



AUCKLAND WOMEN'S HEALTH COUNCIL

ANNUAL REPORT

April 2016 – March 2017

The Auckland Women's Health Council has been in existence for almost 29 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.

Almost three decades later, the need for a woman's voice on these issues remains as strong as ever, owing 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.

Cervical screening and breast cancer screening continue to be important issues for the Council, as does the more recently introduced bowel screening programme. The bowel screening pilot programme implemented in the Waitemata DHB region is set to be rolled out in the Hutt and Wairarapa DHBs from the 1st of July this year, while the pilot continues at Waitemata until the end of this year, whereupon

it will transition to the new arrangements under the Programme at the beginning of 2018.

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 owing 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.

In addition, there are substantial changes proposed to the cervical screening programme, revolving around the introduction of HPV testing, that raise substantial concerns about the future of a cervical screening programme that has been enormously successful in preventing cervical cancer and reducing mortality in this country. The proposed changes to the programme will increase the risk of cervical changes going undetected in older cohorts of women and likely result in a resurgence in cervical cancer incidence in this now vulnerable group.

It is clear that the importance and relevance of the Auckland Women's Health Council remain as high as any time in its history, and that there is still a substantial amount of work to be done to ensure that all women are able to make fully informed choices about their health and wellbeing..

Changes in the AWHC

The last year has been one of transition and change for the AWHC. Lynda Williams, Co-ordinator for the last 22 years was diagnosed with pancreatic cancer in late 2015, and last year led to her resignation from the position effective the 28th of February 2017, although she remains an Executive Committee member. Much of the last year of her tenure has involved succession planning and facilitating the transition to a new co-ordinator, and over the last few months of the year preparing for the physical shift of the office from Waitakere to a new office (now located on the North Shore).

Succession planning involved a range of tasks, ranging from updating the Co-ordinator's job description to reviewing funding and grant applications, including a review of the organisation's main purpose, expectations of the role of the Council in a year's time and the resources the AWHC has for that work, and the need for a strategic plan.

During the year, to support Lynda Williams in her role, other Executive Committee members took on a variety of tasks in particular in support of the transition to a new co-ordinator.

At the 2016 AGM, Cheryl Hamilton agreed to continue as the AWHC Treasurer, and the Council's Executive Committee members were confirmed as Cheryl Hamilton, Debbie Payne, Trish Fraser, Katie Palmer du Preez, Madeline Heron, Jo Fitzpatrick, Pauline Proud and Lynda Williams.

Following advice at the beginning of the year from the Council's auditor that she would no longer be undertaking audits, and with the introduction of new Charities Services annual reporting standards and the Council's decision to report under the Tier 4 standard using cash based accounting, the Council will no longer need audited accounts. The Council acknowledges and thanks Delwyn Arthur for her work in auditing our accounts for the past 16 years – as well as her generosity in keeping the audit fee at an affordable level for a small charitable organisation.

The AWHC Office

For some years, until the end of March 2017, the Council's office was situated in a room in the Co-ordinator's home, and although office hours were officially 25 hours per week, that Lynda Williams was present outside of the publicised office hours effectively meant that she was available five days a week.

Since 2011, the AWHC's monthly meetings have generally been held at AUT's Akoranga campus on the North Shore, although in the last few months of the year were held in the Co-ordinators home.

Co-ordinator's Position

The Co-ordinator's position is a part-time one which involved 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.

Owing to Lynda Williams' resignation, the Co-ordinator's position was advertised as vacant in December 2016 with applications closing at the end of January 2017. Following interviews held in February, Sue Claridge was appointed to the position in March 2017, and the AWHC office was sorted, packed and shifted to the new Co-ordinator's home office in late March. With a similar set-up to the past few years, the AWHC looks forward to the Council being run on the same flexible basis as it has been for some time.

New Year's Honour for Lynda Williams

It was announced on the 31st of December that Lynda Williams was to be the recipient of a New Year's Honour and was to be made a member of the New Zealand Order of Merit. Her citation read:

“For services to women's health

Ms Lynda Williams has been an advocate for women's health and healthcare consumers nationally and has been a prime mover in the establishment and development of women's health organisations.

Ms Williams has more than 25 years' experience counselling women in a range of life and health issues, including miscarriage, stillbirth, neonatal death, childbirth experiences, and trauma arising from hospitalisation and medical procedures. She founded the Auckland Caesarean Support Group in 1984. She set up and coordinated the Childbirth Education Association of Auckland over a period of seven years and supervised childbirth educators completing their training. She assisted in the formation and development of the Auckland Women's Health Council in 1988, which inspired the formation of local groups throughout New Zealand and led to a Federation of Women's Health Councils being established in 1990. She has been Coordinator of the Auckland Women's Health Council and the Auckland Maternity Services Consumer Council since the early 1990s. Ms Williams has represented consumer concerns on a several ethics committees including the Auckland Hospital Ethics Committee, the Green Lane Hospital Ethics Committee, and one of the Auckland Area Health Board Ethics Committees.”

Lynda was invested in a special Auckland ceremony on the 9th of February. The AWHC congratulates Lynda on the Honour and is pleased that her work over many years has been publicly acknowledged. It is appropriate, here, for the Council to formally and publicly offer a vote of thanks to Lynda for her commitment, passion and dedication to both the AWHC and women's health issues over the last 22 years in her formal role as the Council's Co-ordinator.

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 is 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.

Funding

The funding environment has changed over the past few years and it challenging to obtain the necessary grants the AWHC needs to continue its work. The Lottery Community, COGS and Foundation North have been and still are the main sources of funding for the AWHC.

In the past year the AWHC received the following grants and funding:

- \$5,000 from the Trusts Community Foundation (TTCF) towards wages, office rent and telecommunications.
- \$3,000 from Foundation North towards wages, rent, telecommunications and website hosting.
- \$3,000 from Manukau COGS, \$1,800 from Waitakere COGS, \$1,312 from Rodney/North Shore COGS and \$3,000 from Auckland COGS (a total of \$9112 COGS funding) towards wages, mileage, stationery and rent.
- \$28,000 from Lottery Community, which represented the whole amount for which we applied. The funding application was for wages, mileage, stationery, and telecommunications.

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

AWHC Newsletters

The Council's monthly newsletter is sent out by mail and email to subscribers, individuals and groups, MPs and DHB members.

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.

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.

AWHC Website & Facebook Pages

Facebook posts and website articles are important media with which to communicate with the community about women's health issues. The monthly newsletters are also posted on the website some time after each newsletter is issued. Although regular and frequent posts and updates to the Facebook page and website have not been a top priority in the last year, the AWHC recognises the importance of these channels for disseminating information and it is expected that more frequent postings will become the norm in the coming year.

District Health Board Meetings

Over the past 17 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 insight into how the DHBs operate and how they work together to provide services for the population in the greater Auckland region.

Topics discussed in DHB meetings frequently raise issues relating to women's health and that are of concern to AWHC.

Ethics Committees

Two members of the AWHC are members of the Ethics Committee on Assisted Reproductive Technology (ECART). While one member has just finished a five year term, the other remains a member representing consumers. This is an evolving, developing and changing area as technology enables more and more intervention to assist people to become parents. Assisted Reproductive Technologies and their implications for women and their families is an area that AWHC has a long standing interest in and has regularly made submissions on.

Co-ordinator, Lynda Williams, and at times other AWHC Committee members, have been attending HDEC ethics committee meetings since 2009. This long period of engagement has enabled the AWHC to understand how changes introduced in 2012 have affected the function and the role of HDECs. The changes have caused the AWHC to become increasingly concerned about how the Ministry of Health ethics committees are functioning. Of particular concern to the AWHC at the moment is proposed research involving vulnerable populations/groups including those unable to provide informed consent. The AWHC continues to monitor and report on the way that the ethics committees are operating, and to discuss in a variety of *fora* the implications of issues raised.

Cartwright Anniversary & the Cartwright Collective

AWHC Executive Committee members Lynda Williams and Jo Fitzpatrick are members of Cartwright Collective and actively involved in the work of the Collective including the planning and hosting of *fora* over the last few years commemorating the Cartwright Inquiry.

The Cartwright Collective hosted a third day-long forum on the 5th of August, this time focusing on the control of cervical cancer in New Zealand.

The aim of the symposium was to provide an open forum to:

- bring together health practitioners, health consumers and policy maker;
- review the impact of screening in the control of cervical cancer;
- review the emerging issues in HPV immunisation in the control of cervical cancer;
- explore the implications of moving to HPV testing as the primary screening modality to control cervical cancer;
- share knowledge and foster debate.

In 1988, the Cartwright Report provided a blueprint for organised cervical screening and paved the way for other cancer screening programmes in New Zealand. This year the Cartwright seminar looked at the achievements in the control of cervical cancer in New Zealand and explored the implications of options for the future. It included expert speakers from across the screening, research and consumer sectors and panel discussions.

The highlight of the afternoon was Professor Marshall Austin's presentation on the implications of moving to HPV testing. It was filmed and both the full presentation and a 5-minute version with the most significant points were posted to the AWHC website and Youtube.

In a follow-up to the forum the Cartwright Collective developed a plan of action to ensure that the Ministry of Health, the Minister of Health and the National Screening Unit and others are made aware of the significant issues raised by both Brian Cox and Marshall Austin at the forum. The NSU plans to introduce HPV screening to ultimately replace the existing cervical screening programme and this is an issue that continues to cause the Cartwright Collective and AWHC grave concern.

Submissions

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. The written and/or oral submissions produced by the Council during the year included the following:

- A submission on the NHC's consultation document "Fit for Purpose Omics-based Technologies – Think Piece."
- A submission on "New Zealand's Health Research Strategy" for the next ten years.
- A submission on the NSU/NCSP consultation document "Updated Guidelines for Cervical Screening in New Zealand."

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 (see under heading Medical Research on Non-consenting Patients).

Consumer Representation

One of our members is active in regional health IT initiatives as a consumer representative. The Northern Region DHBs have a Governance Group to oversee IT developments with regional impact – which our member attends as a consumer representative. There is also an IT group – called CareConnect – that looks at regional data sharing to facilitate care. These include e-referrals, test results and Shared Care. An AWHC member is on this group and also co-ordinates a consumer advisory group for the Shared Care component of this suite of initiatives.

Individual AWHC members have participated in consumer focus groups on service delivery – both region wide and in their DHB areas. These include feedback on cancer and urology pathways, long term condition services and general service delivery. AWHC has also been active in recruiting other consumers for specific

feedback forums at the request of DHBs or regional services.

Lynda Williams attended regular Metropolitan Auckland Cervical Screening Operational Advisory Group meetings during the year, resigning from this group in March 2017.

As a result of her diagnosis with pancreatic cancer in late 2015, during 2016 and up until March 2017 when Lynda Williams resigned, she added advocating for improved services for cancer patients to her role. She joined a number of focus groups for cancer patients, attended meetings with cancer specialists and patient care staff at both Waitemata DHB and Auckland DHB, and wrote articles about how services could be improved and new services should be designed and developed. These issues in which Lynda was involved included:

- the importance of continuity of care for cancer patients;
- the plan to establish cancer services in the Waitemata and Counties Manukau DHBs, including attending a meeting to discuss co-design of oncology services at Waitemata DHB and a follow-up meeting with Dr Richard Bohmer who has been engaged by the Waitemata DHB to help with plans to provide patient-focused cancer services.

She also agreed to talk to the media about these topics, and her own experiences.

Women's Health Issues in the Media

The AWHC continues to be contacted regularly by reporters seeking comments and interviews on a wide range of women's health issues. During the year Lynda Williams, representing the Council, gave a number of media interviews on a number of issues, including (among others):

- interview on the HDC's lack of action on the issue of the ongoing enrolling of unconscious patients in clinical trials (16 May 2016, *New Zealand Herald*);
- interview with Maria Scott at NZCOM for an article an issue of *Midwifery News*;

- interview with Kathryn Ryan on National Radio's Nine to Noon on Friday 1st of July;
- interview with Olivia Carville for articles on the increase in the numbers of health professionals found guilty of sexually abusing their patients (14 August 2016 and 15 August 2016, *Herald on Sunday, The New Zealand Herald.*) .
- interviewed by The Fifth Estate team (Canadian TV) for a programme they did on New Zealand's PHARMAC agency and whether Canada should set up a similar agency (AIRED IN Canada 9 January 2017).
- Interview with Martin Johnston on the changes is the use of long-term contraception use 28 October, *New Zealand Herald*);
- interview with Sandra Coney and Ron Paterson on Radio New Zealand (Outspoken, RNZ 17 January 2017).
- Interviewed with the Cartwright Collective members by Diana Clement for an article on the Unfortunate Experiment (Issue 410, Metro, March-April 2017).

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.

Medical Research on Non-consenting Patients

This has been an ongoing issue for the AWHC for a number of years, one that has caused considerable concern among members.

On the 18th of April 2016, the AWHC wrote to Health and Disability Commissioner Anthony Hill asking about the consultation he promised in December 2014 on the enrolling of unconscious patients in clinical trials, after receiving no reply to a previous letter.

On the 7th of October the AWHC submitted an OIA request to the HDC requesting information on when the promised consultation document would be released, what the consultation process will involve and the timeframe involved, as well as seeking information on the appointment of the expert advisory panel, when it was established and who is on it.

In November the AWHC received a response to the OIA request. Finally in February 2017 the HDC released the consultation paper Health and disability research involving adult participants who are unable to provide informed consent, with submissions to be lodged by the end of April 2017. The AWHC made a substantial submission on this (which will be reported on the 2017/18 year) which represents a substantial body of work over a long period of time in an effort to achieve protections for some of the most vulnerable sectors of our community.

The Future

Our public health system and the rights of consumers within both the public and private sector, face constant challenges. DHBs and government health agencies have to make difficult decisions regarding the resourcing of different aspects of the public health system and many sectors are grossly under-resourced. PHARMAC cannot fund all groups deserving of new and better drugs and treatment, and the delivery of world's best practice care and treatment is not always possible simply because there is not enough money to provide that care. On the other hand, it can be difficult for consumers to make informed decisions about their health care for a wide variety of reasons. In addition, there are still far too many instances in which health care practitioners are found to have acted unprofessionally or unethically, with breaches of the Code of Rights varying from denying patients the right to make informed decisions through to sexually abuse of patients.

In March 2017 alone two issues that were publicised in the media illustrate issues of informed consent and amply illustrate the need for organisations such as the AWHC. Both issues involve women's reproductive health, one a relic from the 1960s and 70s (the prescribing of Primodos a hormonal pregnancy test) and another more recent incident (the non-consensual insertion of a Mirena IUD by a surgeon), and show that we still have a long way to go to achieve an across-the-board understanding and acceptance among health practitioners, of consumers' rights to make fully informed decisions about their healthcare, including the right to withhold consent.

The resignation of long-term Co-ordinator, Lynda Williams presented the AWHC with an opportunity to look to the future with a different perspective. It was recognised by the Executive Committee early in the process of transition and appointment of a new Co-ordinator, that would not be looking for someone to replace Lynda but someone who might bring new ideas, a new perspective, and different skills and experience.

The succession planning that was undertaken included the writing of a strategic plan over several months focused on the future and the AWHC's role. As a result the organisation was able to clearly restate its vision and goal, clarify its strategic objectives and set down an action plan for how those objectives will be achieved:

The Auckland Womens' Health Council (Council) is a feminist organisation that was established in 1988. It is a voluntary organisation of individual women and women's groups, who have an interest in and commitment to women's health issues. The organisation was primarily formed to provide a voice on women's health issues in the Auckland region but sometimes there are also national and/or international issues.

The Council has a special interest in patient rights, informed consent and decision-making in health care, health consumer advocacy, the Code of Health Consumers' Rights, the National Cervical Screening Programme, and ethics – issues that were highlighted during the Inquiry

into the treatment of cervical cancer at National Women's Hospital In 1987-88 and in the recommendations contained in the report known as the Cartwright Report. Whilst the focus is on women's health some issues concern all health consumers.

Vision

All women in Auckland have agency over their physical, mental, emotional and spiritual well-being and are fully informed of health services available and have access to them, particularly Māori women.

Goal

To provide an independent feminist voice focused on women's/family health and health services in Auckland.

Priorities

1. Women in Auckland have the right to make informed decisions regarding their own health care and treatment.
2. Women in Auckland participate in all decision-making processes for health care services.

3. Women in Auckland have accessible, affordable, available, and accountable health care services.
4. Ensuring the work of the Council continues to be sustainable and to grow.

How the Council Achieves Its Goal

- By contributing to gender, women's health and consumer perspectives to the development of policies.
- By collaborating with other appropriate agencies.
- Through consumer representation to appropriate policy advice and working groups.
- By monitoring medical disciplinary procedures and pharmaceutical industry.
- By attending ethics committee and DHB meetings and raising issues as they arise.
- By disseminating evidenced information using a range of media.