

Report of the 137th Session of the NHMRC 12-13 October 2000 Adelaide

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General Information

The 137th Session of the National Health and Medical Research Council was held on 12-13 October 2000 in Adelaide. Those present were:

Professor Nicholas Saunders (Chairman)	Faculty of Medicine, Monash University
Professor Warwick Anderson	Chair, Research Committee
Dr Jack Best	Chair, Strategic Research Development Committee
Professor Adele Green	Chair, Health Advisory Committee
Dr Kerry Breen	Chair Australian Health Ethics Committee
Ms Prudence Ford	Executive General Manager, Finance and Infrastructure, Health Department of WA
Dr Steven Guthridge	General Manager – Public Health, Territory Health Services, Northern Territory
Dr John Sparrow	Chief Medical Officer, Department of Community and Health Services, Tasmania
Dr A. Wilson	Chief Health Officer, Department of Health, New South Wales
Professor Bryan Campbell	Chief Health Officer, Queensland Health
Professor John Catford	Director of Public Health, Department of Human Services, Victoria
Dr Michael Bollen	person with background in, and knowledge of, the medical profession
Professor Kerin O’Dea	person with a background in, and knowledge of, public health issues
Professor Lesley Barclay	person with a background in, and knowledge of the nursing profession
Professor Ken Bowman	person with expertise in health care training
Dr Jennifer Thomson	person with knowledge of professional medical standards and expertise in post-graduate medical training
Dr Bronwyn Kingwell	person with expertise relevant to the functions of the Council
Mr John Delaney	person nominated by the Aboriginal and Torres Strait Islander Commissioner and having Knowledge of the health needs of Aboriginal persons or Torres strait Islanders
Professor Geoffrey Duggin	person with a background in, and knowledge of, the trade union movement
Professor John Young	eminent scientist with knowledge of public health research and medical research issues, and who has no current connection with Council
Professor Trang Thomas	person with knowledge of the needs of users of social welfare services
Professor Christine Ewan	person with knowledge of environmental issues

Apologies

Dr S. Bowen
Ms C. Kemp
Ms M. Kosky
Professor B. Kearney

Observers

Professor John Spencer

Australian Institute of Health and Welfare

Opening

Professor Nicholas Saunders, Chair of the NHMRC, welcomed members to the Session. In particular the Chair extended a warm welcome to Dr Geoff Brooke, attending his first Council Session. Professor Saunders noted the attendance of Dr David Roder, representing South Australia, and Professor John Spencer, representing the Australian Institute of Health and Welfare.

Report and business arising from the 136th Session of NHMRC (31 July-1 August 2000)

The Report of the 136th Session, having been circulated to members in advance, was accepted.

Communication Plan

Dr Michael Bollen, chair of the communications working committee, presented to NHMRC a progress report of work since the 136th Session. The committee has met once, reported to the NHMRC Executive, and developed and refined a draft communication plan which was presented to NHMRC.

Dr Bollen noted that the working committee saw the responsibility of communications as going beyond publicity, that the ultimate goal of good communication by NHMRC is to see behaviour change as a result of exposure to NHMRC products. Those products include information as well as tangibles such as research funding and publications. The committee sees opportunities to use new mechanisms for communication through which others would advocate on behalf of NHMRC.

NHMRC ratified the terms of reference for the communications committee and suggested the addition of a further term, namely "to advise NHMRC and its committees on communication activities at a very early stage in the development of initiatives".

A number of comments were made relating to the draft communication plan and these are to be considered by the working committee at its next meeting prior to finalising the plan:

- Should an advocacy and facilitatory role be included (or does this usurp the role of Principal Committees);
- What is the longer term (5 year) goal ie what does Council expect to "see" in five years time;
- Is there a need for a "trading name" for NHMRC;
- Radio is a readily accessible medium;
- The plan should be linked to Principal Committee activities;
- Health professionals other than general practitioners should also be identified and mechanisms to inform them included;
- Funds for committee activities are supported;
- It might be useful to obtain baseline information showing the level of understanding of NHMRC and its activities and products;
- There should be a mechanism for ensuring responsiveness such as readily available spokespersons or production of statements of an NHMRC position on emerging issues.

NHMRC asked the working committee to take these matters into account at its next meeting and to ensure that the Chief Executive Officer is included in further development of the plan.

Dr Bollen sought Council approval for funding to redevelop the NHMRC website and to obtain expert assistance in examining community perceptions and developing a logo. The working committee was asked to circulate a proposal, with expected outcomes, out of session for consideration.

Termination of Pregnancy: an information paper

Members noted that this item was discussed in detail at the intervening Executive Committee meeting of 30 August 2000 and that, given the original date of publication and the lack of clarity of purpose, that it should be built on in a more focussed way and separate information documents for general practitioners and women (not excluding their partners) should be prepared by the Health Advisory Committee for presentation to the 138th Session. It was noted that comment on State and Territory legislative requirements is outside the terms of reference for the information documents and thus will not be included.

Report and business arising from the NHMRC Executive Committee (30 August 2000)

The NHMRC Executive Committee has met once since the 136th Session. Issues discussed included:

- Progress towards implementation of the recommendations of the Health and Medical Research Strategic Review;
- Anticipated work programs of the Principal Committees and the involvement of Council members;
- Initiatives in food and nutrition;
- Development of a communication plan for NHMRC; and
- Potential involvement in supporting the Australasian Cochrane Collaboration.

Proposed NHMRC Nutrition and Food Reference Panel

In developing this proposal the Health Advisory Committee sought advice from interested organisations including the Australia-New Zealand Food Authority, the National Public Health Partnership and the Department of Health and Aged Care. The model proposed includes:

- Establishment of a small reference panel comprising members of the Health Advisory Committee and NHMRC with expertise in food, nutrition, toxicology, and public health;
- Establishment of time-limited working committees to develop or re-develop specific guidelines relating to dietary guidelines, overweight and obesity, and recommended dietary intakes;
- Establishment of a pool of experts who can be approached for advice as needed.

This model will maximise the Health Advisory Committee's capacity to respond to issues in food and nutrition, whilst maintaining good working relations with key organisations in the field. Terms of Reference for the NHMRC Nutrition and Food Reference Panel will be developed which will reflect Council's agreement that the Panel will be Council's first point of contact for food, nutrition and dietary issues.

Involvement of Council members in Principal Committee work programs

Each Principal Committee has considered ways of maximising Council involvement with a particular emphasis on involving those members of Council who have expressed a particular interest.

- The Australian Health Ethics Committee has invited two members to be continual observers at its meetings;
- The Strategic Research Development Committee has arranged that two members each year will attend meetings as observers;
- The Health Advisory Committee has arranged for four members to attend meetings in their home states and to be kept informed of all meetings as well as identifying members with specific interests of value to HAC; and
- The Research Committee has invited one member to be an observer and has suggested that three other members nominate sub-committees with which they would like to become involved.

Australasian Cochrane Collaboration Review Groups Selection Committee

NHMRC has been approached to provide assistance with a process of reviewing applications for financial support for Cochrane review groups. This would entail two NHMRC nominees to participate in a selection committee to examine applications and make funding decisions. The Department of Health and Aged Care is keen to involve NHMRC as Council has expertise in grants management processes as well as a close interest in the work of the Collaboration (for research and for evidence based guidelines).

The Department of Health and Aged Care has offered to provide administrative support to the selection committee, the structure of which is flexible and advice is welcome.

NHMRC agreed that participation presents a prime opportunity to influence which review groups Australia supports and this is relevant to NHMRC's strategic responses to research needs. Members agreed that the Chair of NHMRC should prepare a proposal that reflected Council's wish to be involved and sets out Council's suggestions for taking this matter forward. The proposal is to be presented to the NHMRC Executive meeting in December 2000 for final approval.

Principal Committee Reports

Research Committee

Professor Warwick Anderson, Chair of the Committee, summarised progress since the 136th Session. In particular he drew attention the development of the new Program Grants; further development of project grant support into a one-line grant; implementation of the Discipline Panel process in 2000; progress with transition arrangements for block funded institutes; and proposals to revitalise the NHMRC Research Fellowship scheme from 2001.

Professor Anderson advised members of the NHMRC subscription to Celera databases; the introduction of NHMRC Industry Fellowships; and continuing collaboration with the Juvenile Diabetes Foundation International. Professor Anderson noted that many of the initiatives and collaborations reported were a direct response to recommendations in the Health and Medical Research Strategic Review.

Council asked the Research Committee to provide a report to its next Session showing the details of funding in 2001, by grant type and research type (eg public health, medical). Council also asked the Research Committee to bring to the next Session its views on options for re-developing fellowship and post-doctoral research grant programs. This issue is to be discussed by the Executive Committee of NHMRC prior to the 138th Session.

Discipline Panels

Professor Anderson informed NHMRC of the Research Committee's proposals for the future management of Discipline Panels. Of particular importance is the need to maintain confidence in the system by ensuring that membership does not become stagnant and the mix of disciplines is kept up to date. To this end at least one-third of members of Panels will change annually; potential for conflict of interest, especially in narrow fields of expertise, will be monitored carefully; and the mix of disciplines covered by a Panel is likely to vary from year to year.

Although the process has experienced some teething problems, overall the system has worked well and has resulted in improved peer review.

Capacity building

NHMRC agreed that it is important for the Research Committee to consider development of the research workforce. This should include consideration of research funding programs broadly, and NHMRC programs specifically. Strengthened review processes would assist with workforce development

Members were alerted to the fact that the new EnHealth Council is interested in capacity building, especially because Australia does not have national capacity in environmental health that is easily accessible. EnHealth Council wants to develop this area but needs to do so in conjunction with other organisations. NHMRC has been identified as one of those key organisations. It was agreed that a group comprising Professor Anderson, Professor Ewan, and Professor Catford should develop this idea further.

Health and Medical Research Strategic Review

The final response to the Ministerial Implementation Committee was discussed. Members offered their thanks for Mr David Nyskohus, Office of the NHMRC, for his work in developing the report. Small refinements will be made so that the document can be forwarded to Ministers.

Science Innovation Reports

NHMRC members noted the two reports:

- *Innovation: unlocking the future* the final report of the Innovation Summit Implementation Group; and
- *The chance to change* a discussion paper by the Chief Scientist.

NHMRC agreed that it is important that a response be provided to the Prime Minister as quickly as possible. In particular, NHMRC believes that many of its initiatives will be

strengthened by implementation of recommendations contained in those reports. Professor Anderson and the Chair of NHMRC will collaborate on preparing this response.

Strategic Research Development Committee

Dr John Best, Chair of the Committee, advised of the priority areas identified by SRDC for its work program. These are ageing, mental health, indigenous health, oral health and systems of care for chronic disease. SRDC has also prepared a methodology for scoping each priority area in order to make decisions about the best course of action. Scoping will include consideration of overarching issues including health services, rural health, socio-economic determinants and palliative care. This scoping will result in the identification of action which could be taken in each priority area with a focus on capacity building and research funding.

Australian Health Ethics Committee

Dr Kerry Breen, Chair of the Committee, briefed NHMRC on the first meeting of the committee noting that two positions on the committee are still vacant. Associate Professor Colin Thomson has been appointed Deputy Chair of the Committee.

At its first meeting the Committee had identified a work program for the triennium. Key areas of work will include support for Human Research Ethics Committees; review of the existing interim guidelines on research involving Aboriginal and Torres Strait Islander people; xenotransplantation; and genetics (especially the joint enquiry in association with the Australian Law Reform Commission). The Committee has also agreed to work with the Health Advisory Committee in the development of guidelines for persistent vegetative states.

The Committee has commenced development of a communication plan and is considering means of collaborating with other groups in support of Human Research Ethics Committees. Possible avenues are the development of a common application form, examples of which have been developed in Victoria and New South Wales, and electronic sharing of information, including multi-centre trials.

NHMRC agreed that the latter issue would be of assistance to researchers, institutions and ethics committees and asked that AHEC add this to its work program and report to Council in one year's time.

On the issue of xenotransplantation, members were reminded that community safety is still a big issue and that the safety of the animals involved, or potentially involved, should not be overshadowed by the issue of human safety. Council was updated on the membership of the Gene and Related Therapies Research Advisory Panel which now has members with expertise in issues directly related to xenotransplantation.

Health Advisory Committee

Professor Adele Green, Chair of the Committee, reported on the Committee's recent meetings, including a strategic planning meeting. Professor Christopher Silagy has been appointed Deputy Chair of the Committee.

Professor Green gave a detailed presentation setting out priority areas identified by the Committee, as well as items of work from the previous triennium that are still to be

completed. Priority areas in which HAC will initiate work are indigenous health, mental health, biotechnology, health inequalities, safety and quality, and preventive health.

Special care will be taken to scrutinise any new issue before work commences to make sure that the Committee would not be duplicating work carried out in other jurisdictions.

NHMRC was concerned at the very heavy workload facing the Health Advisory Committee and discussed ways in which the work could be expedited, both at the Committee and NHMRC levels. It was agreed that the Committee is responsible for ensuring that documents do not come to NHMRC unless they are complete and that members of Council must accept responsibility for considering each and every final document, although this could be out of session. The Secretariat was asked to develop procedures for handling final reports from the Health Advisory Committee.

Review of Publications

NHMRC was advised of the backlog of older publications requiring review, many of which were prepared by the forerunners to the current Health Advisory Committee. It was noted that formal procedures are required before a document can be rescinded, although it is not clear whether this relates to all documents or only those issued since the introduction of the Act in 1992. This point will be clarified and immediate action taken to cull pre-1992 documents.

Members agreed that any future publications should include clear statements about the likely longevity of the publication as well as clear advice directing readers to sources of information to check on the currency of documents (ie the website). This point will also be a condition of approval for externally development guidelines.

Council agreed that a paper should be prepared for consideration at its next Session giving detailed procedures, and resources required, for managing the backlog of reviews. The procedures should include consideration of publications by experts and/or expert bodies for advice on currency. Council members, especially State representatives, will be included in this referral. It was also agreed that publications should be better managed in future using a database that can signal review times in advance.

Budgets

NHMRC was briefed on levels of funding for each of the Principal Committees in the current financial year, along with forecasts of funding for research over the next few years. It was agreed that presentations to Council should be refined in the interests of providing financial information in summary form, in the most readable way possible.

Gene Technology Bill 2000

Recognising the importance of this Bill, NHMRC devoted considerable time to receiving briefings on aspects of the Bill and discussing the implications for NHMRC. The following presentations were made:

- Ms Elizabeth Flynn of the Interim Office of the Gene Technology Regulator spoke on the role of the proposed Gene Technology Regulator, the impetus for the Bill, the draft Regulations, and potential costing schedules.
- Mr David Nyskohus of the Office of the National Health and Medical Research Council, spoke on the implications of the Bill for health and medical research and on NHMRC in particular.
- Associate Professor Eric Haan, member of the Gene and Related Therapies Research Advisory Panel, described the Panel's work, how it considers applications and advises ethics committees, and the impact of the Bill on the Panel's work.
- Mr Craig Cormick of Biotechnology Australia spoke of community perceptions surveys conducted by Biotechnology Australia, including community views of genetically modified organisms in both food and medicine, the importance of consultation, and the community's preferred suppliers of information.

Members sought clarification on a number of issues raised and discussed aspects of the Bill and the draft Regulations. It was agreed that the key issues should be provided in summary to each Principal Committee for consideration in the context of each Committee's work. Each Principal Committee is to be alert to other matters which may arise as a result of the Bill or draft Regulations.

Report for Endorsement

Joint statement and recommendations on Vitamin K administration to newborn infants to prevent Vitamin K deficiency bleeding in infancy

Vitamin K for newborn babies - information for parents

The above guidelines were issued on 1 August 2000 as interim guidelines using the urgency provisions contained in section 14 of the *National Health and Medical Research Council Act 1992*. Since then, formal public consultation has been conducted as required by the Act and amendments have been made to the joint statement and recommendations and the information pamphlet. Both documents were re-presented to NHMRC for consideration.

Variations to the interim guidelines, proposed by the Health Advisory Committee, are:

Methods - addition of a comment showing progress since the 136th Session, specifically in the area of public consultation.

Issues - addition of a comment relating to the supply of subsequent oral doses in certain circumstances and the need for health services to take this into account when developing local protocols.

Recommendation 2 - wording around the timing of the second and third oral doses amended to give some flexibility.

Recommendation 3 - inclusion of the dosage volume.

Additional information - inclusion of a statement to show that product information is being updated to reflect the joint statement and recommendations.

Variations to the information pamphlet, proposed by the Health Advisory Committee, are:

Page 2 - refined wording to ensure clear answers are given to each question asked.

Page 3 - wording in the section on preferences amended to show that the doctor or midwife will arrange provision of vitamin K in the manner preferred by parents.

In discussion NHMRC requested

Joint statement and recommendations - an addition to Recommendation 4 to reflect the need for health services to ensure protocols are in place to obtain informed consent.

Information pamphlet for parents - delete the words "...and they will provide it..." when seeking preferences from parents. NHMRC did not accept this amendment because it did not add to the meaning of the section.

NHMRC agreed to vary, as noted above, and issue both the joint statement and recommendations and the information pamphlet.

Guidelines on the use of blood and blood products in clinical settings

In September 2000 the Minister for Health and Aged Care announced deferral of blood donations from people who had spent more than 6 months in the United Kingdom between 1980 and 1996. At the same time, the Australian Health Ministers' Council had asked NHMRC to prepare guidelines on the use of blood and blood products in clinical settings. The purpose of the guidelines is to ensure the best possible use of the remaining supplies.

Since then the Health Advisory Committee has established a small working committee of experts comprising stakeholders from the Red Cross, haematology, nursing, surgeons and health care. A consumer nominee is expected to be provided in the near future.

The working committee has a very tight timeframe as the guidelines need to be in place when deferral takes full effect in late December 2000. For this reason the working committee will concentrate first on developing guidelines for the use of fresh blood - a draft will be provided

to the NHMRC Executive at its meeting on 8 December 2000 with a request that they be issued urgently under section 14 of the Act.

The working committee will draw on the experience gained in New South Wales as well as other initiatives, including the Australian Health Ministers' Advisory Council document on autologous blood transfusions, to ensure there is no duplication of effort.

Other business

Clinical practice guidelines for the management of advanced breast cancer

The guidelines are being developed by the NHMRC National Breast Cancer Centre and are currently being reviewed by the Health Advisory Committee. Council agreed that it would consider the draft guidelines out of session so that the guidelines can be approved and released promptly.

Australia-New Zealand Food Authority - Priorities for NHMRC research and activities

The Chair of ANZFA has written to the Chair of NHMRC presenting the views of ANZFA on priorities for future research and activities by the NHMRC. Five areas were specifically named - infant nutrition, impact of nutrition labelling on population health, long term health impact of genetically modified foods, research into food intolerances/sensitivities, and review of health impact of nutrition strategies.

The Health Advisory Committee has included a number of these issues in its work program for the triennium. The Strategic Research Development Committee will consider the issues in detail. It was agreed that the Chair of the Committee should consult with Professors O'Dea and Catford and then have discussions with the Chair of ANZFA.

During the discussion the question of thiamin in flour was raised by Dr Breen, particularly the apparent lack of follow up research which could demonstrate whether this initiative has had an impact. The Chair of SRDC invited Dr Breen to discuss this matter in detail with his Committee.

A response will be forwarded to ANZFA advising of action taken to date pending an approach by the Chair of SRDC.

Council noted the following information:

- NHMRC representation on other organisations - the Research Committee is not yet in a position to finalise its nominees;
- The Tall Poppy Campaign - an information paper on progress;
- Annual Report 2000 - a draft structure will be prepared by the Secretariat in consultation with the Executive;
- Strategic Plan 2000-2003 - was tabled in Parliament on 3 October 2000;

- Commissioner of Complaints - one complaint that had been re-opened has now been finalised with no change to the original decision; one complaint is still under investigation;
- Dates and venues of future meetings - the schedule is reproduced at Appendix A;
- NHMRC Executive meeting December 2000 - will be held in Perth and will include a consultation forum.

DATES OF FORTHCOMING SESSIONS OF NHMRC

2001

15-16 March
14-15 June
25-26 October

2002

21-22 March
20-21 June
17-18 October

2003

10-11 April

DATES OF FORTHCOMING MEETINGS OF NHMRC EXECUTIVE

2000

7-8 December

2001

27 April
17 August
7 December

2002

11 April
8 August
12 December

2003

2 May