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. personcentered 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



experiences in the political agenda

• clarify the concept of patients' experiences (i.e. PREMs)

STAKEHOLDER DIALOGUE: KEY POINTS

discussed the content and recommendations of

They agreed on RECOMMENDATION 1 to

Eleven stakeholders, representing

quality institutions and hospitals,

the policy brief during a meeting.

patient and professional associations,

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

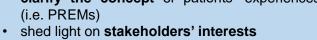


A patient-centered healthcare culture supported by management and politics

- · 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



push forward the importance of patients'

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.









