

AUCKLAND WOMEN'S HEALTH COUNCIL

ANNUAL REPORT

April 2014 – March 2015



The Auckland Women's Health Council has been in existence for almost 27 years. Since the first formal meeting which was held in July 1988 the Council has provided a strong voice on women's health in the Auckland region and has been actively involved in women's health issues at a national level.

The AWHC continues to maintain a special interest in the issues that arose from the Inquiry into the treatment of cervical cancer at National Women's Hospital and in the implementation of the recommendations in Judge Silvia Cartwright's Report which was released in August 1988. These issues include the National Cervical Screening Programme, patients' rights, informed consent, access to patient records, ethics committees, and clinical research.

More than two decades later, the need for a woman's voice on these issues remains as strong as ever, due to advances in technology, the changes in the evidence base for screening programmes, the introduction of electronic medical records and the increasing amount of data sharing, the reduction in the number, membership and function of ethics committees, the increasing influence and power of the pharmaceutical industry, and the increasing lack of informed consent in the health sector.

The National Screening Unit and the National Cervical Screening Programme and BreastScreen Aotearoa continue to be important issues for the Council due to its location within the Ministry of Health and its current oversight by the National Health Board. The Council is aware that the cost savings demanded by the current government and lack of monitoring have had a significant and

detrimental impact upon all screening programmes and has resulted in medical disasters and negative stories in the media.

Meanwhile the bowel screening pilot currently underway in the Waitemata DHB region has received only positive media coverage. Good news stories feature people whose colonoscopy has resulted in an early diagnosis of bowel cancer, but the emotional and physical harms associated with long waiting times for colonoscopy and having to return for repeat procedures that are often not necessary are ignored.

The Council takes a keen interest in the screening programmes that have been established because of the very real risk of turning well people into patients. Other issues of concern due to the increasing numbers of screening programmes being established include the need for fully informed decision-making, the importance of ensuring that any screening programme offers benefits that outweigh the harms and are cost effective, the monitoring and audit processes that are put in place, and the need to ensure there are adequate resources and health services in place for those found to be at risk of having the condition being screened for.

District Health Boards

Over the past 15 years the AWHC has attended most of the meetings of the Auckland and Waitemata District Health Boards. As well as monitoring the Board's activities in relation to women's health issues, attending meetings has enabled the Council to establish an important profile with the DHBs.

The Council has gained considerable insights into how the DHBs operate and how they work together – or don't – in providing services for the population in the greater Auckland region.

Challenge to findings of Cartwright Inquiry

At the beginning of 2014 Linda Bryder published her book on the history of National Women's Hospital. Entitled "*The Rise and Fall of National Women's Hospital*," the book features a chapter on the Cartwright Inquiry which repeats the same misleading and false interpretations and allegations made in her previous book, "*The History of the Unfortunate Experiment at National Women's Hospital*."

As noted in last year's Annual Report, Ron Jones has been working on his own book and has now completed his own history of his time at National Women's Hospital. He is currently looking for a publisher.

Cartwright Anniversary & Consumer Rights Issues

On August 5th each year the AWHC holds a special ceremony at the Statue of Peace in front of the former National Women's Hospital building to commemorate the release of the Cartwright Report. In 2014 members of the Council assembled in front of the statue to acknowledge the women who were part of the "unfortunate experiment" at National Women's Hospital and those who died and suffered as a result of the misreading of slides that led to the Gisborne Inquiry.

After the success of "The Legacy of Cartwright conference" which took place on Friday 27 September 2013, the Cartwright Collective began thinking about organising another conference in two years' time. Regular meetings were held throughout 2014 and a conference has been scheduled for Friday 7 August 2015. "The Future of Cancer Screening in New Zealand" symposium will focus on cancer screening – cervical, breast and colorectal cancer – and finish with a session on the potential for primary prevention.

The 2013 conference produced a small profit of \$1850 which was transferred to Women's Health Action in December 2014 as seeding funding for this year's conference.

Preventing Overdiagnosis conference

In September 2014 the AWHC's co-ordinator attended the second international Preventing Overdiagnosis conference which was held at Oxford University in the UK. The conference featured a number of speakers who are well known researchers and authors and was attended by more than 450 people from over 30 countries. Highlights from both the 2013 and 2014 conferences are available at: <http://www.preventingoverdiagnosis.net/>

Peter Gotzsche's Australian tour

Lynda Williams and the Federation of Women's Health Councils' co-convenor, Barbara Holland, went to Sydney in February 2015 to hear Peter Gotzsche's lectures on mammography screening, and on antidepressants. Lynda and Barbara were also invited to attend the lunch after the third lecture. After the lunch they were both interviewed by a young Danish film-maker who has been following Peter around the world over the past two years in the process of making a documentary about him. Peter is writing another book – this one is on antidepressants - which is due out in September 2015.

Ethics committees

Over the past five years, the AWHC has become increasingly concerned about how the Ministry of Health ethics committees are functioning.

The drastic changes introduced in 2012 have seriously undermined the purpose and function of the ethics committees. The four committees now work to very tight timeframes and have fewer options in dealing with research proposals. The focus has shifted from even further from protecting patients/research participants to approving clinical trials as quickly as possible.

The AWHC has been attending meetings of the Northern A ethics since 2012 and in 2013 attended some meetings of the Northern B ethics committee. The AWHC continues to monitor and report on the way that the ethics committees are operating and in May 2014 the *NZ Herald* featured a front page article which described the practice of enrolling unconscious patients in clinical trials. The AWHC then wrote several letters to Health & Disability Commissioner Anthony Hill requesting that he urgently undertake an inquiry or establish a working party to look into this illegal practice. In December 2014 the AWHC finally received a response to our letters. The Commissioner advised “that the time has now come to commence a more fulsome public information and consultation process, considering the question of research involving incompetent consumers and the issue of whether Right 7(4) requires amendment.” Details were going to be released early in the New Year but the AWHC has not heard anything further from the HDC.

Submissions and consultations

Each year the Council makes written submissions and attends consultation meetings on a variety of health issues that affect the health of women and patient rights. The Council also writes many letters to health authorities and the Minister of Health on various matters. It is worth noting that the current political environment is not conducive to meaningful consultation and there are often unrealistic timeframes given for producing submissions. The written and/or oral submissions produced by the Council during the year included the following:

- Letter to Jonathon Coleman, the new Health Minister, about the need for cervical screening to be publicly funded in the same way that all other screening programmes are.
- Four letters to the Health & Disability Commissioner requesting him to take action on the widespread practice of enrolling unconscious patients in clinical trials.
- A submission on NEAC’s discussion document on “*Cross-sectoral ethics arrangements for health and disability research.*”

Women’s Health Issues in the Media

The AWHC is contacted regularly by reporters seeking comments and interviews on a wide range of women’s health issues. During the year the Council gave a

number of media interviews on a wide variety of issues, including the emergency contraceptive pill, the bowel cancer screening pilot, enrolling unconscious patients in clinical trials, the enrollment of young adults with Down syndrome in a clinical trial, and the incident involving Lakes DHB sending potentially identifying data on 625 women who had had an abortion.

The AWHC Newsletter

The Council's monthly newsletter is sent out by mail and email to over 130 individual women and women's groups, MPs and DHB members and is circulated even more widely via email.

The newsletter provides information on a range of women's health issues and activities, notifies members of discussion documents and reports on women's health issues and submission deadlines, reports on District Health Board activities, and keeps members up-to-date with the work of the Council.

The AWHC newsletter is an important link with other women's groups as well as with individual women. Information is included from other women's groups advising members of courses, workshops, seminars and other events. The Council often receives requests to reprint an article that has appeared in the newsletter.

Although the Council's funding is often precarious the independence of the newsletter and the commentaries on developments within the health care system and the implication for women create a considerable level of interest across a wide range of people involved in the health sector.

The AWHC Office

The AWHC's office hours are officially 8am to 4pm on Tuesdays, Wednesdays and Thursdays, but the co-ordinator's hours are reasonably flexible to allow for meetings and appointments to be attended on the other two days as required.

The Council's office is situated in a room in the co-ordinator's home. The move from the office in Newmarket at the beginning of 2004 has been very cost effective for the Council, and effectively means that the co-ordinator is available five days a week.

Since 2011 the AWHC's monthly meetings have been held at AUT's Akoranga campus on the North Shore.

Co-ordinator's Position

The co-ordinator's position is a part-time position which involves 25 hours per week.

The major tasks include producing the AWHC's monthly newsletter, preparing submissions in consultation with other AWHC members, dealing with phone and email enquiries, attending meetings on behalf of the Council, preparing grant applications for funds, networking with other women's groups, attending District Health Board meetings, responding to media inquiries and doing media interviews for radio and TV, updating the website and reporting to the Council at the regular monthly meetings.

The AWHC Meetings

The Council holds a general working meeting each month to discuss the current projects the Council is working on, to make decisions on particular health issues the Council was dealing with, to discuss grant applications and financial matters pertaining to the operation of the Council, and to deal with the ongoing work of the organisation. Detailed reports from both the co-ordinator and the treasurer are presented and discussed at these meetings.

Federation of Women's Health Councils

The AWHC is a member of the Federation of Women's Health Councils and continues to network with other Federation members throughout New Zealand. The AWHC co-ordinator is a member of the Federation Core Group and takes part in the Federation's AGM which is usually held via a teleconference phone call each year.

The networking and support that the two co-convenors of the Federation have provided to the AWHC over the past few years has been much appreciated by the AWHC's co-ordinator.

Funding

The funding environment has changed over the past few years and once again it is proving difficult to obtain the necessary grants the AWHC needs to continue its work. Changes have been made to the funding rounds for Lottery Community, COGS and the ASB Community Trusts. These three funding agencies have been and still are the main sources of funding for the AWHC.

The AWHC submitted a grant application to The Trusts Community Foundation for envelopes (the cost of postage was about to go up) and wages, and in May received a grant of \$10,000.

A grant application to the ASB Community Trust was submitted in May 2014 for wages and some administration costs and in August received a grant of \$8,000.

Lottery Community dispensed with its March grant round in 2014 which placed a considerable strain on the AWHC finances. The AWHC submitted a grant

application to Lottery Community in May for the director's salary and some administration costs and received the grant of \$25,000 in September 2014.

Grant applications were also submitted to four of the five Auckland COGS committees in May 2014. The Waitakere, Auckland and North Shore COGS committees declined our grant applications. The Council was therefore very appreciative of the \$3,000 that was received from the Manukau COGS committee.

In September, the AWHC applied to the Lion Foundation for \$6,000 for a much needed new photocopier but this was declined.

In December 2014 the AWHC submitted a grant application to Pub Charity for the new photocopier. In February 2015 the AWHC received a grant of \$6,000 and purchased a new Konica Minolta photocopier a few weeks later.

The Council is very appreciative of the ongoing funding for administration costs and the co-ordinator's salary from these funding agencies, but the Council is going to have to apply to a wider number of trusts for the funding it needs.

The Future

Changes in the health system inevitably involve challenges to community and consumer groups as well as others working in both the public and private areas of the health sector. The current government has its own priorities and targets which they insist DHBs and those working in primary health care must meet. However, as Lester Levy, chairperson of the Auckland and Waitemata DHBs, pointed out in February 2015, health targets have unintended consequences.

There have been further changes in the National Screening Unit over the past year, with staff leaving the NSU at a time when significant changes are being introduced to cervical screening.

The sharing of electronic medical records and the introduction of patient portals are also issues that need to be carefully monitored.

Events like these underscore the need for community health groups, especially women's health groups, to continue their watchdog role and their reporting on the changes in the health sector that are adversely affecting the provision of health services for women and their families.