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### **Investigation of a reported cluster of cancer cases at the National Gallery of Australia**

#### **Progress report for Steering Committee Tim Driscoll May 21, 2008**

#### **PURPOSE**

This progress report is designed to provide an update to the Steering Committee regarding the recent and current activities undertaken for the project investigating a reported cluster of cancer cases at the National Gallery of Australia (NGA).

#### **EXPOSURE ASSESSMENT**

The Stage One report of the project was released in March 2007 and has been available on the NGA web site since that time. This report considered past and current exposures at the Gallery. No substantive comment has been received from current or past workers in regards to identified problems or inaccuracies in the report and no changes have been made to the report.

#### **EPIDEMIOLOGICAL ASSESSMENT**

##### ***Cancer registry data***

Stage 2 of the project involves an epidemiological assessment of the rate of cancer in current and previous staff members at the National Gallery. The information on cancer cases will come from the State and Territory cancer registries. The information for all the registries is held by the National Cancer Statistics Clearing House which is operated by the Australian Institute of Health and Welfare (AIHW). The AIHW is authorized to provide the information for all States and Territories except Victoria. Victorian data is supplied directly by the Victorian Cancer Registry.

There was a major delay in being able to request the data from the AIHW and Victoria because permission is first required from the relevant human research ethics committees (HRECs) of all States and Territories, as well as from an institutional HREC and from the AIHW HREC (10 committees in total). These permissions were sometimes contingent on the permission of other committees, and the final permission was not received until the end of July 2007, although there was then a delay while some uncertainty with the allowed format of the consent form was sorted out.

### ***Current staff***

The approved consent forms and Participant Information Statements were sent to all current NGA staff at the end of August. The collection of consent forms was completed in November 2007. At the completion of the process requesting consent forms to be returned, forms had been returned by 170 of a possible 292 (58%) current employees. Of these 170 people, 162 (95%) gave their consent and the remainder (5%) did not.

### ***Previous staff***

For previous staff members, written consent was not required to send their name to the cancer registries because the HRECs agreed that the contact details for a considerable proportion of previous staff members were likely to be out of date and a resulting low participation rate would undermine the validity of the study. However, as required by one of the HRECs, letters providing information about the study were sent (on the 19<sup>th</sup> October) to the last known address of all previous NGA staff members. Obtaining the required contact and employment details (occupation, start and finish dates) for all previous employees was a major undertaking that was organized by the Human Resources section of the NGA.

As a result of receiving the information letter, some ex-employees (20 to 25) contacted the study leader, Tim Driscoll. These people provided information on working conditions when they were at the Gallery, described health problems they had experienced whilst at the Gallery or at a later time, and/or asked for further information about the study and its progress.

### ***Request for cancer registry information***

In early December 2007, the study team was finally in a position to formally request the registry information from the AIHW and the Victorian Cancer Registry. The request was made at that time. The AIHW indicated that it would begin processing the data request in mid January 2008. Victoria did not provide a data for processing the request and it subsequently transpired that the request went missing and so was not initially acted upon. The Victorian data were finally available for supply in mid-April, but it was decided at that time that the data would be supplied through the AIHW.

Unfortunately, there has been a substantial delay in the AIHW providing the information on incident cases of cancer. On 18<sup>th</sup> April I received the information from the National Deaths Index (run by the AIHW) on ex-employees who have died, but for the main analysis I need the information on incident cases of cancer. Although this information has been available to send to me since mid-April (following some difficulties in processing the request at the AIHW's end), the

AIHW has been unwilling to provide the data in the format desired by the study team, a format that has been approved by all the State and Territory cancer registry ethics committees. The issue is that I requested named data, which is required to allow a comprehensive analysis of a suspected cancer cluster. The AIHW ethics committee's interpretation of their mandate was that named data could not be supplied, despite the owners of the data (the State and Territory cancer registries) providing ethics clearance for me to receive this information. Following lengthy negotiations, and as a result of my request and the anticipated similar requests of others, the AIHW ethics committee last week developed new guidelines to use in such requests. I was told this last Wednesday afternoon (14<sup>th</sup> May) and was requested to write to the AIHW ethics committee again, addressing these new criteria. I wrote to the committee on the 16<sup>th</sup> May, describing how my request met the new criteria and repeating my original request for named data. It was indicated to me by the AIHW that I would receive an answer very quickly (expected within one week). As yet I haven't heard anything in response to my request. My request clearly meets the new guidelines and so I am hopeful of receiving the requested data very soon. However, I will not know for sure until I am informed definitively by the AIHW. If the AIHW ethics committee decides not to give me named data, they will instead provide anonymous data and I will perform the analysis as best I can using that information.

### ***Analysis of epidemiological data***

The analysis can take place as soon as the data are received. It is not clear how long the data analysis will take, as this will depend on the quality of the provided data and the type of analyses that these allow. At this stage it is anticipated that the analysis will take between two and four weeks, with time then needed to write and finalise the report.

### **COMPLETION OF THE FINAL REPORT**

Allowing one month to prepare the final report, it is anticipated that the draft version of the final report will be available for consideration by the steering committee, and then staff, in late July 2008. Although this means the report will be finished many months later than initially anticipated, completion is contingent on receiving the data from the AIHW, and the delay with this has been beyond my control. Following feedback from the committee and from staff, the final version of the report will be completed. This should be in late August or early September 2008.



Tim Driscoll  
Study team leader