AUCKLAND WOMEN'S HEALTH COUNCIL

NEWSLETTER

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"THE PATIENT WILL SEE YOU NOW"

Eric Topol's latest book "*The Patient Will See You Now: The future of medicine is in your hands*" was published last year and was one of the most important medical books of 2015. Dr Topol is an American cardiologist, a professor of genomics, and has been described as a leading thinker in healthcare's age of enlightenment. He is also someone who is completely comfortable with the sweeping digital revolution that is happening in medicine right now.

In this his second book, Dr Topol builds on the concept of the digitisation of medicine that he covered in his first book "*The Creative Destruction of Medicine*," and describes the huge potential of smartphones and iMedicine technologies to democratise medicine and enable people to take control of their own data and make their own health care choices. He compares the smartphone's potential to become the "Gutenberg Press" of medicine. Just as the printing press took learning out of the hands of a priestly class, the mobile internet is doing the same for medicine.

The book is divided into three sections. The first section – Readiness for a Revolution – deals with the issue of who is in charge of health care information, and Dr Topol is extremely forthright in pointing out the entrenched culture of medical paternalism, both historically and in the present. Chapter 2 is titled "Eminence-Based Medicine: The long history of paternalism" and traces the paternalistic attitudes of the medical profession back to the original Hippocratic Oath.

The first section also contains a great deal of interesting information on 23andMe, the consumer genomics company, and its personal genome service (PGS), and the FDA's decision to ban 23andME from offering this information to Americans and the reaction to this decision.

The second section – The New Data and Information – deals with all the health data, both macroscopic and microscopic (genomes, microbiome, etc) that are available for analysis and the myriad, and rapidly growing, ways this information can be collected and stored. Dr Topol introduces the concept of the human geographic information system (GIS) which "comprises multiple layers of demographic, physiological, anatomic, biologic, and environmental data about a particular individual. This is a rich, multi-scale, mosaic of a human being, which can be used to define one's medical essence: when fully amassed and integrated, it is what a digitised person looks like, at least for the sake of how medical care can be rendered."

He also derides the use of the traditional stethoscope, preferring instead the use of a pocket ultrasound device that can image various organs.

Throughout this section Dr Topol repeatedly returns to the theme of patient autonomy in the matter of ownership of data, seeing this as the key to what he calls the democratisat-ion of medicine. He describes the revolution in personal and world medicine that the use of smartphones is making possible, such as the use of

"obsolete" smartphones in the delivery of health care in developing countries.

The third section of Topol's book – The Impact – deals with the impact that the previously described changes are having and will have on the way health care will be delivered. The first chapter in this section describes the problems with modern hospitals including the harm factor – hospital acquired infections and medical errors – and the cost factor, and what the hospitals of the future will look like following the transition to what Dr Topol calls "smart medical homes."

The second chapter, Open Sesame, introduces the reader to the open source software movement and open knowledge. This includes massive open online courses (MOOCs), a movement that has several important lessons for medicine. Dr Topol writes: "Clearly, this platform democratised the educational process by bringing high quality lectures from top universities to anyone in the world. It did this at remarkably low cost and high velocity."

Grouping all these opportunities for change under the term MOOM (massive open online movement) Dr Topol describes cancer MOOMs and other medical MOOMs, and outlines the opportunities presented by the government and open medicine, open science, open access to biomedical publications, and opening up medical research.

The third chapter, Secure vs, Cure, deals with the thorny issue of privacy and confidentiality. Dr Topol explores the problems of identity theft and hacking, and keeping patient records secure. Protecting the genomic privacy of an individual is big issue, and Dr Topol states categorically "You have to own all your medical data."

The final chapter is focused on the emancipated consumer and the new iMedicine galaxy. In his concluding paragraph Dr Topol lays down the challenge for patients:

"As with any model, particularly one that is going after a new, emancipated form of medicine, there will be no shortage of naysayers, they'll say that it's ill-founded, underdeveloped, impossible, or even irrational. Yet technology to achieve this is accelerating: we have what were envisioned as futuristic, twenty-third century capabilities now. I consider it inevitable; the biggest question is the matter of timing. For centuries medicine's galaxy has orbited the doctor. If just one of those major forces exerts itself, these changes could happen very quickly. Maybe Angelina Jolie will tip the scales and change medicine's orbit. Or maybe it will be you."

Although this book is written by an American about the American medical system, and most of the changes being brought about by the technological wizardry described in Dr Topol's book are already happening there, there is much that is applicable to other countries. The New Zealand health system – public and private – has already adopted many of them.

As more and more health consumers and patients adopt the technologies that are rapidly coming on to the market, it is more than likely that this revolution in iMedicine will do more to empower patients than the Code of Consumers' Rights ever could.

Merck admits Keytruda data misleading

In December 2015, Merck Sharp and Dohme (MSD) issued a “Dear Doctor” letter in which they corrected the trial data given to doctors, overstating the benefits of the pembrolizumab (trade name Keytruda), the melanoma drug at the centre of MSD’s campaign to gain public funding for the drug.

According to an article by Stacey Kirk that was posted on the Stuff website on 16 December 2015, MSD was “forced to amend trial data” presented at the December conference of the New Zealand Society of Oncologists (NZSO). (1)

In the letter, MSD explained that the materials produced for NZSO in November were derived from a slide previously presented at the American Society of Clinical Oncology (ASCO).

“Despite our best intent, having reviewed this and in the absence of published updated duration date for this patient cohort; the information on this slide does not support the 30 months claim” – the claim being that most patients that responded to first-line treatment were still responding at 30 months. Pembrolizumab is so new that long-term survival data does not yet exist.

This uncertainty about its long-term benefits, as well as the percentage of cancer patients who will benefit , and its high cost are why PHARMAC’s experts committee gave it a low-priority status.

As an article in the December issue of the AWHC newsletter pointed out the campaign to get the government to take funding for pembrolizumab out of PHARMAC’s hands quickly became a political issue. In December 2015 Andrew Little sent out a petition urging New Zealanders to ask John Key to fund the drug, and “make sure John Key stands up to people like Jonathon Coleman and makes the right decision."

The current government’s election bribe in 2008 to overrule PHARMAC’s decision to decline funding for 52 weeks of Herceptin was a very costly mistake in that it completely destroyed PHARMAC’s ability to negotiate with Roche, the drug’s manufacturer, on all its products, not just Herceptin.

Having lost its bargaining power once and paid a huge price for it, John Key and Jonathon Coleman are understandably not keen to repeat the same mistake with MSD over pembrolizumab, especially when the drug company has already had to admit to overstating the benefits of its latest overpriced drug.

It is therefore extremely disappointing that in an effort to win votes in next year’s election, the Labour Party would ignore the lessons that have been learned, and interfere with the integrity of the public health system.

References

1. http://www.stuff.co.nz/national/health/75176914/Keytruda-maker-has-to-correct-data-on-melanoma-drug-after-overstating-benefits

The Switch to HPV Primary Screening

The National Screening Unit (NSU) is in the process of making the switch to human papillomavirus (HPV) primary screening and during October 2015 undertook a consultation process that involved holding 12 public meetings around the country. The November issue of the NSU newsletter reported that they received 87 submissions from individuals and organisations. (1)

Doubts about the wisdom and evidence base for changing from 3-year cervical screening with a cervical smear test, to HPV primary screening with an extended screening interval were raised by a number of those making submissions, including the AWHC. For one thing, the consultation document did not clearly acknowledge that 80%-90% of women clear HPV infections within a few years without the need for any intervention or treatment. The AWHC is also concerned about the impact that being told they have a high risk HPV infection will have on women, as well as the huge increase in referrals for colposcopy that the move to HPV primary screening will entail.

A letter to the editor published in *Cytopathology* in November 2015, that was written in response to an editorial by H.C. Kitchener, "HPV primary cervical screening: time for a change," raised further questions about the evidence base for this change.

R. Marshall Austin, at the Department of Pathology at the Womens Hospital of University of PIttsburgh Medical Center, USA wrote:

"Although this editorial acknowledges the UK Cervical Screening Programme as 'an exemplar,' one which has reduced cervical cancer deaths between 1988 and 2014 by almost two-thirds, discordant data which should raise questions about the ability of primary HPV screening at extended intervals to effectively sustain the accomplishments of cytology-based screening are not acknowledged." (2)

Dr Austin makes several observations about the UK ARTISTIC (A Randomised Trial in Screening to Improve Cytology) trial, (3) and points out that protection against invasive cervical cancer is the most relevant endpoint in efforts to optimise cervical screening. "CIN3 and CIN3+ endpoints can be significantly misleading in this regard, as most CIN3 cases will not develop into invasive cervical cancers over extended follow-up." (2)

A one-size fits all cervical screening programme that is based on HPV primary screening will also not address the inequities that exist in the current screening programme. Only a publicly-funded cervical screening programme will do that.

References

1. http://www.nsu.govt.nz/news/screening-matters-issue-54-november-2015/update-transition-hpv-screening-consultation
2. R. Marshall Austin. "HPV primary screening: unanswered questions." *Cytopathology*. 24 November 2015 DOI:10.1111/cyt.12279
3. http://www.journalslibrary.nihr.ac.uk/__data/assets/pdf_file/0015/60090/ExecutiveSummary-hta13510.pdf

PRIMARY BIRTHING UNITS FOR WEST AUCKLAND & NORTH SHORE

As part of the ongoing consultation on the Auckland DHB and Waitemata DHB Women's Health Collaboration Maternity Plan and following a 2-hour meeting held on 25 November 2015, Waitemata DHB sent out an email on 18 January 2016 announcing that they were now opening community consultation.

The email refers to the Maternity Plan's strategy to "Engage in broad public and stakeholder consultation to ensure the type and location of primary birthing unit best meets the needs of the communities served by the DHBs."

Waitemata DHB is now in the process of gathering a wide range of views from the community, maternity care providers and other stakeholders.

"We believe that the success of any unit is linked closely to community support, and we are particularly interested in the views of women and families from all backgrounds."

The DHB is holding a number of community meetings which will be held in West Auckland and the North Shore, and these are listed on the Health Voice website - http://se2.buzzchannelgroup.com/default.aspx?u=c972319946a8479f91d675d7d36ae19b

There is also the option of completing an online survey – http://www.healthvoice.org.nz/

There is a real need for at least one new purpose-built freestanding birthing unit in West Auckland, particularly as Waitakere hospital's maternity facility is not fit for purpose despite the recent "upgrade" and several previous upgrades which mainly involved new carpet and a lick of paint.

Over the past few decades studies have revealed that the birthing environment has a significant impact on a woman during labour and birth. Healthy women who plan to give birth at home or in a primary birthing unit are more likely to have a normal birth and experience fewer interventions that those who birth in hospital, and that their babies are no more at risk of an adverse outcome than they would in an obstetric unit. New Zealand research has confirmed that for low risk women giving birth in primary birthing unit provides good outcomes for both mother and baby and better levels of satisfaction.

The services that the DHBs provide are meant to be evidence-based. It will therefore be extremely disappointing should either Waitemata DHB or Auckland DHB opt for birthing units built onsite alongside their current maternity facilities as a result of a public consultation based on women's doctor-induced fear of birth and the misguided belief that high tech hospitals are best for them and their babies, and the lack of consumer demand for physiologically appropriate services.

Meanwhile Auckland DHB is apparently going ahead with its plans to establish a primary birthing unit within Auckland City Hospital.

For further information contact Wendy Devereux on: wendy.devereux@waitematadhb.govt.nz

Choosing Where to Labour and Birth

The MSCC has produced a 7th leaflet in its "The facts" series.

"*Choosing Where to Labour & Birth*" provides women with evidence-based information on how the place of birth can impact on labour and birth, as well as the future health and well-being of both the mother and the baby.

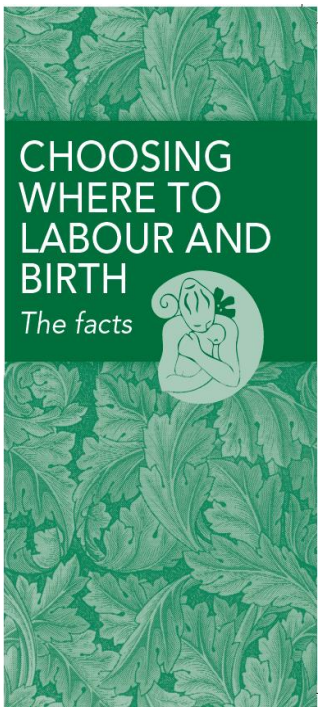
It is often assumed and stated that hospital is the safest place for a baby to be born, especially a first baby. However, few obstetric hospitals provide the kind of birthing space that enable women to labour and birth as nature intended.

The new leaflet emphasises the importance of having access to safe birthing environments that support the hormonal and physiological processes of labour and birth. It provides detailed information on the important hormones of labour and birth, outlines the events which often disturb the cocktail of hormones and lists the interventions that contribute to this.

It also describes how to create a supportive birth space.

There is a small charge for all the leaflets in the MSCC's "The facts" series. An order form for all the leaflets that the MSCC produces in available on the MSCC website:

http://www.maternity.org.nz/what-we-offer/



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UP AND COMING EVENTS

DISTRICT HEALTH BOARD meetings for February/March 2016:

Waitemata DHB (Website address: www.waitematadhb.govt.nz)
The Waitemata Hospital Advisory Committee meeting starts at 11am on Wednesday 24 February 2016 and will be followed by the DHB Full Board meeting which starts at 1.30pm. 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 3 February 2016.

Auckland DHB (Website address: www.adhb.govt.nz)
The Hospital Advisory Committee meeting will be held at 9.30am on Wednesday 17 February 2016 followed by the Full Board meeting 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 Hospital Advisory Committee meeting will be held at 9am on Wednesday 10 February 2016 at Ko Awatea and will be followed by the Full Board meeting at 1.30pm.

The Community & Public Health Advisory Committee meeting will be held at 1.30pm on 20 January 2016 at 19 Lambie Drive, Manukau.

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

NZ LACTATION CONSULTANTS CONFERENCE 2016 will be held on 26 - 27 February 2016 at the Holiday Inn, Auckland Airport, 2 Ascot Road, Mangere, Auckland.

The theme is “Home Grown: Simply the Breast”

Further information is available at www.nzlca.org.nz/conferences.html