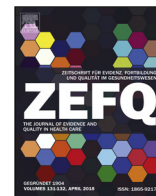




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Shared decision-making and patient and public involvement: Can they become standard in Switzerland?



Partizipative Entscheidungsfindung sowie Patienten- und Öffentlichkeitsbeteiligung: Können sie in der Schweiz zum Standard werden?

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ABSTRACT

The Swiss healthcare system is highly decentralized, making implementation of shared decision making (SDM) and patient and public involvement (PPI) quite slow; nonetheless, change is happening. SDM is now a core communication competency for medical school graduates, as reflected by a dedicated station on the federal exam, and is endorsed by several national societies. Multiple local initiatives are contributing to international best practices, local implementation, and increased capacity. PPI is also gaining momentum, most notably in research, with the development of a national platform for clinical research and inclusion of patients in the evaluation committees for funding. The challenge now is going from example projects by motivated early adopters in academia to making SDM and PPI standard practice.

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ZUSAMMENFASSUNG

Das schweizerische Gesundheitssystem ist stark dezentralisiert, was die Implementierung von partizipativer Entscheidungsfindung (PEF) sowie Patienten- und Öffentlichkeitsbeteiligung („patient and public involvement“, PPI) verlangsamt; gleichwohl ist ein Wandel im Gange. Für Absolventen medizinischer Hochschulen stellt PEF mittlerweile eine Kernkompetenz im Bereich Kommunikation dar, was im Rahmen der Eidgenössischen Prüfung Humanmedizin in einer eigenen Prüfungsstation zum Ausdruck kommt und von etlichen nationalen Fachgesellschaften unterstützt wird. Mehrere lokale Initiativen leisten ihren Beitrag zu international bewährten Praktiken, zur lokalen Implementierung und zur Leistungsverbesserung. Auch PPI nimmt, insbesondere in der Forschung, mit der Entwicklung einer nationalen Plattform für klinische Forschung und der Beteiligung von Patienten in den Begutachtungsgremien für die Vergabe von Fördermitteln an Fahrt auf. Die Herausforderung besteht nun darin, die Stufe der Beispielprojekte motivierter Pilotanwender im universitären Bereich zu verlassen und PEF wie auch PPI zur gängigen Praxis zu machen.

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Introduction

The highly decentralized Swiss healthcare system fosters both individual autonomy and collective solidarity, making it fertile ground for shared decision making (SDM) [1]. Solidarity comes in the form of an obligation to purchase health insurance, regardless of age, and subsidies for up to 37% of the population to help them purchase that insurance [1]. Healthcare decision making and public policy strategies are mostly devolved to the 26 cantons, with each managing in- and outpatient care, as well as public health for their population. Citizens purchasing mandatory health insurance then have a choice of over 40 private companies and, despite a recent rise in health plans with ‘gatekeeper’ models, can potentially access the primary care and specialist physicians they choose. Ambulatory care is largely fee-for-service and provided in practices with one to four physicians. There is little overt rationing and consultations last longer than in other European countries [2]. Conversely, Switzerland has the highest out-of-pocket healthcare expenses in the world. An average family spends the equivalent of over USD \$1'000 not covered by insurance or subsidies [3].

There is no clear mandate for SDM and the decentralized system makes implementation quite slow. Yet, compared to other countries, Swiss citizens by virtue of their purchasing power have some autonomy and choice concerning their care. Longer consultations allowing more time for decision making may contribute to this. The vast majority of citizens report high satisfaction with the healthcare system and consider themselves as being in good health. Swiss physicians were ranked number one in an international comparison of 32 countries in terms of public confidence in health care professionals [4]. Rising challenges include high costs for a sizeable proportion of the population and poor coordination for complex patients [3,5]. Further, a sizable minority of Swiss residents (22%) need to forego health care because of this cost sharing, up to 31% of people with a low income [6].

Two previous publications described the beginnings of a Swiss SDM movement in 2011 [7] and an increasing number of local initiatives in 2017 [8]. Since then, SDM has gradually been recognized as best practice: it is now considered a core competency for physicians beginning in medical school, endorsed by multiple societies [9], and an increasingly popular research topic [10]. In parallel, multiple initiatives are demonstrating the impact of patient and public involvement (PPI) in research, quality improvement and even governance. Nonetheless, the impact of SDM and PPI on routine care (through sustained implementation) and research is less clear. The umbrella term ‘coproduction’ can be used to englobe the myriad ways that patient and public partners are implicated in a broad range of healthcare initiatives. In this article, we aim to describe the activities currently underway to promote coproduction of healthcare service at every level and propose next steps to ensure a durable impact of activities encouraging SDM and PPI.

Shared Decision Making at a National Level

SDM is gradually becoming mainstream in academic institutions and publications from professional societies. The Swiss Medical Association (referred to as FMH from Foederatio Medicorum Helveticorum) published an endorsement of SDM [11]. SDM is now a crosscutting skill in all prevention activities included in the Prevention with Evidence in Practice (PEPra) program. SDM is a core communication competency for medical students, along with motivational interviewing, communication of medical mistakes, advance care planning, transcultural competences and breaking bad news. A SDM station was first included in the federal Objective Structured Clinical Examination (OSCE) for graduating medical students in 2018. Students were expected to recognize

that SDM was appropriate when adding a second, chronic diabetes medication after metformin. In a later federal OSCE case, students were meant to use SDM in the primary prevention of heart disease, instead of using primarily motivational interviewing.

Further, SDM has been the topic of two symposia. The first, held in Lausanne in 2019 on SDM in primary care in Francophone countries included presentations from Canada, France, Belgium and Switzerland [12]. The second, held in Zürich in 2019 was part of an “Excellence in Patient Care” symposium hosted by the Collegium Helveticum and organized by the University of Zurich, the University Hospital Zurich and the University Hospital Basel [13]. Several national specialty societies have endorsed SDM. The Swiss Society of Infectious Disease recently supported decision aids (DAs) for possible antibiotic prescription for urinary tract infections, otitis media and streptococcal pharyngitis [14]. The Swiss Society of Cardiology recommends SDM for several clinical decisions, as does the Swiss academy for medical sciences, notably with regard to cardiac resuscitation (i.e. code discussion) and goals of care discussions (i.e. Advance Care Planning). The Evidence based prevention (Eviprev) guidelines recommend SDM for preventive tests with an uncertain balance of benefits and risks, such as prostate, breast and lung cancer screening. The Smarter medicine foundation, a Swiss network promoting the Choosing Wisely approach to reducing overuse of unnecessary tests and procedures by physicians and the public, has clearly identified SDM as one the key ways to improve care [15].

Patient and public involvement at a National Level

PPI is gaining momentum in Switzerland, reflecting a national and international trend towards participatory approaches. While there is no formal PPI legislation in Switzerland, guidelines and fact sheets have been developed, most notably for research by the Swiss Clinical Trial Organization (SCTO). PPI goals are also included in the Health2020 (published in 2015) and Health2030 (published in 2019) strategies of the federal government. The SCTO recently published a newsletter summarizing Swiss efforts to bring patients’ and the public’s voices into human research [16]. This includes many local PPI initiatives at hospitals and clinical trial units (see detail on page 5) as well as new Swiss PPI training modules in collaboration with European Patients’ Academy on Therapeutic Innovation Switzerland (EUPATI CH).

Patients and members of the public are now included in the evaluation committees for clinical trial funding by the Swiss National Science Foundation. The Swiss Academy of Medical Sciences has published a White Paper that describes PPI as a fundamental condition for relevant and high quality clinical research [17]. They are currently recruiting a patient representative to help develop strategic recommendations for the clinical research coordination platform.

Selected Local Examples of SDM and PPI

Several projects and initiatives at the local and national levels are highlighted in Table 1. In Bern, the focus at the Institute of Primary Health Care has been on the development, test, implementation and dissemination of decision aids for colorectal cancer screening, chronic insomnia treatment [18], and antibiotic prescription in primary health care [19]. The Swiss National Science Foundation funded a project promoting shared decision making for the choice of faecal immunochemical testing and colonoscopy in colorectal cancer screening in primary care [20]. This project enabled the participatory development of outcome measures with and for primary care physicians to measure their practices, the set-up of a citizen advisory group who advised and commented on

Table 1
Categorization of Swiss initiatives with selected examples.

| Development axis | Shared decision making | Patient and public involvement |
|-----------------------|---|---|
| Research | DAs for colorectal cancer screening, insomnia, and deprescribing medications, Bern Encounter DA for choosing medication for tobacco cessation, Lausanne | Set-up of a citizen advisory group who advised and commented on the conduct of the research activities, Bern Funding available for applicants to the Investigator Initiated Clinical Trials Funding mechanism of the Swiss National Science Foundation, National |
| Training | Development of digitally structured encounter DA linked to clinical practice guidelines, Geneva Health coach, advance care planning, SDM and ACP for Patients with aortic stenosis, Zurich SDM training in quality circles of general practitioners, Bern | Mapping of existing initiatives and development of training modules (SCTO/EUPATI), Bern The development of training modules is planned. Geneva and Lausanne |
| Implementation | 4 th and 5 th year medical curriculum involving SDM. Training of residents in general internal medicine. Contribution to national curriculum for GPs. Geneva and Lausanne SDM training with role play and simulated patients for 3 rd and 4 th year Medical Students + SDM train the trainer. Zurich Pragmatic trials in networks of GPs, Bern Creation of decision aids, screening programs, Lausanne Screening programs; 'More time for patients', Geneva DA resuscitation for all elective Patients at the University hospital Zurich | Patient representative soon to be involved in developing SCTO's strategic recommendations, Bern Development of Coproduction Hub, FORCE platform and Patient Laboratory in Oncology at CHUV, Lausanne Patient partner platform - 3P, Geneva . Citizen Science panels of various research projects, Zurich |

the conduct of the research activities [21], and the conduct of two randomized controlled trial testing the effects of multilevel interventions promoting SDM in colorectal cancer screening decisions [22].

Recent efforts at the Geneva University Hospitals in collaboration with international partners aim at bringing patient involvement to scale. They are designing generic DAs (i.e. a standard design with easily adaptable content) and standardized dashboards to provide continuous feedback on patient involvement in decision making in hospital wards [23,24]. The generic DAs use the open access, user-tested online platform SHARE-IT, that makes it easy to generate decision aids in parallel with digital, structured guidelines on the MAGIC authoring and publication platform (MAGIcapp9 [25]. Current research aims at extending SHARE-IT with MATCH-IT so patients can compare multiple alternatives simultaneously [26]. Finally, the Geneva team is developing a decision support tool for patients and their surgeons to visualize trajectories of “patients like me” over the last 20 years after their orthopaedic procedures.

In Lausanne, the Center for Primary Care and Public Health has developed eight DAs for preventive care, including encounter, electronic, and specific DAs for low health literacy populations [27]. A DA for tobacco cessation is being tested in a cluster randomized trial [28]. Three of the DAs for cancer screening were co-designed with support from a citizen advisory group [21]. A new curriculum for 4th and 5th year medical school students trains them in SDM and risk communication over three sessions. The first (1.5 hrs.) provides a theoretical basis, the second (2 hrs.) uses a series of vignettes and role plays to put SDM into practice, and the third (1 hr) explores special topics like SDM with low health literacy patients. Finally, the Lausanne Coproduction Hub (*Groupe lausannois de coproduction*) was founded in January 2021 to bring together local organizations interested in training and research focused on patient and public involvement in healthcare.

In Zürich, a randomized trial was performed using serious illness, goals of care and SDM communication including one DA video and five booklet DAs (Resuscitation, Dyspnoea, Dialysis withdrawal, Nutrition and fluid and Last place of care) for advance care planning with competent severely ill hospitalized adults. The intervention resulted in fewer patients wanting to

be resuscitated or being undecided, a significant reduction of decisional conflict in patients and their loved ones with regard to emergency decisions and significantly more patients dying at their preferred place of care [29]. The development of a Patient Decision aid focusing on both advance care planning and shared decision-making for patients with severe aortic stenosis, funded by the Swiss Academy of Medical Science, is under way. The recently created Swiss pole of the Database of Individual Patients' Experiences (DIPEX) collaboration collects narrative interview studies of people's experiences with health issues as an information resource for others (www.dipex.ch). The interdisciplinary “Mind the Patient” Lab was founded in 2020. It includes clinicians from the University Hospital Zurich, medical ethicists from the University of Zurich, patient representatives, computer scientists from the Swiss Federal Institute of Technology in Zurich, and designers from the Zurich University of the Arts. Its work centres on the development of digital tools for SDM.

A rapid review of the literature using PubMed identified several other projects. A team from the University Hospital Basel developed an online DA for female cancer patients regarding fertility preservation. They demonstrated improved knowledge and decreased decisional regret 12 months after its use [30]. A group of geriatricians from the University of Zürich developed a Fact Box for common decisions in advanced dementia, such as antibiotic use and artificial hydration, and found that patients experienced reduced decisional conflict [31]. Another team at the University of Zürich in Family Medicine developed a SDM tool to encourage deprescribing of inappropriate medication [32]. Finally, a group in Geneva implemented a SDM curriculum with a 2-hour workshop and pocket cards for Internal Medicine residents; they demonstrated better application of SDM concepts in encounters with standardized patients [33].

The five main university hospitals in Switzerland (Basel, Zurich, Geneva, Bern and Lausanne) and their clinical trial units have launched PPI in research initiatives. This includes consulting services for researchers to include PPI in their research and for patients and citizen to join PPI initiatives. Training modules, adapted from the main EUPATI body to address issues in Switzerland, will soon be available.

Next steps – How do we know if we are succeeding?

Concepts like ‘patients as equal partners’ and coproduction are taking hold in Switzerland. Despite the favourable national context and growing number of local initiatives, objective assessments are lacking on the use of SDM, PPI and coproduction. Nonetheless, there may be ways to ensure SDM is occurring. High quality, standardized trainings including SDM communication skills, combined with a centralized source of decision aids could take us beyond general policy statements to make SDM the standard of care. A dissemination of dashboards and other quality measurements, monitoring patient involvement in decision making, such as in Geneva [23], could be an important step forward. A new addition to the law for mandatory health insurance requires providers to participate in quality reporting and improvement (Article 58 of the Federal Law on Obligatory Health Insurance). Patient involvement for the implementation of these measures could ensure that the indicators actually enhance SDM rather than reduce it. Finally, a culture change in research, especially by funding bodies, could make PPI an expected standard.

In conclusion, patient involvement in SDM and research is increasingly encouraged and even prioritized in Switzerland. SDM is a core competency for medical students, physicians and nurses, endorsed by multiple medical societies, and a frequent topic of research. PPI initiatives exist in the five clinical trial units and from several other grassroots groups. The challenge now is going from example projects by motivated early adopters in academic centres to becoming standard practice.

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Conflict of interest

Marie-Anne Durand has contributed to the development of Option Grid patient decision aids (from which Picture Option Grid is derived). EBSCO Information Services sells subscription access to Option Grid patient decision aids. She receives consulting income from EBSCO Health, and royalties. No other competing interests declared.

CRediT author statement

KS and MAD: Conceptualization, Writing – original draft.
All authors: Data curation, Writing – review & editing.

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