

1 Published version on ZEFQ DOI: 10.1016/j.zefq.2022.04.019

2

3 **Shared Decision Making and Patient and Public Involvement – Can They Become Standard in**
4 **Switzerland?**

5 Abstract (118 words)

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

15

16 Introduction

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

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

38 Two previous publications described the beginnings of a Swiss SDM movement in 2011⁷ and an
39 increasing number of local initiatives in 2017.⁸ Since then, SDM has gradually been recognized as best
40 practice: it is now considered a core competency for physicians beginning in medical school,
41 endorsed by multiple societies,⁹ and an increasingly popular research topic.¹⁰ In parallel, multiple
42 initiatives are demonstrating the impact of patient and public involvement (PPI) in research, quality
43 improvement and even governance. Nonetheless, the impact of SDM and PPI on routine care
44 (through sustained implementation) and research is less clear. The umbrella term 'coproduction' can
45 be used to englobe the myriad ways that patient and public partners are implicated in a broad range
46 of healthcare initiatives. In this article, we aim to describe the activities currently underway to
47 promote coproduction of healthcare service at every level and propose next steps to ensure a
48 durable impact of activities encouraging SDM and PPI.

49 Shared Decision Making at a National Level

50 SDM is gradually becoming mainstream in academic institutions and publications from professional
51 societies. The Swiss Medical Association (referred to as FMH from Foederatio Medicorum
52 Helveticorum) published an endorsement of SDM.¹¹ SDM is now a crosscutting skill in all prevention
53 activities included in the Prevention with Evidence in Practice (PEPra) program. SDM is a core
54 communication competency for medical students, along with motivational interviewing,
55 communication of medical mistakes, advance care planning, transcultural competences and breaking
56 bad news. A SDM station was first included in the federal Objective Structured Clinical Examination
57 (OSCE) for graduating medical students in 2018. Students were expected to recognize that SDM was
58 appropriate when adding a second, chronic diabetes medication after metformin. In a later federal
59 OSCE case, students were meant to use SDM in the primary prevention of heart disease, instead of
60 using primarily motivational interviewing.

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

76 Patient and public involvement at a National Level

77 PPI is gaining momentum in Switzerland, reflecting a national and international trend towards
78 participatory approaches. While there is no formal PPI legislation in Switzerland, guidelines and fact
79 sheets have been developed, most notably for research by the Swiss Clinical Trial Organization
80 (SCTO). PPI goals are also included in the Health2020 (published in 2015) and Health2030 (published
81 in 2019) strategies of the federal government. The SCTO recently published a newsletter

82 summarizing Swiss efforts to bring patients' and the public's voices into human research.¹⁶ This
83 includes many local PPI initiatives at hospitals and clinical trial units (see detail on page 5) as well as
84 new Swiss PPI training modules in collaboration with European Patients' Academy on Therapeutic
85 Innovation Switzerland (EUPATI CH).

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

91 Selected Local Examples of SDM and PPI

92 Several projects and initiatives at the local and national levels are highlighted in Table 1. In Bern, the
93 focus at the Institute of Primary Health Care has been on the development, test, implementation and
94 dissemination of decision aids for colorectal cancer screening, chronic insomnia treatment,¹⁸ and
95 antibiotic prescription in primary health care.¹⁹ The Swiss National Science Foundation funded a
96 project promoting shared decision making for the choice of faecal immunochemical testing and
97 colonoscopy in colorectal cancer screening in primary care.²⁰ This project enabled the participatory
98 development of outcome measures with and for primary care physicians to measure their practices,
99 the set-up of a citizen advisory group who advised and commented on the conduct of the research
100 activities²¹ and the conduct of two randomized controlled trial testing the effects of multilevel
101 interventions promoting SDM in colorectal cancer screening decisions.²²

102 Recent efforts at the Geneva University Hospitals in collaboration with international partners aim at
103 bringing patient involvement to scale. They are designing generic DAs (i.e. a standard design with
104 easily adaptable content) and standardized dashboards to provide continuous feedback on patient
105 involvement in decision making in hospital wards.^{23,24} The generic DAs use the open access, user-
106 tested online platform SHARE-IT, that makes it easy to generate decision aids in parallel with digital,
107 structured guidelines on the MAGIC authoring and publication platform (MAGICapp9.²⁵ Current
108 research aims at extending SHARE-IT with MATCH-IT so patients can compare multiple alternatives
109 simultaneously.²⁶ Finally, the Geneva team is developing a decision support tool for patients and
110 their surgeons to visualize trajectories of "patients like me" over the last 20 years after their
111 orthopaedic procedures.

112 In Lausanne, the Center for Primary Care and Public Health has developed eight DAs for preventive
113 care, including encounter, electronic, and specific DAs for low health literacy populations.²⁷ A DA for
114 tobacco cessation is being tested in a cluster randomized trial.²⁸ Three of the DAs for cancer

115 screening were co-designed with support from a citizen advisory group.²¹ A new curriculum for 4th
116 and 5th year medical school students trains them in SDM and risk communication over three sessions.
117 The first (1.5 hrs.) provides a theoretical basis, the second (2 hrs.) uses a series of vignettes and role
118 plays to put SDM into practice, and the third (1 hr) explores special topics like SDM with low health
119 literacy patients. Finally, the Lausanne Coproduction Hub (*Groupe lausannois de coproduction*) was
120 founded in January 2021 to bring together local organizations interested in training and research
121 focused on patient and public involvement in healthcare.

122 In Zürich, a randomized trial was performed using serious illness, goals of care and SDM
123 communication including one DA video and five booklet DAs (Resuscitation, Dyspnoea, Dialysis
124 withdrawal, Nutrition and fluid and Last place of care) for advance care planning with competent
125 severely ill hospitalized adults. The intervention resulted in fewer patients wanting to be resuscitated
126 or being undecided, a significant reduction of decisional conflict in patients and their loved ones with
127 regard to emergency decisions and significantly more patients dying at their preferred place of
128 care.²⁹ The development of a Patient Decision aid focusing on both advance care planning and shared
129 decision-making for patients with severe aortic stenosis, funded by the Swiss Academy of Medical
130 Science, is under way. The recently created Swiss pole of the Database of Individual Patients'
131 Experiences (DIPEX) collaboration collects narrative interview studies of people's experiences with
132 health issues as an information resource for others (www.dipex.ch). The interdisciplinary "Mind the
133 Patient" Lab was founded in 2020. It includes clinicians from the University Hospital Zurich, medical
134 ethicists from the University of Zurich, patient representatives, computer scientists from the Swiss
135 Federal Institute of Technology in Zurich, and designers from the Zurich University of the Arts. Its
136 work centres on the development of digital tools for SDM.

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

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

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

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

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

170 **Acknowledgements**

171 We would like to thank Thomas Brauchli for the search strategy and search he conducted for this
172 article. We would also like to thank all the patients, citizens, clinicians and other stakeholders who
173 make this work possible, meaningful and we hope, impactful.

174

175

176 References

- 177 1. Biller-Andorno N, Zeltner T. Individual Responsibility and Community Solidarity — The Swiss
178 Health Care System. *New England Journal of Medicine*. 2015;373(23):2193-2197.
- 179 2. Deveugele M, Derese A, van den Brink-Muinen A, Bensing J, De Maeseneer J. Consultation
180 Length In General Practice: Cross Sectional Study. *BMJ: British Medical Journal*.
181 2002;325(7362):472-474.
- 182 3. Pahud O. *Erfahrungen der Wohnbevölkerung ab 18 Jahren mit dem Gesundheitssystem –*
183 *Situation in der Schweiz und im internationalen Vergleich*. Bern: Bundesamtes für Gesundheit
184 (BAG);2020.
- 185 4. Blendon RJ, Benson JM, Hero JO. Public Trust in Physicians — U.S. Medicine in International
186 Perspective. *New England Journal of Medicine*. 2014;371(17):1570-1572.
- 187 5. Vincent C, Staines A. *Enhancing the Quality and Safety of Swiss Healthcare*. 2019.
- 188 6. *Health policy in Switzerland*. Paris: Organisation for Economic Co-operation and
189 Development;2017.
- 190 7. Cornuz J, Kuenzi B, Krones T. Shared decision making development in Switzerland: room for
191 improvement! *Z Evid Fortbild Qual Gesundheitswes*. 2011;105(4):296-299.
- 192 8. Selby K, Auer R, Cornuz J. Shared decision making in preventive care in Switzerland: From
193 theory to action. *Z Evid Fortbild Qual Gesundheitswes*. 2017;123-124:91-94.
- 194 9. *La communication dans la médecine au quotidien: Un guide pratique*. Bern: Swiss Academy of
195 Medical Sciences;2019.
- 196 10. Rosca A, Krones T, Biller-Andorno N. Shared decision making: Patients have a right to be
197 informed about possible treatment options and their risks and benefits. *Swiss Med Wkly*.
198 2020;150(28).
- 199 11. Gerber M, Kraft E, Bosshard C. Décision partagée - Médecin et patient décident ensemble.
200 *Bulletin des médecins suisses*. 2014;95(50):1883-1889.
- 201 12. Cornuz J, Selby K. Symposium partage de la décision : synthèse. *Rev Med Suisse*.
202 2019;15(669):1994.
- 203 13. Rosca A KT, Biller-Andorno N, Meier CA, Hunziker S. . Gemeinsame Entscheidungs-findung:
204 keine Modeerscheinung. *Schweiz Arzteztg*. 2020;101(39):1239-1241.
- 205 14. Tools to implement shared decision-making. 2021;
206 [https://www.biham.unibe.ch/research/tools to implement shared decision making/index](https://www.biham.unibe.ch/research/tools%20to%20implement%20shared%20decision%20making/index_eng.html)
207 [eng.html](https://www.biham.unibe.ch/research/tools%20to%20implement%20shared%20decision%20making/index_eng.html). Accessed Mar 4, 2022.
- 208 15. Selby K, Gaspoz J-M, Rodondi N, et al. Creating a List of Low-Value Health Care Activities in
209 Swiss Primary Care. *JAMA Internal Medicine*. 2015;175(4):640-642.
- 210 16. *Regulatory Affairs Watch*. Bern: Swiss Clinical Trials Organization;2021.
- 211 17. *White paper: Clinical research*. Bern: Swiss Academy of Medical Sciences;2021.
- 212 18. Maire Micheline, Scharf Tamara, Duss Simone, et al. Standortbestimmung zum -Insomnie-
213 Management in der Hausarztpraxis. *Primary and Hospital Care*. 2022;22(4):81-84.
- 214 19. Tools to facilitate Shared Decision Making. 2021;
215 [https://www.biham.unibe.ch/research/tools to facilitate shared decision making/index e](https://www.biham.unibe.ch/research/tools%20to%20facilitate%20shared%20decision%20making/index_eng.html)
216 [ng.html](https://www.biham.unibe.ch/research/tools%20to%20facilitate%20shared%20decision%20making/index_eng.html). Accessed Apr 11, 2022.
- 217 20. Auer R. Promoting participatory medicine in colorectal cancer screening. 2017;
218 <http://www.nfp74.ch/en/projects/out-patient-care/project-auer>. Accessed Mar 04, 2022.
- 219 21. Selby K, Cardinaux R, Metry B, et al. Citizen advisory groups for the creation and
220 improvement of decision aids: experience from two Swiss centers for primary care. *Res Involv*
221 *Engagem*. 2021;7(1):37.
- 222 22. Auer R. Randomized Controlled Trial on Colorectal Cancer Screening Among Quality Circles of
223 Primary Care Physicians. 2018; <https://clinicaltrials.gov/ct2/show/NCT03510858>. Accessed
224 Mar 4, 2022.
- 225 23. Agoritsas T. Des approches génériques pour l'implication des patients dans les soins. *Rev*
226 *Med Suisse*. 2019;15(669):1995-1996.

- 227 24. Darbellay Farhoumand P, Le Du S, Perrier A, Agoritsas T. "More time for patients" : a
228 reorganization of medical wards at the University Hospitals of Geneva. *Rev Med Suisse*.
229 2018;14(617):1550-1555.
- 230 25. Heen AF, Vandvik PO, Brandt L, et al. Decision aids linked to evidence summaries and clinical
231 practice guidelines: results from user-testing in clinical encounters. *BMC Medical Informatics
232 and Decision Making*. 2021;21(1):202.
- 233 26. MATCH-IT. 2021; <https://magicevidence.org/projects/match-it/>. Accessed Mar 4, 2022.
- 234 27. Aides à la décision. [https://www.unisante.ch/fr/centre-medical/professionnels-sante/aides-
235 decision](https://www.unisante.ch/fr/centre-medical/professionnels-sante/aides-decision). Accessed Feb 16, 2022.
- 236 28. Selby K. Combining Default Choices and a Decision Aid to Improve Tobacco Cessation (FIRST).
237 *ClinicalTrials.gov* 2021; <https://clinicaltrials.gov/ct2/show/NCT04868474>. Accessed Mar 7,
238 2022.
- 239 29. Krones T, Budilivski A, Karzig I, et al. Advance care planning for the severely ill in the
240 hospital: a randomized trial. *BMJ support*. 2019;21:21.
- 241 30. Ehrbar V, Germeyer A, Nawroth F, et al. Long-term effectiveness of an online decision aid for
242 female cancer patients regarding fertility preservation: Knowledge, attitude, and decisional
243 regret. *Acta Obstet Gynecol Scand*. 2021;100(6):1132-1139.
- 244 31. Loizeau A, Eicher S, Theill N, Martin M, Riese F. Efficacy of fact boxes for informing decision-
245 making on burdensome medical interventions in advanced dementia. *Palliat Med*.
246 2018;32(1):23.
- 247 32. Zechmann S, Senn O, Valeri F, et al. Effect of a patient-centred deprescribing procedure in
248 older multimorbid patients in Swiss primary care - A cluster-randomised clinical trial. *BMC
249 geriatr*. 2020;20(1):471.
- 250 33. Ritter S, Stirnemann J, Breckwoldt J, et al. Shared Decision-Making Training in Internal
251 Medicine: A Multisite Intervention Study. *J Grad Med Educ*. 2019;11(4 Suppl):146-151.

252

253

254

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