Changes to Legislation**

7. On 3 September Cabinet agreed to amend Section 74A of the Health Act 1956 to enable the effective monitoring, audit and evaluation of the NCSP. [CAB Min (01) 27/17 refers]. (Recommendations 14,15, 17)
  - The proposed amendments to the Health Act 1956 would allow NCSP-Register Data and slides to be used and disclosed for monitoring, audit and evaluation. (Recommendation 14)
  - Cabinet agreed that access to NCSP-Register data would continue to be subject to any regulations made under the Kaitiaki Regulations and that further consultation will be undertaken before any changes are made to the Kaitiaki Regulations. (Recommendation 15)
  - Recommendation 17 required an amendment to the Health Act 1956 to allow appropriately qualified persons engaged in monitoring, audit and evaluation of cervical cancer incidence and mortality to have access to the clinical records of women with cervical cancer. Cabinet agreed that clinical records would be made available for this purpose where the woman has given her consent. It is possible that an audit could be compromised by women who do not consent, however, submissions were against auditors having mandatory access to patient files. Cabinet agreed that consent should be sought from the woman at the time of treatment or registration on the Cancer Registry or from next of kin where applicable. If a woman, or, in the event of her death her next of kin, cannot be contacted for consent the Director-General of Health will be able to require the records be made available. This proposal does not fully meet the requirements of Recommendation 17 of the Ministerial Committee of Inquiry, but recognises that almost three quarters of submissions received on the law changes were against auditors having access to medical files. (Recommendation 17)
  - Cabinet agreed that the Health Act be amended to enable Health (Retention of Health Information) Regulations 1995 to be extended to cervical slides and histology specimens. Laboratories will be required to retain slides and reports in safe storage for a minimum period. (Recommendation 30)
8. The Health Professionals Competency Assurance (HPCA) Bill will repeal the Medical Auxillaries Act and replace it with more up to date legislation for the regulation of all registered health professionals. The HPCA Bill will allow the development of specific scopes of practice in specialty areas. (Recommendation 29)
9. On 13 August Cabinet agreed to amend the Health and Disability Commissioner Act 1994 to, amongst other things, place a legal obligation on the Health and Disability Commissioner to share information with registration bodies, ACC, and the Director General of Health, during an investigation, where there is a risk of harm from the practice of a health professional or systemic or

organisational practice or where there are likely to be compensation issues [CAB Min (01) 25/2 refers]. (Recommendation 34)

10. The Injury Prevention and Rehabilitation Bill places an obligation on ACC to report any incident it accepts as medical error to the relevant professional body and the Health and Disability Commissioner. (Recommendation 36)

### **Ethics Committees**

11. Initially it had been intended that the Operational Standards for Health and Disability Ethics Committees would be finalised by the end of September 2001. Due to an extended consultation period it is now unlikely that the Operational Standard will be finalised before the end of October 2001. (Recommendation 18 & 20)
12. A briefing has been sent to the Minister of Health outlining the issues surrounding the Inquiry's recommendation to establish a National Ethics Committee to review proposals for multi-centre and national research.

### **NCSP Operations**

13. The requirement of the NCSP to implement its own system of dealing with complaints will begin to be addressed in November 2001. The scope of a complaints system will need to tie in with legislative changes and the processes for dealing with complaints at the service provider level. (Recommendation 24)
14. Preliminary investigations into the feasibility, format and process for linking Cancer Registry and NCSP Register information has been completed as the first phase of the Cancer Audit. It is proposed that this recommendation is implemented in two phases; 1) electronic links requiring manual intervention and 2) automated electronic links. The scope of regular statistical information to be generated from both registers is currently being worked on. (Recommendation 8)
15. The Workforce Development Project is proceeding to plan. Further meetings have been held with laboratories and CTA. (28, 40, 41 & 44)
16. Preliminary investigations are underway into the requirement to electronically link the NCSP-Register and Laboratories. (Recommendation 31)
17. The NSU and Women's Health Action have reached agreement on a revised schedule for the provision of information for women. This revised schedule reflects the complexity of producing high quality information for women and the requirement to incorporate new legislative changes when they are implemented. (Recommendation 38)

### **Key Milestones Update**

18. The Fourth Briefing Report identified key milestones for reporting in this fifth Report.

- **Recommendation 1:** Completion of comprehensive written protocol for the carrying out of the Cancer Audit. Ethics Committee approval for the Cancer Audit.

Finalisation of the audit protocol and applications to ethics committees is awaiting the finalisation of discussions with the University of Otago on their part in the Cancer Audit work. Ethics Committee approval will require applications to 14 regional committees and could delay the audit.

- **Recommendations 14, 16, 17:** Cabinet Paper submitted.

Cabinet Paper submitted 28 August and again 3 September 2001. [CAB Min (01) 27/17 refers]

- **Recommendation 28, 40, 41, 42:** Workforce Development Project Second Draft Report completed.

The Second Draft Research Report is nearing completion.

## APPENDIX 1.0

TABLE 1.0: SUMMARY OF RECOMMENDATIONS UNDERWAY OR COMPLETE

	<b>Status</b>	<b>Recommendations</b>	<b>Total Number</b>
1.	Complete	4, 9,10, 11, 12, 13, 20, 37	8
2.	Underway	1, 3, 5, 6, 7, 8, 14, 15, 16, 17, 18, 19, 21, 22, 23, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46	37

**TABLE 2.0 IMPLEMENTATION OF RECOMMENDATIONS AND PROGRESS AGAINST REPORTING MILESTONES FOR 10 JULY TO 10 AUGUST 2001**

Ref	Recommendation	Underway/ Complete	Reporting Milestones <sup>1</sup> for 10 July to 10 August 2001	Milestone Achieved
1.	Evaluation of NCSP –  Part 2  Part 3 (Cancer Audit).	Underway  Underway	Draft Report by University of Otago reviewed.  Data matching exercise NCSP-R and Cancer Registry completed.	✓  ✓
2.	Re-enrolment and re-screening of women.		No Reporting Milestone this period.	
3.	Cox's 1997 comprehensive evaluation of the NCSP should be commenced within 18 months.	Underway	Parts 5, 6 and 8 included within the scope of Part 3 (Cancer Audit) – see recommendation 1 above. No Reporting Milestone this period.  Parts 4, 7 and 10 included within scope of NCSP Statistical Reporting. Refer to recommendation 7 below.	
4.	Implementation of Operational Policy and Quality Standards & Evaluation & Monitoring Plan.	Underway	Further project work to take place with regard to implementation of standards for Smear-Takers.  Second Independent Monitoring Group NCSP quarterly monitoring report preparation behind schedule.	x
5.	Full legal assessment of Operational Policy and Quality Standards.	Underway	Documentation review ongoing	
6.	Legal assessment of NCSP Authority.	Underway	Documentation review ongoing	
7.	Statistical Reporting.	Underway	Milestone Delayed.  Peer Review ongoing.	x

<sup>1</sup> Reporting Milestones refer to those tasks and activities that need to be completed in the period covered by the report, against which progress on the implementation of the recommendations is measured.

Those recommendations and their Reporting Milestones marked Current Practice will not be reported in subsequent reports, as they have already been implemented.

Recommendations where there is no Reporting Milestone against which to report for this month are marked No Reporting Milestone this period; work may however be already underway.

<b>Ref</b>	<b>Recommendation</b>	<b>Underway/ Complete</b>	<b>Reporting Milestones<sup>1</sup> for 10 July to 10 August 2001</b>	<b>Milestone Achieved</b>
8.	Regular Statistical Information.	Underway	Request for proposal from University of Otago	✓
9.	Minimum Standards for Cytology Laboratories.	Complete	DHB and Community Laboratory Agreements incorporate minimum volume standards.	✓
14.	Amend S74 of the Health Act 1956.	Underway	Cabinet Paper submitted to EHC	✓
15.	Kaitiaki Regulations.	Underway	Policy work underway.	✓
16.	Legal right to access information from the Cancer Register.	Underway	Cabinet Paper submitted to EHC	✓
17.	Amend Health Act 1956 to enable access to medical files.	Underway	Cabinet Paper submitted to EHC	✓
18.	Change guidelines under-which ethics committees operate.	Underway <sup>2</sup>	The expected completion date for work on this milestone is now 1 November 2001	
19.	Review of operations of ethics committees.	Underway	Work to be undertaken by the National Advisory Committee on Health and Disability Support Services Ethics (The National Ethics Committee).	
20.	Provide guidelines to ethics committees regarding Privacy Act & Code.	Complete	The expected completion date for work on this milestone is now 1 November 2001	
21.	Guidelines to ethics committees for observational studies.	Underway	Work to be undertaken by the National Advisory Committee on Health and Disability Support Services Ethics (The National Ethics Committee).	
22.	National ethics committee.	Underway	A briefing on options for a national ethics committee to be provided to Minister.	✓
23.	Appeal process for ethics committee decisions.	Underway	Work to be undertaken by the National Advisory Committee on Health and Disability Support Services Ethics (The National Ethics	

<sup>2</sup> Was previously identified as Complete. Further analysis indicated a need to redesignate this recommendation as underway. Initial drafting of Operational Guidelines is complete. Ongoing consultation represents further stages of work.

<b>Ref</b>	<b>Recommendation</b>	<b>Underway/ Complete</b>	<b>Reporting Milestones<sup>1</sup> for 10 July to 10 August 2001</b>	<b>Milestone Achieved</b>
			Committee).	
<b>24.</b>	NCSP Complaints System.		No Reporting Milestone this period.	
<b>25.</b>	Electronic Link Cancer Register & NCSP Register.	Underway	Preliminary Investigations completed	✓
<b>26.</b>	Performance Standards for NCSP Register and Cancer Register.	Underway	Preliminary discussions held. Research is being carried out on current standards and scoping of further work.	✓
<b>27.</b>	Standards for the NCSP should be reviewed every two years.	Underway	Project Plan developed	✓
<b>28.</b>	The Government must ensure sufficient cytotechnologists and cytopathologists and training sites.	Underway	No Reporting Milestone this period.  The National Screening Unit's Workforce Development Project continues to focus on this issue as a priority.	
<b>29.</b>	Amend Medical Laboratory Technologists Regulations 1989.	Underway	No Reporting Milestone this period.	
<b>30.</b>	Impose Legal obligations on storage of slides.	Underway	No Reporting Milestone this period.	
<b>31.</b>	Ensure electronic linkage between NCSP Register and Cytology Labs.	Underway	No Reporting Milestone this period.  This requirement will form part of the National Screening Units development of an Information Systems Strategy.	
<b>32.</b>	Develop Standards for accuracy of laboratory coding.	Underway	Standards will be developed in line with review of Policy and Quality Standards – refer to Recommendation 27.	✓
<b>33.</b>	The NCSP should develop a population-based register.	Underway	No Reporting Milestone this period.  The National Screening Unit is represented on the Ministry's Population Register Project led by Personal & Family Health Directorate.  The National Screening Unit is developing policy for the utilisation of a population-based register for	

<b>Ref</b>	<b>Recommendation</b>	<b>Underway/ Complete</b>	<b>Reporting Milestones<sup>1</sup> for 10 July to 10 August 2001</b>	<b>Milestone Achieved</b>
			screening programmes.	
<b>34.</b>	Legal mechanisms should be in place to allow the ACC, Medical Council and the Health & Disability Commissioner to share relevant information with the Ministry's NCSP.	Underway	Cabinet agreed on 13 August to amend the Health and Disability Commissioner Act 1994.	✓
<b>35.</b>	Medical Tribunal to supply information to NCSP.	Underway	No Reporting Milestone this period	
<b>36.</b>	ACC & Medical Council should exchange relevant information regarding claims for medical misadventure.	Underway	No Reporting Milestone this period	
<b>38</b>	Information to Women.	Underway	Scoping document prepared by Women's Health Action. Revised schedule agreed for delivery of information to women documents.	✓
<b>39</b>	Letters to Medical Practitioners.	Underway	Discussions with College of GPs have commenced.	✓
<b>40</b>	Appropriately trained personnel should do cervical screening.	Underway	No Reporting Milestone this period.  The National Screening Unit's Workforce Development Project continues to focus on this issue as a priority.	
<b>41</b>	All pathologists undertaking cytology should be appropriately trained.	Underway	No Reporting Milestone this period.  The National Screening Unit's Workforce Development Project continues to focus on this issue as a priority.	
<b>42</b>	Cytopathologists must participate in continuing education in cytopathology.	Underway	No Reporting Milestone this period.  The National Screening Unit's Workforce Development Project continues to focus on this issue as a priority.	
<b>43</b>	Pathologists ought to be more open-minded.	Underway	A meeting with the Royal College of Pathologists was held to discuss this recommendation.	✓

Ref	Recommendation	Underway/ Complete	Reporting Milestones <sup>1</sup> for 10 July to 10 August 2001	Milestone Achieved
44	The Medical Council should ensure that systems are in place to support the early reporting of errant medical practitioners by their colleagues.	Underway	No Reporting Milestone this period.	✓
45	NCSP should have a system for identifying deficiencies.	Underway	No Reporting Milestone this period.	
46	There should be a process for monitoring the implementation of the Committees Recommendations.	Underway	Dr McGoogan's review ongoing.	✓