



Cartwright

Comes of Age ?

Seminar Report

Maintaining momentum towards a New Zealand health care system with the principles of the Cartwright Report at its foundation.

Women's Health Action Trust
March 2010





Well Women Empowered in a Healthy World!

OUR VISION

Our Vision – embodied in our Mission Statement above - is to ensure that issues related to gender remain on the public health agenda, thereby ensuring women health consumers' needs are recognised, understood and met. We empower women health consumers with up-to-date quality evidence-based information to assist them to make informed decisions around their health and the health of their families.

We will achieve our Vision by -

- 1) Providing women with information and evidence based resources to enable them to make informed choices and decisions around their own health needs
- 2) Promoting women's interests and providing a woman's voice in research, education and policy where there are implications for women's health
- 3) Stimulating debate to strengthen the ability of the public health and non-government organisational (NGO) communities to contribute to the wellbeing of all women in Aotearoa-New Zealand
- 4) Ensuring the viability and increasing the future capacity of WHA

We categorise the work we do to achieve our Vision under three main headings –

- 1) Major Issues of Concern to Womens Health, including Breastfeeding
- 2) Education Services and Information
- 3) Consumer Representation and Networking

Women's Health Action Trust, which grew out of Fertility Action founded by women's health activist Sandra Coney, is now in its 26th year of operation.

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FOREWORD

It may seem that Women's Health Action has a strange obsession with the Cartwright Inquiry and the Cartwright Report. How else to explain so much effort on a seminar 21 years after the release of the report? Surely the Inquiry and the Report are ancient history. How can they possibly have any relevance in a new century and a new millennium?

Quite simply, the Cartwright Inquiry was always about more than one doctor, one hospital and one 'dodgy' experiment. Its implications were deeper and wider. One doctor, one hospital, and one 'dodgy' experiment brought into focus all doctors, all hospitals, and the way in which human and medical research was conducted in New Zealand institutions. Equally, the Cartwright Report was not about how to remedy a specific set of issues raised by the Inquiry in one clinical setting. Cartwright's real power was to illuminate some of the darker recesses of the medical contract with consumers and open them up for examination and discussion. It was about a set of fundamental principles which underlie a quality patient-centred health and disability system. It is this aspect of Cartwright which makes it relevant in this new millennium and justifies a re-examination of these fundamental principles.

Most powerfully for Women's Health Action, Cartwright was a time in New Zealand medical history where a consumer voice was heard, heeded and supported by brave people inside and outside the institutions under scrutiny. Most of these people paid a hefty price for their courage. For the women whose trust was abused, this included a tax on their health and cost some their lives. When we work to 'keep the spirit of Cartwright alive', it is to these women we dedicate our labour.

Twenty one years on, we find there is still work to be done. We hope you will work with us as we do it.

Jo Fitzpatrick
Director, Women's Health Action Trust

FOREWORD

Twenty-one years since the Cartwright Inquiry was a good point to reflect on what was achieved for patients' rights and women's health through that landmark event, and to chart a course for the future.

As Fertility Action, Women's Health Action was at the centre of the Inquiry, as instigator and also as the principal voice for women's interests. In the years that followed, the organisation was strongly focused on ensuring that the recommendations were implemented, whether it was the National Cervical Screening Programme or the Office of Health and Disability Commissioner.

So it was right that Women's Health Action called people together to hear papers and to take part in workshops and plenaries which discussed the weighty topics that had emerged from the Inquiry. The conference attracted many of the principle players from the Inquiry along with others, so the debate had depth and experience.

The compilation of the proceedings from that event through this publication is important to record what occurred and also to provide the basis for future action.

One of the lessons from recent years is that the great advances made through the Cartwright Inquiry will still need to be defended in the years ahead, and as that event recedes into the past, people need reminding of why it happened and what it achieved. The reforms recommended by Dame Silvia Cartwright have been implemented, but there is always a risk they will be eroded or unravelled.

The Cartwright Report continues to provide a blueprint for human rights and ethics in health care in the 21st century. The 'Cartwright comes of age?' seminar report is another step in the journey towards cementing New Zealand as a leader in protecting the rights of health care consumers.

Sandra Coney
Founder, Women's Health Action Trust

ACKNOWLEDGEMENTS

Women's Health Action Trust owes a debt of gratitude to the presenters and participants at this seminar. Your energy, enthusiasm, and commitment to our New Zealand health care system helped bring this seminar about, made it the success that it was, and inspires our work. To those who embraced the idea from the outset and provided suggestions and criticisms along the way, a special thanks. You helped us see it through!

Thanks to Women's Health Action staff, contractors, volunteers and trustees for their hard work in bringing this seminar to fruition, particularly to Jo Fitzpatrick, Christy Parker, Isis McKay, Cathie Walsh, and Maike Blackman. Special thanks to Christy Parker for the prompt and professional preparation of this report.

The seminar report can be accessed from Women's Health Action's website www.womens-health.org.nz. Printed copies are available from Women's Health Action, PO Box 9947, Newmarket, Auckland, 1149 or by email info@womens-health.org.nz.

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Disclaimer

While every attempt has been made in this report to accurately represent the speakers contributions, as well as the opinions expressed by participants in workshop and panels discussions, this report does not cover every individual's contribution.

This report is dedicated to the women whose trust was abused and who paid with their health, and, for some, their lives.

INTRODUCTION

This publication is the result of a Women's Health Action seminar to mark the 21st anniversary of the release of the Cartwright Report. The forum provided critical and consumer perspectives on the major themes and recommendations from the Cartwright Inquiry in today's context and a look forward to the 21st century.

The 20th Cartwright Report anniversary saw praise for how far we have come since the Cartwright Inquiry through changes in ethical, medico-legal and health care practices. Despite these changes there is still much to be gained by looking carefully at the consequences and issues resulting from the Inquiry and assessing them as we move forward. Our experience as a health consumer group attests to the fact that there is still work to be done, and indeed that we may be losing ground in some important areas of the health sector.

The seminar was well attended by a wide range of stakeholders in the health and disability sector. Attendees included key staff from the Ministry of Health, PHARMAC, and the Office of the Health and Disability Commissioner; health professionals including midwives, nurses and doctors; District Health Board representatives; academics from universities nationwide; key staff from a number of NGOs including the Mental Health Foundation, Family Planning Association, Auckland Cancer Society, Eating Difficulties Education Network, Auckland Women's Centre, Auckland Women's Health Council, West Fono Health Trust, WONS; consumer representatives; and representatives from the National Ethics Advisory Committee, the Multi-region Ethics Committee and the National Screening Advisory Committee.

This report provides a summary of the seminar presentations and discussions. The morning session: *'The Foundations of Cartwright'* consisted of four keynote presentations assessing how the underlying principles of the Cartwright Report are working now in the context of significant health service issues.¹

'Unfinished Business' was a series of four workshops focusing on particular outcomes from the Cartwright Inquiry - examining how they are working now and asking what can influence future directions. Two high profile speakers raised issues for a facilitated participant discussion with the aim of working towards recommendations for action. These recommendations are listed at the end of each workshop summary and are collated in the final section of the report.

Women's Health Action offers these recommendations with the hope that they may help guide action, and maintain momentum towards, a New Zealand health care system with the principles of the Cartwright Report at its foundation, and to ensure the specific recommendations of the Cartwright Report are implemented in the spirit in which they were intended.

¹ The full text of these presentations are not included in this report. The papers/powerpoint presentations for the keynote addresses are available from Women's Health Action Trust and from our website www.womenshealth.org.nz

AN UNFORTUNATE EXPERIMENT

BACKGROUND ON THE CARTWRIGHT INQUIRY

In 1987, health activists Sandra Coney and Phillida Bunkle published an article called 'An unfortunate experiment at National Women's Hospital' in the monthly Auckland magazine - Metro. The article outlined an unethical study at National Women's Hospital, the country's premier women's hospital. The study, led by Dr Herbert Green, started in 1966, and involved following women with major cervical abnormalities without definitively treating them, and without their knowledge or consent. By 1987 many had developed cervical cancer and some had died. The revelations led to public outrage and ultimately to a Ministerial Committee of Inquiry.

The Inquiry into the Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital in 1987 and 1988, known as the Cartwright Inquiry after the presiding judge, Judge Dame Silvia Cartwright, is remembered as one of the most significant medical events of the twentieth century. While focused on the treatment of cervical cancer, the Inquiry led to scrutiny of a range of issues related to the practice of medicine in New Zealand including research practices, teaching methods, patients' rights and medical dominance. It exposed a core dynamic of twentieth century medical practice; that doctors, with their appeals to objective, rational and scientific knowledge, knew best; and that patients, particularly women, were irrational, hysterical and incapable of making choices for themselves. The Ministry of Women's Affairs, in their final submission to the inquiry in 1988 captured the scope of the Inquiry well:

The issues at the heart of this inquiry are not unique to National Women's Hospital. They are not limited to a period of time somewhere in the past. They do not conveniently confine themselves, like the structure of a Greek Tragedy, to unities of time and place. Ultimately the issues are about who controls medicine and how; about who benefits from it and who are its victims. Thus, as so many witnesses have so clearly stated, the central issue, above all others, is power.²

The Inquiry, and the subsequent Report of the Cervical Cancer Inquiry 1988 (the Cartwright Report) had important implications for the future of health care in New Zealand that remain relevant today. The report was a blueprint for patients' rights in New Zealand and also recommended the establishment of a Health and Disability Commissioner, a system of ethical review, and the establishment of a National Cervical Screening Programme. It was also the first time that there was a serious focus on patients and consumers in the health care system and a consideration of the need for patient-centred health care.

The Cartwright Report's legacy continues to guide medical practice through, for example, the legislation of patient rights including those to information, choice and consent; sweeping changes to research and teaching practices; and the recognition of the importance of consumer voice in health service planning and delivery. It has informed the work of a generation of women's health advocates committed to a health care system with the Cartwright Report's principles at its foundation.

A full copy of The Report of the Cervical Cancer Inquiry 1988 (The Cartwright Report) can be found on the National Screening Unit website at <http://www.nsu.govt.nz/Current-NSU-Programmes/3233.asp> or purchased from Women's Health Action Trust.

² Coney, S. 1988. The Unfortunate Experiment. Penguin Books: Auckland, pp. 6.

THE FOUNDATIONS OF CARTWRIGHT

To set the scene we asked four strategic people to reflect on the underlying principles of the Cartwright Report and how they are exercised in the speakers' current areas of expertise: health and disability services consumer rights, privacy of health information, population health programmes, and from a consumer perspective.

The presenters were Health and Disability Commissioner Ron Paterson, Victoria University's Professor Kevin Dew, Assistant Privacy Commissioner Katrine Evans, and Women's Health Action founder and health activist Sandra Coney.

CONSUMER RIGHTS – HAVE WE COME OF AGE?

Health and Disability Commissioner Ron Paterson explored the tensions between rhetoric and reality in the exercise, enjoyment and defense of health and disability services consumer rights. Paterson believes much has been achieved with the HDC and Advocacy processes working well; greater awareness of patients' medical, cultural and family needs; improved communication between doctors and patients; and broader recognition of the need for informed consent. However he also identified unrealized hopes under the current New Zealand system including on-going issues with access to services; and a lack of evidence that overall patient and provider satisfaction with the health system has improved. Ultimately Paterson believes that there is still a long way to go to achieve patient-centred, safe care as the universal norm.

FROM INFORMED CONSENT TO INFORMED COMPLIANCE?

Population health and the culture of informed consent

Professor Kevin Dew from the School of Social and Cultural Studies at Victoria University explored the fate of informed choice and consent in the context of public health interventions such as childhood immunization programmes. Dew explored the tension between the ideology of public health which is focused on the universal uptake of interventions with the goal of disease prevention; and the notion that individuals have a right to make informed choices about these interventions. Dew demonstrated the ways in which public health knowledge becomes authoritative through appeals to "scientific rationality", "moral duty" and "public good". Dew also demonstrated how those who do not comply with public health programmes are constructed as "irrational" and as "risky citizens".



Professor Kevin Dew and Ron Paterson.

PRIVACY AND PUBLIC GOOD?

The future of health information

Assistant Privacy Commissioner Katrine Evans examined the right to privacy and public good in an age of shared electronic health records (EHR). Evans outlined some of the benefits for health consumers of electronic health records including increased ability to audit; increased transparency; and increased accuracy. She argued, though, that we cannot afford to ignore the potential risks of EHR which include privacy and security of personal health information; accidental loss of records; increased ease of silent unconsented information collection; and the ability to transfer information within the health system but also outside it to insurers, employers and government agencies. Evans argued for the need to recognize privacy as a major public good not just an individual right. We need to ensure that privacy is an integral consideration from the start of decision-making on information systems. "Privacy by design," will help to achieve the benefits of EHR in a privacy-friendly way.



Katrine Evans (above), Sandra Coney, (above right), and Mrs Joy Bray (right).

REFLECTIONS ON CARTWRIGHT

Health activist and Women's Health Action founder Sandra Coney closed the morning by clarifying the key issues raised by Cartwright. This included challenging interpretations and impressions created by University of Auckland Professor of History Linda Bryder in her recently published book 'A history of the "Unfortunate Experiment" at National Women's Hospital'. We were fortunate to receive a first-hand account of the experience of being a patient at the centre of the 'Unfortunate Experiment' in an address by Mrs Joy Bray. Her experiences as a patient of Dr Herbert Green at National Women's Hospital were a strong reminder of the need to keep the legacy of Cartwright alive in the 21st century.



UNFINISHED BUSINESS

There were three major mechanisms which resulted from the Cartwright Inquiry, the role and function of which were to implement the recommendations: the establishment of the Office of the Health and Disability Commissioner, improving the system of ethics committees and ethical review, and the establishment of the National Screening Unit. The afternoon workshops looked at how these mechanisms are working now, what the issues are and what future directions might be useful.

A fourth key area without a specific mechanism for implementation in the Cartwright Report – patient and consumer centred health care - was added to the workshop sessions. The workshops were led by a facilitator knowledgeable in the field, and began with two high profile speakers presenting their perspectives on the topic. Participant discussion then set out to identify current challenges and recommendations for future action.

THE COMMISSIONER, THE CODE AND PATIENT ADVOCACY

FACILITATOR: Barbara Robson,

Co-convenor, Federation of Women's Health Councils

The establishment of a Health and Disability Commissioner (HDC), the need for a code of patient rights, and a patient advocacy service were all recommended in the Cartwright Report. Barbara Robson opened the workshop by introducing participants to the section of the Cartwright Report relevant to this workshop.³

Recommendations in this section of the report included:

- Information to be provided on treatment/research
- Outlined process for consent to treatment/participation in research
- Outlined system for protecting patients involved in treatment/research at National Women's Hospital including:
 - What the patient should have access to
 - Role of the patient advocate
 - Role of the hospital board

- Human Rights Commission Act to be amended to provide for a complaints process, statement of patients rights, and the appointment of a Health Commissioner

These Cartwright Report recommendations were operationalised with the passing of the Health and Disability Commissioner Act 1994. The Act was considered a key element in the new environment of consumer-focused and consumer-accountable health and disability services. It has become the primary vehicle for dealing with complaints about any health or disability services provider in New Zealand. The purpose of the Act is expressed as being:

to promote and protect the rights of health consumers and disability services consumers, and, in particular, to secure the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights (s6).⁴

This was to be achieved through the implementation of the Code of Health and Disability Services Consumer Rights, the establishment of a complaints process to ensure enforcement of those rights, and the ongoing education of providers and consumers.

³Term of Reference 5, Chapter 11, The Cartwright Report, pp. 212-214.

⁴The Health and Disability Commissioner Act 1994

CHALLENGE SPEAKER: Dr Jo Manning,

Associate Professor & Deputy Dean of the Law Faculty,
University of Auckland.

Dr Jo Manning's presentation was largely affirming of the implementation of the Cartwright Report recommendations relating to a Health Commissioner, a code of patient rights, and a patient advocacy service. She believes these recommendations are working well with few areas for improvement.

The Code of Rights

From Manning's perspective the Code of Rights has been an outstanding success and consumers have claimed it as their own.⁵ Manning noted that consumers are very protective of the Code and that some subsequent amendments to it have been, and remain, controversial. The only serious omission to the Code was the right to confidentiality and privacy of personal health information.

The commissioner and the complaints regime

In her Report, Cartwright laid out only the broad outlines of the complaints regime and the elements of the Code. She envisaged a Health Commissioner, whose role would include negotiating and mediating complaints, accepting cases from and referring them to advocacy, heightening professionals understanding of patients' rights, and taking cases to the disciplinary tribunal and before the Equal Opportunities Tribunal, the forerunner of the Human Rights Review Tribunal. Manning noted that in a broad outline, this is exactly the system that was put in place. But the Health and Disability Commissioner (HDC) has been an evolving jurisdiction and in the 13 years since complaints first came in the door, its mission and procedures have been gradually refined. Manning noted that it is now a mature jurisdiction which has moved to a 'low' blame, but not 'no' blame culture. She noted:

- In recent years, world leading experts in the patient safety movement have called for the abolition of the medical negligence action damages and replacement with a system such as ours. Because of the existence of the Accident Compensation Corporation (ACC) scheme, the need for the complaints regime to be involved in compensation has been removed. This has enabled us to construct a sane, humane and balanced system.
- Ours is not a no-blame system, but it is one of low-blame. Manning considers that this is **generally** appropriate because most practitioners are well intentioned and want to benefit their patients. Their mistakes, though they can devastate, even destroy lives, are for the most part unintentional. There is an important distinction between the complaints regime and the criminal justice system.
- Manning noted her concerns around ACC's ongoing role in compensating for treatment injury and feels that this is at risk.

Serious cases

Manning is not convinced that we have the system right in the most serious cases that come before the Commissioner, such as where the practitioner's competence is of serious concern or there is a repeated pattern of seriously sub-standard care. Manning is concerned that the system in these cases:

- Takes too long
- There are multiple hearings
- And with name suppression, the process may remain confidential for too long, possibly contrary to the public's interest in knowing about an incompetent practitioner

In Manning's estimation Helen Cull's concerns in 2001 about timeliness, multiple hearings and complaint fatigue have not been adequately dealt with in these comparatively rare cases.⁶ Manning is not sure of solutions to these ongoing difficulties but suggested possibly leap-frogging a Commissioner investigation and going straight to a disciplinary inquiry with jurisdiction over all providers (not just registered ones), or for the Commissioner himself to hold public hearings with strengthened powers.

Complainant power

Manning emphasized that complainants are the HDC's most valuable resource because they are the means by which potentially dangerous practitioners can be identified and something can be done to rehabilitate them, or in the worst cases to stop them practicing to protect the public.

The system needs to be consumer-friendly, and provide no disincentive to consumers to make an initial complaint. The fact that the system is free, efficient, confidential, largely lawyer-free and relatively informal provides an important advantage over the civil damages action.

Manning acknowledged knowing less about advocacy but supports it as a cost effective and potentially therapeutic resolution, provided it is used in appropriate cases where there is no public safety concerns or issues of wider public interest.

Ideally the complainant would be able to choose the form of resolution that they prefer. Manning acknowledged that if she or a family member had an adverse medical event resulting in death or serious injury about which she had a serious concern, she would want to have an official Health and Disability Commissioner's report that stated what happened, what went wrong and why, who was involved and responsible (if she thought that were the case), and what remedial action was taken. It would be a serious document kept in the family's important papers for all time that would be part of their ongoing story.

⁵The Code of Health and Disability Services Consumer Rights became law on 1 July 1996 as a regulation under the Health and Disability Commissioner Act 1994

⁶ Review of Processes Concerning Adverse Medical Events, Helen Cull QC, 2001 www.moh.govt.nz/moh.nsf/pages/mh/1154?Open

Manning has noted with concern the trend for a smaller proportion of complaints being investigated - down from 15% in 2005 to 7-8% in 2009. She acknowledges the difficult tradeoffs involved - the more complaints which result in resource-intensive investigation, the longer the backlog of complaints awaiting investigation. She also acknowledges the enormous work of the HDC in reducing the backlog of complaints. However Manning believes that if a complainant or family member has suffered a significant injury or a death, they should have a right to an investigation of their complaint if that is what they want. Again, this is an issue to which there are no easy answers, especially in difficult economic times where the health budget faces increasing pressure.

CHALLENGE SPEAKER: Denise Wilson,

Lawyer and Former Chair, Auckland Ethics Committee

Denise Wilson's presentation focused on the implications for consumers from the recent changes made to Right 7(10) of the Code of Health and Disability Services Consumer Rights. While Wilson believes that the Health and Disability Commissioner (HDC) is working well she argued that the change made to Right 7(10) has weakened the Code of Rights and there is also room for improvement with the patient advocacy service.

Amendment to Right 7 (10)

Wilson compared the original version of Right 7(10) with the amended version; key changes being that access to tissue without consent was now permitted under the Code, for specified purposes (research, quality assurance, external audit and evaluation) subject to ethics committee approval.

Wilson referenced the outrage and hurt caused by the Greenlane Heart Library. The lesson to be learnt was that what hurt family members the most was the fact that they had not been asked whether tissue could be stored. The hospital's Maori advisor, Naida Glavish, commenting on the storage of the specimens without consent said, "I believe their intentions were honorable, but absolutely not ethical".

Wilson asked :

- Does the approval of an ethics committee make a research study ethical?
- How do we balance the greater good argument against individual rights/autonomy? There is pressure for greater good especially around access to tissue/tissue banks/ personal health information.
- How important is consent to participation in research?

How are things working now as compared with Cartwright recommendation:

- Wilson believes the HDC is working well
- There are some issues with the Code of Rights
- Wilson pointed out that patient advocacy is a nationwide service but noted that advocates were not appointed to hospitals as Cartwright proposed

Issues for the future

- Tissue Banking – Wilson believes that the right to informed consent has been compromised following changes made to Right 7(10) of the Code. Changes to the Code of Rights recommended in the 2008/2009 review of the Health and Disability Act are also threatening the right to informed consent. Wilson demonstrated that following the change to Right 7(10) patients/consumers may now be included in research without their consent.
- Wilson is concerned about the fate of the Code of Rights in an economically constrained health service.

WORKSHOP DISCUSSION POINTS

Compensation

- Participants concerned about the process of receiving compensation. It was argued that the system must better provide for compensation. Could an alternative route to compensation be provided, noting compensation may be forthcoming via Human Rights Review Tribunal if there is a decision in breach of the Code of Rights? Explore alternative options for funding compensation – eg Carter Holt Harvey in Australia paying compensation for cases of asbestosis
- An appeal mechanism should be provided
- Discussion about compensation for research participants

Consumer involvement and consultation

- Could laypeople/consumers be involved in reviewing complaints to provide a consumer perspective? Professor Jenny Carryer noted that in nursing, lay people tend to apply lower standards to nursing practice than the nursing profession itself and therefore may set the bar too low.
- Better process for consumer driven change to the Code. It was argued by participants that consumers' ability to effect change is compromised. Process for change to date has allowed change to occur without consumers' knowledge or consent (as in amendment Right 7 (10)); but where there has been overwhelming consumer support for a change this hasn't happened (eg adding a Right to Compassion). It was noted that the current process is disempowering. It was also noted that the consultation process regarding the right to compassion was good. This raised the question about whether the process or the outcome is the primary consideration and whether one can substitute for the other.

The changes to Right 7(10) of the code

- Concern around the clause for ‘future unspecified use’ – particularly related to use of tissue for research purposes but also extends to use of personal health information.
- The present regulatory framework is like a blank cheque - there are not enough protections for consumers around the access of their tissues for research.
- Questions were asked by participants about where the pressure came from for the change to Right 7 (10)? Which groups lobbied for this change and why?
- Participants expressed a level of unease around the integrity and rigour of ethics committees – is the principal purpose to facilitate research or protect research participants?
- Call to review/reconsider Right 7 (10). Suggested revision to delete research, but retain quality assurance, external evaluation and audit.
- Increase awareness that consumers can ask for specimens to be returned. Consumers need to know that they have the right to ask for the return of tissue - in the absence of other protections, consumers need to know that they can exercise this right. Problem is that consumers then can miss out on some of the benefits offered by retention of their tissues eg. the Newborn Metabolic Screening Programme.

Use of personal health information

- Primary Healthcare Organisations’ (PHOs) enrolment forms tend to provide for all-encompassing sharing of personal health information; some people uneasy about this but if they have questioned it, they are advised they can’t enrol if they don’t agree to all terms and conditions. Suggestion that PHOs should be engaging with their enrolled populations about the safe sharing of health information, noting that it is mandatory for some information to be shared. Participants noted general acceptability of sharing of non-identifying aggregated data.

The right to be consulted

- Benchmark for consultation processes where service changes are proposed. It was noted that the decision from the Court re Auckland District Health Boards’ Labtests ‘consultation’ found a disappointingly low standard to be acceptable. This has now set a legal precedent. Should the New Zealand Public Health and Disability Act 2000 (sections 38,39, and 40) be amended to include a right to be consulted on changes to health care/services/the Code?

RECOMMENDATIONS

- Reverse the change made to Right 7(10) of the Code of Health and Disability Services Consumer Rights.
Suggested wording of Right 7(10):
No body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved, or used otherwise than -
- *With the informed consent of the consumer;*
Or
- *For the purposes of one or more of the following activities, being activities that are each undertaken to assure or improve the quality of services:*
 - *A professionally recognized quality assurance programme;*
 - *An external audit of services;*
 - *An external evaluation of services.*
- The HDC should take steps to improve consumer participation and consultation.
 - Ensure that consumers are consulted on future proposed changes to the Code of Rights and develop a better process for consumer driven changes to the Code
 - Consider involvement of consumers in complaint reviews.
- The HDC should work towards being able to provide complainants a choice of process/pathway for resolution of the complaint. Consumers should have a right to an investigation in a serious case such as where the practitioner’s competence is of serious concern.
- Review the process for dealing with the most serious cases in the context of the Cull Report 2001 recommendations.

FACILITATOR: Jo Fitzpatrick,
Director, Women's Health Action Trust

The Cartwright Report was strongly critical of the care the women at the centre of the Inquiry had received. In addition to recommending sweeping changes to our processes around ethical approval of research, the requirements for informed consent, and the establishment of the Health and Disability Commissioner role and the Code of Rights, the need for care to become patient rather than provider centred was emphasized. The discourse of patient-centred healthcare is well established but is the practice of it? Is this unfinished business?

CHALLENGE SPEAKER: Professor Jenny Carryer,
Department of Nursing, Massey University

Professor Jenny Carryer focused on the rhetoric versus the reality of patient centred health care. She critically assessed the changes we have made towards a more patient or consumer oriented health care system yet demonstrated some of the many ways in which medical dominance is still intact.

Carryer gave examples of thoughtless practices in health settings and noted that historically the patient has not been at the centre of care. She questioned how such practices could have been approved ostensibly on the basis of minimizing disruption to institutions and to health professionals themselves.

Patient centredness is, as much as anything, a state of mind and our historical state of mind has been slow to reach that point. Post Cartwright the notion of patient centredness has grown more central to the quality agenda. There is much talk about the 'expert patient' and about shared decision making. The key principles are now largely accepted and they include the key responsibility of health professionals to provide full information at all times and to involve people in decision-making in a transparent manner. Protection of dignity is of paramount importance and there is continual discussion about the need for and value of continuity of care.

However Carryer believes we have not moved very far beyond the rhetoric of "patient" centred care. Issues of current concern include:

- Central to patient centred care and notions of the expert patient is the idea of patient responsibilities but the possibility of patient (victim) blaming is always present. There is potential for this to be exacerbated by the resource-constrained environment, which is the current and future situation in health service delivery
- The return to provider centred care and provider centric basis for decision making - eg. the Primary Health Care Advisory Council was recently disbanded in the wake of concern about a new service models package. The GP and medical professional bodies (the New Zealand Medical Association and Royal New Zealand College of General Practitioners) expressed serious reservations that the multi disciplinary council had assigned insufficient importance to the role of the doctor in first contact care. Carryer argued that the service models package was very focused on patient centred care, on issues of access, and of planning for a current and future context where GP availability is very scarce in many areas.
- Institutional structures have a major influence on patient centred care. Nurses have long been educated in a patient or rather person-centred framework but research shows that within months of commencing practice they have absorbed and adopted the dominant institutional ethos, largely as a survival mechanism. They often regain that focus when they work in different environments such a hospice, which by their nature are people centred.
- We use the rhetoric of consumer choice - but are choices meaningful? The rhetoric of choice assumes options are available. In many areas choice is inconsistent or severely restricted eg. of GPs/services.

Carryer concluded by emphasizing that patient centred care is both an attitude and a practice focus and it is hard to say which one comes first? Currently she thinks our structures, as well as our funding and leadership models, continue to favor a medical model of care and leadership rather than a patient centred model. There is a self-fulfilling circuitous process in place in which attitudes and beliefs shape our infrastructure and our infrastructure shapes our attitudes and practice. There is a huge amount of work to be done before the rhetoric of people or patient centred care becomes our reality.

CHALLENGE SPEAKER: Judi Strid,

Director of Advocacy, Office of the Health and Disability Commissioner

Judi Strid began by reminding us that ‘patient centred care’ is too narrow as health consumers include the users of disability services, and ‘consumer centred care’ is a more appropriate term. Strid’s presentation focused on what she considers is the unfinished business of the Cartwright Report – the shift towards consumer centred services and the establishment of national interpreting services, the two being interrelated.

Strid noted that the Report of the Cartwright Inquiry:

- Recommended statutory recognition of patients’ rights
- Identified the need for the focus to shift from the doctor to the patient
- Identified the need for interpreters

Strid provided a summary of the Code of Rights and noted that the 10 rights provide a consumer-centred quality framework:

- Respect, dignity, fairness
- Appropriate standards
- Communication, information, consent
- Support, complaints
- Includes teaching and research settings

What does consumer-centred care look like?

- Improvements at an individual level (Code of Rights)
- Need to shift to the expert rather than compliant patient as the norm – compliance is still valued.
- Strid argued that the latter is still to happen in relation to the design of and approach to health and disability services. She did however note areas of improvement including the ‘Optimizing the Patient Journey’ initiative. There are pockets of putting patients first but this needs to be systematized.

Changing behavior

Strid also explored ways of changing clinician behavior:

- Change thinking
- Focus on putting consumers/patients first rather than seeing them as needing to fit into institutional culture
- Valuing partnership with consumers/patients to achieve optimum results rather than just being nice to them - how do we make the concept of partnership meaningful?

A strengths based approach to promoting consumer centred care is to demonstrate examples of what great care looks like. It is important to provide this feedback to providers. Strid outlined the need for best practice examples based on consumer experiences which describe excellent:

- Technical care and service provision
- Communication
- Continuity
- Personal approaches that are attentive and show genuine interest in the person
- Personalized efforts for each consumer

Interpreting services

Strid’s key points about interpreting services are:

- Communication is a right, an essential part of great care and consumer-centred care
- It is often compromised for those who don’t understand or use spoken English due to the lack of a systemic approach to interpreting and translation services and a lack of policies about how they are funded.
- At present we have an ad hoc inequitable situation that can depend on where you live and what language you use

Steps towards developing services

Strid outlined the steps taken towards the development of interpreting services over the years. Despite this work there is still a need for a nationally coordinated cross-sectoral interpreting service.

Why a national cross sectoral approach?

- Focus on consumer rather than sectors or languages - if you take a consumer-centred approach it doesn’t make sense to just have a health and disability approach as the language barrier remains for all other aspects of the person’s life.
- Oversight of whole interpreting and translation area
- Facilitate linkages between services to reduce duplication
- National standards and workforce planning
- National policy and funding strategy
- Systematic rather than piecemeal service development and provision
- Need for stocktake and attention to gaps

Benefits of a national approach

A coordinated national approach offers the potential to:

- Address inequitable access for consumers
- Provide better information about services
- Address training and education issues
- Reduce duplication particularly in relation to workforce planning, quality improvement, standards and new technologies

WORKSHOP DISCUSSION POINTS

A main focus of discussion was how to turn the rhetoric of patient centred health care into a reality. It was agreed that there are some pockets of practice where this is being done well, despite the system eg. consultants dealing directly with patients so that patients don’t get lost in the system- however this is not sustainable. How do we create sustainable change?

Medical dominance intact?

- The main problem is dominant culture and bureaucracy
- Primary Health Organisations (PHOs) are not being implemented as intended and this is obstructing change towards patient centred health care - GPs are still dominating primary care. Carryer noted that there are 81 PHOs and the smaller ones are more community aligned but are less so the bigger they are - eg. Pegasus has 300 GPs. Concerns that PHOs are devolving - increasing charges etc.

- Noted that the medical profession appears to be looking for opportunities to return to clinician dominated services. For example, in terms of maternity services - constant challenges to section 51 and erosion of midwifery autonomy, and the demise of the Primary Health Care Advisory Council.

Mobilizing the younger generation of health consumers?

- Concern expressed that knowledge is being lost about how things used to be and that things are slipping away. Young people don't have an understanding of changes in health care. What are people willing to fight for? Changes to health services are being justified by the mantra that "this is what the people want", but is this true?
- Discussion focused on strategies for mobilizing young people to identify and respond to changes.

Forming alliances and collaborations

- We need to generate new alliances, between health professionals and consumers, between professional bodies of health professionals and health consumer groups.
- Nurses have a model and aptitude for coalitions and collaborations; this is not part of the GP culture.
- Elements of the current health service restructuring are reminiscent of changes in the 90s.
- Need to get a range of people on board - national colleges, need accountability to peers. Need to look at organizing in the 90s - how alliances were built.

Independent quality agency/interpreting services

- Horn Report - do we need an independent quality agency?⁷ Need vocal support for this or it is likely to get lost. Independence is the key to a successful quality agency, it should not become a Ministry of Health branded unit.⁸ Need to include consumers in the work of this agency.

- Clinicians described difficulties with paying for quality Interpreting Services - Judi Strid affirmed the need for a national policy for interpreting services including New Zealand Sign Language (NZSL), Te Reo Maori, and for those unable to communicate effectively in English.

RECOMMENDATIONS

- Support the establishment and implementation of a nationally funded and coordinated cross-sectoral interpreting and translation service including Te Reo Maori, New Zealand Sign Language, and for those unable to communicate effectively in English. Effective communication in health and disability services is a right.
- Forge new alliances and collaborations between health consumer groups and health professional bodies to facilitate collective responses to issues of concern.
- Strategize ways to facilitate young people as vocal health consumers able to identify and respond to changes in health policy and services.
- Health and disability services remain, for the most part, clinician dominated. Resource constraints are likely to further consolidate this. Work is needed to identify and promote opportunities and innovations to support the shift towards patient centred health care.
- Need to challenge the devolution of Primary Healthcare Organizations (PHOs) and promote the implementation and continuation of PHOs as intended by the Primary Health Care Strategy 2001.
- Broad support for the establishment of an independent quality agency. The independence of this agency will be vital to achieving its objectives. Consumer participation and representation in an independent quality agency will also be vital to its success.



Judi Strid, Professor Jenny Carryer and Jo Fitzpatrick.

⁷ Meeting the Challenge: enhancing sustainability and the patient and consumer experience within the current legislative framework for health and disability services in New Zealand, Report of the Ministerial Review Group, July 09

⁸ Hon Tony Ryall, Minister of Health announced the establishment of a new independent Quality and Safety Improvement Commission on the 12th February 2010

FACILITATOR: Barbara Holland,
Co-convener, Federation of Women's Health Councils

The Cartwright Inquiry found widespread failings in the ethical review processes for research and new treatment procedures, including a lack of independence, a poor record for ensuring informed consent to inclusion in research, and inadequate procedures for approval and surveillance of research and treatment. The report recommended the establishment of an independent nationwide system of ethics committees to ensure that the research goals of seeking new knowledge could be attained within a system where protection of research participants is paramount.

However in the decades since the Cartwright Report, research possibilities have expanded and ethics committees have come under increasing pressure. A primary tension has been the need to balance a strong mandate to ensure individual rights and safety with growing pressure to facilitate research. In balancing the interests of individuals and the research imperatives in an increasingly competitive academic and clinical climate (which includes areas of uncertain clinical realities), there has been a growing contention that research knowledge is used for the common good so individuals have an obligation to contribute to this common good.

Barbara Holland posed the following questions for workshop participants to consider in the context of the presentations:

- Have the interests of autonomous participants been moved from the centre-stage to focus on the interests of researchers?
- Have we got the right balance of interests (systems/participants/knowledge sharing)?
- In the light of the Code of Rights 7(10) changes, has active participatory choice become benevolent protectionism?

CHALLENGE SPEAKER: Professor Donald Evans, The Bioethics Centre, Medical and Surgical Sciences, Dunedin School of Medicine, University of Otago Professor.

Don Evans introduced his presentation by outlining the Cartwright Report recommended criteria and terms of reference for ethics committees focusing on the broad areas of independence, compliance, scope and consent. He then considered today's system of ethics committees in the context of the Cartwright Report recommendations.

Independence

In Evans' opinion good progress has been made here. Ethics committees have moved from a "cozy relationship between ethics committees and institutions" to independent ethics committees – independent of researchers and sponsors of research, as well as in constitution and public perception.

However he identified that a current risk is that the Ministry of Health now makes appointments (hires/fires) people for ethics committees and sponsors research. In this context how independent are ethics committees really working out in practice? We need to assess the independence of ethics committees from researchers and sponsors; and in constitution and public perception. We need to assess how New Zealand models compare with elsewhere.

Compliance

Evans questioned whether monitoring the conduct of research is apparent, or actual? He noted that ensuring compliance with the conditions of ethics committee approval is an international problem. He explored New Zealand's informal solution and current possibilities.

Scope

Evans argued that there is not enough protection around new treatment proposals. Research and practice is getting unequal attention in New Zealand. We need to consider and develop models for improvement.

Consent

The vexed question of privacy and the protection of patient information is an on-going issue for New Zealand's ethics committees.

CHALLENGE SPEAKER: Richman Wee,

Chair and Legal member of the Multi Region Ethics Committee

Richman Wee began his presentation by outlining Cartwright's emphasis that participant/patient welfare be paramount to ethics committee consideration of research/treatment. He then focused on the key themes of interests, independence, and innovation.

Specific Cartwright Report recommendations

- *The paramount consideration in teaching or research which involves patients is the welfare of those patients* 5c(vi).⁹
- *Put patients' health and welfare first... ensure the primacy of the principle of patients' welfare is observed* 8a.¹⁰

The protection of the interests of participants is the role of ethics committees

Wee outlined the primary role of ethics committees which is to:

- Protect participants in research and innovative practice and consumers of health and disability services.
- Primary role - to safeguard the rights, health and wellbeing of consumers and research participants.
- The cardinal principle is: respect for the dignity of persons.

How do ethics committees safeguard interests?

This is in part achieved by how ethics committees themselves are set up, with attention to the following aspects:

- Appointment
- Composition
- Where and how they are located within research regulatory system
- Independence

What system do we have now?

- Regional ethics committees with Multi Region Ethics Committee reviewing multi-regional/national studies re: one application – one committee review
- Independence very important:
*Cartwright recommendation 5b(i)- scientific and ethical assessment of all research projects to be developed and maintained to meet modern standards and in achieving impartiality.*¹¹

Wee believes that ethics committees are achieving impartiality, meeting public interest, and achieving accountability & transparency. However he argued that this includes a duty to collaborate with researchers to ensure the interests, rights, dignity, and welfare of participants is protected. This implies a somewhat more interactive open process.

Innovation

Wee argued that we need to ensure our ethics committee processes can be responsive to new and emerging forms of research which raise new kinds of ethical issues. He noted:

- Cartwright's findings and recommendations about practices and standards that "began in the mid-1950s and early 1970s"
- Now we have new challenges with recent and emerging research, especially in biotechnology and genomics and the commercialization of research.
- Ethics committees require investigators to consider upfront the risks involved – physical, mental, psychosocial (privacy, stigma)
- Includes process matters – payments received by participants as fair and reasonable - what is the effect of these?
- Are we seeing a different kind of consumer engagement? Public sponsorship/investment blurs boundaries.

Other concerns

New Zealand's ethics committees also face the following issues moving forward:

- Consent
- Shared information & privacy
- The location of ethics committees within the regulatory system (particularly in light of current system review changes)
- Achieving impartiality – can ethics committees be truly impartial with Ministerial appointments?
- Innovative treatments & practice – there is the potential for significant shifts in treatment and management – use of genetic information can lead to risks of psychosocial stigma.

WORKSHOP DISCUSSION POINTS

Keeping informed

- Maintaining a register of medical (clinical & Phase I) trials. This is currently voluntary – should it be mandatory? The issue is that there is no enforced publication of adverse effects.

Compliance and accountability

- Who holds researchers accountable for their ethical practices? Ethics committees? Eg. Bryder given permission by the Auckland University ethics committee to do a history of National Women's Hospital and ended up doing a very different project. Some people Bryder interviewed thought they were being interviewed for one project and Bryder was actually working on another. This meant that their information was used in a different context and form to what they had agreed - how is this ethical? Where is the accountability to the original terms of approval?
- There is a tension between the required "collaboration" and "review" tasks of ethics committees

⁹ Chapter 11, The Cartwright Report <http://www.nsu.govt.nz/Current-NSU-Programmes/3233.asp>

¹⁰ Chapter 11, The Cartwright Report

¹¹ Chapter 11, The Cartwright Report

- Do ethics committees have a role in ongoing monitoring once they have given approval for a project or should they keep to their earlier role of assisting researchers to tease out the ethical issues? If they discover later that the research is not fulfilling their requirements, ethics committees can withdraw approval - but do they?
- Where there are significant public good issues there needs to be significant and meaningful public consultations. eg. when talking about genetic or biotechnology issues.

Transparency

- Ethics committees previously worked on consensus/ unanimous decision making. Now decision making based on voting. If a vote has decided the success of an application there needs to be clarity on why and how decisions are made and this process should be available by request under the Official Information Act.
- New Zealand has a robust system of ethical review. However it is time for an independent review of the autonomy of New Zealand's health and disability ethics committees given their current location in the regulatory framework. The review should include the independence of ethics committees from researchers and sponsors, particularly in the context of Ministerial appointments. The Officer of the Auditor General or the Law Commission could be suitable for such a review.
- Processes for ensuring researcher compliance to the terms of ethics approval need to be further developed. Issues include monitoring, compliance to the terms of approval, and actions taken when a failure to comply is identified.

RECOMMENDATIONS

- The revised Declaration of Helsinki, released in October 2008, now states that "Every clinical trial must be registered in a publicly accessible data base before recruitment of the first subject." (paragraph 19).¹² The Australian New Zealand Clinical Trials Registry should include all clinical and Phase I trials, and New Zealand specific information should be easily identifiable.



Richman Wee, Professor Don Evans and Barbara Holland.

FACILITATOR: Dr Julia Peters,
Clinical Director, Auckland Regional Public Health

This workshop provided an update of the current status of the National Screening Unit (NSU) with a particular focus on the breast and cervical screening programmes, the establishment of which directly resulted from the recommendations made by Judge Cartwright. The recommendation made was for the establishment of a National screening programme for cervical cancer:¹³

A nationally planned population-based screening programme should be implemented urgently.

There should be full consultation with consumer groups, including women's health groups, the Ministry of Women's Affairs, the Health Department and all relevant health professionals to ensure that:

- (i) Administrative problems are kept to a minimum.
- (ii) Optimum numbers of women who are or have been sexually active are reached by the programme.
- (iii) Cultural, privacy and financial considerations are taken into account, so that screening is acceptable and available to all women. Given the difficulties in establishing an efficient programme and the likely marked increase in numbers of women suffering from disease of the genital tract, this is an urgent priority.

Jacqui Akuhata-Brown, Group Manager of the National Screening Unit provided an update on the cervical and breast cancer screening programmes and Ruth Herbert identified issues for future improvement.

CHALLENGE SPEAKER: Jacqui Akuhata-Brown,
Group Manager, National Screening Unit

Jacqui Akuhata-Brown began her presentation by addressing the goals and aims of the national screening programmes, in particular the National Cervical Screening Programme (NCSP). Established after Cartwright the programme is committed to improving information for women. It also monitors screening providers. The NCSP is reliant on a range of service providers. These include primary health care services, laboratories, colposcopy services, regional services and independent service providers.

Impact of Cartwright Report recommendations for cancer screening

The Cartwright Inquiry resulted in the following outcomes in relation to cancer screening:

- Establishment of the National Cervical Screening Programme in 1990/91
- Emphasis on information for women

- National Policy and Quality Standards
- Guidelines for Cervical Screening in New Zealand – incorporating the management of women with abnormal cervical smears
- Training for Medical Practitioners and laboratory personnel - National Screening Unit trains colposcopists
- On-going advice and review of the programme

National Screening Unit

The recommendations from the Cartwright Report led to the establishment of the National Screening Unit. The role of the unit is as follows:

- Central point of guidance for the sector
- Lead and coordinate national screening programmes
- Purchase services
- Monitor and evaluate quality of programmes
- Build and maintain relationships within the health sector – aims to have consumer representatives on all groups
- Ministry changes, and in particular the establishment of the National Health Board will result in changes to the NSU
- The Ministry is being restructured - public health split in 5 directions. National Screening on National Health Board from early November.

National Cancer Screening Programmes

- National Cervical Screening Programme (NCSP)
- BreastScreen Aotearoa (BSA)

National Cervical Screening Programmes (NCSP)

- Aim: To reduce the incidence and mortality of invasive cervical cancer by the detection and treatment of high grade changes
- Goal: To screen 75% of all women aged 20 to 70

Akuhata-Brown presented statistics of NCSP Coverage from September 08 - May 09. There has been an increase in coverage but there is a lot of work to be done to reach Maori and Pacific women. There has been a significant decrease in the incidence of cervical cancer.

NCSP changes and challenges

Since the Cartwright Inquiry:

- Knowledge of the causes of cervical cancer (Human Papillomavirus)
- New and improved tests

NCSP currently:

- Prevents at least 70% of cervical cancers
- Is highly cost effective
- Has one of the highest proportion (74.8%) of women participating in the programme in the developed world
- Low coverage of Maori, Pacific and Asian women - this is a major priority moving forward.

¹³ Term of Reference 9a, Chapter 11, The Cartwright Report

BreastScreen Aotearoa (BSA)

- Aim: To save lives through early detection of breast cancer by two yearly screening
- Goal: To screen 70% of eligible population to reduce breast cancer deaths by 30% in eligible women aged 45 to 69 years

Akuhata-Brown presented statistics of BSA coverage for the 24 months ending June 2009. Maori and Pacific women remain under screened. However there have been improvements. Women are $\frac{1}{3}$ less likely to die from breast cancer in 2006 than in 1990.

BSA challenges moving forward include the need to:

- Reduce inequalities and increase coverage for Maori and Pacific women
- Aim is 70% coverage priority by 2011
- Targeted approach
- Digital conversion – improve technology and quality
- Information management

CHALLENGE SPEAKER: Ruth Herbert,

Independent health consultant

Independent Health Consultant Ruth Herbert outlined what she sees as a number of challenges facing cancer screening programmes in New Zealand and identified possible solutions for moving forward, including proposing establishing a national population register which various screening programmes could use to identify unscreened people.

The Cartwright Report (1988) stated:

*“The benefits of a well-planned New Zealand-wide cervical screening programme are now indisputable.....implement within ‘a reasonable period’ a population-based cervical screening programme for New Zealand women”.*¹⁴

Since then....

- Regional cervical screening and registers
- National cervical screening and register (NCSP)
- National breast cancer screening (BSA)
- Gisborne Cervical Screening Inquiry 2001¹⁵
- Cervical cancer audit
- Colorectal/bowel cancer screening – bowel screening programme has the same issues and challenges as breast screening and cervical screening.

The challenges of screening programmes

Herbert described screening as being like a 3-legged stool: national infrastructure, quality, and participation. You can't take attention off any of these legs, they are all equally important for holding up the stool. With cervical screening participation rates were good, but there were quality failures that resulted in the Gisborne situation.

National infrastructure

The Report from the Ministerial Review Group 2009 (Horn report)¹⁶

The Ministry of Health be asked to consider if the National Screening Unit should remain a national service and be moved to the National Health Board, or if it is better to devolve its functions to District Health Boards to manage either regionally or locally. Unless unanticipated issues arise, this should be concluded in the 12 month timeframe for moving Non-Departmental Expenditure. (Annex 4 pg 13).

It is important that national screening programmes are designed and managed in a consistent way – many aspects of the delivery of screening programmes can be determined regionally/locally but this must occur within a national framework.

Quality

- The programme must be funded to a level that ensures quality is not compromised
- If there are funding cuts quality will be compromised
- Mustn't risk repeating past failures
- Independent vs in house monitoring – evaluation needs to be done independently.
- There will be a question of whether any of the National Screening Programme quality management could appropriately be done by the new national quality agency – maybe by providing an independent critique to in-house monitoring
- Quality is linked to national infrastructure – if we don't ensure optimum quality at all times it risks cracks. We can't assume that all is well – we must be vigilant and remember past failures.

Participation – the challenge?

Many different screening programmes all face the same challenges – how to reach the hardest to reach people ie. those most in need? Poor participation rates invariably mean inequalities. There are significant inequalities in the New Zealand Cancer Screening programmes.

- There is a big difference between opportunistic screening and an organized screening programme and big differences between 'population screening' and 'population based screening'

¹⁴ Chapter 11, The Cartwright Report

¹⁵ Cervical Screening Inquiry 2001 <http://www.nsu.govt.nz/Current-NSU-Programmes/1617.asp>

¹⁶ Meeting the Challenge: enhancing sustainability and the patient and consumer experience within the current legislative framework for health and disability services in New Zealand, Report of the Ministerial Review Group, July 09

- Population screening programmes use health promotion activities to encourage people to self refer. Population based screening programmes use some form of national register (database of the population) to identify eligible people and invite them to participate (personal invitation). We don't do that in New Zealand, we rely on GPs, health promoters, or women themselves.

For over 25 years there have been calls to establish a national population register that national screening programmes could use to identify eligible people:

- 1985 – Skegg et al – in making recommendations for a NZ national cervical screening programme - pointed out that *“the full potential of cervical screening will be realized only with effective systems to invite all women for screening”*.¹⁷
- 1988 – Cartwright Report *“... a population-based cervical screening programme for New Zealand women”*.¹⁸
- 1999 – Gisborne inquiry recommendation *“The National Cervical Screening Programme should work towards developing a population based register and move away from being the utility based register that it now is”*.¹⁹

A national population register

Herbert suggests the time is right to establish a national population register from which to identify and invite unscreened people for a wide range of screening and prevention programmes.

- Over 95% of New Zealanders are now enrolled with a Primary Healthcare Organisation (PHO) and hence the national PHO database has details of nearly all the NZ population
- There have been significant advancements in cleaning up the National Health Index register
- A combination of the PHO databases and the NHI could function well as a national register

Herbert suggested that the current Minister of Health should be encouraged to prioritise the establishment of a national population register and noted this would almost certainly result in increased participation in the national cancer screening programmes. New Zealand will continue to limp along until there is one.

Herbert also suggested there is an opportunity to use our valuable workforce of health promoters in a more effective way. We currently have health promoters focusing on different disease groups. Herbert sees an opportunity for health promoters to become more inclusive, more holistic, working with individuals and their whanau on all their screening needs.

The way forward

Herbert suggested that if New Zealand had a national population register and a more holistic and more targeted health promotion and recruitment system that this will result in:

- Increase in participation
- Reduction in 'Did Not Attend' (DNA) and 'Did Not Return' (DNR)
- Reduction in inequalities
- Reduction in morbidity and mortality

WORKSHOP DISCUSSION POINTS

Changes in cervical screening techniques

- Cervical screening has changed - it can now identify high grade abnormalities. What is the effect of changing the goal in that way? Akuhata-Brown responded that the goal has been modified on the premise of detecting and treating high grade as opposed to low grade abnormalities – particularly women of child bearing age.
- What is the practical effect of this? Do you ignore low grade abnormalities? Akuhata-Brown responded: No. New guidelines – detection and treatment of low grade as of this year in October. We have HPV testing in women under 30 – identification of high or low risk. A clinical decision is discussed with those women. We can monitor what is happening in terms of treatment.

Coverage

- Fact: women with advanced cervical cancer have patchy screening histories.
- Risk increases with age. Generally, coverage per age group is over 75%. There is a drop off in coverage with 60-65 years group and less in the 20-24 group.
- In relation to 20 year old first visit – they are not sent invitations, it is up to the primary care physician.

Participation

- If 95% of women are registered surely that is a good start.
- Non-attendance of women at colposcopy clinic appointments is the single most important issues - particularly for Maori. Akuhata-Brown responded that there is a programme to look at the issue. The National Screening Unit is asking who it needs to work with? Bus clinic had 100% turn out rate. Need to look at current environment and what women need.
- Some screening programme providers are working directly with PHOs and GPs to recruit for screening. This must be done carefully to ensure it is appropriate for consumers. There is some concern that we spend time and energy trying to find people when we would be better to have consumer focus on “Did not attend” (DNAs) i.e. use energy that way.

¹⁷ Skegg DC, Paul C, Seddon RJ. Recommendations for routine cervical screening. New Zealand Medical Journal, 1985;98:636–9.

¹⁸ Chapter 11, The Cartwright Report, <http://www.nsu.govt.nz/Current-NSU-Programmes/3233.asp>.

¹⁹ Cervical Screening Inquiry 2001 <http://www.nsu.govt.nz/Current-NSU-Programmes/1617.asp>

- How many women need to be screened to prevent one event? Historically, Maori women were not convinced this was a programme they wanted to pursue. They would rather look at programmes to prevent smoking. Too big an issue to address in this forum.
- Surprise at some of the issues being discussed. E.g. Maori and Pasifika women don't feel motivated when well and busy. Maori women are often embarrassed, and/or can't afford to see Primary Care Practitioners.
- What are the reasons that people don't get screened? There is nothing apparently wrong, don't want to go etc.
- Also cost is a barrier. 6% funded, but gets very political. GP charges. Screening quite expensive. It has improved now in that women are not screened so often. Has come down a lot - i.e. to three years instead of one.
- Funding is directly linked to under-screened women but it is the responsibility of providers, not the National Screening Unit (NSU), to reach these women. There are lots of strategies out there. The problem is that unscreened populations are most at risk – with the highest number of high grade abnormalities picked up.

Quality of practice

- Quality of practice needs addressing. A person can be taught how to take smears, but no-one checks practice after training. Akuhata-Brown responded that the NSU runs training. The on-going assessment needs to sit with people they work for. The national screening programme is not an employer, but can offer advice.

Risks and benefits of screening

- Cervical screening is the thing that has worked. Since 2007 there has been a good increase in coverage. Particularly Pacific groups and Maori participation has improved the most because of targeted promotion – TV ads, radio, printed media and health promoters support. Every month there is an increase.
- Where there is a need, population based screening programmes are excellent. However screening programmes should only be run when the benefits outweigh the risks, eg. breast cancer screening at age 45 – is this right?

National register

- Where there is a need, population based screening programmes are excellent. There is a risk of loss of privacy with a national based register.
- It isn't a person's duty to be screened but there is a push to include everyone. Need to be careful that we respect rights to informed choice and consent.
- Concern expressed that rolling all screening programmes together could result in people rejecting all of them and create resistance to screening in general. Reassurance from Jacqui Akuhata-Brown that National Cervical Screening Programme register will not be used for other programmes.
- There was some confusion that Ruth Herbert was suggesting that all screening programmes be rolled

together and that this would create resistance to screening in general and have huge ethical issues. Herbert clarified that she wasn't suggesting combining screening programme registers. Rather she suggested establishing a register of names and contact details (from Primary Healthcare Organisations and National Health Index registers) to be used as a source of identification and recruitment by the different screening programme registers.

RECOMMENDATIONS

- National screening programmes should be designed and managed in a consistent way – many aspects of the delivery of screening programmes can be determined regionally/locally but this must occur within a national framework.
- National screening programmes must be funded to a level that ensures quality is not compromised.
- The barriers for women attending colposcopy clinics needs to be addressed as a priority. Responses should be community specific, one size will not fit all.
- Evaluate the extent to which cost is a barrier to participating in screening programmes and identify solutions.
- Screening is not compulsory. Neither is it benign - holding both benefits and risks for women. All activities to promote uptake of screening should take into account the Code of Health and Disability Services Consumer Rights, in particular the right to make an informed choice and give informed consent.
- A shift of focus in health promotion from disease or intervention specific activities to a more inclusive, integrated approach, working with individuals and their whanau on all of their screening and disease prevention needs, is likely to help improve participation rates and should be considered.
- Investigate the establishment of a National Population Register from which to identify and invite unscreened people for a wide range of screening and prevention programmes. Investigation would need to take into account the risk of coercion and rights informed choice and consent.



Workshop discussion.

BACK TO THE FUTURE:

CARTWRIGHT FOR THE 21st CENTURY

The seminar concluded with a panel discussion in which consumer, social science, legal, nursing and medical leaders envisioned the way ahead for our health care system with the principles and recommendations of Cartwright Report as its foundation.

Sandra Coney provided a consumer perspective and focused on how to raise consumer voices. She believes young people are concerned but the punishment they receive for speaking out can be a major disincentive. Coney believes that informing the public is the key and that if you get the information out there people will act. We need to develop strategies for encouraging public discussion and engagement.

Ron Paterson provided a medical law perspective and also identified the lack of public debate as a key issue. He asked where are our public intellectuals who will speak on health issues and generate debate? He also identified access to services as a major issue and acknowledged the gap between rhetoric and reality.

Professor Jenny Carryer provided a nursing perspective. Health is the single most important asset that we have and we need to advocate for a recognition of health as something much more than elective surgery and waiting lists. Carryer called for the need for collective organizing that refuses to let health be reduced to a narrow set of tightly focused health system priorities.

Professor Charlotte Paul provided a medical and public health perspective. She expressed her concern that the legacy of the Cartwright Inquiry may be misunderstood and misused. Paul emphasized the importance of research and articulated her concern that consumer groups may undermine the ability to research. Paul recognized our common interest in our criticism of Bryder's history of the 'Unfortunate Experiment'. She noted that professionally based interests, affiliations and cultures are stronger than gender as a determinant of attitude and behavior.

Kevin Dew provided a sociological and critical public health perspective. He emphasized the importance of forums such as this and identified the tension between public good and social justice as a key issue .



Professor Kevin Dew,
Professor Charlotte Paul,
Professor Jenny Carryer,
Ron Paterson (not visible),
and Sandra Coney.

AUDIENCE DISCUSSION POINTS

- The memory of the Cartwright Inquiry is fading and we need to undertake urgent action to keep the legacy alive, through, for example, education in schools and tertiary institutions. This is being done well in some places but could be better on a national level. Are the Cartwright Inquiry and Report included in health education in schools? One nurse described talking to consumers directly about the Cartwright Inquiry when taking them through the informed consent process.
- The Cartwright Report's impact was not just on how to do health or medical research – it shaped how research should be done in all disciplines and contexts.
- Concern expressed about the effects of the current health restructuring on ethics committees. The changes may be positive or negative but are unknown at this point - it was noted that the present system is very complicated.
- At present providers are responsible for rationing health dollars. The community needs to be involved in making decisions about what this country can afford and what kind of health system we want to have.
- Consumer voice needs to be strengthened across the health sector and at every level.
- 21 years after the release of the Cartwright Report the statistics for Maori women dying of cervical cancer are poor. Inequalities of health, particularly for Maori, require urgent and on-going attention and culturally specific responses.



Seminar participants

SUMMARY OF RECOMMENDATIONS

The following recommendations constitute a call to action. They are intended to guide developments, and maintain momentum towards a New Zealand health care system with the principles of the Cartwright Report at its foundation, and to ensure the specific recommendations of the Cartwright Report are implemented in the spirit in which they were intended. They are for the specific agencies to which they are addressed, and also provide a road map for consumers/consumer groups who continue their work in overseeing the implementation of the Cartwright Report.

THE COMMISSIONER, THE CODE AND PATIENT ADVOCACY

- Reverse the change made to Right 7(10) of the Code of Health and Disability Services Consumer Rights.

Suggested wording of Right 7(10):

No body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved, or used otherwise than -

- With the informed consent of the consumer;

Or

- For the purposes of one or more of the following activities, being activities that are each undertaken to assure or improve the quality of services:

- *A professionally recognized quality assurance programme*
 - *An external audit of services*
 - *An external evaluation of services*
- The HDC should take steps to improve consumer participation and consultation.
 - Ensure that consumers are consulted on future proposed changes to the Code of Rights and develop a better process for consumer driven changes to the Code
 - Consider involvement of consumers in complaint reviews.
 - The HDC should work towards being able to provide complainants a choice of process/pathway for resolution of the complaint. Consumers should have a right to an investigation in a serious case such as where the practitioner's competence is of serious concern.
 - Review the process for dealing with the most serious cases in the context of the Cull Report 2001.

PATIENT CENTRED HEALTH CARE

- Support the establishment and implementation of a nationally funded and coordinated cross-sectoral interpreting and translation service including Te Reo Maori, New Zealand Sign Language, and for those unable to communicate effectively in English. Effective communication in health and disability services is a right.
- Forge new alliances and collaborations between health consumer groups and health professional bodies to facilitate collective responses to issues of concern.
- Strategize ways to facilitate young people as vocal health consumers able to identify and respond to changes in health policy and services.
- Health and disability services remain, for the most part, clinician dominated. Resource constraints are likely to further consolidate this. Work is needed to identify and promote opportunities and innovations to promote the shift towards patient centered health care.
- Need to challenge the devolution of Primary Healthcare Organisations (PHOs) and promote the implementation and continuation of PHOs as intended by the Primary Health Care Strategy 2001
- Broad support for the establishment of an independent quality agency. The independence of this agency will be vital to achieving its objectives. Consumer participation and representation in an independent quality agency will also be vital to its success.

ETHICS COMMITTEES

- The revised Declaration of Helsinki, released in October 2008, now states that “*Every clinical trial must be registered in a publicly accessible data base before recruitment of the first subject.*” (paragraph 19). The Australian New Zealand Clinical Trials Registry should include all clinical and Phase I trials, and New Zealand specific information should be easily identifiable.
- Where there are significant public good issues there needs to be significant and meaningful public consultations. eg. when talking about genetic or biotechnology issues.
- Audit the applications to the Multi Region ethics Committee relating to women’s health to determine whether the applications have been assessed with the protection of the patient/ consumer as the primary consideration.
- New Zealand has a robust system of ethical review. However it is time for an independent review of the autonomy of New Zealand’s health and disability ethics committees given their current location in the regulatory framework. The review should include the independence of ethics committees from researchers and sponsors, particularly in the context of Ministerial appointments. The Officer of the Auditor General or the Law Commission could be suitable for such a review.
- Processes for ensuring researcher compliance to the terms of ethics approval need to be further developed. Issues include monitoring, compliance to the terms of approval, and actions taken when a failure to comply is identified.

CANCER SCREENING PROGRAMMES

- National screening programmes should be designed and managed in a consistent way – many aspects of the delivery of screening programmes can be determined regionally/ locally but this must occur within a national framework.
- National screening programmes must be funded to a level that ensures quality is not compromised.
- The barriers for women attending colposcopy clinics needs to be addressed as a priority. Responses should be community specific, one size will not fit all.
- Evaluate the extent to which cost is a barrier to participating in screening programmes and identify solutions.
- Screening is not compulsory. Neither is it benign - holding both benefits and risks for women. All activities to promote uptake of screening should take into account the Code of Health and Disability Services Consumer Rights, in particular those the right to make an informed choice and give informed consent.
- A shift of focus in health promotion from disease or intervention specific activities to a more inclusive, integrated approach, working with individuals and their whanau on all of their screening and disease prevention needs, is likely to help improve participation rates and should be considered.
- Investigate the establishment of a National Population Register from which to identify and invite unscreened people for a wide range of screening and prevention programmes. Investigation would need to take into account the risk of coercion and informed choice and consent.



PO Box 9947
Newmarket
Auckland

Ph. (09) 520 5295
Fax. (09) 520 5731
email: info@womens-health.org.nz
www.womens-health.org.nz