RMIT
UNIVERSITY

School of Management
Building 80,
445 Swanston Street

GPO Box 2476
Melbourne VIC 3001
Australia

22 September, 2016

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

RE: National Cancer Screening Register Bill 2016 and National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016

Dear Senate Standing Committees on Community Affairs members, as addressed

Thank you for the opportunity to raise my concerns relating to the National Cancer Screening Register Bill 2016 and National Cancer Screening Register (Consequential and Transitional Provisions) Bill 2016, and particularly to how this will impact on Human Papillomavirus (HPV) Research national and internationally, persistent HPV infection being a precursor to cervical cancer.

My Background: I am a behavioural researcher at RMIT University, Melbourne, with a focus on HPV and HPV vaccination factors in culturally and linguistically diverse (CALD) communities to reduce the morbidities and mortalities of cervical and other HPV-related cancers in these populations. CALD communities have disparate rates of cervical screening and HPV vaccine uptake, generally lower than other population groups nationally. I regularly draw on data and publications disseminated by the Victorian Cytology Service (VCS) and National HPV Vaccine Program Registry (NHVPR)

I cannot overstate the importance of the VCS, who also auspice NHVPR in ensuring that we HPV researchers nationally and internationally receive timely detailed data on population trends that can be applied in our research. It also enables us to determine where targeted solutions need to be applied rather than a generalist approach. A quick search of Google Scholar will reveal the extent and impact of VCS and NHVPR translational activities. In fact national and international researchers draw on these publications and publicly available clean data to set their national policies due to the integrity of the data management and reputational trust in VCS and NHVPR processes and systems.

The VCS staff have expert content knowledge, regularly disseminate their findings globally, advise on policy nationally and internationally and forecast trends. Given the data contained within VCS and NHVPR relates to a sexually transmitted virus and is therefore culturally sensitive, the staff also have reputational integrity and trust among the general CALD and Indigenous communities, the populations most at risk.

My concerns:

1. That Telstra, a 'commercial for-profit entity, is to be granted the management of these sensitive registries as part of their Telstra-Health business unit.

2. That academics and researchers will be denied access to data regarding HPV morbidities fundamental to research and policy.
3. That the current Telstra Board (pg. 38 -39 2016 Annual Report) have no background or expertise in reproductive health research relating to these morbidities and therefore will not continue the dissemination of the current translational activities as undertaken by VCS and NHVPR
4. That people whose intimate details are recorded on the registry, particularly CALD and Indigenous women, are vulnerable to having their privacy breached or hacked due to Telstra' s 'repeated internet failures (Sydney Moring Herald media report published May 25, 2016)

The Annual Report 2016 is focused on its commercial activities, and in no section does it demonstrate a commitment to health research despite its Telstra-health activities being launched as a 'stand-alone business unit' in October 2014. The Strategy focuses on 'bringing the digital revolution to health care'. The Chairman and CEO message reinforces 'returning capital to shareholder'; its 'Build new growth businesses' refers to Telstra health as *'another growth opportunity...and will develop innovative technology solutions across the health industry.*"

Whilst the Annual Report maintains that it brings 'new solutions to solve key health challenges' there is no data publicly available that reports on the impact on the health and well-being of the Australian population (as opposed to VCS and the NHVPR who deliver real-time publications). On page 15 it reports that it will '*integrate 'existing databases and improve access for patients and practitioners to medical records."* At no point does it demonstrate an understanding of the current broader activities, nor state its commitment to honouring the translational activities through research and dissemination.

I can only assume that these activities will be disbanded thereby creating a vital data vacuum for the research community. The VCS and NHVPR have proven track records in data management and dissemination as it relates to cervical cancer and HPV immunisation programs and should be retained as the best group to manage this sensitive data, and resourced to continue to deliver to the research community the vital information we require.

Yours sincerely,

Margaret Heffernan, O.A.M., PhD