

Telstra seeks to make this supplementary submission to the Senate Community Affairs Legislation Committee to clarify a number of matters arising from evidence provided by the Victorian Cytology Service Ltd (VCS) before the Committee which have the potential to cause confusion or misunderstanding.

### **1. Challenges associated with establishing the National Cancer Screening Register (NCSR)**

The challenges in establishing the NCSR are not unique to Telstra. They would equally apply to any other party establishing and operating the NCSR, including:

- migrating and merging data sets from existing state and territory cervical registers that support the current two yearly Pap tests;
- scaling with the required clinical and technical expertise to support both:
  - the national roll out of the renewed National Cervical Screening Program, including appropriate follow ups from existing pathways during the transition;
  - the expansion of the National Bowel Cancer Screening Program (no state based register has operated the National Bowel Screening Program); and
- building community acceptance.

#### ***The renewed National Cervical Screening Program***

The NCSR will implement the renewed National Cervical Screening Program, including the evidence based recommendations of the Medical Services Advisory Committee (MSAC) that a primary human papillomavirus (HPV) test conducted every 5 years should replace the current 2 yearly Pap test for cervical screening. The existing state or territory registers are only designed to support the current Pap test at scale.

As part of the renewed National Cervical Screening Program, approximately 1.4 million women aged between 25 and 74 years (both HPV-vaccinated and unvaccinated) will be invited to participate in cervical screening (by undertaking an HPV test) every 5 years. The NCSR includes establishing streamlined invitation and reporting to support the renewed National Cervical Screening Program, including new clinical guidelines for women with a positive test result.

The Victorian Cytology Service are collaborating with Cancer Council NSW researchers to recruit over 120,000 women to participate in the Compass trial, which is the first trial of cervical screening in an HPV-vaccinated population.

The new HPV test is not currently available on the Medicare Benefits Schedule. Its introduction also involves the broader development and implementation of:

- consumer resources and health professional training;
- new clinical guidelines for women with a positive test result;
- new pathology laboratory performance measures and standards;
- workforce changes; and
- register changes.

#### ***The expansion of the National Bowel Cancer Screening Program***

The NCSR will implement the expansion of the National Bowel Cancer Screening Program. This is currently run by the Commonwealth Department of Human Services. The National Bowel Cancer Screening Program currently invites men and women turning 50, 55, 60, 64, 65, 70, 72 and 74 to screen for bowel cancer. The NCSR will expand this program through the introduction of two-yearly screening for all Australians aged 50 to 74. By 2020, the NCSR will support around four million Australians being invited to screen each year.

#### ***Community acceptance***

We are confident that the benefits offered by the NCSR when compared to existing operations will garner community acceptance. This includes:

- greater options for report notifications;
- clinical and participant portals providing the opportunity for greater accessibility and interaction by participants and healthcare professionals;

- options for SMS and email delivery of selected messaging;
- streamlined work flows;
- introduction of paperless work practices compared to existing operations;
- increased use of technology to support modern registry practices;
- proven secure platform integration with many of the interfaces required for the delivery of the National Cancer Screening Register, including Medicare, the HI service, My Health Record and major Pathology and GP desktop providers.

It is important to note that the NCSR is being implemented in partnership with state and territory governments. The NCSR will be overseen by a number of governing bodies managed by the Commonwealth Department of Health and with the required clinical and data expertise. Operation of the NCSR will be strictly informed by evidence-based program policies and protocols developed through the screening programs' governance structures. These include the Commonwealth, state and territory governments, the Australian Institute of Health and Welfare and key clinical experts.

We have already built a dedicated and experienced team with the requisite mix of deep clinical and technical expertise to provide the necessary operational support and follow up to screening participants, healthcare professionals and other end users in accordance with the evidence-based program policies and protocols. As outlined to the Committee, the Telstra Health team delivering the NCSR are a team of experts, who have a vast array of experience necessary to support the establishment of the NCSR on a national scale. 12 members of the NCSR team have previous population health register operation experience, including bowel and cervical register experience. A summary of the team's experience and qualifications is attached.

The technology platform which will be configured to run the NCSR has been operational since 1999, including running a cord blood register since 2012.

## **2. Approaches by Telstra Health to VCS**

Representatives from Telstra Health met with representatives of VCS at 2pm on Thursday 12 May 2016. Shane Solomon (MD Telstra Health), Nicole Scurrah (Chief Operations Officer, Telstra Health) and Professor Ruth Salom (Head of Integrated Solutions NCSR, Telstra Health) attended on behalf of Telstra Health. Associate Professor Marion Saville (Executive Director/Secretary, VCS), Sandy Anderson (Chairman, VCS), Les McLean (Director Corporate Services, VCS) and Sam Morris (Partner, Shinewing) attended on behalf of VCS.

The meeting was an introductory one following Telstra's appointment to operate the NCSR. The discussion was of a general nature. At this meeting Telstra Health invited VCS to propose how its expertise could be used to advance the national program. We said that we were open to consider any arrangements that VCS may propose, including commercial arrangements. Telstra Health did not 'decline to enter into a business arrangement with VCS'. VCS did not propose any 'business arrangement' to Telstra at that meeting. VCS has not proposed any 'business arrangement' for Telstra to consider following that meeting.

Telstra Health has not separately met with the VCS team since that initial meeting. The Victorian Department of Human Services has required that all information be sent via the Victorian Department of Human Services for management and engagement with VCS. We understand that this is because the Victorian Department of Human Services is the formal authority with which we must deal in relation to the NCSR, and the Victorian Department of Human Services contracts (with associated data custodian rights) with VCS to deliver the cervical cancer screening component.

As the establishment of the NCSR involves the transition and migration of nine separate cancer screening register databases into a single national register, significant collaboration is required with each of the state and territory governments to migrate the data in their existing cervical registers. We are also liaising with the Commonwealth Department of Human Services in respect of the transition and migration of the existing national bowel register. It is necessary to migrate data from the existing registers, and ensure that processes, policies, and procedures are aligned across the differing jurisdictions so that we can implement a national consistent approach.

The information requests sent to the Victorian Department of Human Services are the same as those sent to other state based cervical cancer screening registers. We do not believe we have sought any intellectual property in data sets. We have created a common data model to be used for the NCSR and we have shared this with the states and territories. We sought an understanding of the data structures used in the existing registers (name of participants, mailing address, results, the name of the physician on the pathway and correspondence). Data cannot be migrated without being structured. This data can only be structured and recorded in a small number of ways and does not markedly differ between registers. Moreover, provision of these data sets is not unusual in data migration activities in healthcare environments.

We also sought copies of, and an understanding of, each register's standard operating procedures. This would be undertaken by any register operator. This is to effectively map the old processes to the new processes created for the renewed National Cervical Cancer Program. The importance of understanding how each register currently operates is because in the absence of a standardised approach, each existing register will include details and processes for women who have returned a positive Pap test prior to the transition to the new HPV test. These will need to be followed up according to and with an understanding of the existing data structure and processes used in each jurisdiction.

The existing processes are of no value to the new HPV testing process and are only relevant during this transition process to the new HPV testing regime, which will have its own unique processes and procedures. The clinical pathways for both the expanded National Bowel Cancer Screening Program and the renewed National Cervical Screening Program are signed off by the Commonwealth Department of Health and do not require any intellectual property from VCS.

Other states and territories have not objected to the provision of this information and have already provided de-identified data sets.