In this paper I will use the term Indigenous to refer to Australia’s Aboriginal and Torres Strait Islander peoples. I also ask readers to note that Australia’s South Sea Islander population is recognised by the Queensland Government. South Sea Islander people have married into and work in the Aboriginal and Torres Strait Islander community. Although I am not writing on behalf of South Sea Islander people or other Indigenous nations, I recognise that issues raised may apply to Indigenous people in other world settings.

While this paper explores the problem of cervical cancer in Indigenous women, from an Indigenous perspective it really doesn’t matter what the health issue is. If we genuinely want to move forward as a community and as a nation, then we need to start thinking about how we practise individually and also as part of a team. Additionally, we need to encourage others to start thinking about the way in which they work and practise.

We need to explore how to engage the support of others. This will require effort and a commitment to examine our own professional frameworks and their underpinning principles. It will require thinking about and analysing the processes that we use daily to identify and address health issues.

Many Indigenous Health Workers, including myself are tired of being involved in events which end up being nothing more than “talk-fests” where there are no real outcomes, no real strategies to encourage or support people and no commitment or follow-up to make a difference.

The rate of Indigenous women presenting late, dying at young ages and dying in high numbers from cervical cancer is alarming. Furthermore, death from cervical cancer has a negative effect far beyond the affected woman herself; it also affects the physical, social and emotional well-being of the community and destabilises, undermines and impacts on the community’s social capital. More specifically, it has an impact on the partners of the women, the family and the extended family, including siblings and children.

Many issues underpin or impact on this health outcome, including the ongoing process of colonisation as it continues to affect Indigenous people. There is the work to address the appalling rate of death and dying, which usually relies on the goodwill or social capital of the community. And there is the expectation that the social capital in many communities, including Indigenous communities, is alive, robust and healthy.

Evidence demonstrates that Indigenous people die at a much higher rate than the general community, especially from stroke and heart disease, injury, respiratory diseases such as pneumonia and chronic bronchitis, and diabetes (which alone occurs at about eight times the national rate)\(^1\). The gap between the two communities has increased in recent years. Factors that increase the risk of these disorders in the Indigenous community include higher tobacco and substance misuse rates and poorer nutrition. In addition location and

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### A MODEL FOR ENGAGING AND EMPOWERING INDIGENOUS WOMEN IN CANCER SCREENING

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### Terminology

In this paper I will use the term Indigenous to refer to Australia’s Aboriginal and Torres Strait Islander peoples. I also ask readers to note that Australia’s South Sea Islander population is recognised by the Queensland Government. South Sea Islander people have married into and work in the Aboriginal and Torres Strait Islander community. Although I am not writing on behalf of South Sea Islander people or other Indigenous nations, I recognise that issues raised may apply to Indigenous people in other world settings.

### General factors

While this paper explores the problem of cervical cancer in Indigenous women, from an Indigenous perspective it really doesn’t matter what the health issue is. If we genuinely want to move forward as a community and as a nation, then we need to start thinking about how we practise individually and also as part of a team. Additionally, we need to encourage others to start thinking about the way in which they work and practise.

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**Figure 1**

environmental factors impact heavily, such as remoteness from, lack of and barriers to services including health, housing, education, employment and legal support. Often there is lack of access even to clean running water.

The increased incidence and death rates documented for cancer and other diseases have been linked to poor perceptions of health and to social isolation, resulting in withdrawal from community services. Often this withdrawal occurs because people have seen no real improvement in their own health over the years and can foresee no prospect of change to their health or to the systems that ideally should address their health needs. They have no real resources, either material or human and they have become so disillusioned by prior processes and practices, that it is difficult for people not to feel indifferent, or apathetic about their health.

They can see that current services are culturally ineffective and culturally unsafe and they can see that new services and programs are being developed without their input. They know that these services and programs will be equally as ineffective and equally as unsafe as those already in existence. Yet because they have become so burnt-out, have become so disillusioned, feel so unsupported and have no power or control over the way money is invested and how services are developed, they just give up and refrain from entering into the discussion altogether.

**Cervical cancer screening rates**

Figure 1 shows the current cervical screening rates according to age in 13 Indigenous Queensland communities compared to those of the general Queensland population. It can be seen that Indigenous rates are much lower, a state of affairs which is unacceptable. Figure 2 demonstrates that the participation rates in cervical screening in these communities vary from as low as 20 per cent up to 65 per cent. The average participation rate in Aboriginal communities is 31.6 per cent and in Torres Strait Islander communities, the average rate is 56 per cent. The average participation rate for 13 Indigenous communities is 41.5 per cent for 1999 - 2000. This rate is below the state average of 56.7 per cent and only one of the 13 communities has a participation rate higher than the state average. For 13 Indigenous communities, cervical cancer mortality rates are at least 10 times higher than the State average.

The evidence from Queensland demonstrates that Indigenous women are presenting and dying more often and at younger ages from cancer of the cervix, a largely preventable condition. Specifically, epidemiological data from discrete or defined Indigenous communities in Queensland over the period 1982-1996 indicate that the death rate from cancer of the cervix amongst Aboriginal women was 13 times higher than the state average. Data from Torres Strait communities indicate that the death rate was 21 times higher than the state average. Other Australian states and territories also report higher levels of incidence and mortality rates of cervical cancer for Indigenous women.

Cancer Screening Services, part of the Queensland Cervical Screening Program located within Queensland Health, have worked to improve these figures within Aboriginal communities through the development and implementation of the Queensland Indigenous Women's Cervical Screening Strategy 2000 - 2004.

**The lifestyle message**

The problem with the 'lifestyle message' approach to health promotion and other internalised messages is that not only do these approaches fail to address the primary determinants of health, they also divert public and policy attention away from more important issues. They also serve to blame individuals and communities for their diseases and illnesses, failing to shore up the support networks needed, including strengthening the social capital of each community.

![Figure 2](image-url)
The effectiveness of such an approach is questionable, particularly when health problems among Australia’s Indigenous people are exacerbated by the ongoing process of colonisation, which can be considered responsible for the introduction and provision of unhealthy foods and the destruction of the prior, healthier hunter-gatherer lifestyle.

Colonialism, paternalism and ethnocentrism cause Indigenous roles, systems and processes to be dismantled and fractured, where many Indigenous people are still living on the fringe or living segregated lives at a geographical or emotional distance from family and kin. Assimilation, dislocation, family separation, racism and discrimination are a part of everyday Indigenous life.

Removing the barriers and engaging the community

Barriers to access are created if there is failure to offer culturally safe screening services, or a failure to recognise the need for culturally sensitive follow-up after diagnosis and treatment. Indigenous people need to be involved in setting up these processes. However, being actively engaged through advisory group representation is not enough. Indigenous people need to be employed in positions which can guide these processes daily. They need to have appropriate wages, a recognised career path and access to ongoing education and training. The process needs to be inclusive.

An effective strategy is to put in place networks and systems which engage and support strong Indigenous voices at the negotiating and decision-making table. But encouraging strong voices can be difficult if people feel powerless and sense that networks and systems are tokenistic. As well, it can become extremely draining if the same person or group of people is approached whenever there is an issue to be addressed or a job to be done. Also, it can cause consternation if there is a sense of urgency, simply because there is funding available yet the issue has not been identified by the community as one deserving priority. This again leads to apathy.

Engaging a participatory process that encourages and supports the community will require continually recognising where the community is at with their own business to allow Indigenous people to have real input. The process will mean that the xenophobic practice of “rubber-stamping”, which often stems from government policy and which requires Indigenous people to simply endorse someone else’s ideas or notions, will not be tolerated. Rubber-stamping leaves the community disillusioned and apathetic, destroys goodwill and willingness to be involved, leaving no community or no individual to draw upon.

Once an issue is identified, timeframes for action may differ from those of non-Indigenous people. In fact, identifying an issue does not mean that it is appropriate for the community to address the issue immediately.

Building social capital

Research shows that people who actively participate in their community and who have a strong sense of belonging and supportive family ties, including cultural and community relationships, have more social capital and more interest in improving their health and attaining better health outcomes, than people who are socially isolated.

For clarification, the term ‘social capital’ describes features of social life and includes:

- The extent of involvement by people in their community;
- The trust people invest in each other and in governments and institutions; and
- The connections between people and their communities and families.

Social capital also describes how much we can help, or are able to help each other. Government policies and practices have repeatedly interfered in the Indigenous way of life and living, determining that most Indigenous family structures are dislocated. The fact that many people to this day still do not know other family members or where they fit within the community itself, creates feelings of anger and frustration and causes deep heartbreak and often shame.

Other factors contributing to lack of social capital and to a poor health status include: having a lower socio-economic status - or, in other words, having low incomes and no economic base; having high rates of unemployment and a disproportionate level of poor educational attainment; and cultural and ethnocentric barriers to services.

Improving the social capital provides a mechanism to engage and increase genuine participation and it is often only after this process that people become strong in voice and strong in health. Being strong in voice, people are more likely to engage in health planning thus increasing good health and access to services, decreasing mortality rates and morbidity burden and lowering the cost to the health system.

Community capacity development approaches have shown impressive achievements when strengthening social networks, building knowledge and skills and in improving communication among sectors of the community. But how do we do support this practice?

People need to be involved in consultation strategies that support and encourage the community’s social capital. Achievements in building social capital are more successful if people have a sense of belonging, a sense of control over research and program development and in having ownership of services and programs.

A strategic approach

The inexcusable rates of cervical cancer in Australian Indigenous women prompted an Aboriginal woman, the late Ms Maureen Kirk, to carry out research in Queensland in order to promote change. Recommendations developed out of Ms Kirk’s research were documented in the Queensland Indigenous Women’s Cervical Screening Strategy 2000-2004. This strategy began to acknowledge and respect difference, putting in place strategies to remove barriers and to increase access to the cervical screening pathway.

It was after the completion of Ms Kirk’s research and with input through genuine participatory action by Indigenous peoples across Australia, that the Queensland strategy was developed, determining and documenting six key action areas to target specific areas of identified need, including the development of a national code of practice for screening services.

The participatory process to endorse a national code relied strongly on utilising and developing the social capital in many communities. This strategy and the code of practice were
endorsed nationally by many Indigenous and non-Indigenous organisations. It took three years to develop the strategy and another three years to develop the service guidelines, but the process and timeframe were strongly supported.

The Queensland strategy has begun to address the imbalance of health outcomes. Four years after its implementation, much work has been done. While many of the key actions have been put into practice and some improvement in cancer mortality and morbidity is evident, some actions are still outstanding. Furthermore, some do not now meet today's health needs; new strategies may need to be developed. This process will depend on input once again from the community and support from other organisations, to assist with the development of the social capital needed to engage the community.

Cervical screening guidelines

The Principles of Practice, Standards and Guidelines for Providers of Cervical Screening Services for Indigenous Women are being implemented nationally. The guidelines (copies of which are available from The Cancer Council Australia) were developed to help break down some of the access barriers in cervical screening services and seek to better engage Indigenous women in the screening pathway. Readers are invited to be involved in the implementation process and constructive feedback is encouraged.

The guidelines, which are readily adaptable to other services, are being distributed to Indigenous and non-Indigenous service providers and to individuals on request. They include three useful case studies as examples of good practice and an audit tool to help determine gaps in service provision and service delivery.

Conclusion

It is vital to recognise the importance of engaging the Indigenous community in an ongoing, genuine decision-making process by encouraging and supporting the social capital needed in each community. Additionally, Indigenous Health Workers have a unique and important role and there is a need for the development of nationally accredited competency-based education and training program to support them in their role, specifically in the area of breast and cervical cancer.

There are workforce issues, as well as education and training issues for Indigenous Health Workers that require urgent attention. Health worker education and training must be offered locally. The health worker role and the importance of the participatory process to encourage and support the social capital of communities have been recognised by a number of organisations, which have made a commitment to be involved in supporting and further developing the health worker role, including education and training.

Supporting organisations of these needs include the National Aboriginal and Torres Strait Islander Women’s Forum, which has health worker representation from each state and territory, the Australian Government through the Department of Health and Ageing, the Office of Aboriginal and Torres Strait Islander Health in Canberra and the Australian Screening Advisory Committee.

Although many people have put forward similar recommendations over the years, the policies, strategies, systems, processes and networks in place today still do not fully address the issues, which are to:

- Recognise the history and stop the ongoing practice of colonisation;
- Stop the “blame the victim” mentality;
- Recognise the importance of and build up social capital within communities;
- Recognise that the community might be burnt-out or apathetic and put in place strategies to address this;
- Value the unique role of Indigenous Health Workers at all levels;
- Advocate for designated women’s health roles;
- Ensure you have a code of practice within your own organisation;
- Ensure non-Indigenous staff are culturally respectful and culturally aware;
- Stop racist, discriminative, tokenistic and assimilative policies and practices;
- Stop practices and processes which "rubber-stamp" someone else’s ideas;
- Support access to culturally effective and safe education and training;
- Build and maintain equal partnerships;
- Not support or enforce unrealistic or culturally ineffective timeframes; and
- Encourage and support strong (Indigenous) voices at the negotiating and decision-making table.

I encourage all readers to be involved, to make a commitment to make changes and to support the way in which Indigenous people need to work, professionally and culturally. This will require examining one’s own professional frameworks, ethics and values, including the principles of practice and of the services offered. It will require thinking about and analysing the processes, systems and policies that we all use daily to identify and address health issues. By doing this, it can make a difference.

References

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