

Patient Engagement in Switzerland

The perspective of stakeholders

Executive Summary

Study Objectives

The objectives of this research were to:

- give an overview on the current situation of patient involvement in Switzerland taking into consideration the regulatory set up and the federalist structures.
- assess whether the voice of patients is considered in Switzerland and to describe the achievements of patient engagement in the perspective of different stakeholders.
- analyse if current policies and processes support the integration of patients.
- provide insights into stakeholders' perceptions regarding the implementation of patient involvement in Switzerland over time and how priorities have changed, or new ones emerged.
- analyse patient engagement in view of the Health2020 and Health2030 programs, to assess whether the political objectives defined in Health2020 have been met according to the stakeholders.

Methods

A qualitative exploratory study design was chosen by performing individual semi-structured interviews with representatives of the different stakeholders. The chosen approach was inductive and bottom-up, so the participants were able to express their opinions and experience without starting with a set theoretical framework. The interview guide included open-ended questions for participants to provide their views on patient engagement, to reflect on official Swiss legal framework regarding patient engagement and to provide information on existing collaborations.

Participants were recruited by directly contacting agencies representing the main stakeholders on the topic. Six stakeholders from five different agencies/organizations in Switzerland completed web-based interviews between October 2022 and January 2023. Informed consent was obtained from all participants prior the interview. A thematic analysis was adopted. The coding process was conducted in two steps: (1) The interview guide topics provided the initial codes and (2) some inductive codes were created from the collected data.

Results

Participants' description of their work showed that many activities are already taking place in patient engagement. Many initiatives by the stakeholders or in collaboration with other institutions and players already exist.

For most participants, patient engagement means research to be carried out 'with' or 'by' patients and members of the public rather than 'to', 'about' or 'for' them. As a prerequisite for successful patient engagement, participants advocate empowerment of both patients and physicians, creating a partnership between them. This requires training to empower both parties. Education, awareness and sensibilization about patient engagement were considered as important. Patients as stakeholders should have the same weight as physicians, regulators, and payers so that as players they can fully influence decisions with their input. In this context patients' proper access to information is key for health literacy.

Professional self-regulation has been the traditional approach to quality improvement. This approach has however been challenged by the participants. They placed great hopes in the quality strategy of the federal government, which was adopted by the FOPH in spring 2022. Specific training in the curricula of medical

education have been proposed by the participants. However, training and education are needed on both the patient and professional sides. On the one hand, patients must be willing and able to take a more active role. On the other hand, professionals should really want and be able to communicate with patients at eye level and in a kind of partnership. The major challenge is that universal approaches may not work to meet the diverse needs of individual patients in their particular settings. In the whole spectrum between chronic and acute care, there are so many different players involved. Patient data and digitalization as part of health literacy has been brought up too. Without a political move to make health data accessible this will not succeed. Almost all participants see room for improvements of the current PI situation in Switzerland.

The participants were asked to provide feedback on the legal framework and the Swiss health care system. As they were not fully aware of the objectives set in the Health2020/2030 regarding patient involvement these were briefly summarized, and the discussion continued to be broader and more generic. The Swiss healthcare system relies on a federalist structure, where the federal government, cantons and local municipalities have different competencies and implementation of health is defined at this level. This structure is seen by all participants as an issue for implementing patient engagement. Patient engagement should be more systematic, national and introduced throughout Switzerland and legally anchored. An institutional dialogue should be initiated. An ultimate goal would be to have patients involved in health policy issues or discussions. This could be via a committee linked to the parliament, whereby the patient committee would be at least consulted on important discussions. There could be also some kind of hearings.

There are many activities, initiatives and players in the field of patient engagement. Many collaborations also exist with different organisations, but the landscape is fragmented as there is not an umbrella organization overseeing all the activities. The fragmented nature of this system makes it complicated to exchange information even between doctors and hospitals within the same canton. Funding and resources have been brought up by almost all participants being an issue, which is also coupled with politics, as having a lack of lobby means a lack of money.