


# POLICY BRIEF

## Giving Patients a Voice about Cancer Care: Should Switzerland Do More to Collect Patients' Experiences of Cancer Care?

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### CONTEXT

One objective of the healthcare system is to **improve the care and experience of care of people going through the system**, by providing care **responding to people's needs** (i.e. person-centered care).

 To evaluate this, **data need to be collected directly from the patients**, asking them about their experiences.

This information is key to **drive quality improvement initiatives**.

### CANCER & CANCER CARE

Most individuals will encounter cancer, either **as a patient or as a caregiver** to a family member or friend.

Person-centered care is especially important in cancer care, as cancer has an **emotional, social and financial burden** on patients and their families, in addition to the **health burden**.

### CHALLENGE

In Switzerland, there is information on the safety and effectiveness of cancer care (e.g. publication of survival rates), but...



...**reports from patients themselves about cancer care are missing and needed** to complete the assessment of the quality of cancer care and its person-centeredness.

### RECOMMENDATION 1



Develop a **position statement** on the **importance** and **value** of patients' reports on their **experiences** of cancer care



### RECOMMENDATION 2



**Collect patients' experiences of cancer care at the national level**, by implementing a national survey or by integrating data collection in cantonal cancer registries



**Main facilitators and barriers to RECOMMENDATION 2**, based on the literature and experiences in other countries:




- A **patient-centered healthcare culture** supported by management and politics
- Awareness of the **value of patients' reports**
- **Patients' involvement** in all steps
- Adequate **IT infrastructure**



- Insufficient **financial resources**
- Lack and cost of **human resources** to collect patients' reports
- **Privacy legislation**
- Concerns about **data confidentiality**
- Issues in **adopting a common standard** due to Swiss federalism and cantonal organization of healthcare services

### STAKEHOLDER DIALOGUE: KEY POINTS

Eleven **stakeholders**, representing patient and professional associations, quality institutions and hospitals, **discussed** the content and recommendations of the **policy brief** during a meeting. 

They **agreed** on **RECOMMENDATION 1** to

- push forward the importance of patients' experiences in the **political agenda**
- **clarify the concept** of patients' experiences (i.e. PREMs)
- shed light on **stakeholders' interests**

They **agreed** on **RECOMMENDATION 2**, but **disagreed** on the relative importance and benefits of integrating **patient-reported experiences (PREMs) versus patient-reported outcomes (PROMs)** in cancer registries.

They mentioned additional important **facilitators** at the patient level:

- using **short questionnaires** with simple, disease-specific and relevant questions
- having the clear objective of **using the results to implement change**.



<https://www.slhs.ch/en/learning-cycles/topics-cat/prems-in-cancer-care>



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Join the poster session on zoom  
August 25 13.00-13.45 & August 26 12.15-13.00  
<https://unil.zoom.us/j/96477935996>