

# A Vulvar Cancer Cluster in Indigenous Women in Arnhem Land



**Report 2017**

A Vulvar Cancer Cluster in Indigenous Women in Arnhem Land: Report 2017  
Version 1.0  
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# 1 Executive Summary

In response to reports from outreach gynaecologists of excess cases of vulvar cancer and its precursor lesion, vulvar intraepithelial neoplasia (VIN), in the East Arnhem (EA) health district of the Northern Territory (NT), an initial epidemiological investigation was undertaken from 2007. This identified evidence of a cluster of vulvar cancer among young (aged less than 50 years) Indigenous women resident in EA, with an incidence rate over 50 times higher than the national Australian rate for the same age group, and the highest identified anywhere in the world.

Subsequently, research undertaken by the Menzies School of Health Research in collaboration with other research institutions and the NT Department of Health has found this cluster to be as an unusually aggressive form of Human Papillomavirus-dependent vulvar cancer. EA Indigenous women treated for vulvar cancer or VIN are more likely to experience a recurrence of the disease following treatment, more likely to experience more recurrences, and have a higher mortality rate than other Northern Territory residents affected with this disease.

While HPV is likely to be involved in the aetiology of vulvar cancer in this population, the very high incidence is not explained by a higher prevalence of vulvar infection with HPV or a particularly virulent strain of HPV. Genetic studies have found evidence of an inherited predisposition to vulvar cancer among EA Indigenous women and results to date indicate that, rather than one or two genetic variants of large effect size, this cluster may be driven by the cumulative burden of multiple rare functional genetic variants. No evidence has been found to suggest that this cluster is driven by other environmental risk factors, including smoking, sexually transmitted infections, immunosuppressive conditions or cultural practices.

The cluster investigation has included a disease control component throughout, undertaken in conjunction with the Department of Health. Since 2007, the research team has assumed responsibility for several aspects of the disease control response including monitoring the cluster, community engagement, and developing community and clinical education resources. With the end of the research component at the end of 2017, these responsibilities will return to the NT Department of Health.

These research findings have two main implications for disease control strategies:

1. While there is evidence that genetic susceptibility is responsible for this cluster of vulvar cancer, a genetic variant suitable for screening was not found. Consequently, genetic testing of women is not possible to identify individuals at excessive risk.
2. HPV type 16 was found in specimens of vulvar cancer from the affected women. The current HPV vaccine includes HPV16 and is likely to be protective against vulvar cancer in the affected population.

Based on the findings of the studies reported here, we make the following seven recommendations:

## **Recommendation 1:**

- a) Sisters and daughters of confirmed cases should be screened for vulvar cancer annually as part of a Well Woman Check.
- b) Other EA women should be screened every two years.
- c) The training tool for health workers and the Women's Business Manual should be amended to recommend this.

**Recommendation 2:**

Clinical staff undertaking vulvar screening should liaise with an Aboriginal Health Practitioner or Community Worker to ensure that appropriate family members are targeted for additional screening, acknowledging that understandings of kinship may differ.

**Recommendation 3:**

The Gynaecology Outreach Service (GOS) should formally describe its current screening and treatment protocols, in order to identify whether these need to be amended to accommodate additional screening of relatives of cases or more regular follow-up after treatment, and to standardize practice across clinical specialists.

**Recommendation 4:**

A business case should be prepared by the Clinical Quality and Patient Safety Branch, System Performance and Innovation Division of the Department of Health for submission to (1) NT government, (2) federal government, or (3) philanthropic sources for funding of a catch-up program of vaccination for Indigenous women resident in EA aged 35-45 years, or those aged less than 35 and unvaccinated or incompletely vaccinated. This would be a limited undertaking, with relatively small numbers in a defined geographical area. The funding request must include additional staffing requirements in the budget, as community health centres and staff of the existing vaccination program do not possess the capacity to undertake this additional work, which would require considerable outreach activities to find eligible women at each vaccination time point.

**Recommendation 5:**

Long term surveillance of the impact of the vaccine on VIN and vulvar cancer rates is required, and should be undertaken by the NT Centre for Disease Control. Surveillance would be improved by updating the current database used by the GOS, and linking this to the NT HPV vaccine register or collecting vaccination status within the database.

**Recommendation 6:**

Responsibility for maintaining community awareness of vulvar cancer should comprise part of the role of Women's Health Educators within the Remote Health Program, supported by Remote Area Midwives (Remote Health) and Sexual Health Coordinators (CDC). Both the vulvar cancer community animation and the updated vulvar cancer training tool should be supplied to the educators for their use in carrying out health education and awareness activities.

**Recommendation 7:**

The updated vulvar cancer training tool and the vulvar cancer community animation should be supplied to Family Planning Welfare Association NT, Well

Women's Cancer Screening Program, Remote Health, CDC, Cancer Council NT, Northern Territory General Practice Education, Aboriginal Medical Services (Miwatj, Malabam, Danila Dilba), and directly to all clinics in the affected communities. These organisations will then be responsible for ensuring that new staff receive appropriate instruction in the identification of vulvar cancer and VIN.

## 2 Project Report

Investigation of the cluster of vulvar cancer among young Indigenous women resident in Arnhem Land has been undertaken in three stages over ten years. A complete list of investigators and partner organisations can be found in Section 5.

### 2.1 Background

In response to reports from outreach gynaecologists of excess cases of vulvar cancer and its precursor lesion, vulvar intraepithelial neoplasia (VIN), in the East Arnhem (EA) health district, investigations were undertaken from 2007. Funding was acquired from the National Health and Medical Research Council (NHMRC) for three projects investigating the epidemiological features and potential causes of the cluster (2007-2010; 2011-2013; 2014-2017).

Vulvar cancer is a relatively rare malignancy and has consequently not been well studied. Squamous cell carcinoma (VSCC) comprises the majority (>90%) of vulvar cancers.<sup>1</sup> Mortality rates have remained steady, or increased in some regions, and patients suffer from associated morbidities that reduce quality of life.<sup>2-4</sup>

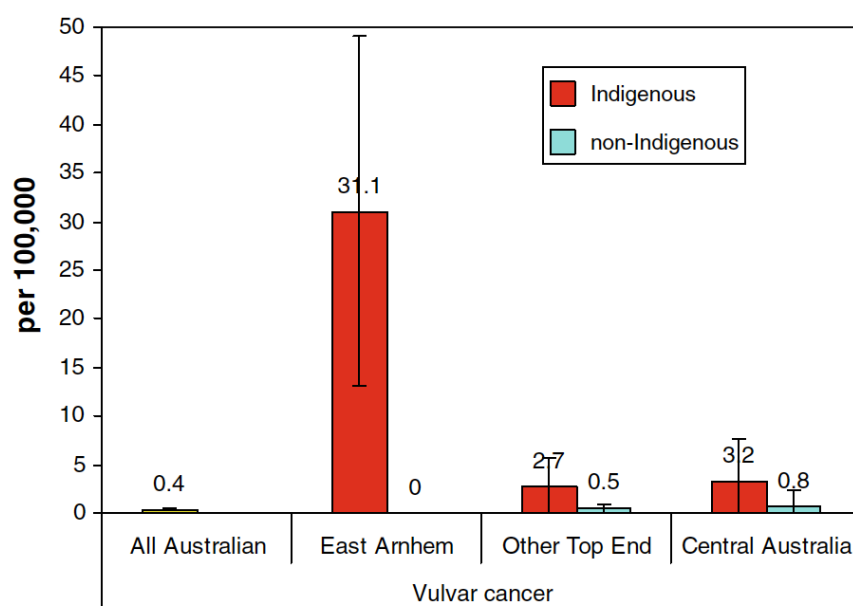
There are two distinct aetiological pathways for VSCC, resulting in separate forms of the disease.<sup>1,5,6</sup> One is associated with infection with human papillomavirus (HPV), usually affects younger women, arises from vulvar high-grade squamous intraepithelial lesions (HSIL) (formerly usual type VIN (uVIN))<sup>7</sup> and results in basaloid or warty carcinoma. The other variant is HPV-independent, usually affects postmenopausal women, is associated with differentiated VIN (dVIN) arising in an area affected by vulvar dermatoses such as lichen sclerosus, and leads to keratinizing VSCC.

Treatment for VSCC and VIN has evolved only marginally and continues to be associated with substantial physical morbidity and psychosexual dysfunction.<sup>8,9</sup> Vulvar neoplasms are largely treated through surgery, irrespective of disease sub-type. A trend towards less radical surgery and an increase in the use of sentinel lymph node biopsies has gone some way towards reducing morbidity for patients with localized disease without affecting survival.<sup>8,10</sup>

### 2.2 Epidemiology and Confirmation of a Cluster

An initial epidemiological study was undertaken in 2007-08 in order to describe the epidemiological feature of this possible cancer cluster. NT-resident women with a confirmed histological diagnosis of vulvar cancer or VIN between 1 January 1996 and 31 December 2005 were identified. Seventy-one women were identified (32 vulvar cancer and 39 VIN), of whom the majority were Indigenous, aged less than 50 years and living in remote communities in the EA district.<sup>11</sup>

For the period 1996-2005, the age-adjusted incidence rate of vulvar cancer in EA Indigenous women aged 0-49 years was 31.1 per 100,000 (95% CI 13.1-49.1), over 50 times higher than the national Australian rate (0.4 per 100,000, 95% CI 0.4-0.5) for the same age-group (Figure 1).<sup>11</sup>



**Figure 1 Age-adjusted incidence rate of vulvar cancer in the age group 0-49 years for Australian women (1996-2001) and NT women by Indigenous status and district (1996-2005)**

For VIN, the age-adjusted incidence rate for EA Indigenous women aged 0-49 years was 34.7 per 100,000 (95% CI 15.2–54.3), compared with 6.7 per 100,000 (95% CI 2.0–11.4) for Indigenous women living elsewhere in the Top End of the NT.

The incidence of vulvar cancer in NT women aged less than 50 years (Indigenous and non-Indigenous women combined) is the highest in the world (Figure 2).



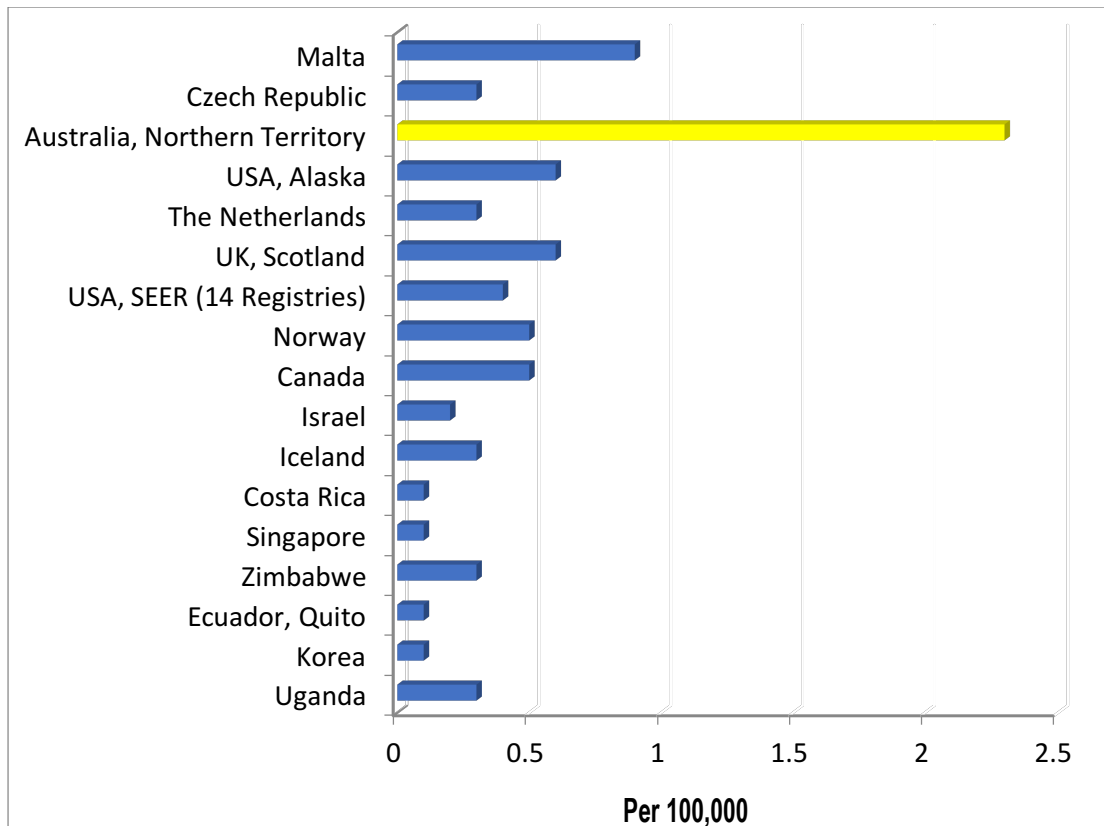


Figure 2 Incidence of vulvar cancer around the world in women aged less than 50 years

## 2.3 Human Papillomavirus Studies

Given that excess of vulvar cancer was restricted to younger women (aged less than 50 years), it was hypothesized the increased incidence of vulvar cancer in this population was the result of either:

- high prevalence of oncogenic genital HPV genotypes, or
- the presence of a highly virulent variant of HPV16 (the HPV genotype that causes most vulvar cancer).

A cross-sectional survey of 551 Indigenous women aged 18-60 years and living in EA found the prevalence of vulvar/vaginal/perianal high-risk HPV to be 39%, which is higher than that reported in previous studies.<sup>12</sup> The prevalence of cervical high-risk HPV was 26%, which was similar to that reported by studies of other Australian women.

HPV16 was the most common type detected in both sites. There is some evidence to suggest that persistent infection of HPV16 at the vulva but not cervix may contribute to the excess. Investigation of this possibility in the EA population would require a long-term prospective longitudinal study, the feasibility of which has not been assessed.

Biopsies of vulvar cancer and VIN from women from EA and from other regions of the NT were genotyped for HPV.<sup>13</sup> Biopsies from Arnhem Land were similar to those from other regions in the detection of any high-risk (HR) or possible HR

and detection of HPV 16 specifically (Table 1). All HPV 16 variants detected were of the European prototype.

**Table 1 Proportion of vulvar cancer and VIN biopsies with oncogenic HPV, NT 19XX-20XX**

| Condition biopsied        |             |               |         |
|---------------------------|-------------|---------------|---------|
| HPV detected              | Arnhem Land | Other regions | p-value |
| VIN                       |             |               |         |
| Any HR or possible HR HPV | 95%         | 84%           | 0.356   |
| HPV16                     | 60%         | 80%           | 0.364   |
| Invasive cancer           |             |               |         |
| Any HR or possible HR HPV | 100%        | 80%           | 0.473   |
| HPV16                     | 70%         | 70%           | 1.000   |

These findings indicate that HPV is likely to be involved in the aetiology of disease in this population, but neither a higher prevalence of vulvar infection with HPV nor a particularly virulent strain of HPV explains the extent of the excess incidence of vulvar cancer in Indigenous women in EA.

It is expected that the vaccination of young people against HPV will contribute to a decline of vulvar cancer in this population, although there is insufficient data to quantify the expected decrease. The new nonavalent vaccine, currently being introduced, will likely increase the effectiveness of vaccination in relation to vulvar cancer, as it targets a wider range of HPV types.<sup>14</sup> HPV vaccination has been available to women currently (in 2017) aged under 35, because vaccination was offered to women aged up to 26 years when the vaccine was introduced in 2007. Women currently aged over 35 have no vaccination protection.

## 2.4 Anthropological Study

A qualitative research study was undertaken through in-depth, open-ended interviews with purposively recruited participants including women who had had IVC or VIN, Aboriginal Health Workers, and doctors and nurses involved in caring for affected women. This study identified factors affecting diagnosis and treatment of women with vulvar cancer or VIN in EA communities, including: the private nature of the disease, the sense of shame associated with the condition, limited resources for health service delivery in EA, and a range of issues associated with the experience of relocation to metropolitan centres for treatment and specialist care.<sup>15,16</sup> Interviewees were also asked about possible environmental exposures that might be contributing to vulvar cancer development, but no promising candidates for further investigation were identified.

## 2.5 Genetic Study

Gynaecologists from the Outreach Service reported that vulvar dysplasia appeared to cluster within particular family groups, suggestive of a genetic risk factor causing an inherited susceptibility, either to the oncogenic effects of HPV, or perhaps to another cause of vulvar cancer. Given the features of the disease in this population, it was hypothesised that any causative genetic variants were likely to be rare, to have a large effect size, and to stem from a mutation in a common ancestor.

A genetic case-control study of the vulvar cancer cluster was undertaken in 2011-2013, in which saliva samples were collected from 30 cases of vulvar cancer or VIN resident in the affected communities, and 62 unaffected controls, matched on age and community of residence.<sup>17</sup> Genomic DNA was extracted from the samples, and genetic profiles generated by single nucleotide polymorphism genotyping using Illumina HumanOmni 2.5 BeadChips. Genome-wide association and identity-by-descent analyses, adjusted for relatedness within the sample, identified genomic regions of interest that are strongly suggestive of the involvement of a genetic risk factor.

More detailed genetic profiling was undertaken in 2014 using whole genome sequencing of 23 cases and 9 controls, and subsequent analyses have employed a variety of bioinformatics pipelines to prioritise variants of interest; this was a challenge given how little is known about normal genetic variation within this population. A group of four affected sisters was used as an initial filter, and then widened to include the whole sample. This approach identified a group of genetic variants in over 20 genes, the majority of which are involved in urogenital cancer pathways. These results indicate that, rather than one or two variants of large effect size, this cluster may be driven by the cumulative burden of rare functional variants.

Further whole genome sequencing is currently being undertaken in additional individuals to increase the sample size and allow a formal statistical 'burden' test to be completed prior to undertaking functional studies. The findings of the functional studies will assist in characterising the aetiology of this poorly understood malignancy.

## 2.6 Other Environmental Risk Factors

An increased prevalence of immunosuppressive conditions (such as diabetes, HTLV-1 or HIV) could also contribute to higher incidence of vulvar cancer.<sup>11</sup> No case of HIV has ever been notified for an Indigenous person resident in the EA health district (pers. comm., P. Markey, 2017). Human T-Lymphotropic Virus-1 (HTLV-1) is endemic to Central Australia, but is virtually unknown in both East Arnhem and West Arnhem districts.<sup>18</sup> Diabetes is more common in Indigenous Australians, particularly those living in remote communities; however, the prevalence of diabetes in EA has been estimated to be half that of Central Australia.<sup>19</sup> Taken together, this suggests that immunosuppressive conditions are not the driving force behind this cancer cluster.

Women who participated in the genetic study were asked about their smoking status, and data relating to sexually transmitted infections and other HPV-related

neoplasia (e.g. cervical, vaginal, perianal, anal or oropharyngeal) were extracted from their medical records.<sup>17</sup> No association was found with any of these factors and diagnosis with VSCC or VIN except for previous diagnosis of cervical intraepithelial neoplasia (CIN). It is worth noting that the very high rates of smoking and STIs in this population may obfuscate any association between these factors and vulvar cancer. However, rates of smoking and STIs are also high in other remote Indigenous communities that do not experience a high incidence of vulvar cancer.

The anthropological study (s 2.4) identified no promising candidate environmental exposures for further investigation as risk factors.

## **2.7 Current Epidemiology: Incidence and Recurrence**

In recent years, the difference in vulvar cancer incidence between Indigenous and non-Indigenous Australians in the NT has been gradually diminishing.

Age-standardised rates of invasive vulvar cancer for the period 2006-2014 were 8.95 per 100,000 [95% CI 5.26, 14.84] for Indigenous women and 1.02 [0.42, 2.32] in non-Indigenous women. The age-standardised rates of VIN for the same period were 5.45 per 100,000 [3.01, 10.01] in Indigenous women and 2.45 [1.51, 3.99] in non-Indigenous women.

In East Arnhem Indigenous women aged less than 50 (the group in which the original problem was identified), age-standardised rates of IVC have dropped to 13.17 [4.26, 31.28], compared to 3.99 [1.29, 9.53] for young Indigenous women in other Top End districts.

This apparent reduction in the gap in vulvar cancer incidence between East Arnhem and other Top End Indigenous women may be the result of increasing incidence of vulvar cancer worldwide (particularly HPV-dependent VSCC) in recent decades.<sup>2-4,20,21</sup> Further, the increased attention to vulvar cancer prior to the first analysis may have led to increased ascertainment of cases in NT women outside Arnhem Land.

In Arnhem Land, however, we have evidence of a cluster of unusually aggressive HPV-dependent vulvar dysplasia. Indigenous women resident in Arnhem Land diagnosed with VSCC or VIN are more likely to experience a recurrence after treatment than non-Indigenous women or Indigenous women living elsewhere in the Northern Territory. They also experience less time before recurrence, and have higher mortality.

Indigenous women had 2.3-fold higher risk of recurrence compared with non-Indigenous women. The cumulative incidence of recurrence was higher for Indigenous than non-Indigenous women after five years (48.8% vs 30.2%) and ten years (64.1% vs 36.6%). At 5 years after diagnosis, Indigenous women had on average one recurrence per woman, and non-Indigenous women had 0.5.

The cumulative mortality for Indigenous women was 17.9% vs. 3.7% for non-Indigenous women after 5 years, rising to 19.5% vs. 19.6% after 10 years.

The differences in the natural history of HSIL (uVIN) and dVIN have resulted in different approaches to treatment. HPV-dependent HSIL has classically been

known to develop slowly, occasionally spontaneously regress, and be less likely to progress to invasive cancer than HPV-independent dVIN.<sup>22</sup> Thus, HPV-independent lesions have demanded immediate surgical treatment, whereas HPV-dependent uVIN could be treated with topical immune modulators (e.g. imiquimod) and monitored for longer periods before intervention. In this population, however, the unusually aggressive nature of the disease indicates that treatment needs to be prompt and thorough.

### 3 Disease Control Program

In collaboration with the Department of Health, the project team initiated a disease control program in 2006, focused on early detection and treatment. This comprised two main streams of activity: a community education program and a staff training program.

#### 3.1 Community Education Program

Raising and maintaining awareness of the increased incidence of vulvar cancer in Indigenous women resident in the EA district has been a priority. The sense of shame associated with the disease and the limited access to healthcare in these remote communities may contribute to delays in seeking treatment. With no choice of doctor in many remote communities, women in Arnhem Land would, for instance, have difficulty talking to a male clinician about an issue deemed to be 'women's business'. To overcome these barriers, the community education program has focused on:

- Communicating the scale of the problem
- Providing information on signs and symptoms
- Recommending preventive action (HPV vaccination and regular Well Women's Checks).

This has been effected through a combination of community based events and the development of resources to remain in the communities (Figure 3). Women's cancer education events have been held periodically throughout the life of the project, often in conjunction with the Sexual Health Coordinator from the Centre for Disease Control Nhulunbuy, who offered Well Women's Checks to attendees for opportunistic screening.

The resources for the communities have evolved over time: from an illustrated flipchart in English and Yolngu Matha; to an audio book with illustrations and recordings in English, two dialects of Yolngu Matha, and Anindilyakwa; to an animation in English and Yolngu Matha. While the first two iterations proved useful and culturally appropriate, the physical nature of the resources meant they were easily lost, particularly in clinics with high staff turnover. The animation will be hosted on the Menzies website, and will remain more democratically accessible to clinics, healthcare workers and community members on phones, tablets or computers.



**Figure 3:** Community education activities utilising vulvar cancer resources

### **3.2 Staff Training Program**

Early detection and treatment relies on primary health care staff being aware of the need to look for signs of vulvar dysplasia, and how to identify it. Clinics in remote communities in the Northern Territory experience exceptionally high turnover of staff. Half of all nurses and Aboriginal health practitioners working in remote clinics leave within four months, 66% leave remote work altogether each year, and individual clinics can experience a 128% turnover of staff in 12 months.<sup>29</sup> These retention patterns compromise health professionals' awareness of the cluster and how to identify vulvar dysplasia. The staff training program aimed to:

- Provide clinical information on vulvar cancer and VIN, including how to recognise and diagnose it
- Encourage health professionals to include vulvar examination in cervical screening and antenatal care

These goals were achieved through:

- The development of a clinical training package, widely distributed on CD-ROM to relevant stakeholders
- Including vulvar cancer education in the orientation of remote practitioners and gynaecology staff
- Modifying the women's health check protocol in the Women's Business Manual

The high staff turnover means that these efforts need to be ongoing. We are in the process of updating the training tool, with the aim of increasing its utility in ongoing staff training efforts, and will likely take the form of a web-based application.

## **4 Recommendations**

Although the investigation of this vulvar cancer cluster has been undertaken as a series of research projects lead by the Menzies School of Health Research, the NT Department of Health has primary responsibility for monitoring the cluster and undertaking appropriate disease control action. The investigation has been funded by three NHMRC research project grants, the last of which concludes at the end of 2017. As this research program concludes, and based on its findings, we make the following seven recommendations to the Department of Health.

### **4.1 Clinical Follow-Up**

The genetic investigations found evidence that this cluster of vulvar cancer is partly a result of an inherited predisposition to developing vulvar cancer in the presence of HPV infection. As this predisposition was found to involve the cumulative burden of multiple genetic variants, rather than a single clear causative variant, genetic screening is not appropriate. First degree relatives of cases of vulvar cancer or VIN are, however, likely to be at increased risk. For this reason, it is recommended that first degree relatives receive more frequent clinical screening.

On 1 December 2017, the National Cervical Screening Program will be implemented, and the two-yearly Pap test for women aged 18-69 years will change to a five-yearly HPV test for women aged 25-74 years. Given the finding that vulvar cancer is unusually aggressive in this population, five-yearly checks are too infrequent. Vulvar screening should be linked to the STI and general health checks that comprise the remainder of the Well Woman Check rather than to cervical screening protocols.

#### **Recommendation 1**

- a) Sisters and daughters of confirmed cases should be screened for vulvar cancer annually as part of a Well Woman Check
- b) other EA women should be screened every two years, and
- c) the training tool for health workers and the Women's Business Manual should be amended to recommend this.

#### **Recommendation 2**

Clinical staff undertaking vulvar screening should liaise with an Aboriginal Health Practitioner or Community Worker to ensure that appropriate family members are targeted for additional screening, acknowledging that understandings of kinship may differ.

#### **Recommendation 3**

The Gynaecology Outreach Service (GOS) should formally describe its current screening and treatment protocols, in order to identify whether these need to be amended to accommodate additional screening of relatives of cases or more regular follow-up after treatment, and to standardize practice across clinical specialists.



## 4.2 HPV Vaccination

While improved surgical techniques for localised disease have reduced morbidities without adversely affecting survival, little progress has been made towards improving treatment for advanced primary or recurrent disease.<sup>23</sup> One potential avenue for addressing this deficit may be through vaccination policy. A national HPV vaccination program was implemented in Australia in 2007 for females, and extended to include males in 2013.<sup>24,25</sup> In 2012, coverage for areas classified as Very Remote (including East Arnhem) was comparable to elsewhere for Dose 1, but by Dose 3 was around 10% lower than other areas in Australia.<sup>26</sup> Further, members of our Indigenous Reference Group report that girls in affected communities are increasingly refusing the vaccine.

It is therefore expected that the incidence of VIN and VSCC will decrease commensurately in coming decades, although eradication may be hampered by lower three-dose coverage, decreasing participation, and by the prevalence of a broader range of oncogenic HPV strains in Arnhem Land.<sup>12</sup>

Women aged over 26 years when the vaccine was introduced remain unprotected, and many will have already experienced HPV infection. While there is no evidence that HPV vaccination improves clearance where HPV infection or lesions are pre-existing, there is evidence that women vaccinated irrespective of initial HPV status, who were subsequently treated for cervical lesions, had a lower risk of recurrent lesions.<sup>27,28</sup> There may, therefore, be value in extending HPV vaccination coverage to include older women at risk of developing vulvar dysplasia to mitigate the longer-term effects as well as those already affected.

HPV vaccination should ideally take place prior to initiation of sexual activity. A clinician raised concerns that the current program, which vaccinates 12-13 year olds, may be too late to provide optimal benefit. This should be investigated, and evidence collected regarding the ideal age for vaccination in these communities.

Our findings provide support for: increased resources for HPV vaccination in Arnhem Land with the new nonavalent vaccine, to ensure maximal three-dose coverage; consideration of the extension of free vaccination to women aged up to 45; and consideration of the provision of HPV vaccines to unvaccinated or incompletely vaccinated women diagnosed with HSIL (formerly uVIN) or HPV-dependent VSCC.

A discussion paper outlining the evidence relating to extending HPV vaccination to non-vaccinated women in the EA district was prepared for the NT Department of Health between 2014 and 2016, but no action has resulted.

### Recommendation 4

A business case should be prepared by Clinical Quality and Patient Safety Branch, System Performance and Innovation Division of the Department of Health for submission to (1) NT government, (2) federal government, or (3) philanthropic sources for funding of a catch-up program of vaccination for Indigenous women resident in EA aged 35-45 years, or those aged less than 35 and unvaccinated or incompletely vaccinated. This would be a limited undertaking, with relatively small numbers in a defined geographical area. The funding request must include additional staffing requirements in the budget, as community health centres and staff of the existing vaccination program do not possess the capacity to

undertake this additional work, which would require considerable outreach activities to find eligible women at each vaccination time point.

### **Recommendation 5**

Long term surveillance of the impact of the vaccine on VIN and vulvar cancer rates is required, and should be undertaken by the NT Centre for Disease Control. Surveillance would be improved by updating the current database used by the GOS, and linking this to the NT HPV vaccine register or collecting vaccination status within the database.

## **4.3 Health Education Program**

Maintaining community awareness of the risk of vulvar cancer, the signs and symptoms, and appropriate preventive and therapeutic actions represents a significant ongoing challenge. Further, it is important that all efforts to increase and maintain awareness are culturally appropriate, with particular regard given to the sensitivities attendant to women's business.

### **Recommendation 6**

Responsibility for maintaining community awareness of vulvar cancer should comprise part of the role of Women's Health Educators within the Remote Health Program, supported by Remote Area Midwives (Remote Health) and Sexual Health Coordinators (CDC). Both the vulvar cancer community animation and the updated vulvar cancer training tool should be supplied to the educators for their use in carrying out health education and awareness activities.

## **4.4 Clinical Awareness Program**

Clinics in remote communities in the Northern Territory experience exceptionally high turnover of staff. Half of all nurses and Aboriginal health practitioners working in remote clinics leave within four months, 66% leave remote work altogether each year, and individual clinics can experience a 128% turnover of staff in 12 months.<sup>29</sup> These retention patterns compromise continuity of care and health outcomes.

### **Recommendation 7**

The updated vulvar cancer training tool and the vulvar cancer community animation should be supplied to Family Planning Welfare Association NT, Well Women's Cancer Screening Program, Remote Health, CDC, Cancer Council NT, Northern Territory General Practice Education, Aboriginal Medical Services (Miwatj, Malabam, Danila Dilba), and directly to all clinics in the affected communities. These organisations will then be responsible for ensuring that new staff receive appropriate instruction in the identification of vulvar cancer and VIN.

## **5 Investigators, Indigenous Reference Group and Partner Organisations**

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## **Partner Institutions**

### **Menzies School of Health Research**

Menzies School of Health Research is Australia's leader in Indigenous and tropical health research. Menzies works to better diagnose, prevent and treat disease and to partner with health services and communities to improve health outcomes. Menzies' areas of expertise include Indigenous child and mental health, the social determinants of health, tropical and emerging infectious diseases, preventable chronic diseases, nutrition and international health.

### **Menzies Institute for Medical Research**

Menzies exists to perform internationally significant medical research leading to healthier, longer and better lives for Tasmanians. We aim to advance human health and wellbeing by contributing significantly to knowledge on prevention and treatment of diseases including arthritis, cancer, multiple sclerosis, cardiovascular disease, diabetes type-2, osteoporosis, mental health, obesity and dementia.

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