One for the girls?: Cervical cancer prevention and the introduction of the HPV vaccine in Aotearoa New Zealand

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Abstract

This article presents a critical feminist perspective on New Zealand's HPV immunisation programme. The programme, delivering the HPV vaccine to young women, has been progressively rolled out since September 2008 and heralded as a major development in cervical cancer prevention and women's health more generally. However, the programme has also been the subject of fierce debate, for both its context and the strategies used in its implementation. Women's health advocacy groups have been highly critical of aspects of the programme's implementation. Concerns have included the gendering of sexual health responsibility by targeting the vaccine only at young women; the disregard of consumer rights to informed choice and consent in the marketing of the programme; and the failure to integrate the programme with the National Cervical Screening Programme which risks undermining the life saving success of cervical screening in New Zealand.

This article demonstrates the importance of careful and consultative programme planning and decision making to ensure population health policies deliver the best health outcomes to women. There are lessons to be learned from New Zealand's approach to introducing the HPV vaccine which demonstrate the continued importance of the contribution of critical gender perspectives in the development of health policy more generally.

Introduction

This article presents a critical feminist perspective on the introduction of the HPV immunisation programme in Aotearoa New Zealand. HPV vaccines have been heralded as a major development in the prevention of cervical cancer, and in women's health more generally. Their delivery through a publicly funded programme has constituted a significant commitment of public health dollars in New Zealand. While investment in women's health has been welcomed, women's health advocacy groups have been highly critical of aspects of the approach to the vaccine's delivery in New Zealand, leading them to question the net benefits for women's health as a consequence. This article examines the roll out of New Zealand's HPV immunisation programme drawing on both gender equity perspectives and a Cartwright Inquiry lens. The issues identified are used to demonstrate the importance of careful and consultative programme planning to ensure that investment in new disease prevention technologies delivers the best health outcomes to women, and that the lessons of the Cartwright Inquiry are not forgotten by those responsible for New Zealand public health policy and practice.

Cervical cancer prevention in New Zealand

Cervical cancer prevention, detection and treatment are issues of national importance in New Zealand following the public scandal that lead to the Cartwright Inquiry in the late 1980s. Founded by health activist Sandra Coney, Women's Health Action came to national prominence

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when, in 1987, Coney, and fellow health activist Phillida Bunkle published an article called 'An unfortunate experiment at National Women's Hospital' in the monthly Auckland magazine *Metro*. The article outlined an unethical study at National Women's Hospital, the country's premier women's hospital. The study, led by Dr Herbert Green, started in 1966, and involved following women with major cervical abnormalities without definitively treating them, and without their knowledge or their consent to participate. By 1987 many had developed cervical cancer and some had died.

The revelations led to public outrage, and ultimately to a Ministerial Committee of Inquiry, known as the Cartwright Inquiry after the presiding Judge Dame Silvia Cartwright. While focused on the treatment of cervical cancer, the Inquiry led to scrutiny of a range of issues related to the practice of medicine in New Zealand including research practices, teaching methods, patients' rights, and medical dominance. The resulting report, released in 1988, was a blueprint for patients' rights in New Zealand and recommended the establishment of a Health and Disability Commissioner, a code of health consumer rights, a system of ethical review of research involving human participants, and the establishment of a National Cervical Screening Programme (Committee of Inquiry, 1988).

The Cartwright Inquiry, intersecting with the feminist women's health movement, presented a profound challenge to medical power in New Zealand and the 'doctor knows best' mentality that pervaded the times. Women's health advocates, groups and collectives dedicated themselves to empowering women to be active partners in their health care; supporting women to make informed choices about health interventions by being able to access evidenced-based information; questioning the medicalisation of women's life processes; and increasing women's understanding of their bodies and bodily processes. A number of these advocates and groups were active in ensuring the Cartwright Report recommendations were implemented and that they maintain accountability to health consumers. While the goals and activities of women's health groups have shifted over time, there remains a commitment to ensuring that the legacy of the Cartwright Inquiry is not forgotten.

Cervical cancer is one of the most preventable cancers and the establishment of a National Cervical Screening Programme since 1990 has had a significant impact on rates of cervical cancer in New Zealand. Established with the aim of reducing the incidence and mortality of invasive cervical cancer through the detection and treatment of high grade cervical cell changes, the programme has largely contributed to a 50% reduction of cervical cancer incidence and a 65% reduction in mortality (National Screening Unit, 2010). The programme currently covers approximately 70% of eligible women, but Maori, Pacific, and Asian women remain under-screened with only around 50-60% coverage (National Screening Unit, 2010). Currently approximately 160 women are diagnosed with cervical cancer every year and 60 women die; half of these women have never been screened and a third have been screened infrequently or irregularly (National Screening Unit, 2010). The data demonstrates the effectiveness of cervical screening as a secondary prevention strategy for cervical cancer in New Zealand. The major priority for the programme moving forward is improving the rates of screening of Maori, Pacific and Asian women (Women's Health Action Trust, 2010).

HPV vaccines

During the 1960s and 1970s, while Dr Herbert Green conducted his experiment at National Women's Hospital, increasing epidemiological evidence pointed to a sexually transmitted factor as the cause of cervical cancer. During the 1980s and 1990s, while this 'unfortunate experiment' culminated in a Ministerial directed inquiry and the subsequent Cartwright Report, the

Human Papilloma Virus (HPV) was identified as the primary causal agent in cervical cancer, detected in nearly all cases (99.7%) (Jones et al, 2007, para.1).

HPV, known as the 'wart virus', is a family of viruses with over 100 different types. Types 6 and 11 are believed to be responsible for 70-100% of genital warts. Types 16 and 18 are associated with approximately 70% of cervical cancers, and are also associated with cancers of the vulva, vagina, penis, and anus. HPV affects both men and women and is largely transmitted through sexual or close intimate contact. HPV is the most common sexually transmitted infection in the world, with an estimated 75% of sexually active people affected with at least one HPV infection at some point in their life (Australia and New Zealand HPV Project, 2010, p.2). However, approximately 90% of those infected spontaneously clear the infection, usually within two years. When the immune response fails to clear the infection, it becomes persistent and there is an increasing risk of developing cervical cancer over time; this may take up to 30 years. Among women with persistent HPV infection, additional cofactors for cervical cancer include smoking, hormonal contraceptives, and other sexually transmitted infections (Jones et al, 2007, para.9). It is clear that the quality of one's immune system plays an important role in determining who will clear HPV infection and who will be at risk of developing cervical cancer (Jones et al, 2007, para.9).

The discovery of HPV's causal relationship to genital cancers, of which cervical cancer has the highest incidence, resulted in a race to develop vaccines against HPV infection, the theory being that if you can prevent HPV infection, cancer will not occur. Pharmaceutical industry giant Merck was the first off the mark with the development of Gardasil. First licensed for use in 2006 in the United States, Gardasil targets HPV types 16 and 18 (associated with 70% of cervical cancers) and types 6 and 11 (associated with genital warts) and is recommended for girls aged 11-12 years before they are likely to have commenced sexual activity and become exposed to the virus. This age group is also believed to have a greater immune response to the vaccine (Caseldine-Bracht, 2010). The vaccine came at a very good time for Merck Pharmaceuticals which was seriously crippled after its big seller, Vioxx, was pulled from shelves because of safety concerns, resulting in the filing of over 4000 law suits and a major loss in revenue (Caseldine-Bracht, 2010, p.102). As the most expensive vaccine to ever enter the market, worldwide sales for Gardasil reached $1.4 billion by 2008 with programmes delivering Gardasil, or its competitor GSK's Cervarix, being rolled out in the United States, Canada, the United Kingdom, across Europe, and in Australasia (Rothman & Rothman, 2009). The rapid market penetration of this new and expensive vaccine, with an arguably premature evidence base demonstrating its safety and efficacy, has been attributed to an immense and expensive marketing and lobbying campaign by Merck, the ethics of which have been subject to extensive critique (Caseldine-Bracht, 2010). For example, the marketing approach broke with the traditional practice of identifying vaccines with the disease they were preventing. Rather, the HPV vaccine was promoted primarily to guard, not against HPV viruses or sexually transmitted diseases, but against cancer (Rothman & Rothman, 2009). This was a powerful marketing strategy given growing anxieties about the increase in the prevalence of cancer around the world, and strong desires to progress preventions and cures (Clarke & Everest, 2006).

HPV vaccines rapidly secured their status as blockbuster pharmaceuticals yet their introduction worldwide has been deeply contested. The vaccine has many vocal and enthusiastic proponents including clinicians, public health officials, those who have experienced cervical cancer, and politicians. This enthusiasm has been for good reason. Globally cervical cancer is the third most common cancer in women, and the seventh overall, with an estimated 529 000 new cases in 2008 (GLOBOCAN, 2008). Eighty-five percent of the global burden occurs in developing countries without effective cervical screening programmes and thus the vaccine,

if effective, holds the potential to have a significant impact on the health of women in these countries (GLOBOCAN, 2008). In New Zealand, cervical cancer is now the eighth most frequent cancer among women overall, yet the third most frequent cancer amongst women aged between 15 and 44 years and remains an important women's health issue (Ministry of Health, 2010). Prominent women's health clinicians in New Zealand captured the enthusiasm about HPV vaccines when they stated: "The introduction of the HPV vaccine is the single most important advance in the prevention of cervical cancer since the introduction of cervical cytology half a century ago" (Jones et al, 2007, para. 34).

However, the vaccine has also had fierce opponents as well as those who have urged a more cautious approach to this new pharmaceutical. The Christian Right has opposed the vaccine on the basis of moral concerns, arguing that vaccinating pubertal children against a sexually transmitted infection will result in the erosion of 'family values' by undermining the abstinence before marriage approach to sexuality education and therefore resulting in a possible increase in unsafe sexual activity (Casper & Carpenter, 2008). Many women's health advocates, bioethicists and feminist academics, while welcoming the opportunity to reduce the incidence of cervical cancer, have advised caution about embracing the vaccine in the West. Questions have been raised about the need for the vaccine in developed countries given that there are already successful secondary prevention strategies in the form of cervical screening available to women, and that most women clear the virus naturally. It has been suggested that the focus of resources should remain on strengthening cervical screening programmes given they are a proven and effective secondary prevention strategy, with a strong focus on addressing ethnic and regional inequalities in access to screening (Canadian Women's Health Network, 2007). Caution has also been urged about embracing the vaccine and its potential benefit given the infancy of the vaccine with unanswered questions about its safety and long-term efficacy. Targeting the vaccine only at young girls has also been cautioned against, as has the marketing of the vaccine as the 'cervical cancer vaccine' rather than the 'HPV vaccine'. As Haug (2009, p. 795) argues: "the theory behind the vaccine is sound: if HPV infection can be prevented, cancer will not occur...But in practice, the issue is more complex". Given the Cartwright Inquiry and a national focus on cervical cancer prevention New Zealand provides an interesting context to explore the complexities of the roll out of the HPV immunisation programme.

New Zealand's HPV Immunisation Programme

The roll out of New Zealand's fully funded HPV Immunisation Programme began in September 2008 in two phases. The first phase offered Gardasil through GPs and primary health care practices for women born in 1990 and 1991 (17 and 18 year olds). The second phase began late in term one last year (2009) with the delivery of a school-based programme to girls in year eight (aged 12 years), and a two year catch up programme for girls in years 9-13 (aged 13-18 years). Uptake of the vaccine, at the end of the first year of the school-based programme, was not as high as expected. The first year saw 86,000 girls and young women have the vaccine, most of them in schools. This equated to uptake by approximately half of the girls offered the HPV immunisation in the schools that chose to deliver the programme. Uptake has been higher among Maori and Pacific teenagers with 62% and 71% uptake respectively (Ministry of Health, 2010). Maori and Pacific teenagers were a specific target for the vaccine because they are under-represented in cervical screening and treatment services and therefore over-represented in the incidence of cervical cancer (Ministry of Health, 2010). The second year of New Zealand's school-based HPV immunisation programme is now near completion.

Reflecting concerns in other developed countries where the vaccine has been introduced, women's health groups in New Zealand have questioned both the ethics and the safety of the policy

decisions surrounding the introduction of HPV vaccines as part of a publicly funded programme. Concerns have centred on five key aspects of the programme's implementation: the haste in developing and implementing the programme; targeting the vaccine only at young women; the way the programme was communicated; the lack of an integrated prevention strategy for cervical cancer; and direct to consumer advertising by the pharmaceutical company. These aspects of the programme are explored below followed by a discussion of their implications.

The haste in developing and implementing the programme

It is widely acknowledged that once the decision was made to fund a free HPV immunisation programme for all girls and young women, the programme was developed and implemented with great haste resulting in insufficient sector consultation and a lack of public education before the programme was commenced. In November 2006 the Immunisation Technical Working Group recommended to the Minister of Health that HPV vaccines be included in the National Immunisation Schedule, following its 2008 review, for girls aged 15 years, or if sufficient funding was available, for girls aged 11-13 years with a catch up programme for girls aged 12 to 15 years (Immunisation Technical Working Group, 2006). The recommendation came with the caveat that it was important to determine the prevalence of HPV types causing clinical disease in New Zealand women, and that there was an identified need for public education about the link between HPV, sexual activity and cervical cancer (Immunisation Technical Working Group, 2006).

However in May 2007, as part of the 2007 Budget announcements, the Minister of Health, Pete Hodgson, made the announcement that the Government had decided not to fund Gardasil at that point and would continue to monitor the vaccine's roll out overseas, a decision met by criticism by prominent women's health clinicians (McConnell & Reid, 2007). In November 2007 the Herceptin Heroes took to the streets to protest PHARMAC's decision not to fund 12 months of Herceptin treatment for breast cancer, and the government was accused of failing to invest in women's health[1]. It was reported at this time that Prime Minister Helen Clark had asked the Ministry of Health to investigate fast-tracking the introduction of the vaccine (McManus, 2008). In May 2008, as the Herceptin debacle continued to rage, the prime minister announced an HPV immunisation programme with $177 million funding over five years. By the next month the HPV Immunisation Programme National Implementation Plan was released and by September the same year the first stage of the programme was underway, less than two months before the general election. Investment in women's health had become a key election issue with the National party in opposition pledging to fund 12 months of Herceptin for breast cancer treatment. It seems likely that the haste in developing the HPV programme was driven, at least in part, by the political environment rather than the need for an urgent policy response to a critical women's health issue, given the downward trend in cervical cancer rates and the success of New Zealand's cervical screening programme.

The haste in developing and implementing the programme was not without consequence. Prior to the introduction of HPV vaccines, a very low level of understanding about HPV and the HPV/cervical cancer connection had already been identified in the population (Anhung et al, 2003; Braun & Gavey, 1999; Giles & Garland, 2006; Hall et al, 2008; Mays et al, 2000; Pits & Clarke, 2002; Cooper Robbins et al, 2010; Sherris, et al). In fact, cervical cancer prevention policy in New Zealand, in its focus on cervical screening, had largely ignored the HPV connection, and sexual behavioural strategies for preventing cervical cancer, fearing that highlighting the connection with HPV would stigmatise women and reduce screening participation (Braun & Gavey, 1999). However despite the recommendations of the Immunisation Technical Working Group, this lack of public knowledge and understanding about HPV, and its connection

to cancer, wasn't addressed through a public education campaign prior to the introduction of HPV vaccines in New Zealand. Base-line prevalence data collection of the various HPV types causing clinical disease among New Zealand women was also not undertaken prior to commencement, affecting any future conclusions that will be made about the effectiveness of the programme (Holland, 2009).

Women's health advocates also questioned the haste to implement a national HPV immunisation programme given the relative infancy of the vaccine with unanswered questions about its safety and efficacy. A detailed analysis of the evidence about the vaccine's safety and efficacy is beyond the scope of this article, with its focus on the programme rather than the vaccine itself. However, concerns have centred on the uncertainty about the duration of immunity (Lewis, 2007); the lack of clinical trials of the vaccines on prepubescent girls to whom the vaccine is targeted (Canadian Women's Health Network, 2007); the fact that the current vaccines only target two of the 15 oncogenic strains of the HPV virus (Haug, 2009; Lewis, 2007); that while the vaccines appear to be relatively well tolerated in the trials, long term safety data can only be determined over many years (Haug, 2009); and the actual relationship between HPV infection at a young age and development of cervical cancer 20 to 40 years later is not known (Canadian Women's Health Network, 2007). It is acknowledged that the first phase three trials of the HPV vaccine with clinically relevant endpoints, cervical intraepithelial neoplasias grades 2 and 3 (CIN 2/3), are promising and this is welcomed as good new by women's health advocacy groups[2]. Still, the overall effectiveness of the vaccine for protection against cervical cancer remains unanswered in the absence of more long term studies and thus shouldn't be overstated (Haug, 2009).

Questioning the safety and efficacy of the vaccine has left women's health advocacy groups vulnerable to accusations that they are against the vaccine and its benefits, and are obstructing great leaps forward in women's health. This is an unfair representation. Women have very good reasons to be suspicious of any pharmaceutical product being touted as safe and 'for their own good' (Caseldine-Bracht, 2010, p. 102). The cautious approach of women's health advocacy groups to new health technologies has been learnt from experience, often following the devastating consequences of a failed pharmaceutical product that was approved for use and entered the market with great promise. The controversy surrounding Hormone Replacement Therapy provides a recent example, but there are many others. If the vaccine could eradicate cervical cancer with few side effects and no other implications, women's health groups would have reason to celebrate. However when it comes to pharmaceutical interventions, faith in 'magic bullets' has been consistently undermined. This is not to infer that pharmaceutical innovations and the pharmaceutical industry as a whole are considered a threat to women; pharmaceuticals form a very important part of women's health care and women deserve the best opportunities possible to prevent and treat disease. Rather, women's health advocacy groups look to ensure ethical practices in how pharmaceuticals comes to market and a tempered and evidence based approach in their integration into publicly funded health care. As Caseldine-Bracht (2010, p. 107-108) argues:

> The objection to [hasty legislation] is not an objection to the vaccine itself; rather, it is an objection to unnecessarily pushing [out a programme] without carefully considering all of the alternative possibilities and implications that surround it. Given the complex interconnections between giant pharmaceutical companies and the government, women simply cannot rely solely on the information they receive from any of these sources. The issue is complex. A number of legitimate and scientific questions surround the efficacy and safety of this vaccine. These concerns and questions deserve to be seriously considered.

Targeting the vaccine only at young women

Reflecting programme development elsewhere, New Zealand's HPV immunisation programme is gender specific in that it is only publically funded for girls and young women, while HPV,

which is largely transmitted through sexual or intimate contact, can be transmitted by any sexual partner regardless of their gender. The gendering of HPV prevention began from the conception of HPV vaccines, the clinical trials for which only included women presumably because they bear the disease burden of HPV, and has been carried through to policy guiding programme delivery. Targeting HPV vaccines solely at girls and young women is problematic in that it both contributes to, and maintains, the social construction of sexual and reproductive health as 'women's problems', placing a disproportionate burden on women to take responsibility for sexual health and the prevention of sexually transmitted infections (Caseldine-Bracht, 2010; De Melo-Martin, 2006; Kubba, 2008).

Studies show that young people's understandings about HPV are gendered, with neither young women nor young men perceiving men to be susceptible to HPV nor of HPV as being a severe problem for men (De Melo-Martin, 2006). Cooper Robbins' et al (2010) research with Australian school girls who have already received that vaccine demonstrated that young women failed to understand HPV as a sexual health issue and had a concerningly low level of understanding about the vaccine they had already received. One young participant commented (p. 3401): "Boys don't have a cervix, and it's not like a sexual disease, it's just cancer...One cancer...It's [HPV is] an STI, and it only happens to girls...". Of their findings Cooper Robbins et al (2010) note that even though there was some knowledge of HPV being related to sex, the role that males played in transmission was unclear to the girls:

> When a girls' focus group was asked if boys could catch HPV, all of the girls answered "no" and then explained "They can get AIDS" and "They can get diseases." The moderator prompted "So HPV is sexually transmitted, but you can't get it from boys?" The girls then said "That doesn't make sense" and "I think it's if you sleep with too many boys" and "If guys don't get it, how do we get it then?" (p. 3401)

The gendering of HPV leaves boys and young men unaware of their role in HPV transmission. This risks long term implications for their own health due to a lack of awareness of HPV-related cancers that can affect men. It also leaves young men unaware of the potential impacts of HPV transmission on their sexual partners, regardless of their gender, paving the way to entirely ignore young men's role in HPV-related cancer prevention by practicing safer sex. While safer sex alone is not 100% effective in preventing HPV-related cancers it offers young men the ability to contribute towards the prevention of cervical cancer in female sexual partners, and their best chance at preventing other HPV-related cancers in themselves or in male sexual partners (Winer et al, 2006). It is also worth noting that a gender-neutral HPV immunisation programme could potentially be more effective than a programme targeting only females; the rubella vaccine being a good example. As Caseldine-Bracht (2010, p.104) notes, "When the rubella vaccine was introduced in the 1960s, it was originally recommended that only women of childbearing age get inoculated. However only when both boys and girls got the vaccination was rubella finally eradicated".

Given that boys and young men were not included in the clinical trials of the vaccine, there was a reluctance to include them in the HPV immunisation programme on the basis of a lack of evidence. It is likely that the added cost of including boys and young men in the programme was an additional factor. This decision is reflected by all western countries who introduced an HPV immunisation programme, although it is worth noting that boys and young men are now being included in some programmes internationally. Despite the decision to only fund the New Zealand programme for girls and young women, programme planning could have paid careful attention to how to ameliorate the inevitable gendering of HPV prevention that resulted. This could have been achieved through a public education campaign aimed at raising awareness of HPV as a sexual health issue prior to the introduction of the vaccine; through a communica-

tions strategy for the vaccine that articulated HPV as relevant to men's and women's health; by marketing the vaccine as the 'HPV vaccine' rather than the 'cervical cancer vaccine'; and through integration of the programme with school-based sexual health education whereby the importance of all sexual or intimate partners practising safer sex was communicated alongside the offer of the vaccine to young women in an integrated message about the importance of sexual health and disease prevention. But more on that shortly.

The programme's communications strategy

Rather than addressing the gaps in the public's knowledge about HPV as a sexual health issue, and its causal role in genital cancer, the approach to communicating the programme through its singular focus on cervical cancer actually worked to further obscure this connection. Contributing factors included the branding of the vaccine as the 'cervical cancer vaccine', the programme slogan selected for the roll out of the programme 'join the fight against cervical cancer', and the information provided in the first batch of consumer information resources.

The decision to brand and communicate the vaccine as the 'cervical cancer vaccine' rather than the 'HPV vaccine' seemed more influenced by marketing strategy than evidence-based public health policy decision making. It is problematic for a number of reasons. Not only is it factually incorrect, it also further obscures the relationship between HPV, cervical cancer, and Gardasil. This undermined young women's and their parent's ability to make an informed choice about the vaccine, and may be overselling the vaccine in terms of its efficacy because the actual impact on cervical cancer remains unknown. It also works to further consolidate the gendering of HPV by suggesting that it is only those with a cervix who may have an interest in the vaccine and cancer prevention. Some commentators have also suggested that it unfairly plays on generalised fears surrounding the words 'cervical cancer' and implies that every adolescent is equally at risk of cervical cancer (Holland, 2009).

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Compounding the singular focus on cervical cancer, the 'join the fight against cervical cancer' programme slogan risked overstating the extent to which young women are at risk from cervical cancer by implicitly suggesting that we are in the midst of a cervical cancer epidemic requiring a united community response. The 'urgency' or 'crisis' messaging was consolidated by the setting of very high uptake targets of 95% of all girls by 31 December of the sixth year after which they became eligible, targets similar to those of the epidemic response vaccine – Meningococcal B (Ministry of Health, 2008). As I have already demonstrated, New Zealand's rates of cervical cancer have been tracking down through effective screening, with priority now being given to increasing participation by Maori, Pacific and Asian women.

Criticism was also directed towards the consumer information resources developed to support the roll out of the programme, contending that they read more like lightweight advertising brochures intended to maximise uptake rather than resources to support health consumers to make an informed choice by providing full and balanced information about a complex issue. Uncertainties about the length of immunity were not effectively communicated in the

resources which included fact sheets, a pamphlet, posters, a consent form, DVD, flip chart and PowerPoint presentations. There was ineffective messaging about the need for regular lifetime cervical smears regardless of vaccine uptake, and about how the various prevention strategies work together. Safer sex messaging was consistently excluded from the resources, and none of the promotional materials or resources attempted to communicate HPV as anything other than a women's health issue. There was no visual representation of boys/young men in the resources, and no resources, nor sections of the resources, address boys and young men directly. The use of cancer precursors as a surrogate end marker, rather than cervical cancer itself, to make claims about the vaccine's efficacy was not communicated in any consumer information. As Haug (2009, p.795) argues:

> There is a strong feeling amongst those commentators who have evaluated the roll out of the HPV programme in the West, that the benefits, risks, and limitations of the vaccine have not been well communicated... Even if effective, the vaccine still only partly prevents infection, an infection that in a few cases will cause cancer 20-40 years from now.

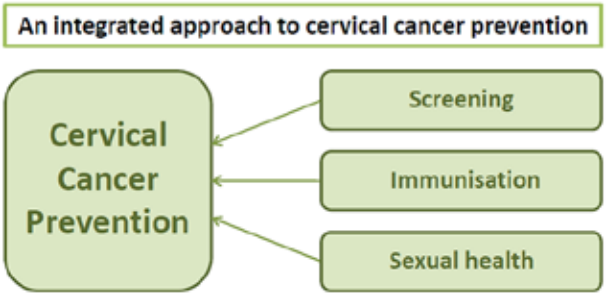
By focusing solely on cervical cancer and adopting an arguably aggressive emphasis on uptake rather than balanced information in the roll out of the programme, the messaging in the resources overemphasised the individual risk of developing cervical cancer; failed to adequately communicate the risks, limitations and uncertainties about the vaccine; and overstated what is known about the benefits[3]. Cooper Robbin et al's (2010) Australian research heightens fears that this may have left young women and their parents with a falsely heightened sense of risk of developing cervical cancer, and with the impression that this new vaccine would offer lifetime protection, and one's only hope of prevention.

The lack of an integrated prevention strategy for cervical cancer

There is broad agreement amongst policy makers and women's health groups that the HPV immunisation programme was introduced in New Zealand without being adequately integrated into a wider cervical cancer prevention strategy that includes safer sex education, cervical screening, and education about immunity supporting activities. This was despite World Health Organisation (2009, p.130) guidelines that state:

> HPV vaccines should be introduced as part of a coordinated strategy to prevent cervical cancer and other HPV diseases. This strategy should include education about reducing behaviours that increase the risk of acquiring HPV infection, and information about the diagnosis and treatment of precancerous lesions and cancer.

An integrated model of cervical cancer prevention is demonstrated by the following diagram and was advocated by a range of stakeholders including those very supportive of an HPV immunisation programme. It would have involved careful planning and messaging to ensure that the promotion and delivery of each separate prevention intervention supported the broader strategy. For example, a promotional message for the vaccine would have communicated that the 'tool kit' for preventing cervical cancer now has three main instruments: the vaccine, along with safer sexual health practices, and regular cervical screening for women aged 20 – 70 years of age.



A lack of integration between the various prevention strategies meant that messaging for the new HPV vaccine was done in such a way that potentially worked to undermine the existing strategies (sexual health education and cervical screening) by suggesting that one's only hope of preventing cervical cancer was through the

vaccine, and that before the vaccine, there was nothing. This effectively erased the existence of the other prevention options and their important role in cervical cancer prevention.

A stark example of this was in the HPV vaccine information DVD produced by the Ministry of Health as a key information resource for the roll-out of the school-based programme. The DVD contains two versions, one for 12-15 year olds and one for 16-18 year olds. Neither version of the DVD mentioned the existence of the cervical screening programme, the role it plays in cervical cancer prevention, nor the need for cervical screening when the girls are older regardless of whether they have received the vaccine. In fact at one point in the DVD version for 16-18 year olds, a woman describing her experience of cervical cancer states: "I was 23 when I got diagnosed, there was no vaccine available so there was pretty much nothing to stop me going through what I was going through..." (Ministry of Health, 2008, 1.39-3.03 mins)[4]. As stated previously, safer sex messaging was consistently excluded across all of the programme communications and vaccine information resources. Neither was there any effort made to integrate the school-based programme into existing school-based sexuality education programmes where these messages could have been delivered in a safe, holistic and age appropriate way as provided for in the health and physical education curriculum (Ministry of Education, 1999). It is debatable whether this desexualisation of HPV and cervical cancer was due to the desire to circumvent the opposition of conservative Christian groups or because New Zealanders are still unable to acknowledge the importance of educating young people about sex and sexual health.

Direct to consumer advertising

Finally, women's health advocates were concerned about the role played by the pharmaceutical company responsible for distributing Garadsil in New Zealand, CSL Biotherapies, in aspects of the programme delivery. In particular women's health groups objected to CSL Biotherapies' 'Remind me – free email and text message reminder service', where young women who received their first dose of Gardasil through their primary health care provider were offered the opportunity to sign up with CSL Biotherapies and receive reminders to attend for their follow up shots. Women's health advocates considered it unethical for industry, given its extensive commercial interests in uptake, to have front line engagement with health consumers participating in the programme, regardless of good intentions. New Zealand also has permissive laws about the direct to consumer advertising of pharmaceuticals, and CSL ran an extensive marketing campaign with the slogan 'Your best shot against cervical cancer' which again risked overemphasising young women's risk of getting cervical cancer while failing to communicate an integrated cervical cancer prevention message, suggesting that the vaccine was the preferable, if not only, option for preventing cervical cancer.

Back to the future: why the Cartwright Inquiry still matters

Given the already very low knowledge about HPV in the population, the aspects of the HPV immunisation programme described above resulted in an environment where girls and their parents were deciding to have a vaccine, the functions of which they did not understand, and that was communicated outside of the context of the other established prevention strategies. Evaluation of young women and their parents' knowledge and understanding about HPV, cervical cancer, and the role of the vaccine following the first year and a half of the HPV immunisation programme in Aotearoa New Zealand is not yet available. Unfortunately recent Australian research is not reassuring. Cooper Robbins' et al (2010) Australian based study of young women and their parents who have already participated in the school-based HPV programme identified significant gaps in the knowledge and understanding both about HPV's role

in the development of cervical cancer and the HPV vaccine's role in the prevention of cervical cancer.

Uninformed decision making is concerning both for ethical and safety reasons. The right to information about health interventions, to make informed choices, and to give informed consent prior to receiving health interventions, are ethical principles in health care that received close examination during the Cartwright Inquiry in New Zealand. The Inquiry identified significant and sustained failures in the doctors' ethical practices in relation to information sharing and informed consent, and as a result the Inquiry report recommended that such principles needed to be legislated so that they held the status of rights. This resulted in the Code of Health and Disability Service's Consumer Rights, which became law in 1996. The Code of Rights confers a number of rights on all consumers of health and disability services in New Zealand, including the right to information, the right to make an informed choice, and the right to give informed consent to treatments/interventions. Right 6 is the right to be fully informed. The consumer can expect an explanation of the options available including an assessment of the expected risks, side effects, benefits, and costs of each option. Right 7 outlines the right to make an informed choice and give informed consent. The Code of Rights significantly empowered consumers' interests when engaging with doctors or other health providers and when considering medical interventions. Evidence shows that government policies such as guidelines, targets, advice and information resources have a significant impact on health consumers' ability to make an informed decision about an intervention when they encounter the offer by a health professional (Alderson et al, 1997; Dew, 1999; Watson, 2007).

The primacy given to informed decision making by women's health advocacy groups in New Zealand is not about consumer rights for their own sake. Nor is it even about an ideological commitment to the shift in power relations within medicine that resulted from the Cartwright Inquiry, although these groups are active in ensuring that consumer rights are acknowledged by, and form the basis of, New Zealand health policy, as well as practice. The emphasis placed on the importance of informed decision making is because uninformed decision making can be bad for women's health. In the case of HPV, if young women do not understand the relationship between HPV and cervical cancer, and the benefits and limitations of the various prevention strategies, they cannot make informed decisions about their future health practices, such as the importance of practicing safer sex, and the need to participate in screening when they are older. The deep irony is that this potentially places young women at increased risk of the disease we are investing so heavily in trying to prevent. It is important to remember that the current generation of HPV vaccines will, at best, only protect against two types of the HPV virus responsible for 70% of cervical cancers. This maintains regular cervical cancer screening as a vital activity for the prevention of cervical cancer regardless of whether young women have had the vaccine or not. Also, given that the length of immunity offered by Gardasil remains unknown (evidence currently demonstrates at least five years), young women who have had the vaccine at 11 or 12 years old may no longer be protected against any of the cancer causing types of HPV when they become sexually active, and thus when they need immunity most (Olsson et al, 2007). It is imperative that young women understand that they are not protected for life from cervical cancer and that they still need to consider cervical screening. As Hazel Lewis, Clinical Leader of the National Cervical Screening Programme argues: "By far the greatest risk for women is that those who have been vaccinated, and even those who have not, may mistakenly believe that cervical cancer is no longer a problem and will be less conscientious about turning up for regular smears" (2007, p.2).

It is in this light that women's health groups in New Zealand held very serious concerns that the aspects of the roll out of the HPV immunisation programme outlined in this paper may have

inhibited young women's, and their parents', ability to understand the limitations of Gardasil, the benefit of safer sex, and the importance of participating in cervical screening when they are older regardless of whether they have the vaccine. Again Cooper Robbins et al's (2010) research is not reassuring with some young women and their parents believing they were now completely protected against cervical cancer and that smears would no longer be necessary. One parent explained why they held this impression: "...just the adverts on TV. It just brought across the idea to most people that this is going to stop you getting cervical cancer" (Cooper Robbins et al, 2010, p.3401). Full information and informed decision making about HPV vaccines is not just about consumers' right to know, effective cervical cancer prevention actually depends on it.

Gender and vaccine policy

Improvements in women's health do not solely depend on advancements in disease prevention technologies, although these are welcome when their safety and efficacy has been objectively and extensively established without the influence of the commercial interests of the pharmaceutical company set to benefit from them. As I have demonstrated in this paper, the potential for improvements in women's health offered by these technologies depends heavily on careful and consultative policy and programme development to ensure new interventions fulfil their potential benefit to women, rather than place women at greater risk.

It is reasonable to assume HPV vaccines are only the first of a proliferating range of prevention technologies for many diseases including sexually transmitted infections. Indeed, a vaccine for Chlamydia is already in development and although it may be another 10-20 years before it comes to market, it is worrying that even at this early stage in development, women are being identified as the only recipients again because they bear the disease burden (Medical News Today, 2007). It is thus important to reflect on, and learn from, the implementation of HPV immunisation programmes to support future policy and programme development.

Women should not have to bear the burden of preventing sexually transmitted infections simply because they predominantly bear the disease burden resulting from these infections. Sexual health, and the prevention of sexually transmitted infections, is a community problem and requires community solutions. Insisting that future vaccines developed for the prevention of sexually transmitted infections must not be gender-specific should be a goal for women's health advocacy. It is also important to insist on gender sensitive and equitable policy that addresses the need for all sexual partners, regardless of their gender, to share responsibility equally for sexual and reproductive matters, and provides information about how this is done. This may help to shift dominant social constructions about sexual responsibility whilst also ensuring people are given the best opportunity to prevent disease by having all the information.

Once vaccines are developed, policy makers need to take a sober and critical look at the net benefits they offer and be wary of the intoxication of being marketed a disease-free future at any cost. This means carefully considering the risks and benefits of these disease prevention technologies, and ensuring that only medical and scientific evidence is part of the decision-making process. As Haug (2009, p.796) argues, "If other matters weigh in, such as profit for a company or financial or professional gains for physicians or groups of physicians, the balance is easily skewed. The balance will also tilt if the adverse events are not calculated correctly". This also means ensuring that this information is communicated to health consumers in ways that they can understand, and to enable them to get the bigger picture. There is no one size fits all approach; methods of communication should be innovative and culturally specific.

Enthusiasm about the potential benefits offered by new disease prevention technologies, while understandable, must not overwhelm the importance of their cautious introduction and

integration into an overarching strategy for the prevention of the disease they target. This will ensure that new technologies sit alongside and do not compromise existing successful disease prevention instruments, and support health consumers' ability to make informed choices about the range of these interventions. Young women's future health practices, and thus their ability to enjoy the benefits of technological developments which may help them towards future disease prevention, depends on it.

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Notes

1 PHARMAC's decision to fund 9 weeks versus 12 months treatment with the very expensive Herceptin (trastuzumab) for HER2 positive early breast cancer, on the basis that there was insufficient evidence to support the efficacy and safety of 12 months treatment regime, resulted in national controversy and a campaign to have the full 12 months treatment funded.

2 Clinical trials are conducted to allow safety and efficacy data to be collected for health interventions. Phase III trials are randomised controlled multicentre trials on large patient groups. They aim at being the definitive assessment of how effective the drug is, in comparison with 'gold standard' treatment.

3 Responding to criticism, the Ministry of Health has moved away from the crisis messaging and has now changed the programme slogan to 'It takes three' rather than 'Join the fight'. Some of the information resources have now also been revised to improve the level of consumer information and messaging about cervical screening. There is some commitment to rebranding the vaccine as the 'HPV vaccine' although this is constrained because of the large number of resources already in distribution.

4 Responding to concerns raised by women's health advocacy groups the Ministry of Health has revised the HPV DVD, inserting voiceovers which provide messaging about the importance of cervical screening when girls are older.

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