Patient Reported Outcomes Measures in Victoria
Expression of interest from the UGICR to participate in DHHS PROMs pilot
October 2016

Background of the Upper Gastrointestinal Cancer Registry
The Upper Gastrointestinal Cancer Registry (UGICR) is a new clinical quality registry designed to describe patterns of care following diagnosis of primary cancers of the pancreas, oesophagus, stomach, liver and biliary system (i.e. upper gastrointestinal cancers) with a view to improving patient outcomes and quality of care. The registry operates out of Monash University and is currently nearing the end of its pilot of data collection for people with newly diagnosed pancreatic cancer. This pilot phase has included patients from three tertiary hospitals in Victoria with plans to expand to many additional Victorian sites over the next two years.

The UGICR collects patient data relating to diagnosis, treatment and outcomes with additional data items collected for risk adjustment. The Victorian Department of Health and Human Services has provided seed funding for the initial setup of the registry, with the Pancare Foundation and industry partners also providing sponsorship.

Proposal for integrating PROMs into Upper Gastrointestinal Cancer Registry as part of the DHHS PROMs pilot
One aim of the UGICR project is to implement PROMs data collection, to complement the clinical data collected by the core registry. The UGICR is intending to implement PROMs data collection in 2017 beginning with patients who have been newly diagnosed with pancreatic cancer.

Patient group: Initially, PROMs data collection will involve those patients with a newly diagnosed pancreatic cancer who have (or will) undergo resection surgery for their cancer. The reason for beginning with this patient group is because those patients who are not suitable for resection are often very unwell; it is therefore particularly important that our PROMs data collection processes are well established before we involve such patients.

Frequency of PROMs administration: Monthly with baseline PROMs as close to date of diagnosis as possible.

Anticipated numbers: It is anticipated over a 12 month pilot period there would be about 50-60 patients in the UGICR who are suitable for surgical resection of their tumour and therefore would be approached for PROMs data collection

Method of administration: Participants will be encouraged to complete PROMs questionnaires online via a secure platform but a paper-based questionnaire option will also be offered. The plan will be to incorporate available technologies such as SMS notifications and/or emails where possible to improve questionnaire completion rates in the future.

PROMs Questionnaires: The UGICR is planning to use the EORTC QLQ-C30 which is a questionnaire that has been develop to assess the quality of life of patients with cancer\(^1\). In addition to this some questions from the EORTC item bank which are relevant to pancreatic cancer would also be included.

PROMs reporting: PROMs form an important component of a consumer-centred approach to care so ultimately, the UGICR would like to implement a system of PROMs data collection that includes real time or close to real time feedback of PROMs results to the patient’s treating clinician(s).

\(^1\) EORTC QLQ-C30 accessed 27/10/2016 at http://groups.eortc.be/qol/eortc-qlq-c30