

# **Seychelles Oncology Unit Patient Survey**

## **Technical Handbook**

Dr Johanna Rapanarilala      Dr Sylvie Pool  
Dr Nyasha Manyeruke      Dr Ernest Guevarra

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# Preface

This handbook is a guide on the design, development, training, and implementation of the **Seychelles Oncology Unit Patient Survey**. This handbook was first put together for the first iteration of the survey in 2025.

This is a pre-release version (**v0.0.0.9000**) released on **13 April 2025**.



**Part I.**

**Design**





# **1. Survey design**



## 2. Questionnaire design and development

The key approach to questionnaire design and development for this project was to build on existing tried and tested oncology patient satisfaction and/or experience survey instruments utilised in other countries and in various contexts to ensure content validity (see Section 2.1 for a description of these questionnaires). Questions from these existing instruments were either extracted verbatim or were modified to align with the local context. Localisations included adjustments to terminology to match what is used locally and the addition of response options relevant to the Seychelles local setting and specific cultural context of the population. The questionnaire design was further guided by the six domains of healthcare quality (see Note 1) put forth by the Institute of Medicine or IOM<sup>1</sup>.

### **i** Note 1: IOM six domains of healthcare quality

**Safe:** Avoiding harm to patients from the care that is intended to help them.

**Effective:** Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).

**Patient-centered:** Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.

**Timely:** Reducing waits and sometimes harmful delays for both those who receive and those who give care.

**Efficient:** Avoiding waste, including waste of equipment, supplies, ideas, and energy.

**Equitable:** Providing care that does not vary in quality because of personal characteristics such as geographic location and socioeconomic status.

### 2.1. Reference questionnaires

Following are the reference questionnaires used by the study team to develop the Seychelles Oncology Unit Patient Survey.

## 2. Questionnaire design and development

### 2.1.1. Le Baromètre cancer

The *Le Baromètre cancer* is a nationwide survey carried out in France every five years. Now on its fourth edition which collected data collected in 2021 from nearly 5000 individuals aged 15 to 85, the survey offers insight into how the French population perceives and responds to cancer which are then used in the for public health monitoring and research.

The survey is run by Santé publique France in collaboration with the Institut National du Cancer. Given the survey's every five years frequency, it is able to provide data that can be analysed to track trends over time in how people perceive cancer, their awareness of prevention methods, and how they engage with screening programs.

For the purpose of the survey questionnaire development for this study, the Baromètre cancer questionnaire for 2015 was used<sup>2</sup>.

### 2.1.2. Cancer Awareness Measure Plus

The *Cancer Awareness Measure Plus (CAM+)* is a recurring survey designed to collect nationally representative data on public attitudes, awareness, and behaviours in the United Kingdom regarding key areas such as early diagnosis, screening, and cancer prevention. The findings from CAM+ are utilised by Cancer Research UK to guide strategic decision-making, operational planning, communication efforts, and the development of behavioural interventions, as well as to inform evidence-based policy development.

The original *Cancer Awareness Measure (CAM)* survey was developed and validated between 2007 and 2008 through a collaboration between Cancer Research UK, University College London, King's College London, and the University of Oxford, in response to the absence of a validated tool for assessing public awareness of cancer. In addition to the general CAM, a series of cancer-specific CAMs were also developed. These instruments were initially designed to be administered via face-to-face or telephone interviews.

Since 2008, Cancer Research UK has routinely collected CAM and CAM+ data. While the frequency of data collection has varied over time, biannual data collection was established in 2020, with a transition to annual data collection planned for the future.

Beginning in 2014, the survey has been continuously updated, modified, and expanded to reflect emerging evidence and changes in the external environment. These enhanced iterations are referred to as the *Cancer Awareness Measure Plus (CAM+)*, highlighting the inclusion of additional questions and substantial revisions to the original instrument. In 2019, the survey was further adapted to facilitate online data collection.

For the purpose of the survey questionnaire development for this study, the 2011 version of the toolkit for the original CAM developed in 2008<sup>3</sup> was used along with the 2019 version of the CAM+<sup>4</sup>.

### 2.1.3. Consumer Assessment of Healthcare Providers and Systems

The *Consumer Assessment of Healthcare Providers and Systems (CAHPS®)* is a long-term initiative by the Agency for Healthcare Research and Quality (AHRQ) aimed at improving understanding of patient experiences in healthcare. It supports research to develop valid and practical tools for assessing and reporting patient experiences, and for using these insights to enhance care quality. Over its more than 25-year history, CAHPS has produced standardized surveys widely used by healthcare providers and policymakers to evaluate and improve patient care across various settings.

Launched in 1995 to address inconsistent and limited data on patient perspectives, CAHPS initially focused on health plans. It has since expanded to cover a broader range of healthcare services. Now in its sixth phase (CAHPS VI, as of 2022), the program continues to evolve while maintaining its voluntary, research-focused nature.

For the purpose of the survey questionnaire development for this study, the CAHPS® Cancer Care Survey for drug therapy version was used<sup>5</sup>.

## 2.2. The Seychelles Oncology Unit Patient Survey questionnaire

The current development process has produced a 59-item survey instrument composed of 6 sections (see Note 2).

### **i** Note 2: Survey instrument sections

- Section 1: Demographics (10 questions)
- Section 2: Patient journey to diagnosis and referral to Oncology Unit (9 questions)
- Section 3: Communication and interacting with the Oncology Team (29 questions)
- Section 4: Scheduling and access (6 questions)
- Section 5: Comfort and environment (3 questions)
- Section 6: Overall experience (2 questions)

### 2.2.1. Demographics

The **Demographics** section collects patient characteristics information on

- age;
- gender;
- location of residence;
- disability status;
- languages spoken;

## 2. Questionnaire design and development

- marital status;
- level of education;
- employment status;
- type of occupation/job; and,
- living arrangements.

Demographic information allows us to perform stratified analysis of patients' reported experience of cancer care potentially detecting inequities/disparities.

### 2.2.2. Patient journey to diagnosis and referral

The **Patient journey to diagnosis and referral to Oncology Unit** section elicits patients' experience before reaching the Oncology Unit with a focus on assessing their knowledge, attitudes, and practices/behaviours on help-seeking. In addition, this section draws information on how the general health service/system performs in getting the patient to a confirmed diagnosis and eventual referral.

### 2.2.3. Communication and interaction

The **Communication and interacting with the Oncology Team** section draws out the patients' experience of and satisfaction with their communications and interactions with the Oncology Team once they have been referred to the unit with the aim of assessing the patient-centredness of care once referred to the Oncology Unit.

### 2.2.4. Scheduling and access

The **Scheduling and access** section obtains the patients' experience of and satisfaction with the scheduling and access to the Oncology Unit both in terms of routine and urgent care. This assesses the timeliness and responsiveness of care once referred to the Oncology Unit.

### 2.2.5. Comfort and environment

The **Comfort and environment** section asks patients of their satisfaction with the overall level of comfort and the various aspects of the physical space and amenities available at the Oncology Unit.

### 2.2.6. Overall experience

The final section on **Overall experience** elicits the patients' satisfaction with the overall experience of the services at the Oncology Unit.

### **3. Data management plan**





## **4. Data analysis plan**



## **Part II.**

# **Training**



## **5. Participant selection**



## **6. Informed consent**





## **7. Paper-based data collection**



## **8. Electronic data collection**



## **Part III.**

# **Deployment**



## **9. Deploying the survey instrument**





## **10. Data extraction, transformation, and loading pipeline**



## **11. Data analysis workflow**



## References

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