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Patron: His Excellency the Right Honorable Sir Ninian Stephen, AK, GCMG, GCVO, KBE.

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25th August 1988

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MEMBER ORGANIZATIONS

MEMBERS OF NATIONAL BREAST STUDY COMMITTEE

MAMMOGRAPHY PROJECT DIRECTORS

I forward herewith an amended set of Minutes of the Meeting of the National Breast Study Committee held on the 14th July 1988. Would you please destroy the version circulated on 27th July 1988.

Member Organizations would you please place these Minutes before your Medical and Scientific Committee/Breast Study Committee as appropriate.

L. A. Wright
Executive Director

NJG
RM
RRL ✓
DR.

AUSTRALIAN CANCER SOCIETY INC.

MINUTES OF THE MEETING OF THE NATIONAL BREAST STUDY COMMITTEE HELD IN THE BOARD ROOM, 500 GEORGE STREET, SYDNEY, ON THURSDAY, 14 JULY, 1988.

Present

Mr I. Russell (Chairman)
Dr M. Fett
Mr C. Furnival
Ms J. Hall
Dr S. Redman
Dr M. Rickard
Mrs D. Shugg
Prof M. Tattersall
Mr L. Wright (Secretary)
Dr R. Melville (by invitation)

The meeting was opened at 10.15 am.

1. Apologies & Welcome

The Chairman thanked the members for attending and welcomed particularly Dr Rickard, representing Prof Hare and the Mammography Sub-committee.

Apologies were noted from Dr M. Byrne, Prof W. Hare (hospital), Prof A. Langlands, Dr H. Mitchell, Dr R. Reed, Mr S. Renwick, Dr I. Ring.

2. Minutes of the Previous Meeting

The minutes of the meeting held on 28 March, 1988, were confirmed.

3. Mammography Sub Committee - Report

A report of the meeting of the Sub-committee held on 8 July, 1988, was tabled.

3.1 Approved Pilot Projects

Dr Rickard said that all of the approved projects had been represented at the meeting, except for Perth where Dr Adamson was overseas. She said that there was no definition of what constituted an approved project but it appeared that any project receiving government funds for its operation or evaluation was classified as a 'pilot project'.

The Secretary said that he had been in touch with Dr Albertyn in Adelaide. A pilot project was receiving funding and staff recruitment had commenced. He said that he had briefed Dr Albertyn on the role of the NBSC and its sub-committees and asked that she advise when the project was to commence.

The meeting engaged in a discussion of how to define a pilot project.

Dr Fett referred to the Model Project Plan for Mammography Pilot Projects produced by the AIH as providing a model for comparison.

The requirements of the RACR for projects to meet set standards in mammography and data collection before being 'accepted' and so qualifying for medicare rebate benefits was seen as a useful guide.

Dr Melville said that the SDBC project had been submitted to the State Cancer Council for approval and that seemed to be a good test of status.

The meeting formed the view that pilot projects should examine issues that warranted examination and would contribute to the formulation of a national strategy. There should not be duplication in the objectives of projects.

Ms Hall pointed out that if eligibility to qualify patients for medicare rebate depended on projects being approved it would be necessary to recognize in some way those which met the required standards. The Chairman commented that standards were the concern of the RACR but some general criteria seemed necessary to prevent just any centre from declaring itself to be a pilot project.

Professor Tattersall asked what role the NBSC should play. He said that the AIH was responsible for evaluating data collection and the RACR would control the quality of mammography. He said that there was also a need to set standards for surgery, for counselling and for public health aspects.

The Chairman replied that as the ACS delegate to the AHMAC Steering Committee on Breast Cancer Screening, he would suggest that the AIH be responsible for economic aspects and the NBSC provide an overview on professional matters, recognizing the perogatives of the Medical Colleges to set standards for their members. He said that he did not think it was a role of the NBSC to determine which projects were to be 'pilot projects'.

Mr Furnival said that as there seemed to be a sufficient quantum of projects covering a variety of approaches, the designation of pilot projects should be frozen and additional projects assessed only on whether they met the required standards for funding. The Chairman summarised the pilot projects already identified, seven in all, and agreed that it seemed a sufficient number, particularly when compared to overseas models. He said any additional pilot projects should have to conform to the AIH criteria and also focus on additional, significant questions.

Dr Melville asked that the SDBC project be added to the pilot projects as it would examine a unique 'user pays' system.

Mr Furnival, supported by Professor Tattersall, moved that the NBSC recommend to the AHMAC Steering Committee that no further pilot projects by funded unless they meet AIH criteria, incorporated significant new questions and were supported by their State Health Department.

The motion was carried. The Chairman said that the SDBC should provide the required information to the AHMAC Steering Committee to seek approval as a pilot project.

3.2 Physical Examination

Although only Wesley included physical examination at the first visit, it was performed at all others on recall and this met the AIH criteria.

3.3 Standard of Equipment

The statement on the quality of equipment in use on pilot projects was noted, however, it was observed that a number of facilities which offer mammographic screening do not have the desired level of equipment.

It was suggested that this might be controlled by giving medicare rebates only when high quality equipment was used. The same concern was expressed about other components for a high quality screening service, e.g. adequacy of staff and levels of staff training.

The Mammography Sub-committee is to be asked to examine the questions of standards and how they can be improved to a uniform level and maintained.

The committee saw the role of the NBSC to ensure that the standards of mammography and mammographic interpretation were of a high order. To achieve this it should be set a target date by which all mammographic examination in Australia would be carried out using dedicated equipment and processors, trained radiographers under the charge of radiologists committed to maintaining the standards which should be specified by the RACR.

3.4 Mammography in Young Women

The committee endorsed the decision by the RACR to circulate a policy statement on mammography in young women in the MJA, although publication in journals reaching GP's was also recommended.

3.5 Terminology in Mammographic Reporting

Dr Fett said that he was concerned that the terminology used by pilot projects for describing screening results was not uniform. He said that while there may be merit in examining different methods for recording the screening result, there was a strong justification for standardising the recording of the clinical recommendation. A suitable classification would be:

1 Repeat examination - technically unsatisfactory.

2 Re-screen after standard interval.

3 Needs follow-up (including early re-screen).

The meeting agreed that common terminology would be ideal and discussed terminology and interpretation used by the various projects. The use of a percentage scale by Rachel Forster was noted.

The meeting concluded that variety in recording assessments was acceptable providing the criteria for recall and a policy for management were agreed and adhered to.

Professor Tattersall commented that all projects were taking two mammographic views and suggested that a single view option could be included.

Mr Furnival said that the evidence was that an initial single view led to a much higher recall rate and this contributed to patient anxiety.

Ms Hall said that it might be possible to do a simulation from recorded results of the outcome using single view only.

The report of the Mammography Sub-committee was received.

4. Report of the Royal College of Surgeons

A report of a Working Party on Staffing Implications of Breast Cancer Screening Programs was tabled.

The Chairman said that there should be a meeting convened of the RACS, RACR and RCPA to discuss the implementation of a mass mammographic screening program. The RCS report would be a useful discussion document at such a meeting and committee members should report to their respective Colleges on the existence and scope of the report prior to the proposed meeting.

He said that the ACS would be convening meetings with the Colleges to discuss barriers to implementation of the NCCP and the issues in the RCS report would be relevant.

Dr Melville said that he and Mr Russell were to convene the workshop on breast cancer for the ACS and a two-step procedure would be followed; at the first workshop the medical participants would be gathered to resolve issues of science, medicine and standards and then, in a second workshop, those conclusions would be considered by a wider forum of government, insurance and consumer groups. An important issue would be who was to pay for mass screening - the consumer, the government through medicare or private health insurance.

Mr Russell said that relevant documents for the workshops would be the Forrest Report, the RCS report, Report of the Health Targets and Implementation Committee and the Wigg report on radiotherapy facilities.

5. Australian Institute of Health

Dr Fett tabled two documents;

'SECU Background Information' and
'The Use of Individual Record Data in the National Evaluation of Breast Cancer Screening Projects'

The Secretary said he would copy the documents and send them to committee members.

6. Pathology Sub-Committee

The Chairman tabled a letter from Dr Reed notifying of an intention to hold a workshop on intra-ductal lesions.

The letter was received.

7. Meeting of Mammography Directors

The report of the meeting held on 11 May, 1988, was tabled.

7.1 'Screened Woman'

Mr Furnival commented that of the cancers detected at the Royal Womens' Brisbane project some 36.7% of women admit to having a lump.

Dr Rickard said that the Rachel Forster project accepted only asymptomatic women and those presenting with symptoms were re-directed to their GP.

7.2 Separation of 'Diagnostic' and 'Screening' Clinics

It was agreed that 'diagnostic' and 'screening' sessions should not be conducted concurrently but separate days or time blocks should be allocated for each.

7.3 Occult Breast Cancer

Professor Tattersall said that it would be useful to have a record of interval cancers not discernible on recheck of screening mammogram.

The report of the meeting was received.

8. AIH Discussion Paper - "The Use of Individual Record Data in the National Evaluation of Breast Cancer Screening Projects"

It was noted that the paper would be circulated after the meeting.

The provisions for preserving individual confidentiality was noted. It was advised that the Royal Perth project would utilise anonymous project numbers. Dr Rickard said that a decision had not been made for the Rachel Forster project but there was a feeling of vulnerability about providing identifiable patient information.

Dr Fett confirmed that publication of data arising from projects would require project sanction and reports would acknowledge project authors.

The meeting supported the transfer of anonymous individual data to SECU and the publication of data with project approval and proper acknowledgement. The meeting said that there should be no transfer of information to a third party without project approval but acknowledged that AIH would be bound by its charter in providing information to the Minister.

8.1 Screening Cycles

Professor Tattersall asked whether the whole target population should be screened before re-screening commenced.

The question caused a lively debate as some projects did not have a target population defined by area, ethnicity, or other factors and some that did e.g. Rachel Forster, could not at its present accrual rate complete initial screening during the project life.

One solution preferred was to end initial screening after twelve months and define those screened by then as the 'target population' to be re-screened.

It was agreed that recruitment, staff and machine capability and identification for recall were critical factors that should be assessed for each project.

9. Register of Minimal Breast Cancer

The Chairman said this matter would be discussed by the AACR on 18 July.

10. Other Business

10.1 AIH

Dr Fett referred members to the publication by AIH of a Model Project Plan for Mammography Pilot Projects which would speed application approvals and facilitate the evaluation process.

He said that the AIH would recommend that all projects use the software package devised by the Newcastle project. This raised some concern in projects already under way and Dr Rickard commented that the Newcastle package was untested.

Dr Fett said that the flow of funds was not AIH - Project direct but would be transferred via the Commonwealth Dept of Community Services & Health and the State Health Department. He said that project applications should reach the Institute by 31 July and by using the Model Project Plan project directors should find the procedure reasonably easy.

10.2 Next Meeting

It was decided to meet again in about three month's time. The date selected is 13 October, 1988.

.....
CHAIRMAN

.....
DATE

THE USE OF INDIVIDUAL RECORD DATA IN THE NATIONAL EVALUATION OF BREAST CANCER SCREENING PROJECTS

DISCUSSION PAPER

Prepared by SECU, AIH

24 June 1988

Background

Concern has been expressed regarding the provision of data on screened women from breast cancer screening pilot projects to the Screening Evaluation Co-ordination Unit (SECU). These concerns relate to issues of confidentiality and publication/authorship rights.

At a meeting on breast cancer screening sponsored by the Australian Cancer Society in May 1988 it was proposed that SECU should prepare a paper discussing the issues involved in the provision of data, with the paper to be circulated to all breast cancer screening pilot projects for comment. The concerns which remain would then be referred to the AHMAC Breast Cancer Screening Evaluation Steering Committee, which is overseeing the national evaluation, for its consideration. The Steering Committee will probably hold its first meeting in mid-1988.

SECU is a unit of the Australian Institute of Health (AIH), which is a Commonwealth statutory authority independent of the Commonwealth Department of Community Services and Health. AIH has responsibility for developing and collecting national health related statistics and making recommendations to improve the health of Australians. The provision of confidential data is central to the continuing activities of the AIH in performing all its functions. The role of the SECU is entirely consistent with AIH's charter.

To maintain confidentiality of any data transmitted to AIH, the AIH Act provides penalties for any disclosure of this data without authorisation from the original provider of the data (extract attached). These provisions of the Act, which apply to SECU, are in the process of being strengthened in recognition of the crucial importance of the maintenance of confidentiality.

The requirement for pilot projects to provide data and reports to SECU arises from the recommendations contained in the report of the AHMAC Working Party on Breast Cancer Screening Evaluation, which have been endorsed by AHMAC.

The Working Party on breast Cancer screening recommended that pilot projects send unit record data on individual screened women to SECU. SECU has been guided by this report in its activities to date. (When constituted, the AHMAC Breast Cancer Screening Evaluation Steering Committee will also provide guidance to SECU.)

Pilot project data is required by SECU to enable it and the Steering Committees to examine in depth the likely effectiveness, cost and implications of different models of nationwide screening programs and to make recommendations to governments.

The requirement for pilot projects to provide reports and data to SECU is a condition of the pilot projects receiving substantial Commonwealth financial support for the conduct of project evaluations.

Issues

The concerns expressed relate to the issues of:

1. The necessity for SECU to receive unit record data on all screening participants;

2. Protecting the confidentiality of women screened by pilot projects, in relation to the provision of data to SECU;

3. Rights of publication and authorship; and

4. Controlling the transmission of data received by SECU to third parties.

Each of these issues is considered in turn.

1. The SECU requirement for unit record data

Data could be provided to SECU in the following forms:

- Tabulated data

- Unit record data , with individual records identified by either:

    - name of woman
    - Medicare card number
    - project allocated woman identification number

- Unnumbered anonymous unit record data.

As mentioned above, the AHMAC Working Party Report on Breast

Cancer Screening Evaluation recommended that unit record data be provided to SECU. This report has been endorsed by AHMAC and therefore the recommendations contained in the report have been formally endorsed by all the Departments of Health throughout Australia.

Tabulated data would need to be prepared by pilot projects in accordance with detailed specifications provided by SECU. Tabulated data have the advantages that SECU would need to perform minimal analysis and the confidentiality of screened women could not be breached. However, the provision of tabulated data to SECU would have the following adverse consequences for the nationally co-ordinated evaluation:

- the conventional approach to analysis, that is, of sequential, repetitive hypothesis development, data analysis and hypothesis testing would be protracted to an unsatisfactory degree, because this would require repeated requests for additional tabulations from at least seven different pilot projects spread around the nation.

- SECU would have very limited capability to detect and critically assess significant variations among projects in data quality and techniques for preparing tabulations. Such variations could have a major impact on the conclusions reached in the national evaluation, with the risk of serious flaws in the recommendations provided to Governments.

Thus, the provision of tabulated data would seriously impair the value of the national evaluation and would increase the risk of erroneous conclusions being reached.

The provision of unit record data also has the advantages of:

- analyses to generate tables with different cut points could be performed rapidly, without the necessity for asking at least seven pilot projects to reanalyse their data, thereby enhancing the timeliness and flexibility of analyses and at the same time minimising duplication of effort.

- ease of data preparation by pilot projects, as data files could be generated by the screening clinic;

- timeliness of data transmission, as no prior data preparation or analysis is required. This will greatly facilitate the provision of timely advice to Governments;

- the reconciliation of apparent anomalies on individual women's records will be possible; and

2. Protecting the privacy of screened women

Assuming that unit record data are provided to SECU, the relative merits of the various approaches to providing unit record data are as follows:

i) **Unit records identified by name of woman**

Records identified by name (and birth date) have the advantage that they can be linked with other sources, such as the Medicare data base and the envisaged National Death Index and National Cancer Statistics Clearing House, as well as having the advantages of records identified by project allocated ID numbers (see iii) below).

However, they have the disadvantages that record linkage is difficult using name and birthdate alone (due to name changes and trivial errors) and any unauthorised disclosure of data would result in maximal breach of confidentiality of individual women.

ii) **Unit records identified by Medicare card number**

Records identified by Medicare card number have the advantage that they can be linked with the Medicare data base, as well as having the advantages of records identified by project allocated ID numbers (see iii) below). Linkage with the Medicare database would facilitate the collection of treatment data for those women followed up and treated in the private sector.

However, this approach has the disadvantages that it raise concerns about "Big Brother" record linkage and unauthorised disclosure could result in a breach of confidentiality of individual women, if the numbers were to be linked to names. Furthermore, when women are asked to bring their cards along they may wonder if they will be charged and a proportion will fail to bring their cards, resulting in the requirement for a project allocated ID number anyway.

iii) **Unit records identified by project allocated ID numbers**

Records identified by project allocated ID numbers have the following advantages:

- confidentiality is fully protected because individual records can only be linked to names by the pilot project. People outside the pilot project would not have access to the name-number link file and knowledge of each woman's identity would be under the exclusive control of the pilot project;

- records from different aspects of the screening process can be linked within SECU for each screened

woman (e.g. screening data with behavioural science data, clinical assessment data, economic data, etc), thereby facilitating data transmission and analysis; and

- records from different screening attendances for each screened woman can be linked together by SECU.

The only disadvantage of project allocated ID numbers is the lack of record linkage capability offered by name and Medicare number, although such linkage could be performed retrospectively as required in individual cases, with the co-operation of the pilot project.

iv) **Unnumbered anonymous unit records**

Unnumbered, anonymous unit records have the advantage of full protection of confidentiality, although the degree of protection is no greater than that of project allocated ID numbers. However, unnumbered records have the following disadvantages:

- the computing aspects of data transmission and analysis become much more difficult and protracted, due to the need for record linkage before sending to SECU;

- the linkage of repeat screening attendances by individual women could not be done at SECU, and would require projects to perform linkage and provide SECU with data which had already been provided; and

- it would not be possible for SECU to seek from pilot projects additional information on particular records.

Thus,unit record data should be provided to SECU, with each record being identified by a project allocated identification number which is specific for each woman screened and for each woman to whom individualised recruitment information is given. In addition, all records from each pilot project should be identified by a project identifier, which would be unique for each project. (A two character project identifier should suffice.)

3. Rights of publication and authorship

The agreement between the Commonwealth and the States/Territories for the provision of evaluation funding does not in any way restrict the use of data generated by pilot projects using Commonwealth funding. Pilot projects and associated investigators are free to analyse and publish the data at any time and in any manner, as far as the Commonwealth is concerned.

In relation to analysis and publication by SECU, at this very early stage, the current thinking within SECU is to have three "Government sponsored" reports on breast cancer screening evaluation:

1. Synthesis of data from pilot projects
2. Review of published literature
3. Strategy options for nationwide screening programs

Report 1. could be collectively authored by SECU and all of the mammography pilot projects. Practically, this would be achieved by creating a multi-centre network entitled something like "The Australian Breast Cancer Screening Pilot Program", with all project directors and evaluation investigators being named members. Report 1. and any scientific article journals coming from this report would then be authored by ABCSPP. In Report 1. and associated publications, the identity of each project would not be disclosed without the prior approval of the relevant pilot project and the relevant State/Territory Health Department.

Report 2. would be authored by SECU (and any others who wished to contribute) and would fully cite Report 1. where information from Report 1. was used.

Report 3. would be authored by the Steering Committee and SECU, and would also fully cite Report 1. where information from Report 1. was used. This report would be submitted to AHMAC, which would have the authority to approve or withhold from publication.

Any journal publications using pilot project data which SECU staff intended to prepare would be authored on a basis agreed to in writing by SECU and relevant pilot projects, and would only be submitted for publication with the prior written agreement of SECU, relevant pilot projects and relevant State/Territory Departments of Health.

4. Controlling the transmission of data received by SECU to third parties

SECU undertakes to supply pilot project data to third parties only with the prior, written authority of the pilot project and State/Territory Health Department concerned. Any such provision of data by SECU would be controlled by a rigorous agreement schedule which is being developed by AIH and which contains provisions which refer to penalties under the AIH Act and the Crimes Act. A copy of this agreement schedule would accompany the request to the pilot project for authority to release data.

29. (1) Subject to this section, a person (in this subsection called the "informed person") who has:

(a) any information concerning another person (which person is in this section called an "information subject"), being information acquired by the informed person because of:

(i) holding an office, engagement or appointment, or being employed, under this Act;

(ii) performing a duty or function, or exercising a power, under or in connection with this Act; or

(iii) doing any act or thing under an agreement or arrangement entered into by the Institute; or

(b) any document relating to another person (which person is in this section also called an "information subject"), being a document furnished for the purposes of this Act;

shall not, except for the purposes of this Act, either directly or indirectly:

(c) make a record of any of that information or divulge or communicate any of that information to any person (including an information subject);

(d) produce that document to any person (including an information subject); or

(e) be required to divulge or communicate any of that information to a court or to produce that document in a court.

Penalty: $2,000 or imprisonment for 12 months, or both.

(2) Nothing in this section prohibits:

(a) a person from divulging or communicating information, or producing a document, to the Minister if it does not identify an information subject;

(b) a person from divulging or communicating information, or producing a document, to:

(i) a person specified in writing by the Australian Institute of Health Ethics Committee; or

(ii) a person specified in writing by the person who divulged or communicated the information or produced the document directly to the Institute; or

(c) the publication of conclusions based on, statistics derived from, or particulars of procedures used in, the work of the Institute, if they are not published in a manner that identifies an information subject.

(3) A person to whom information is divulged or communicated, or a document is produced, under paragraph (2) (a) or (b), and any person under the control of that person is, in respect of that information or document, subject to subsection (1) as if the person were a person exercising powers, or performing duties or functions, under this Act and had acquired the information or document in the exercise of those powers or the performance of those duties or functions.

(4) In this section:

(a) "court" includes any tribunal, authority or person having power to require the production of documents or the answering of questions;

(b) "person" includes a body or association of persons, whether incorporated or not, and, in the case of an information subject, also includes a deceased person;

(c) "produce" includes permit access to;

(d) "publication", in relation to conclusions, statistics or particulars, includes:

(i) the divulging or communication to a court of the conclusions, statistics or particulars; and

(ii) the production to a court of a document containing the conclusions, statistics or particulars; and

(e) a reference to information concerning a person includes:

(i) a reference to information as to the whereabouts, existence or non-existence of a document concerning a person; and

(ii) a reference to information identifying a person or body providing information concerning a person.

SECU BACKGROUND INFORMATION

28 June 1988

Abbreviations

AIH	Australian Institute of Health
AHMAC	Australian Health Ministers Advisory Council; responsible to AHMC
DCSH	Commonwealth Department of Community Services and Health
AHMC	Australian Health Ministers Conference
SECU	Screening Evaluation Co-ordination Unit

1. What is SECU?

SECU stands for Screening Evaluation Co-ordination Unit. The Unit is located in the Health Status Division of the AIH in Canberra.

2. How can SECU be contacted?

Correspondence should be addressed to:

Head
Screening Evaluation Co-ordination Unit
Australian Institute of Health
GPO Box 570
CANBERRA ACT 2601
Australia

Telephone: (062)435000
Facsimile: (062)571470

3. What are the roles of SECU?

SECU has the following roles:

- co-ordinating the national evaluation of breast and cervical cancer screening pilot projects;
- assisting the development of strategy options for nationwide screening programs;
- undertaking or organising research into particular issues as needed;
- providing support to the two Steering Committees.

4. **What was the origin of SECU?**

In December 1987, the two AHMAC Working Parties on Breast Cancer Screening Evaluation and Cervical Cancer Screening submitted their reports to the AHMAC Sub-Committee on Breast and Cervical Cancer Screening, which, with minor amendments, submitted their reports to AHMAC for approval. In each report there were recommendations for the establishment of a National Evaluation Co-ordination Unit at the AIH. These recommendations, along with the remainder of the reports, were endorsed by AHMAC.

Subsequently, the AIH and DCSH entered into an agreement for SECU to be established, and funding was provided by DCSH in February 1988.

Upon submission of the reports, the Sub-committee and the AHMAC Working Parties were disbanded.

5. **What is the significance of the AHMAC Working Party reports?**

The two Working Party reports, with some minor amendments by the AHMAC Sub-Committee, have been endorsed by AHMAC and therefore the recommendations contained in the reports have been formally endorsed by all Departments of Health throughout Australia. identify the areas requiring investigation by the nationally co-ordinated evaluation. They also provide detailed guidance in the areas of performance measures and data sets as well and identifying important issues in the development of nationwide screening programs. These reports, which have been widely circulated to all pilot projects and to other interested groups, specify the directions which are being pursued by SECU: SECU sees its role as assisting, wherever possible, to implement the recommendations of the reports.

The reports also recommended the establishment of two Steering Committees (see 10 and 11 below).

Copies of the reports are available from SECU.

6. **How is SECU funded?**

SECU is funded by a grant from the "New Initiatives for Women" package, administered by DCSH. This grant expires on 30 June 1990. The AIH also contributes substantial resources to SECU in terms of salary, computing and support services.

7. Who makes up SECU?

SECU comprises the following staff:

- Head: Dr Michael J. Fett (an epidemiologist)
- Epidemiologist: Dr Robert Hall
- Economist: Mr Rob Carter
- Social scientist: Dr Rosemary Knight
- Executive officer: Ms Joanne Maples (temporary)
- Administrative support officer: Ms Sarah Worthy
- Research assistant: Ms Wendy Whitfield (temporary)

8. How will SECU co-ordinate the national evaluation?

Under the guidance and direction of the Breast and Cervical Cancer Screening Steering Committees, SECU will seek to co-ordinate the national evaluation by:

- making suggestions to potential pilot projects to ensure that all realistic options for screening programs are represented among the pilot projects;
- assisting projects to develop project plans and then monitoring the implementation of these plans;
- facilitating the adoption by pilot projects of standard data recording forms and software;
- facilitating the adoption by pilot projects of standard data items, classifications and codes, and standard performance measures;
- reviewing, recommending and assisting with the development, procurement and installation of software useful for managing the operations of screening clinics and collecting data.

The facilitation process will involve:

- hosting workshops and meetings of people involved in different aspects of the evaluation of pilot projects;
- hosting annual conferences of people involved in the pilot projects and interested partners;
- developing model documentation for consideration and comment by pilot projects;

- evaluating available software and making recommendations;

- circularising reports on progress and developments in pilot projects.

9. **What assistance can SECU provide to pilot projects?**

SECU can provide assistance in:

- developing and constructively reviewing project proposals;

- developing and constructively reviewing project plans;

- identifying requirements for computer facilities and advising on possible solutions;

- identifying potential sources of expertise and knowledge;

- informing projects of progress and developments in other pilot projects and in the national evaluation;

- acting as co-investigator in the evaluation of pilot projects;

- bibliographic resources.

10. **What will SECU require of pilot projects and why?**

SECU will require projects to provide reports and data as specified in the project plans prepared by each pilot project for DCSH. This requirement is a condition for the pilot project to receive substantial Commonwealth financial support for the conduct of project evaluations.

Pilot project information is needed to enable SECU and the Steering Committees to develop strategy options for nationwide screening programs: Project reports will be required so that the precise details of the pilot project operations can be understood. Data and tabulations will be required so that the effectiveness and cost of different patterns of operations can be assessed. With this information, it will be possible for the Steering Committees and SECU to examine in depth the likely effectiveness and cost of different models of nationwide screening programs and to make recommendations to governments.

11. To whom is SECU responsible and accountable?

In fulfilling its roles, SECU is responsible to the AHMAC Steering Committee on Breast Cancer Screening and the AHMAC Steering Committee on Cervical Cancer Screening.

In matters relating to the financial control of its grant, SECU is responsible to DCSH.

Administratively, SECU is responsible to the Head, Health Status Division, AIH.

12. What are the roles of the Steering Committees?

The AHMAC Working Party reports recommended the establishment of two Steering Committees, one for breast cancer screening and the other for cervical cancer screening, and also made recommendations on their membership. The Committees are currently being formed and should meet in mid-1988. While it is possibly too soon to specify the roles of the Committees in detail, two main areas of activity will be to oversee and provide guidance and assistance to the nationally co-ordinated evaluation, and to oversee the development of strategy options for nationwide screening programs. The Steering Committees will be answerable to AHMAC.

13. What is the relationship between SECU and DCSH?

The Department is responsible for the allocation and administration of Commonwealth funds to SECU and to the pilot projects.

SECU is functionally independent of the Department. SECU works closely with the Department to ensure that the Department is informed of progress in the nationally co-ordinated evaluation, and to ensure that SECU is aware of the Department's views. SECU provides assistance to the Department where this is appropriate to SECU's roles, and provides advice on issues relevant to the successful conduct of the national evaluation.

The Department also has input to the national evaluation through its representatives on the Breast and Cervical Cancer Screening Steering Committees.

Note: This information will be updated from time to time and circulated to interested groups and persons.

AUSTRALIAN CANCER SOCIETY INC.
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Patron: His Excellency the Right Honorable Sir Ninian Stephen, AK, GCMG, GCVO, KBE.

BIII/5.3

29 June, 1988.

MEMBER ORGANIZATIONS

NATIONAL BREAST STUDY COMMITTEE

Attached for information is the agenda for the meeting of this Committee, to be held in Sydney on 14 July, 1988.

L.A. Wright,
Executive Director.

cc: Mr W. Fleming

AUSTRALIAN CANCER SOCIETY INC.

THERE WILL BE A MEETING OF THE NATIONAL BREAST STUDY COMMITTEE HELD IN THE BOARD ROOM, 3RD FLOOR, 500 GEORGE STREET, SYDNEY ON THURSDAY, 14 JULY, 1988, COMMENCING AT 10.00 AM.

Airline ticket for interstate travel is enclosed. Claim for incidental expenses should be made at the meeting.

L.A. Wright,
Executive Director.

29 June, 1988.

A G E N D A

1. Apologies & Welcome

Apologies received from Dr I. Ring, Dr S. Renwick.

2. Minutes of the Previous Meeting

The minutes of the meeting held on 28 March 1988, will be tabled for confirmation.

Copy attached - ATTACHMENT 1

3. Mammography Sub-Committee - Report

The sub-committee will meet on 8 July 1988 and a report of proceedings will be tabled at the meeting.

Prof. Hare will report on decisions of the RACR on quality control in mammography.

4. Facilities and Resources for Mass Screening

A general discussion on the Australian scene is proposed.

Attached as background is a report of the Royal College of Surgeons.

ATTACHMEMT 2

5. Mammography Directors' Meeting

A meeting was held on 11 May 1988, of directors of projects and representatives of the DCSH and AIH.

A copy of the record is attached.

ATTACHMENT 3

6. Pathology Sub-Committee

Dr Reid to report on progress.

7. National Cancer Control Plan (NCCP) - Breast Cancer

Arrangements being made by the ACS to coordinate a review of resources and public education will be reported at the meeting.

Discussions held with representatives of the RACS, RACR and RCPA will be reported.

8. Minimal Breast Cancer Registry

The Chairman will report.

9. Other Business

9.1 Date of Next Meeting.

ATTACHMENT 1

AUSTRALIAN CANCER SOCIETY INC.

MINUTES OF A MEETING OF THE NATIONAL BREAST STUDY COMMITTEE HELD IN THE CONFERENCE ROOM, 3RD FLOOR, 500 GEORGE STREET, SYDNEY ON 28 MARCH 1988.

Present:
Mr I. Russell (Chairman)
Dr M. Byrne
Dr M. Fett
Dr C. Furnival
Ms J. Hall
Prof A. Langlands
Dr H. Mitchell
Dr S. Redman
Dr R. Reed
Dr S. Renwick
Dr I. Ring
Prof M. Tattersall
Mr L. Wright (Secretary)

The meeting was opened at 10.05am.

1. Apologies:

Apologies were noted from Prof W. Hare and Mrs D. Shugg.

2. Minutes of the Previous Meeting:

The minutes of the meeting held on 23 October 1987 were corrected and confirmed.

3. Business Arising from the Minutes:

3.1. Discussions with RACS and RACR

The Chairman confirmed that formal discussions on the provision of mammography had yet to be held but said that he had had informal discussions with the President of the RACS.

Both Dr Furnival and Mr Renwick urged that discussions be arranged during the RACS meeting in Brisbane in April where the 'screening' was on the program. The appropriate level recommended was Chairman NBSC - Chairman RACS Breast Sub-committee.

The division within the RACR between 'diagnostic' and 'imaging' needed clarification and it was debated whether the NBSC should liaise with the College or with its Mammography Sub-committee.

The Chairman sought direction on whether College representatives should be invited to a NBSC meeting or a separate meeting between representatives of each be sought. The latter course was favoured.

4. Report of AHMAC Working Party:

4.1. Role of Australian Institute of Health

Dr Fett reported that the evaluation of projects would be the responsibility of the newly titled Screening Evaluation Coordination Unit (SECU). He said that the AIH role in screening would primarily be in the evaluation of projects and SECU would require advice on medical issues from outside, possibly from the NBSC.

Dr Fett advised that the Department of Community Services & Health (DCSH) was providing $10,000 seeding grants to the States to get projects moving and funding was guaranteed in 87/88 and 88/89. This raised the question of funding through the ensuing years of the life of the pilot projects and Dr Fett said that the present Government could not guarantee funds beyond its own life.

4.2. Provision of Data

Professor Tattersall said that the Rachel Forster project would not provide individual 'identifiers' to the Health Department. Mr Russell said that the Essenden project, similarly, would not give this information.

The possible use of Medicare records was suggested and it was said that patient agreement would be needed for the release of details by the HIC and in the light of recent political events it was unlikely that the Government would wish to suggest this. Dr Ring said that Queensland might do a State analysis and provide aggregate information.

The use of the electoral roll or project identifiers was discussed and dismissed.

The consensus was that no system which allowed individual identification outside the project was likely to be accepted and the best compromise would be a system to aggregate members and outcomes at a State level with this information going forward to the SECU.

Dr Furnival pointed out that one of the agreed recommendations was that one project should utilise Medicare records. Dr Mitchell said that this recommendation should stand so that the Health Commission would have to confront the issue.

The recommendations in the AHMAC Report were reviewed and the following comments made.

R6 - applied to breast screening only.

R10-R11 - Appx 3 was substantially as developed by the NBSC Data Sub-committee and was acceptable to the Rachel Forster project.

There was general discussion on the acceptability of the data collection. Dr Ring said that only the NBSC provided a forum for discussion on the issues of standardisation and time was too short to develop the recommendation to suit all views. He said time was needed to review the results and get uniformity.'

The availability of Federal funds where projects refused to supply information was an issue raised and Dr Mitchell said that Canberra was well aware of the sensitivities and might call on the NBSC to attempt to resolve these problems.

Dr Ring affirmed the aim of the core data sub-committee was to achieve standardisation of core data for evaluation purposes.

The Chairman suggested that the data sub-committee might re-convene with all projects represented, and Dr Fett also.

Dr Fett supported the role of NBSC in coordinating technical inputs particularly as the Essendon project was developing its own software and Rachel Forster was developing a service data set. He said that the AIH would provide a format for discussion.

Other matters raised were the need for a set of definitions to be used by all projects, double view mammography as standard, policy for recall of benign lesions and data on unscreened women.

R7 - now 3 projects recommended.

The discussions centred on the inclusion of women in screening statistics who presented with symptoms and were therefore 'diagnostic' cases.

The problems of population based call forward including symptomatic women who otherwise would not have presented generated a range of opinions.

It was considered that Project Directors should meet to discuss and decide

definition of screened women
interval case
criteria for recall
definition of 'false negative'
Target population
when does screening end
what is symptomatic screenee
(?previous history of breast lump)

It was agreed that representatives of AIH, pathology sub-committee, mammography sub-committee and core data sub-committee should be present.

5. Sub-committee Reports:

5.1. Report of Pathology Sub-committee

Dr Reed in tabling his report and recommendations (copy attached) said that his committee had achieved general consensus but not total uniformity.

Professor Tattersall said that the sub-committee should make a statement on the dependability of cytology in determining benign tumours (false negatives). He also said that the ratio of four non malignant to one malignant was a factor to be considered in developing the reporting.

Dr Reed said that these matters could be looked at at a future meeting.

Dr Byrne expressed concern at the difficulty of controlling non institutional pathology centres. Dr Reed said that the desired format would be circulated.

The report was received.

5.2. Mammography Sub-committee

The Chairman tabled a report for Professor Hare who was overseas for some time.

The Committee decided that a meeting of the sub-committee should be convened as a matter of importance and that Dr Rickard should be asked to convene the meeting. The RACR Mammography Sub-committee representative should be invited.

The work of the committee would be to establish end points for 'on-referral'. A suggested flow sheet was tabled.

The question of who should perform the clinical examination when an abnormality was discovered was discussed. Views differed as to whether this should be a surgeon, a general practitioner or even specially trained nurses. The preferences of the patient for minimal delay, explanation of procedure and female examiner were highlighted by Ms Hall and supported by Dr Mitchell who said that the screening process should be carried out by women.

5.3. Core Data Sub-committee

Dr Ring said that the recommendations of his committee had largely been incorporated in the AHMAC report. He said that time was a problem with only 2.5 years left to provide the data for evaluation and decision making. There was general expectation that Government funding would be made available for the ongoing needs of the projects but the Chairman was asked to have the ACS write for confirmation of this.

The point was made that studies would not be accepted by women as a substitute for services and the Government could not long delay making a decision on services and funding.

Dr Redman asked who would study non-compliance-projects of AIH? It was decided that projects would have to conduct initial studies.

5.4. Economic Evaluation

Ms Hall pointed out that there was no sub-committee and asked what role the NBSC saw for itself.

It was agreed that the NBSC should limit itself to medical and technical matters leaving economic issues to AHMAC and the AIH with Ms Hall as the bridge. Ms Hall was asked to provide quarterly reports to the NBSC on economic aspects and financial judgements being made.

Professor Tattersall said that the NBSC should prepare for the move to national screening when the pilot projects led to mass population screening and consider the economic problems in the provision of training and equipment.

6. Status Reports:

A review was made of each of the projects planned.

It was noted that the NBSC lacked a South Australian member. The Chairman said that it had been intended to seek a general practitioner and this would be reactivated.

7. Minimal Breast Cancer - Patterns of Care:

The Chairman tabled a protocol adopted in Victoria to collect data about the detection and management of minimal breast cancer. He

said that the Cancer Registry received pathology reports on ninety per cent of notified breast cancers and that this would facilitate identification of minimal breast cancers.

He expressed support for this survey to become nation wide.

Dr Furnival asked if all State cancer registries could undertake the task. Mr Russell undertook to approach the AACR and asked for speedy comments on the protocol.

He said that the ANZ College of Surgeons journal was publishing an article on Patterns of Care in its next issue which he would have circulated.

8. Other Business:

8.1. Rebates for Screening Mammograms
Professor Tattersall said that the question of medicare rebates for screening remained a vexed question involving preventive health measures, consumer protection and quality of service.

The meeting noted that the RACR hoped to control this issue by a system of accreditation.

8.2. New Issues
The Chairman invited members to raise new issues for inclusion on future agendas.

8.3. Next Meeting
The next meeting will be held in Sydney on Thursday 16 June 1988.

The meeting was closed at 3.00pm.

_____
CHAIRMAN

_____
DATE

ATTACHMENT 2

COLLEGE COMMISSION ON THE PROVISION OF SURGICAL SERVICES

Report of the Working Party on Staffing Implications of Breast Cancer Screening Programmes

Members

Professor P. S. Boulter (Chairman)
Professor R. W. Blamey
Miss Phyllis George
Professor G. Westbury
Ex officio:- Sir David Innes-Williams

In attendance:

Ms. Frances Blythe
Mr. Craig Duncan

Introduction

This is the report of the Working Party established by the College Commision on the Provision of Surgical Services to investigate staffing implications arising from the implementation of a breast cancer screening programme for women aged 50 to 64 as recommended by the Forrest Report. The general principles of the Forrest Report were welcomed by the Working Party. It was agreed that an analysis of the conclusions should be made and there should be recommendations to deal with problems in staffing and training arising from its forthcoming implementation.

RETROSPECT

The British Trial - Methods and Results

The majority of women who have been screened during the recent British study have been found to be clinically and radiologically normal. However, in the initial rounds of examination, up to 20 per cent of those who were screened were, for radiological or clinical grounds, deemed worthy of further investigation in the review clinic in both Edinburgh and Guildford. These clinics have been conducted by women doctors with special experience in screening working in collaboration with radiologists and surgeons. In the review clinic further physical examination, more X-rays (including standard views and magnification mammograms), ultrasonic studies and cytology have been

practised. These methods, which involve a high degree of expertise and sophisticated equipment, have confirmed in some women the need for further assessment by the project surgeons and up to 10 per cent of screened women have been referred on to project surgical teams. It was noted that the value of the initial clinical examination increases as the screening entry age lowered, being greater in premenopausal women. The clinical part of the examination in the initial screening clinic has had the merit of permitting discussion of symptoms with women and thus initiating investigation of problems which might not be indicated by mammography alone which will consistently miss between 5 and 10 per cent of cancers.

It was noted by the Working Party that continuity of investigation from initial screening to the surgical opinion which followed the final stage of assessment, was a continuum best achieved within the environment of the screening centre maintaining the concept of screened women being well-women until the definition of a need for hospital treatment transforms them into patients.

Recruitment and Referral in the British Trial

The collaboration of General Practitioners has been vital. Women were invited individually from practice lists made as accurately as possible to compensate for errors that occur both in the records of individual practices and in the central lists of Family Practitioner Committees. An acceptance rate of 70 per cent has been achieved in the study and this should be regarded as less than satisfactory in the knowledge that in Sweden and Holland there had been acceptance in excess of 80 per cent. Direct from the screening clinic there was an automatic reference to the review clinic and there has been a pre-agreed policy that the project surgeons should see those women in whom surgical assessment was required, thereby using the specialized experience of the associated breast unit. This system has worked well and there has always been an escape clause whereby patients or their doctors could ask for reference to other surgeons. This has seldom happened in practice.

Reference to surgeons for further action is indicated in as many as 20 per thousand screened woman. It is essentially for further investigation and consideration rather than purely for biopsy. This should only be done by surgeons after due consideration of investigations conducted previously and reviewing doctors and radiologists.

Biopsy Rate

It was noted that the number of biopsies tends to fall with improved expertise but artificially low biopsy rates should not be sought as cancers could thus be missed. In general, the biopsy rate achieved in the screening studies demonstrated a rising efficiency of the whole screening exercise. It is predicted in the Forrest report that the number of biopsies carried out as a result of the presence of the screening Programme will be contained more efficiently if women are referred to breast units where special techniques particularly appropriate to impalpable lesions have been perfected.

PROSPECT

Future Reference Pattern

At the start of a screening programme there should, where possible, be an agreement with General Practitioners that women should be referred to units where appropriate expertise is concentrated. It was agreed that a recommendation should be made to the Royal College of General Practitioners that this type of referral is essential to maximise the benefit of screening programmes and to reduce unnecessary surgery which should result from reference to clinicians as yet unversed in modern practice. Whenever possible, reference from screening centres should be to surgical teams closely associated and ideally women should be seen within the screening assessment centre. It was likely to be more expeditious and efficient for reference to be to surgeons from multidisciplinary breast teams rather than to general surgical out patients.

Training of Clinicians with an Interest in Breast Disease

There are, at present, very few doctors who have the necessary experience to perform the tasks of assessment in screening centres and more of these should be trained. Training should be conducted by those few specialist doctors who have already become familiar with the techniques of modern investigation through their experience in the review clinics. It was agreed that the participation of radiologists and surgeons in this training programme was mandatory. It was further agreed that as the ultimate objective of screening is to find those women who have a problem needing invasive investigation or treatment then surgeons must be an integral part not only of the working but also the educational environment of the training centres.

Training of Surgeons

Four national training centres in breast screening have been designated: Guildford, Nottingham, Kings College Hospital and Manchester. While a major responsibility of these centres is to train clinic doctors, radiologists and radiographers, there is a clear need for these centres to participate in the training of surgeons and to promote interdisciplinary discussion between screening doctors, surgeons, radiologists and pathologists.

In each region a screening centre has been identified and these can soon commence work. There is, therefore, urgency in both organization and aspects of training. There is, as yet, no clear pathway for the gaining of expertise in the surgical problems of screening and training programmes should be established in collaboration with the training centres and possibly with an input from the Royal Colleges of Surgeons. These Colleges should actively support training programmes for surgeons who wish to gain special experience to enable them to participate effectively in the surgical consequences of screening.

Quality Control of Surgery

It is essential that the results of surgical assessment and the resultant surgical procedures arising from screening which have been the subject of detailed audit during the period of the British Trial must continue to be

monitored very carefully. Centres undertaking surgical assessment and management of screened women should have a system for audit and continuous and careful statistical analysis.

Regional Breast Units

The surgeons who already have special experience should work, whenever possible, within designated sub-regional centres serving 4 districts (ie. a population of 1 million). Here the problems of screening should be dealt with in a multidisciplinary way and all modern investigative modalities are available. It was felt unlikely that present resources would permit of more than three of these centres per N.H.S. region in the first instance. The surgeons concerned should play a major part in passing this expertise on to surgical trainees so that an increasing number of men and women with a specialist interest in breast disease is achieved. This means that the subregional centre should become a practical working entity and that rigid adherence to district boundary although administratively attractive, is clinically undesirable.

The clinical work of a district screening programme if it is to be done properly will involve three sessions of surgical time and this allows of the very necessary component of teaching. Thus in each region a calculation can be made dependent upon the number of districts. Probably Britain needs at least 10 more surgeons with a special interest in breast disease and that inevitably those who elect to work in units with such a special interest will shed some of their other clinical commitments within general surgery which will allow of increased concentration of experience in other facets of surgery to those surgeons whose major interest is not in breast surgery.

Quality Control of Mammography

There was concern at the small number of radiologists presently trained in mammographic interpretation. It was agreed that it was at present impractical to expect every district to be able to cope with the radiological workload of the screening programme and that in each region several radiologists with a special interest should conduct the majority of the work in the first place. They should be supported by radiographers with mammographic expertise. Every effort should be made to provide X-ray machinery of quality and adaptability to allow of the sort of imaging which is now possible. It was felt that the Royal College of Surgeons should institute discussions with the Royal College of Radiologists and the U.K. Mammographic Association.

Other Investigative Modalities

Cytology now plays an important role in assessment of breast disease, both in the screening centre and in hospital breast clinics. It was agreed that there should be discussions with the Royal College of Pathologists to ensure that cytological expertise will be plentiful in the future.
These techniques must be available to assessment centres and breast units.

Skill in histopathological assessment has developed very greatly during the period of the British study. This applies very specially to the assessment of border-line pathology which is a particular problem of lesions in screened

women. The skills now available in specialized centres can not be taken for granted in all laboratories and collaboration between pathologists and clinicians is highly desirable and a reference role for specialist breast pathologists is essential.

Summary

The Working Party welcomed the progress that had been made in the preliminary trials which had depended on collaboration between screening doctors, radiologists and surgeons in the trial centres. The collaboration should continue and surgical input into screening centres and their assessment clinics was essential both in practice and in that training which would allow of the emergence of the new variety of clinicians with specialist interest in breast assessment and treatment. Subregional centres should incorporate all the disciplines concerned with the screening and investigation of women with breast problems. Preferential referral should wherever possible be made directly by the screening centres to these specialist clinical groups.

The Royal Surgical Colleges should participate in the training of clinical doctors and specialist surgeons in breast disease. The Colleges should liase with the Royal Colleges of Radiologists and Pathologists both in training and staffing matters and with the Royal College of General Practioners in the establishment of an appropriate reference pattern.

Recommendations

1. The Royal Surgical Colleges should take an active training and monitoring role in the clinical services concerned with screening for Breast Cancer.

2. There should be intercollegiate discussion with the Royal College of Radiologists and the Royal College of Pathologists on matters both of services and training and with the Royal College of General Practitioners to develop an appropriate and acceptable referral policy.

3. Breast screening centres should have appointed surgical input:-

   (i) To participate in and to oversee clinical assessment.

   (ii) To carry out the surgical procedures indicated by the screening findings.

   (iii) To participate in the training of doctors working in screening centres.

4. The surgeons involved in screening centres should be members of a multidisciplinary regional or subregional breast team.

ATTACHMENT 3

RECORD OF A MEETING

A meeting was held under the auspices of the Australian Cancer Society on Wednesday 11 May 1988, in the Conference Room, 3rd Floor, 500 George Street, Sydney, for Directors of Mammography Screening Projects, representatives of the Australian Institute of Health and others.

The purpose of the meeting was to discuss the definition of certain steps in the screening program to establish a common basis for the evaluation process.

Present:

Mr I. Russell	(Chairman)
Dr M. Rickard)	
Dr L. Irwig)	Rachel Forster Project - Sydney
Ms J. Hall)	
Dr C. Baker	Royal Womens Hospital Brisbane Project
Dr C. Hirst	Wesley Hospital Brisbane Project
Prof. J. Forbes	Hunter Valley/Newcastle Project
Ms S. Hurley	Essendon Melbourne Project
Dr M. Fett)	
Dr R. Knight)	Australian Institute of Health
Mr R. Hall)	
Mr R. Carter)	
Dr P. McCann	Department of Community Services & Health
Dr R. Melville)	Australian Cancer Society
Dr R. Reed)	
Mr L. Wright	Secretary

Dr I. Ring was prevented from attending by an airline difficulty.

The 'terms of reference' for the meeting was a letter from the Chairman to participants specifying the matters to be discussed. Copy attached. ATTACHMENT 1

The meeting was opened at 2.10 pm.

The Chairman welcomed the participants and emphasised that the aim of the meeting was to share information, identify common ground and where possible agree on definitions and procedures.

Definition of Target Population

Dr Baker tabled the definitions in use in the Brisbane project.

The meeting agreed that the target population of the various projects would be defined in different ways depending on the method of definition, but all should include geography, sex and age.

The consensus view was all presenters should be screened but those presenting from outside the target population should be separately identified. Patients with symptoms would be screened and (apart from those complaining only of pain) would be recalled to the review clinic for clinical assessment.

Presenters who had been treated for breast cancer would have a 'screening mammogram' (unless there had been recent satisfactory mammography). The patient should then, ideally, be advised to have continuing review by her treating clinician who would receive a report for the screening centre.

The potential problem of additional xray exposure for patients who had recently had a mammogram was discussed. Opinion varied over the appropriate course of action. Mr. Russell indicated that in the Victorian project, if the woman had had a mammogram (other than a xerogram) in the previous six months, attempts would be made to obtain the relevant films. If they were considered inadequate or were unobtainable, further films would be taken. Dr Rickard felt that this was impractical and replied that all patients in the Rachel Forster project would be re-xrayed irrespective of when they had last had a mammogram.

When Does Screening Cease

Discussion took place about the point at which screening ceased and therapeutic action commenced. It was agreed that data should be collected until the pathological diagnosis was established (either by needle aspiration or open surgical biopsy). On the other hand, from a budgetary point of view, while the cost of hospitalisation and surgical biopsy might be met by medicare, private insurance or direct contribution by the patient, the cost of treatment arising as a result of the screening process should be recorded for cost-evaluation analysis.

Cost Evaluation

The A.I.H. representatives briefed the meeting on the breakdown of costs to be standardized for evaluation i.e.

Recruitment/Education

Screening - Radiology - including rescreening
Film reading
Notification of women

Recall
Investigation to confirm diagnosis - procedures
pathology
confirmation of action taken

Details of treatment of breast cancer and other breast diseases would be recorded but not costed.

Other cost centres would include research, evaluation, quality control and training.

A.I.H. was preparing a check list and guidelines for apportionment of costs.

Government Funding

Dr McCann advised that the Commonwealth would provide $2.6m for the three years to 6/90. Funding beyond 6/90 would be a perogative of which-ever Government was then in power.

Funds would be provided to establish the Screening Evaluation Control Unit (SECU) in the A.I.H. Seeding grants of $50,000 were being provided for a joint Queensland project (RWH/Wesley), Rachel Forster (NSW), Essendon (VIC), SA and WA. The projects would be funded through State Health Departments approval of a 'project plan' prepared by the designated projects.

Criteria for Recall

Recall would be necessary when there was a technical problem with the first screening or when further investigation and re-screening was indicated.

Interval Cancer

A cancer presenting between screening appointments, where review of the preceeding film reveals no indication of malignancy, is an interval cancer and the interval since screening should be noted.

Dr Rickard described the process used in the RFH project where re-screenees also received ultra-sound. Screenees with diagnosed benign conditions were not processed further. Those not so diagnosed were referred to a combined surgical/radiologic clinic for 'blind' follow up.

There was a discussion on the appropriate management of simple cysts and whether or not all cysts should be aspirated as a standard procedure.

There was a long discussion on the definitions of 'missed cancer' 'interval cancer' and 'false negative'.

A detected abnormality classified as benign which later proves to be a cancer is a 'false negative'.

Where no evidence of malignancy is detected and cancer is detected subsequently and the check of the initial x-ray confirms no evidence of abnormality, is an 'interval cancer' and the interval since screening should be noted.

A 'false positive' is when a diagnosis of malignancy is made or cannot be excluded and the lesion is found on biopsy to be benign.

Patient Identification for National Evaluation

Dr Fett advised the meeting that legislative controls on the handling of patient data by the A.I.H. were being strengthened. Best use could be made of data from the projects if individuals could be linked to Medicare records in the H.I.C. He said the areas of concern were patient consent and confidentiality of data.

He said the information on individuals might be provided by date of birth, medicare no., name, project record no. or as project aggregate statistical data. He stressed that as the A.I.H. would have involvement in the National Death Index and the Cancer Statistics Clearing House individually identifiable data would be of greatest value.

Dr Baker said that RWH could provide Medicare nos, Wesley said they would provide project identification nos only and Essendon said they would supply only aggregated statistics.

Dr Fett said it would be beneficial to link all the projects into a national cooperative project such as the US Breast Cancer Detection Demonstration Project.

The Chairman said that national evaluation depended upon pooling non-identifiable personal data and all project directors should attempt to provide this.

Model Project Plan

Dr Fett said that contracts for funding of projects would incorporate the necessity for the submission of a project plan. He tabled a model prepared by SECU (copy attached) and said SECU was also preparing a skeleton procedures manual.

Closing Remarks

The Chairman said he had found the meeting to be a beneficial exchange of views and said he would consider whether a further meeting would be useful in discussing policies for management of benign conditions, in-situ cancer and pre-cancerous conditions. A research project might also be considered.

The Secretary distributed copies of the Canadian booklet, "Breast Imaging Services: Mammography Guidelines".

The meeting was closed at 5.00 p.m.

.....
CHAIRMAN

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Patient Identification for National Evaluation

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He said the information on individuals might be provided by date of birth, medicare no., name, project record no. or as project aggregate statistical data. He stressed that as the A.I.H. would have involvement in the National Death Index and the Cancer Statistics Clearing House individually identifiable data would be of greatest value.

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The Chairman said that national evaluation depended upon pooling non-identifiable personal data and all project directors should attempt to provide this.

Model Project Plan

Dr Fett said that contracts for funding of projects would incorporate the necessity for the submission of a project plan. He tabled a model prepared by SECU (copy attached) and said SECU was also preparing a skeleton procedures manual.

Closing Remarks

The Chairman said he had found the meeting to be a beneficial exchange of views and said he would consider whether a further meeting would be useful in discussing policies for management of benign conditions, in-situ cancer and pre-cancerous conditions. A research project might also be considered.

The Secretary distributed copies of the Canadian booklet, "Breast Imaging Services: Mammography Guidelines".

The meeting was closed at 5.00 p.m.

.....
CHAIRMAN

.....
DATE

RECORD OF A MEETING

A meeting was held under the auspices of the Australian Cancer Society on Wednesday 11 May 1988, in the Conference Room, 3rd Floor, 500 George Street, Sydney, for Directors of Mammography Screening Projects, representatives of the Australian Institute of Health and others.

The purpose of the meeting was to discuss the definition of certain steps in the screening program to establish a common basis for the evaluation process.

Present:

Mr I. Russell	(Chairman)
Dr M. Rickard)	
Dr L. Irwig)	Rachel Forster Project - Sydney
Ms J. Hall)	
Dr C. Baker	Royal Womens Hospital Brisbane Project
Dr C. Hirst	Wesley Hospital Brisbane Project
Prof. J. Forbes	Hunter Valley/Newcastle Project
Ms S. Hurley	Essendon Melbourne Project
Dr M. Fett)	
Dr R. Knight)	Australian Institute of Health
Mr R. Hall)	
Mr R. Carter)	
Dr P. McCann	Department of Community Services & Health
Dr R. Melville)	Australian Cancer Society
Dr R. Reed)	
Mr L. Wright	Secretary

Dr I. Ring was prevented from attending by an airline difficulty.

The 'terms of reference' for the meeting was a letter from the Chairman to participants specifying the matters to be discussed. Copy attached. **ATTACHMENT 1**

The meeting was opened at 2.10 pm.

The Chairman welcomed the participants and emphasised that the aim of the meeting was to share information, identify common ground and where possible agree on definitions and procedures.

Definition of Target Population

Dr Baker tabled the definitions in use in the Brisbane project.

The meeting agreed that the target population of the various projects would be defined in different ways depending on the method of definition, but all should include geography, sex and age.

The consensus view was all presenters should be screened but those presenting from outside the target population should be separately identified. Patients with symptoms would be screened and (apart from those complaining only of pain) would be recalled to the review clinic for clinical assessment.

Presenters who had been treated for breast cancer would have a 'screening mammogram' (unless there had been recent satisfactory mammography). The patient should then, ideally, be advised to have continuing review by her treating clinician who would receive a report for the screening centre.

The potential problem of additional xray exposure for patients who had recently had a mammogram was discussed. Opinion varied over the appropriate course of action. Mr. Russell indicated that in the Victorian project, if the woman had had a mammogram (other than a xerogram) in the previous six months, attempts would be made to obtain the relevant films. If they were considered inadequate or were unobtainable, further films would be taken. Dr Rickard felt that this was impractical and replied that all patients in the Rachel Forster project would be re-xrayed irrespective of when they had last had a mammogram.

When Does Screening Cease

Discussion took place about the point at which screening ceased and therapeutic action commenced. It was agreed that data should be collected until the pathological diagnosis was established (either by needle aspiration or open surgical biopsy). On the other hand, from a budgetary point of view, while the cost of hospitalisation and surgical biopsy might be met by medicare, private insurance or direct contribution by the patient, the cost of treatment arising as a result of the screening process should be recorded for cost-evaluation analysis.

Cost Evaluation

The A.I.H. representatives briefed the meeting on the breakdown of costs to be standardized for evaluation i.e.

Recruitment/Education

Screening - Radiology - including rescreening
Film reading
Notification of women

Recall
Investigation to confirm diagnosis - procedures
pathology
confirmation of action taken

Details of treatment of breast cancer and other breast diseases would be recorded but not costed.

Other cost centres would include research, evaluation, quality control and training.

A.I.H. was preparing a check list and guidelines for apportionment of costs.

Government Funding

Dr McCann advised that the Commonwealth would provide $2.6m for the three years to 6/90. Funding beyond 6/90 would be a perogative of which-ever Government was then in power.

Funds would be provided to establish the Screening Evaluation Control Unit (SECU) in the A.I.H. Seeding grants of $50,000 were being provided for a joint Queensland project (RWH/Wesley), Rachel Forster (NSW), Essendon (VIC), SA and WA. The projects would be funded through State Health Departments approval of a 'project plan' prepared by the designated projects.

Criteria for Recall

Recall would be necessary when there was a technical problem with the first screening or when further investigation and re-screening was indicated.

Interval Cancer

A cancer presenting between screening appointments, where review of the preceeding film reveals no indication of malignancy, is an interval cancer and the interval since screening should be noted.

Dr Rickard described the process used in the RFH project where re-screenees also received ultra-sound. Screenees with diagnosed benign conditions were not processed further. Those not so diagnosed were referred to a combined surgical/radiologic clinic for 'blind' follow up.

There was a discussion on the appropriate management of simple cysts and whether or not all cysts should be aspirated as a standard procedure.

There was a long discussion on the definitions of 'missed cancer' 'interval cancer' and 'false negative'.

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DATE

AUSTRALIAN CANCER SOCIETY INC.
A & C Building, 500 George Street, Sydney. Telephone (02) 267 1944
GPO Box 4708, Sydney, NSW. 2001. Australia. FAX: (02) 261 4123
Telex: AA 71036. Telegraphic address: Austcancer Sydney

Patron: His Excellency the Right Honorable Sir Ninian Stephen, AK, GCMG, GCVO, KBE.

Member Organisations:
ACT Cancer Society
Anti-Cancer Council of Victoria
Anti-Cancer Foundation of the Universities of South Australia
Cancer Foundation of Western Australia
New South Wales State Cancer Council
Northern Territory Anti-Cancer Foundation
Queensland Cancer Fund
Tasmanian Cancer Committee

The establishment of a national policy for Breast Cancer Screening will depend on the evaluation and comparison of the various pilot projects already underway or planned to commence shortly. To achieve comparison and evaluation it is desirable that there be as much agreement as possible about various "definitions".

Issues which require resolution are for example:-

The definition of the target population and of the screenee. Should the screened population include only asymptomatic women. How should patients with breast lumps or breast symptoms be handled? Should patients with a previous history of breast cancer be excluded?

When does screening cease? Should it cease when a decision is made that there is an abnormality or should the screening process continue until pathological diagnosis is established?

What are the criteria for re-calling patients. How should these patients be handled on recall.

What is the definition of an interval cancer? How should we define false negatives and false positives? How should a detected benign abnormality be classified?

Apart from matters of "definition" there are issues relating to confidentiality. When the National Evaluation Unit is established data will be sought from the screening projects. A decision must be made as to whether patient-identified data will be made available to a national centre.

Thesematters were discussed at the recent meeting of the National Breast Study Committee and it was decided to invite "policy makers" from the proposed and active screening units to meet with representatives of the Pathology, Mammography and Data Subcommittees of the National Breast Study Committee and with representatives of the Australian Institute of Health.

As you know the meeting is planned for the 2pm on the 11th of May at the Australian Cancer Society and I look forward to meeting you then.

With kind regards,

Yours sincerely,

IAN S. RUSSELL

Model project plan for mammography screening pilot projects

SECU - 10 May 1988

SECU believes it is highly desirable that all mammography screening pilot projects develop a project plan along the lines suggested here in order to facilitate the effective and efficient conduct of the nationally co-ordinated evaluation.

It is recommended that the project plan contain the following:

- major milestones in the implementation of the service delivery aspects of the project;
- major milestones in the implementation of the epodemiological, economic and behavioural science evaluations of the project;
- the dates by which these milestones will be reached;
- an outline of the contents of reports and the types of data to be provided to SECU; and
- the dates by which these reports and data will be provided to SECU.

In preparing the project plan, each pilot project should seek to give calendar dates to as many of the events listed as possible. For events where this is not possible, an indication should be given as to when dates can be provided.

Where timetable events have already passed (e.g. a project has already screened many women), the project should specify a date within the next six month on which the required information will be provided to SECU.

The details of the documentation and data to be provided to SECU will need to be developed over the next few months in consultation with SECU. Guidance is given in the AHMAC Working Party Report and will be elaborated in the reports of the SECU sponsored workshops in economics (held on 20-21 April 1988) and behavioural science (to be held on 19-20 May 1988). It may prove desirable to also involve the AHMAC Breast Cancer Screening Evaluation Steering Committee when this new body is formed.

SECU will also be preparing and distributing a project

plan covering its own operations.

Milestone / Documentation / Data	Dates of delivery to SECU
Service delivery	
Description of target population	First screening
Procedure manuals and updates of procedure manuals for service delivery: - recruitment - screening - follow-up - counselling - radiol. maintenance/monitoring - film processor maintenance	First screening; and Major change in proc.; and Every 6 months (Specify dates)
In relation to the screening clinic, inform SECU when: - funds are provided - new equipment is installed - clinic becomes operational	When it happens (Specify dates where applicable)
In relation to the follow-up clinic, inform SECU when: - funds provided - new equipment installed - clinic becomes operational	When it happens (Specify dates where applicable)
Clearance of project by an ethics committee	When it happens (Specify date)
Information package for women	When prepared (Specify date) When modified
Protocol for obtaining informed consent	When prepared (Specify date) When modified

The service delivery procedures manuals should describe all aspects of operations, including resources employed.

Milestone / Documentation / Data	Dates of delivery to SECU
Evaluation	
Protocols and procedure manuals for collecting data on: - Epidemiology (inc service del.) - Economics - Behavioural science	First screening; and Major change in proc.; and Every 6 months (Specify dates)
Recruitment data in relation to: - Epidemiology - Economics - Behavioural science	100th screen; and Every 6 months (Specify dates)
Screening data in relation to: - Epidemiology - Economics - Behavioural science	100th screen; and Every 6 months (Specify dates)
Follow-up/diagnosis data in relation to: - Epidemiology - Economics - Behavioural science	20th follow-up; and Every 6 months (Specify dates)
Treatment data in relation to: - Epidemiology - Economics - Behavioural science	5th case; and Every 6 months (Specify dates)
Surveys of target population	When available (Specify dates)
Surveys of screening attenders	When available (Specify dates)
Surveys of follow-up attenders	When available (Specify dates)
Surveys of booked non-attenders	When available (Specify dates)

Evaluation protocols and procedure manuals should describe the data set in detail and all technical aspects of data collection, storage, analysis and transmission to SECU.

The provision of data after the 100th screen, 20th assessment and 5th case is intended to test data transmission mechanisms and to identify at an early stage possible data limitations and incompatibility.

A member of the Australian Cancer Society
Director: Dr Nigel Gray A.M. MB, BS, FRACP, FRACMA

Anti-Cancer Council of Victoria

57-lr-05/3

May 16, 1988

Memorandum to: Professor R Lovell
cc GG, NJG, DH, DR, JC

From: Susan Hurley

Subject: ACS Meeting, Sydney, May 11, 1988

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I attended the above meeting, which was held under the auspices of the National Breast Study Caommittee, at the invitation of Mr Ian Russell. A background letter from Ian Russell describing the purpose of the meeting is attached.

Present
Ian Russell (Chairman)
Laurie Wright (ACS)
Michael Fett, Robert Carter
Robert Hall, Rosemary Knight (SECU)
Paul McCann (Commonwealth Health Department)
John Forbes (Newcastle project)
Mary Rickard, Les Irwig, Jane Hall (Rachel Forster project)
Richard Reed
Christine Baker (Royal Women's Hospital, Brisbane)
Cherrell Hirst (Wesley Hospital, Brisbane)

There was much discussion about definitions of the target population, screening, false negatives etc, but little agreement. The proposed national evaluation was discussed at length and I provide the following summary.

1. Paul McCann expressed surprise at my presence as he had been informed that the ACCV was no longer involved in the AMEH project. He said that submissions for evaluation funds had been received from a number of projects (including Melbourne), that recommendations for funding were before the Minister of Health and an announcement was expected in the week beginning May 16th,

2. The SECU group are still keen to obtain patient identified unit record data. They have drawn up draft contracts (model project plan, attached) which they would like pilot projects to sign in return for evaluation funds. Note that the model project plan requires supply of unit record data at very frequent intervals.

3. Ian Russell seemed to believe that SECU will have a major role in project evaluation and resesarch activities. He encouraged SECU to re-apply to the AMEH project management committee for supply of unit record data.

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PARKVILLE 3052
TELEPHONE: 347 0122

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4.2.3 Quality Control of Mammography

All programmes should have the following essential features :

1. Community awareness and education programmes
2. Recruitment strategies that maximize participation
3. Initial call and recall of all identifiable eligible women
4. Adequate machine maintenance and surveillance of radiological safety
5. Mechanisms for monitoring and assessing the quality of film exposure, processing and reading
6. Screened women are informed of positive and negative results
7. Availablity of support and counselling services
8. Access to expert diagnostic and therapeutic services by women who screen positive
9. Linkage to population-based cancer and death registers

4.2.4 Equity of Access

All programmes should promote equity of participation by groups of eligible women irrespective of their geographical location, ethnic origin, or social position.

4.3 GOALS AND TARGETS FOR SCREENING FOR CANCER OF THE UTERINE CERVIX

Deaths from carcinoma of the uterine cervix are increasing in young women and although falling are still substantial in older women. Although sexually transmitted agents are suspected, the precise etiology is unknown, and for the forseeable future prevention must be based on the established effective cytological examinations known as Pap smears, which are able to test for neoplasia before invasive cancer occurs. Despite our knowledge on how to prevent cervical cancer, some 340 Australian women die from invasive cancer of the cervix each year, largely because screening and management are not appropriately organised.

4.3.1 National Goals

To reduce deaths from invasive carcinoma of the uterine cervix by -

1. Developing organized population-based cervical cancer screening programmes in each State or Territory.
2. Increasing the proportion of women who are screened regularly.

4.3.2 National Targets

Organized Programmes

1. By 1989, each State or Territory should have defined who is responsible and accountable for the screening programme.

2. By 1989, a feasibility study of ways to develop and maintain a list of women in the target population should be undertaken. Such a study should include an exploration of the use of the Commonwealth Electoral Register and Medicare files.

3. By 1990, organized population-based cervical cancer screening programmes should be established in each State or Territory.

4. By 1990, data from State or Territory programmes should be collected in such a way that national monitoring is facilitated.

Proportion of women screened regularly

5. The proportion of women between the ages of 20 and 69 with a Pap smear at least every 3 years should increase to 50% by 1990, to 75% by 1995 and be universal by 2000.

4.3.3 Strategies that will contribute to these Targets

Organized population-based cervical cancer screening programmes

1. Programmes should include mechanisms/facilities, and sufficient funding for -

   - reaching the target population at defined intervals
   - follow-up of women with an abnormal smear report
   - quality assurance in the taking and examination of cervical smears
   - program evaluation and epidemiological research.

2. Active attempts should be made to increase the participation of eligible women in cervical cancer screening programmes with evaluation of the cost-effectiveness of alternative strategies. Methods to increase participation should include call and recall systems, public and professional education, and the provision of alternative services for the taking of smears.

Screening Interval

3. The Australian Cancer Society should convene a meeting early in 1988 to obtain consensus on the optimal screening interval. The following organisations should be asked to send representatives:

   - Gynaecological Section of COSA
   - Oncological Nurses Section of COSA
   - Australian Society of Gynaecological Oncologists
   - Australian Society of Cervical Pathology and Colposcopy
   - Royal Australian College of Obstetricians and Gynaecologists
   - Australian Society of Cytologists
   - Royal Australian College of Pathologists

- Royal Australian College of General Practitioners
- National Health and Medical Research Council
- Australasian Epidemiologal Association
- Australian Cancer Society

Note: Information on the natural history of cervical neoplasia in Australian women in the 1980s and the costing of different screening intervals will be provided by the ACS.

National Policy Coordination

4. There should be a national policy co-ordinating group for cervical cancer screening, to promote the development of national policy, to encourage collaboration between States and territories in the development of cervical cancer screening programmes, to provide a forum for the exchange of information and ideas on the delivery of cervical cancer screening services, and to facilitate the monitoring of national trends in screening.

Funding

5. The Commonwealth Department of Community Services and Health should consider alternative funding arrangements to the current fee-for-service system for Pap smear reporting. In particular it is urged to consider removal of the rebate item for Pap smear reporting and to reallocate the money as specific annual programme grants to the States or Territories for cervical cancer screening programmes. The amount provided to each State should be proportional to its female population. The money should be block granted to approved laboratories (in both the public and private sectors) conditional upon their participation in quality control, follow-up of women with abnormal smears, and participation in a statewide register of smears.

4.4 GOALS AND TARGETS FOR THE PREVENTION OF SKIN CANCER

Skin cancer is the most common type of cancer in Australia, and rates here are the highest in the world. The lifetime risk is 2% for melanoma and 70% for other common types (mainly basal cell carcinoma and squamous cell carcinoma). Although the case fatality is low, there are significant numbers of deaths each year - some 800 from melanoma and 200 from other types of skin cancer. Skin cancers are also important because of their large demands on preventive and curative health services.

4.4.1 National Goals

1. To reduce morbidity and mortality from melanoma and other skin cancers through early detection.

2. To reduce the incidence of these other skin cancers through reduction in ultraviolet exposure.

4.4.2 National Targets

Early Detection of Melanoma and Other Skin Cancers

1. By 1993 40%, and by 2000 80% of the public should recognise the appearance of, or changes in, skin lesions that may signify cancer.