



AUCKLAND WOMEN'S HEALTH COUNCIL

ANNUAL REPORT

April 2015 – March 2016

The Auckland Women's Health Council has been in existence for almost 28 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 very aware that the cost savings demanded by the current government and the lack of monitoring have had a

significant and detrimental impact upon all screening programmes and continues to result in negative stories in the media.

The bowel screening pilot currently underway in the Waitemata DHB region has now completed two screening rounds and a recent report to the board stated that the key challenges at the end of round one were to increase coverage, increase equity of participation and develop the register so that it is fit for purpose. There has been a lower participation rate during round two which was not unexpected as this has occurred in other countries. The pilot has been extended for a further two years during which time the final evaluation report will be considered (June/July 2016) and a decision made regarding a possible national roll-out.

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 16 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, as outlined in the recent article in *NZ Doctor*.

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.

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 2015 several 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 27 September 2013, the Cartwright Collective organised a second conference which took place on Friday 7 August 2015. "The Future of Cancer Screening in

New Zealand” symposium focused on cancer screening – cervical, breast and colorectal cancer – and finished with a session on the potential for primary prevention. It was a highly successful conference attended by over 100 people, and was attended by Ministry of Health and National Screening Unit some of whom were speakers.

At the beginning of 2016 the Cartwright Collective began organising another conference, the topic being about the changes being introduced to cervical screening.

Ethics committees

Over the past six 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. The AWHC continues to monitor and report on the way that the ethics committees are operating. Following the publication in May 2014 of a front-page article in the *NZ Herald* which described the practice of enrolling unconscious patients in clinical trials, the AWHC has repeatedly written to the 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.” However, this has not happened and the HDC has ignored all further correspondence.

Health Quality & Safety Commission Forum

Two AWHC members attended the HQSC Forum held in Wellington in May 2015. Atul Gawande, American surgeon, writer and public health researcher, gave two presentations at the Forum, and Ron Paterson gave a presentation on Judi Strid’s story. Several members of Judi’s family attended the event to hear Ron’s presentation.

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:

- A submission on the Ministry of Health's "Maternity Quality Initiative 2015-2018" consultation document.
- A submission on ACART's "Informed Consent and Assisted Reproductive Technology: Proposed advice to the Minister of Health.
- A submission on the Ministry of Health/NSU's consultation paper on "National Cervical Screening Programme: Changing the primary laboratory test."
- Several letters and emails to the Health & Disability Commissioner requesting him to take action on the widespread practice of enrolling unconscious patients in clinical trials.

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 number of issues, including the use of surgical mesh, the status and health of women in New Zealand, the emergency contraceptive pill, Judi Strid's patient journey, cancer screening and the epidemic of overdiagnosis, and attending DHB meetings.

The AWHC Newsletter

The Council's monthly newsletter is sent out by mail and email to 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 Foundation North (formerly the ASB Community Trust). 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 wages and some of the AWHC's administration costs, and in May received a grant of \$5,000.

A grant application to the ASB Community Trust was submitted in May 2015 for wages and some administration costs and in August received a grant of \$8,000.

Lottery Community dispensed with its March grant round in 2015 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 December 2015.

Grant applications were also submitted to four of the five Auckland COGS committees in May 2015. This year the AWHC received a grant from all four of the COGS committees - \$2,000 from Waitakere COGS, \$4,000 from Auckland COGS, \$1,201 from North Shore COGS committees and \$3,000 from the Manukau COGS committee.

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, repeatedly points out, health targets often have unintended consequences.

There have been further changes in the National Screening Unit over the past year or two which have only served to increase the sense of alienation that women's health groups feel about what is happening with the breast and cervical screening programmes. This was heightened at the end of 2015 when the NSU/MOH undertook an extremely rushed consultation process on proposed changes to the primary cervical screening test.

The sharing of electronic medical records and the introduction of patient portals are other issues that need to be carefully monitored. The Federation of Women's Health Councils, and a member of the AWHC have been very involved in attending meetings on these issues and keeping the AWHC and other women's health groups informed about what is going on.

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.