



AUCKLAND WOMEN'S HEALTH COUNCIL

NEWSLETTER

MAY 2016



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CHANGES TO CERVICAL SCREENING

Despite the serious reservations that continue to be raised about the NSU's (National Screening Unit) plan to change the primary cervical screening test from the current liquid-based cytology test to primary HPV (human papillomavirus) screening, the NSU recently announced that it will make the switch to HPV primary screening in 2018. (1) (2)

New Zealand currently has one of the best cervical screening programmes in the world. It was established in 1990 in the wake of the Cartwright Inquiry into the treatment of cervical cancer at National Women's Hospital. Since then the numbers of women who get cervical cancer and the number of women who die from it have reduced by 60%. (3) MOH statistics reveal that there are now 150 – 160 women who are diagnosed with cervical cancer each year, and about 50 women who die from it.

Many women's health groups are therefore understandably anxious at the thought of the NSU making changes to New Zealand's excellent screening programme, and question whether the HPV test will actually be of much benefit to those women who are currently not being regularly screened.

Maori women

Women who are un-screened and under-screened feature highly in those diagnosed with cervical cancer, and Maori women are disproportionately represented in these statistics. Maori women have a registration rate for cervical cancer twice that of non-

Maori women, and a mortality rate about 2.5 times that of non-Maori. (4) The most efficient and effective way of increasing the rate of regular cervical screening for Maori women and for other under-screened women is to introduce free cervical screening. The AWHC has been actively lobbying for this for some years as we are often contacted by women who do not understand why breast cancer screening is publicly funded, but cervical screening is not.

Need for adequate information

There are in fact several issues that give cause for concern. One of the most important ones is the information the NSU produces for people about its screening programmes. The AWHC and others have protested for some years about the changes needed to the pamphlets and booklets about breast cancer screening. Women need to know about the risks associated with breast cancer screening which include over-diagnosis and over treatment. The NSU has been extremely reluctant to include such information and when it does it is unacceptably brief and downplays the risks...

Use of international statistics

Likewise, when discussing cervical screening the Ministry of Health and the NSU usually begin by announcing that around 275,000 women die from cervical cancer each year and continue to provide international statistics, but do not mention what the actual figures are for women living in New Zealand. Of course, NZ health agencies are not alone in doing this, but that does not make it acceptable to set the scene for discussions about proposed changes to cervical screening by overdramatising the incidence of cervical cancer in this way.

The facts are that over 85% of cervical cancer cases are found in low-resource countries, with the incidence and death rates being the highest in sub-Saharan Africa, Central America, South-Central Asia and Melanesia. (5) Most of these countries do not have organised cervical screening programmes, nor do they have the necessary follow-up diagnostic and treatment services.

While the information about cervical screening, and HPV and cervical cancer that is on the NSU website states that:

“It is estimated that about 80 percent of sexually active women will become infected with HPV at some point in their lives. Most HPV infections have no symptoms, and in nearly all cases (especially in women under 30) the infection will clear on its own in 6-24 months, without the woman even knowing she had it,” (6) the information in the pamphlets on cervical screening does not mention this important fact. (7)

Benefits and risks of the HPV test

Hopefully these resources will all be updated prior to the introduction of primary HPV screening and the important facts emphasised, eg how the body nearly always clears HPV infections without the need for colposcopy or treatment. Women who are identified as having one of the high-risk types of HPV are particularly vulnerable in terms of making informed decisions about the risks and benefits of further investigations.

New website

The March issue of the NSU newsletter features an article about the new consumer-friendly website that the NSU is developing on

cervical and breast screening which is due to be rolled out in mid-2016. (8)

The article states that “the website will also be accompanied by a social marketing campaign and new consumer resources to help increase screening rates especially for under-screened and un-screened women. The new website, social media and consumer resources are being designed with the help of advertising agency FCB.”

This is not good news. The experience of women’s health groups is that advertising agencies are often not good at producing health information for consumers, as they do not understand the Code of Consumers’ Rights or the need for informed decision-making. They see their brief as being promotional resources rather than providing evidence-based information on the benefits and risks of cervical and breast cancer screening.

The elephant in the room

The elephant in the room is the influence of big pharma. At the NSU/MOH consultation meeting the AWHC attended in October last year there were more representatives from Roche in the room than consumer representatives.

It was also obvious from a careful read of some of the 87 submissions the NSU received that the drug company was behind some of the statements that when the switch to HPV screening is made New Zealand women must have access to Roche’s FDA-approved HPV test, as other tests were inferior, or not FDA-approved. For example, one submitter, who of course wished to remain anonymous, wrote:

“I strongly recommend that the Cobas® HPV test is considered for use in New Zealand because it is the only clinically validated, FDA-approved and CE-IVD marked assay for first-line, primary screening of cervical cancer.” (9) Another anonymous submitter even described women’s right to have access to Roche’s test as an equity issue.

It is difficult to know exactly who or what is behind the NSU’s rushed move to adopt an HPV test as the primary cervical screening test. And only time will tell whether it will save money and/or save lives.

References

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2. www.nsu.govt.nz/news/screening-matters-issue-55-march-2016/planned-changes-cervical-screening-test-2018
3. www.nsu.govt.nz/national-cervical-screening-programme/about-cervical-screening-programme
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RELOCATION OF GISBORNE INQUIRY WEBSITE

For more than a decade the Gisborne Cervical Screening Inquiry website was located at www.csi.org.nz. The website had background information about the Inquiry, all the transcripts of each day of the Gisborne Inquiry proceedings, the Inquiry Report, and the ensuing monitoring reports which were undertaken by Dr Euphemia McGoogan.

When much to our dismay the AWHC discovered the website was no longer there, there were considerable misgivings about what had happened to all that historical information. During the Gisborne Inquiry women’s health groups found themselves being asked to provide the Ministry of Health with the minutes of national cervical screening advisory group meetings that took place after the Cartwright Inquiry because the Ministry no longer held any record of these meetings.

After an unsuccessful search on the internet, the AWHC put in an Official Information Act request to the Director General of Health, asking where the website had gone and whether all the Gisborne Inquiry information had been stored somewhere. An exchange of emails followed which finally produced the following link to the Inquiry website which is now located on the National Library website –

<http://ndhadeliver.natlib.govt.nz/ArcAggregator/arcView/frameView/IE1044843/http://www.csi.org.nz/>

What a relief!

HDC REVIEW OF DRUG TRIALS

The long-awaited consultation on the practice of enrolling unconscious patients in clinical trials will hopefully take place this year.

In April this year the AWHC sent Health and Disability Commissioner Anthony Hill a copy of Professor Jo Manning's paper which was published in a recent issue of the *Journal of Law and Medicine*, and asked when "the fulsome public information and consultation process" he promised would take place in 2015 will occur. He has not responded.

However, when contacted by Martin Johnson, health reporter for the *NZ Herald*, the Commissioner's office responded by saying that "the consultation was deferred to this year 'due to continued growth in HDC complaint volumes and workload.' A consultation document would be issued in September." (1) Hopefully that means September this year.

"Planning for the consultation including reviewing international and local literature on these issues, process design, and the appointment of an expert advisory panel is well under way." (1)

In an apparent effort to sound reassuring, the HDC is also quoted as stating that "informed consent lies at the heart of the Code of Health and Disability Consumers' Rights in New Zealand, which has now been extant for 20 years. Any change to those rights, of their application, should not occur without consideration of whether change is necessary and with due regard to ensuring sufficient protection of consumer rights."

Professor Manning's recently published paper clearly states that in New Zealand non-consensual studies on incapacitated adults, who are particularly vulnerable to exploitation and harm, are of doubtful legality under current laws. She describes how three different pieces of legislation have been enacted in the United Kingdom which permit non-consensual research to proceed, subject to a comprehensive regime of strict protections for participants, and argues that an excellent model can be constructed from them.

"In late 2014, the New Zealand Health and Disability Commissioner agreed to investigate this issue with a view to proposing law reform, but the promised public consultation has never eventuated. It must do so without further delay for the protection of participants and researchers, and in the interests of society." (2)

This conclusion also emphasises the need for urgent action:

"Doubts about the lawfulness of conducting research studies on incompetent patients in New Zealand need to be removed. Clear and ethically acceptable law needs to be made, so that the position is clear to the public, patients and the research community." (2)

Maybe a Professor of Law's paper in a medico-legal journal will achieve what countless unacknowledged letters from the AWHC failed to do.

References

1. www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11639419
2. Professor Joanna Manning. "Non-consensual clinical research in New Zealand: Law reform urgently needed." *Journal of Law and Medicine*. 2016 23 JLM 516.

NATIONAL MATERNITY CLINICAL INFORMATION SYSTEM

Over the past few years work has been underway on developing a new way of collecting, sharing and viewing maternity data with the intention of supporting women to be more involved in their own care, and enabling electronic access to their own maternity information. (1)

The Maternity Information Systems Programme is one of a number of projects underway that will eventually see all New Zealanders and the health professionals caring for them having electronic access to their health information. This particular programme has proceeded in a stop/start fashion with much of the focus in the last two years on the development of the Maternity Clinical Information System (MCIS) for the DHBs.

So far five DHBs have implemented the MCIS in their maternity services. MidCentral DHB was the first, with South Canterbury, Whanganui, Tairāwhiti and Counties Manukau being the next four DHBs to roll it out. As with any new IT system there are teething problems. A recent update from the Ministry of Health suggests these have been significant.

On 4 May 2016, Counties Manukau DHB notified the MOH of their intention to stop using the MCIS. However, “they have subsequently reviewed their position” and the Ministry is “in discussion with the DHB to agree a way forward with the project.” It would be very interesting to know how the MOH got them to change their mind and play ball.

Jill Lane, Director of Services Commissioning (whatever that is) at the MOH, states in the update that the Ministry together with the vendor, Clevermed, continues to refine the MCIS so midwives, obstetricians, anaesthetists, neonatologists and others can easily record and access relevant clinical information for the care of women and their babies.

If the MCIS is to become a national system it is critical that problems are addressed. However it would seem a national MCIS isn't going to happen any time soon anyway, given the expectation that in five years' time only ten DHBs will have adopted MCIS. (2)

The MOH update also states that “parallel development of an electronic maternity record for community based Lead Maternity Carers by the Midwifery and Maternity Provider Organisation will contribute to the success of the MCIS in the DHBs and ensure clinical information is shared between community providers and DHBs.

This is good news although there is still more to learn about the MMPO development and what information will be viewable and/or transferred to and from DHBs, and when.

The Ministry of Health website assures women that their information will only be shared with those authorised to see it, and all access will be recorded. “All your information is confidential and there will be a number of protections in place to ensure it is secure.” (3)

The network being used to transfer information to and from the MCIS is Connected Health, a secure network

established some years ago for health providers “to ensure data is not lost, transferred incorrectly or subject to intrusion.”

There is no indication when the sharing of information from the other existing community based maternity systems e.g. GP systems, will be enabled.

The MOH update advises the Ministry and Clevermed will also work towards the development of a “women’s view” to enable women to access their own information via an online portal. This was promoted to women as a major selling point of the maternity information systems programme, but appears to have taken a back seat as the needs of the DHBs have predominated. It is good to see this featuring again, especially with the MMPO development. Women need to be very sure that the development of the “women’s view” will be adequately resourced, that women will be involved in its development, that women will have online access to more than their booking information and labour and birth and discharge summaries and that all participating DHBs will offer it.

References

1. <http://healthitboard.health.govt.nz/our-programmes/national-solutions/maternity-information-systems-programme>
2. http://www.health.govt.nz/system/files/documents/publications/new-zealand-health-strategy-roadmap-of-actions-2016-apr16_1.pdf
3. <http://www.health.govt.nz/your-health/services-and-support/health-care-services/sharing-your-health-information/upcoming-changes-maternity-information-systems/security-and-privacy-your-maternity-information>

AWHC GENERAL MEETING 19 May 2016

Detailed minutes of this meeting are available on request. Matters discussed included:

- Financial reports
- Grant applications
- Submission on Omics
- HDC consultation on clinical trials
- Lack of ACC coverage for participants in drug company trials
- Cartwright Collective conference
- Succession planning

Further information on some of the topics listed above is contained in this issue of the AWHC newsletter.



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UP AND COMING EVENTS

DISTRICT HEALTH BOARD meetings for May/June 2016:

Waitemata DHB (Website address: www.waitematadhb.govt.nz)

The Waitemata DHB Board meeting opens to the general public at 12.45pm on Wednesday 29 June 2016 and will be followed by the Hospital Advisory Committee meeting which starts at 2pm. Both meetings will be held in the DHB Boardroom, Level 1, 15 Shea Terrace, Takapuna.

The **combined Waitemata DHB and Auckland DHB** Community & Public Health Advisory Committee meeting starts at 2pm on Wednesday 8 June 2016.

Auckland DHB (Website address: www.adhb.govt.nz)

The Auckland DHB Board meeting opens to the general public at 12.45pm on Wednesday 22 June 2016 and will be followed by the Hospital Advisory Committee meeting which starts at 2pm. Both meetings will be held in the A+ Trust Room in the Clinical Education Centre, Level 5, Auckland City Hospital.

Counties Manukau DHB (Website address: www.cmdhb.org.nz)

The Community & Public Health Advisory Committee meeting will be held at 1.30pm on 25 May 2016 at 19 Lambie Drive, Manukau.

The Hospital Advisory Committee meeting will be held at 9am on Wednesday 15 June 2016 at Ko Awatea and will be followed by the Full Board meeting at 1.30pm.



ETHICS COMMITTEE meetings – dates for the four MOH ethics committees are at: <http://www.ethics.health.govt.nz/about-committees/meeting-dates-venues-minutes>



The Cartwright Collective in association with Women's Health Action and the Auckland Women's Health Council is holding a one-day forum on the control of cervical cancer and the future of cervical screening in New Zealand.

9.30am – 3.30pm Friday 5 August 2016 at 164 Balmoral Road, Balmoral, Auckland.

For further information email: info@womens-health.org.nz or phone 09-520 5295