Smarter Health Care
National Research Programme

Synthesis Working Paper:
Patient participation

March 2022

Patient
Participation

About this Synthesis Working Paper

The NRP 74: Research for better health care

The National Research Programme "Smarter Health Care" (NRP 74) aims to promote innovative health services in Switzerland and to tackle the practical challenges the health care system is facing today. To this end, researchers are investigating a wide range of aspects, from the better use of health data and the care of older people at home to case management in emergency wards.

The NRP 74 includes 34 research projects at universities and higher education institutions throughout Switzerland. It is implemented by the Swiss National Science Foundation (SNSF) on behalf of the Federal Council, has a budget of CHF 20 million and runs from 2016 to 2022.

Six critical areas with a Synthesis Working Paper for each

To address some of the overarching issues facing the health care system today, the NRP 74 has integrated significant research findings from single projects into six topic-specific syntheses. In these six critical areas, researchers analysed their results from different professional perspectives, putting them in a larger context and devising recommendations to meet the current challenges in today's health care system.

These areas are:

- Quality of care
- Patient participation
- Coordination and care models
- Cost and reimbursement
- Health care data
- Building a strong research community (EHCL+)

All six topic-specific synthesis can be consulted on www.nrp74.ch.

The Synthesis Team

This synthesis report on the theme of "Patient participation" has been compiled by a team led by a member of the NRP 74 steering committee, comprising a second steering committee member, a principal investigator, and two doctoral students engaged in NRP 74 projects as well as part of NRP 74's Emerging Health Care Leaders (EHCL) programme.

- Milo Puhan, NRP 74 Steering Committee, Universität Zürich (lead since September 2021)
- Bernhard Burnand, NRP 74 Steering Committee, Unisanté, Université de Lausanne (lead until September 2021)
- Reto Auer, Principal Investigator, Berner Insitut für Hausarztmedizin (BIHAM), Universität Bern
- Katharina Tabea Jungo, Emerging Health Care Leader EHCL, Berner Insitut für Hausarztmedizin (BIHAM), Universität Bern
- Michael Deml, Emerging Health Care Leader EHCL, Université de Genève
- Editorial Advisor: Christine D'Anna-Huber, cdh Wissenschaft im Text, Lugano

Swiss National Science Foundation
Programmes division
National Research Programmes
Wildhainweg 3, P.O. Box
3001 Berne

+41 31 308 22 22
nrp74@snf.ch
www.nrp74.ch

Table of Contents

Figures

Tables

Editorial

This synthesis working paper describes the journey of the synthesis team from individual and diverse NRP 74 projects and an initial focus on “patient choice” to an overarching view of “patient participation” in the Swiss health system. Recommendations on how patient participation can be enhanced for more efficient and patient centred care and research resulted from this journey. The process has been challenging since it required much conceptual work, the identification of key insights across projects, stakeholder involvement as well as a thorough understanding of the current context of health care and research in Switzerland.

This report makes it very clear that focusing on patient choice in single decisions (e.g., about diagnostics or treatments or on insurance models) falls short of improving efficient and patient-centred prevention and care. Instead, as inspired by Michie, positive support for health and health use behaviours requires consideration of individuals' abilities, motivations, and opportunities, as well as multiple contextual factors at the individual, community, and policy levels. Nine NRP 74 projects, together with insights from stakeholder interviews, dialogues, and the international literature, contributed to recommendations for enhancing patient participation and offer policy-orientation in Switzerland. The four recommendations on (1) patients as care team members, (2) providing curated high-quality information, (3) strengthening patient organizations and (4) involving patients in research are broad and span the patient level, the health care professional level and the health system and policy level. They are then thoroughly discussed and sharpened through several sub-recommendations. The NRP 74 projects provide evidence for specific solutions to address these recommendations.

Our two outstanding scholars of the NRP 74 Emerging Health Care Leaders (EHCL) community, Katharina Tabea Jungo and Michael Deml, were instrumental for the tremendous work that went into this report. They were supported greatly by Reto Auer and Bernard Burnand as well as by Christine D'Anna-Huber, our scientific writer. Much appreciation also goes to the highly committed NRP 74 investigators who successfully carried out their projects and contributed a lot to dissemination as well as to the stakeholders who were always available to provide feedback and inspire research from the practice and policy side. I would therefore like to thank the synthesis team as well as the NRP 74 investigators and stakeholders for their great engagement for the NRP 74 and this specific synthesis paper. This work is not just important for the NRP 74 but for the Swiss health care system in general and the future of health services research and its integrated science and practice community in Switzerland. Special thanks also go to Manuela Oetterli and Rolf Heusser for their commitment and support and without whom the NRP 74 could not be successful.

Zürich, in March 2022, Prof. Dr. Milo Puhan

Executive Summary

Deriving policy advice from NRP 74 research

The *Synthesis Working Paper "Patient participation"* provides scientifically based recommendations for decision-makers, designed to make the Swiss health care system more efficient. Efficiency in this context means that with the given resources more health for all is achieved.

The recommendations are mainly based on the scientific findings delivered by nine projects of the Swiss National Science Foundation's National Research Programme "Smarter Health Care" (NRP 74). These projects represent the part of the NRP 74 that specifically dealt various aspects of patient involvement.

The process leading to this working paper was largely driven by doctoral students engaged NRP 74 projects who are members of the NRP 74's Emerging Health Care Leaders (EHCL) programme. They interviewed researchers, consulted the current literature on the topic and interacted with stakeholders from practice, administration and politics. This Synthesis Working Paper thus bridges education, research and practice, contributing at multiple levels to proactively address some of the major challenges facing Swiss health care.

Context: Shared decision-making for a better use of health resources

Patient choice is a relatively new and still somewhat vague concept, the definition of which is not conclusively agreed upon in scientific literature. In contemporary clinical practice, there is, however, a growing trend to provide more choices to patients and to assign them a more central role in their own care decisions. This evolution has to do both with scientific advancements as well as with the demographic context of a rapidly ageing society in which multimorbidity is becoming prevalent, leading to an increasing number of treatment options available to patients or health service users in general. Participation, however, does not only refer to the ability to decide between different options or to refuse care altogether. Promoting shared decision-making is seen as a way to improve the efficient use of health resources and thereby the quality of health care delivery.

In the Swiss health system, the "right to choose" plays a central role. Choice may be indirectly limited by the fact that compulsory health insurance only partially covers the costs. Patients can also waive their freedom of choice by opting for an insurance model that restricts the choice of health professionals and care. Despite these limitations, the Swiss healthcare system allows patients to decide for themselves which healthcare providers they wish to consult and which healthcare facilities they want to receive care or treatment from. Little is known, however, about patients' choices in practice (for example, regarding different forms of treatment) or about the degree of their involvement in interactions with health professionals and institutions. This is a major gap that several NRP 74 research projects are addressing.

At the political level, there have been calls for[1] more patient participation for some years. For example, better consideration of patients' rights and better involvement of patients are important goals of the Federal Council's health policy agenda Health2020 and are seen as central to the success of the reform of the Swiss health system.[2] *Non-governmental actors* such as patient and consumer protection organisations are also committed to making the voice of patients better heard and to informing them about their rights and options for action. *Health services research* also increasingly involves patients and their perspective, experience and knowledge in different roles and at different stages of research projects, which is believed to benefit quality, relevance and clinical results.

Approach: Evidence for Switzerland

Questions about what framework conditions and structures are necessary to better involve patients in health-related decision-making processes touch on many aspects. Research can contribute answers through scientific investigation. Nine projects of the NRP 74 have addressed patient participation and provide evidence in several specific areas. For this synthesis report, we have placed these findings, the insights gained in extensive exchanges with NRP 74 project leaders and relevant stakeholders as well as the information gathered by consulting the current scientific and grey literature in Switzerland into a conceptual framework.

This framework, inspired by Michie et al. (2011)'s capability, motivation, opportunity, and behaviour system (COM-B) and behaviour change wheel, demonstrates practical and research implications at three different levels: (1) the patient/service user level, (2) the health care professional level, and (3) the health system level. By analysing how these three levels interact and influence each other as mediators of patient participation, it becomes possible to broadly outline where the NRP 74 research contributes novel insights to current discussions and developments. From these we have, in a highly iterative process involving stakeholders from practice, administration and politics, derived evidence-based recommendations offering policy-orientation to decision makers on how to improve patient participation in the Swiss health care system.

The projects presented in this Synthesis Working Paper dealt with the following topics:

Patient/Service User Level

- Enhancing migrant women's agency
- Addressing social inequalities in the provision of health care
- Cost-effectiveness of home treatment for acute mental illness
- Exploring long-term care choices for an elder population

Health Care Professional Level

- Participatory medicine for informed decisions
- Optimising medication with the help of electronic devices
- Vaccine sceptical patients and doctors

---

[1] Patients' rights and patient participation in Switzerland, report in fulfilment of postulates 12.3100 Kessler, 12.3124 Gilli and 12.3207 Steiert (FOPH, 2015).

[2] "Health2020: 2018 Review & 2019 Outlook" (FOPH, 2019).

Health System Level

- Case management to relieve emergency services
- Diagnosing Dementia: cantonal policies and ethical issues.

Four recommendations for improving patient participation

The *Synthesis Working Paper "Patient participation"* results in four broad recommendations, each of which is further discussed and sharpened and into several sub-recommendations.

Patients as care team members

Patients and service users, as well as their families, should be involved by clinicians in decisions about their own health according to their preferences. They and their family members should be viewed by clinicians as members of the care team, with varying degrees of involvement based on their preferences, values, and abilities. To enable this, health professionals should be appropriately trained.

Provide curated high-quality information

Patients, service users, communities, and populations should be enabled to access and discuss reliable and appropriate information from health care providers to support their health decisions and help them navigate different health care settings (e.g., hospital, home care, transitions from one setting to another, etc.). It is important to distinguish between information provided to patients/service users already in contact and familiar with the health care system and those who are not (e.g., with regard to prevention and health promotion activities in general), as these different groups of patients may not be reached through the same channels. As part of this effort, patient and service user associations should be encouraged to work with health professionals, health systems, and academic institutions to provide this information in a form that is accessible and understandable to patients/service users, with a special focus on marginalized groups. Providing information to patients and service users is not sufficient in and of itself. Rather, such health information must be tailored to the needs and level of knowledge of patients.

Strengthen patient organizations

Patient and service user organizations should be strengthened. This entails professionalizing them and securing their funding so that they become independent and strong. It also means that adequate training must be imparted to patients and service users who are patient representatives and/or involved in participatory research.

Involve patients in research

Patients and service users should be invited and supported by researchers, policy makers, and clinicians to participate in patient-centred research. For example, they should be encouraged to participate in the development of research questions and to help design appropriate research approaches. Guidelines and best practices should be available to assist researchers with patient/service user participation issues in research.

1. Introduction: Involving patients in their own health and care

Summary

This chapter introduces the notion of patient participation as a relatively new and still somewhat vague concept, the definition of which is not conclusively agreed upon in scientific literature. In contemporary clinical practice, there is, however, a growing trend to provide more choices to patients and to assign them a more central role in their own care decisions.

Putting the patient at the heart of the health care system

Scientific advancements as well as the demographic context of a rapidly ageing society in which multimorbidity is becoming prevalent, lead to an increasing number of treatment options available to patients (or, in many cases more accurately: service users). But choice does not only refer to the ability to decide between different options or to refuse care altogether. Promoting shared decision-making is also seen as a way to improve the efficient use of resources and thereby health care delivery itself. For the purpose of this synthesis, the term *patient participation* is therefore preferred to *patient choice*.

Choice however is not necessarily a good thing, as it can also place responsibility for negative health outcomes for patients.

Due to scientific advancements, treatment options for many diseases have increased in recent decades. Treatment decisions today are less about choosing the only available treatment and more about selecting between a range of different treatment options. In this context, one could argue that patient choice is a relatively new concept that is playing an increasingly important role in health care.

It should be noted that at the outset of this synthesis report, the term *patient choice* was chosen as the common denominator for NRP 74 projects concerned with ways to better improve patient engagement. For reasons we will discuss in the next sections, we prefer the use of the term *patient participation* instead as it more adequately encapsulates the focus of this report and better aligns with the report's recommendations for future action.

A growing trend with possible pitfalls

In contemporary clinical practice, there is a growing trend to provide more choices to patients[3] and to assign patients a more central role in their own care decisions. Choice in this context refers to the ability to decide between different treatment options and to refuse care altogether. As such, health care professionals are expected to offer choices to patients because this is believed to empower patients, enhance their autonomy and improve health care delivery (Zolkefli, 2017).

Furthermore, in a context of demographically ageing societies (UN, 2019), multimorbidity is becoming increasingly prevalent (Souza et al., 2021) and the share of patients who regularly take multiple medications (polypharmacy) is increasing (Wastesson et al., 2018). Patients are therefore confronted with an

---

[3] The use of the term *patient* here refers to all individuals involved in the medical decision-making process. In this context, it may be more appropriate to speak of service users rather than patients.

increasing number of health care-related decisions. Together with their health care providers, they are often called upon to decide what treatment options work best for them, based on their preferences, needs, and other social contexts.

Maximizing opportunities for patient participation seems to be the ethically and morally right thing to do (Zolkefli, 2017). However, idealizing maximized patient participation as the gold standard in clinical practice can also be problematic, as patients may not necessarily want to bear the responsibility for exercising choice in all aspects of their health care, not least because such choices may entail negative health outcomes. Understanding and overcoming the tension between maximizing choice and exercising choice with potential negative consequences, be for the individual patient and/or for the health care system as a whole, is one of the key challenges pertaining to patient participation.

Crucial, but ill defined

Despite becoming increasingly popular in the literature, the term *patient participation* remains a somewhat vague. There is no consensus on the definition in the current scientific literature, and the concept is used differently across disciplines (Fotaki, 2006). The National Health Service (NHS) in England, for instance, views it as a mechanism for building patient capacity, improving access to the health care system, and making health care services more responsive to patient needs and expectations (PMLiVE, 2011). In the Swiss health care system, the “right of free choice” plays a central role in the design of the health system. It means that patients are entitled to freely choose health care professionals or public care facilities (e.g., public hospitals, etc.).

Patient participation, however, is not limited to which providers patients consult or where they seek care but relates to all aspects of any health care decision affecting them. When researchers and clinicians refer to patient participation, they often also evoke the concepts of “patient preferences”, “patient empowerment”, “patients as partners”, “patient-centred care” and “shared decision-making.” Although all these terms have become popular buzzwords in recent years (Zolkefli, 2017), they do refer to highly relevant aspects of health services research.

2. Patient participation in Switzerland

Summary

This chapter summarizes the current situation in Switzerland related to patient participation, and the efforts aimed at enhancing opportunities for patient participation within the Swiss health system on different levels and by different actors.

Switzerland recognizes the "right to free choice"...

In the Swiss healthcare system, the "right to free choice" plays a central role. Choice may be indirectly limited by the fact that compulsory health insurance only partially covers the costs. Patients can also waive their right to choose by opting for an insurance model that restricts the choice of health professionals and care facilities (e.g., a family doctor model). Despite these restrictions, the Swiss health care system in principle allows patients to decide which provider they wish to consult and in which health care facilities they would like to receive care or treatment.

... but needs to better listen to patients' voices

Different instances however are calling for more patient involvement.

- At the government level, a greater consideration of patients' rights and better patient involvement are important goals of the Federal Council's health policy agenda Health2020 and are seen as central to the success of the reform of the Swiss healthcare system.
- At the non-government level, several patient and consumer associations are committed helping patients' voices to be better heard by healthcare providers and to educating them about their rights and choices. Also concerned with the topic are professional associations like the Swiss Academy of Medical Sciences as well as the Swiss Medical Association (FMH).
- Research in Switzerland, outside of NRP 74, is also increasingly focusing on topics such as patient-centred communication or shared decision making. Participatory research, involving patients or communities at different project stages is also becoming increasingly popular in Swiss health services research, while the Swiss National Association for Quality Development is using patient experience (PROMs and PREMs) for conducting its annual satisfaction surveys for inpatients in acute care settings.

2.1 Free choice is central

As we have seen, the “right of free choice” is central to the Swiss health care system. Still, theoretically, there some situations in which patient choice can be restricted. First, within the framework of compulsory health insurance, patients’ freedom of choice can be limited, for example in the case of inpatient stays as patients should, in practice, be treated in hospitals in the canton they reside in. Second, patients’ freedom of choice may be restricted if their complementary health insurance system does not cover the costs of all available treatment options. Third, patients may waive their freedom of choice by self-selecting certain health insurance models (FOPH, 2020). In fact, 38% of all adults insured under mandatory health insurance in Switzerland have opted for a “Hausarztmodell” (managed care, gatekeeping system), and 9% of insurees for a health maintenance organization (HMO) model (FOPH, 2019).

A research gap

Despite these restriction on choice, the Swiss health care system in principle allows patients to decide which provider they wish to consult and in which health care facilities they would like to receive care or treatment. However, little is known about patient participation or the level of patient involvement in interactions with health professionals and institutions. This is a major gap several NRP74 research projects are addressing.

2.2 Government efforts to promote patient participation

In 2013, the Federal Council adopted the comprehensive strategy entitled "Health2020". This strategy identified the empowerment of insurees and patients as one of the health-policy priorities to be pursued (FOPH, 2018). To achieve this objective, the following measures were proposed: 1) taking greater account of patients and insurees in health policy processes (e.g., by means of delegated co-determination), 2) increasing the health skills and individual responsibility of patients and insurees so that they can navigate the health system more efficiently, and 3) placing greater emphasis on patients' rights (FOPH, 2018).

In the Federal Council's health strategy 2020-2030, adopted in December 2019, promoting health literacy is one of the objectives. It also states the need to, "empower citizens to make well-informed, responsible and risk-aware decisions that determine their own health and that of their relatives with support from qualified health care professionals" (FOPH, 2021). The Federal Council proposes concrete measures that should be taken under the following lines of action:

- *Improve public information:* "The entire Swiss resident population should have access to transparent, coherent and consistent information on the opportunities and risks of new developments in medical technology, on cost developments in the health system, on the increased linkage of digital health data and on avoiding environmental risks. Improved health literacy raises the level of individual responsibility and discourages people from accessing solidarity-based institutions unnecessarily."
- *Improve the way information on health and diseases is handled:* "Not everyone has sufficient health literacy to be able to make responsible and risk-aware decisions in all situations. Digitalisation can help them to do so. New possibilities in prevention, diagnosis and therapy could, however, mean that greater demands are placed on health care professionals in educating and advising both healthy and sick people. The federal government, cantons and service providers need to work together to develop and coordinate measures that equip health care professionals and institutions to deal with these challenges."

2.3 Role of non-governmental actors

In Switzerland, there are several patient and consumer associations representing the interests of patients, such as Stiftung für Konsumentenschutz (SKS), Fédération romande de consommateurs (FRC), Schweizerische Stiftung Patientenschutz (SPO), Associazione consumatrici et consumatori della Svizzera italiana (ACSI), Schweizerische Gesundheitsligenkonferenz (GELIKO), and the Dachverband schweizerischer Patientenstellen (CVSP). In 2020, these associations assembled to form the new association Prosalute which seeks to establish itself as an influential advocacy body for strengthening the rights of patients, premium payers, and consumers (prosalute.ch, 2021). In addition, there is the European Patients' Academy on Therapeutic Innovation (EUPATI) in Switzerland, which aims at providing a cooperation platform for the empowerment and involvement of patients in the processes underlying medical research and development (EUPATI, 2021).

There is also interest in patient participation topics among professional associations. For instance, in 2016 the Swiss Academy of Medical Sciences published a report on patient and family engagement (SAMW, 2016). This report does address patient engagement not only with regard to health services, but also in terms of health-related research. Similarly, in 2018, the Swiss Medical Association (FMH) in collaboration with the *Interdisziplinäres Institut für Ethik im Gesundheitswesen der Stiftung Dialog Ethik*, published quality criteria for patient information material and decision support tools based on the example of the interprofessional cross-sector treatment pathway for colorectal cancer (FMH, 2018).

2.4 Research on patient participation

Outside of the National Research Programme 74 (NRP74), there are several ongoing programmes and research projects linked to patient participation in the Swiss context. There is a growing research interest in patient-centred communication focusing on patient-provider interactions. An evidence-based learning platform designed for medical students for example aims at improving patient-centred communication (DocCom, 2021). The original platform was developed and validated in the United States and subsequently translated into German.

Other researchers in Switzerland have published on shared decision making between patients and providers, focusing on, for example, advanced care planning in people with dementia and shared decision making in preventive care (Selby et al., 2017, Bosisio and Barazzetti, 2020). Several other publications concern decision aids that can be used in clinical care when discussing treatment options with patients (Rosca et al., 2020, Agoritsas et al., 2015). In a recent paper, Selby et al. report their experiences with citizen advisory groups involved creating and improving decision aids for colorectal cancer screening (Selby et al., 2021a). Citizen advisory groups proved to be a viable way to repeatedly incorporate end-user feedback into the development process.

Some previous research projects in Switzerland have examined patient participation and patient preferences in relation to the type of care, e.g., long-term follow-up care in childhood cancer survivors (Michel et al., 2016), patient preference for a maintenance inhaler in chronic obstructive pulmonary disease (O'Hagan et al., 2018). Others have examined the choice of the care setting, e.g., the selection of the preferred place of death in cancer patients (Kern et al., 2020), and the hospital choice (Gurtner et al., 2018), among others.

Measuring what matters to patients: PROs, PROMs and PREMs

In recent years, the use of patient-reported outcomes (PROs), patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) has become increasingly common. These outcomes are directly reported by patients without interpretation of the patients' responses by anyone else (e.g., health care providers). The outcomes pertain to patients' quality of life, health and functional status (Weldring and Smith, 2013). PROs, PROMs, and PREMs are crucial for decision making centred on patient health and well-being. In Switzerland, the Swiss National Association for Quality Development in Hospitals and Clinics (ANQ) conducts regular assessments of the satisfaction of inpatients using patient-reported outcomes (Weldring and Smith, 2013).

In 2017, a report by the Organisation for Economic Co-operation and Development (OECD) emphasized the need to address the current lack of standardized patient-reported indicators of performance (OECD, 2017). Standardizing concepts, definitions, and metrics used would allow for comparing performance across countries and health care settings.

2.5 Involving patients in research

Participatory research is becoming increasingly popular in Swiss health services research. There are several approaches to participatory research, including: consulting patients (often referred to as *service* *users)* at selected project stages, involving a patient advisory board in study designs, having patient as project collaborators, and giving patients a role or even a leading part in the conduct of research projects. The following paragraphs present some examples of such participatory research efforts.

It should be noted that some guidelines and recommendations already exist for considering and implementing patient and public involvement in research. For example, the Swiss Clinical Trial Organization (SCTO) has published a Patient and Public Involvement (PPI) fact sheet that provides guidance on how to involve patients in clinical research (e.g., at what stages patients can be involved, how they can contribute, how to find the right patients, etc.) (SCTO, 2021).

Patients as partners

Various publications reflect the different ways patients can be involved in research in Switzerland. In one example patients informed the design of a clinical trial in postbariatric hypoglycaemia (Hepprich et al., 2020); in another, patient preferences were incorporated in early drug development (Cook et al., 2019).

In 2015, the Geneva University Hospitals (HUG) launched a project called "Patients as Partners”, which aims to establish a close collaboration between patients and health care providers (Koller and Costa, 2021, HUG, 2021). The Patients as Partners project entails a paradigm shift, as it strives to move away from a paternalistic model in which providers take the lead, trying instead to create a close partnership between patients and providers at every stage of the patient care process (e.g., treatment discussions, decision-making, follow-through, etc.) as well as in other hospital-related areas (e.g., hospitality, governance, and teaching). With such an approach, HUG professionals contribute to better communication between patients and providers as well as more open relationships between various parties.

The "PIONEERS" project of the Department of Health of the Bern University of Applied Sciences aims at establishing and evaluating service user involvement using the action research method in the field of psychiatric care (BFH, 2021a). It also seeks to improve capacity building structures within the department to improve user involvement, support researchers, disseminate guidelines and best practices, and expand the existing patient group (BFH, 2021b).

At the University of Lausanne, Prof. Manuela Eicher and colleagues, specializing in patients' experiences of oncology treatments, are developing a "patient laboratory". Several studies are currently underway to investigate the experiences of these patients. In one of these, Prof. Eicher is investigating patient and health care provider experiences in adoptive cell therapies (ISREC, 2021). This study uses an evidence-based co-design, a multi-stage approach that allows staff and patients to co-design health services and/or care pathways (Point Of Care Foundation, 2021). This approach facilitates high levels of patient and health care provider engagement, allows for the identification of priorities for improvement, and aims to achieve meaningful changes in health care delivery.

Another example is the SCAPE study which looks to explore patient experiences related to cancer care, as this domain is under-researched despite being critical to evaluating and improving that type of care (SCAPE, 2021).

Engaging communities: Citizen science

To some extent there is an overlap between patient participation in research and citizen science. In 2018, the Citizen Science Centre Zurich, a collaboration between the University of Zurich and ETH Zurich, published criteria to guide citizen science projects based on several rounds of discussions with relevant stakeholders (Citizen Science Centre Zurich, 2021b, Citizen Science Centre Zurich, 2021a).

Further, since 2020, the Swiss National Science Foundation (SNSF) has been involving representatives of patients and the public in evaluating funding for clinical research submitted to the SNSF Investigator

Initiated Clinical Trials (IICT) programme. This programme focuses on research questions that are important to society as a whole, but are not among the priorities of the industry (SNSF, 2021). This is the first time that patient and public representatives are involved in the grant application evaluation process.

3. Current challenges – and ways to address them

Summary

This chapter describes specific challenges to addressing patient participation.

First of all, in order to synthesize the findings of the NRP 74 research about patient participation in a meaningful way, a few concepts need to be clarified at the level of terminology.

Patient: The term patient, implying illness or passive suffering, does not always seem appropriate to describe individuals seeking care. In this report, patient implicitly always simply refers to a user of health services of service user.

Patient participation: There are different aims and approaches to the involvement of patients –resulting not least in the lack of uniform guidelines or standardized approaches for involving patients/service users in health services research.

Patients can be involved in treatment decisions or in service development, their views can be incorporated in the evaluation of services, in the training of health professionals, through testimonials about their own experience with health services or in all aspects of the research cycle. *Patient choice* being too narrow in scope to encompass all these different meanings, we opt instead for the term *patient participation*.

Not an end in itself: Another challenge inherent to the term *patient participation* is its value-charged nature, which assumes that improved and/or maximized patient participation is always the ideal approach and turns a blind eye on the fact that there can be caveats concerning choice in healthcare.

Other challenges *are specific to the Swiss context:* The mandatory basic health insurance model requires individuals to choose an insurance scheme from a variety of options but does not give them the choice not to participate at all.

Finally, there are *systemic prerequisites* that must be in place at the provider and health care system-levels allow patients to make truly informed health-related choices.

One of the main challenges associated with the concept of patient participation lies primarily in its definition, which, as already stated, remains vague and lacks precision. Indeed, patient participation is a multifaceted concept which, over time, has been studied and understood by a variety of conceptual, theoretical, and methodological approaches. Moreover, the discourse among clinicians and researchers often implicitly assumes that the ideal standard is to improve and maximize patient participation. Since *patient participation* as a concept evokes different meanings for different groups, it is difficult to come to a common understanding of what we mean when we talk about participation. Research projects with a patient participation component are often not directly concerned with patient participation, but with one many related concepts (e.g., patient preferences, shared decision-making, etc.), as these concepts and their operationalization affect patient participation or the lack thereof.

Although patient involvement and participatory research are becoming more popular and more widely uses, their definition remains challenging. For example, although they are now widely promoted, the terms and scope of patient involvement in research designs are often unclear, or their goals not explicitly stated by researchers in their publications or the description of their research approach. Thus, another major challenge related to patient participation stems from the lack of uniform guidelines or standardized approaches for involving patients/service users in health services research.

Not just a question of semantics: Patients vs. service users

It is not always appropriate to use the term *patient* in health services research. *Service user*, less connoted with illness, may be more fitting, since healthy individuals also seek care and are important actors in health care systems. In other instances, particularly decisions involving children or minors, it is often the caregivers or parents who make the choices for the children they are responsible for. In these cases, caregivers or parents are not the direct recipients of health care, treatment, or services so the term *patients* does not apply to them. In situations where patients are unable to give consent or communicate their wishes, as may be the case with critically ill individuals who are cognitively impaired, the full meaning of choice is difficult to determine. In other cases, it may be beneficial to include family members, such as spouses and adult children of elderly patients, or members of the social support network, in discussions about the health outcome desired by the patients/service users.

Participation is not an end in itself

Another challenge inherent to the term *patient participation* is its value-charged nature, which reflects recent public health efforts to promote improved and/or maximized patient participation as the ideal approach. However, it is worth questioning whether this is always appropriate. Morally and ethically, is often seems right to give patients the greatest possible freedom of choice, but in certain circumstances this can also lead to negative health outcomes (from a biomedical perspective) for the patients themselves, the providers or the health care system. Therefore, in addition to examining the mediating factors that promote patient participation, we should also critically assess the consequences that such approaches might have, particularly in terms of health outcomes, social impact, public health consequences, and patients' wishes.

Limits to choice specific to the Swiss context

A particular challenge in the Swiss context is that the mandatory basic health insurance model requires individuals to choose one insurance scheme from a variety of options. However, while there is a choice of available insurance schemes, individuals residing in Switzerland do not have the option of not participating in the system at all. In addition, in this model of health insurance, service users with limited means can choose the least expensive insurance scheme, which comes with a relatively high co-pay or deductible. As a result, a sizable proportion of patients do not seek necessary care for financial reasons unless there is an actual health emergency requiring medical attention.

System level prerequisites

In addition, it must be emphasized that patient participation is a strongly patient-centred concept, it is important to keep in mind that true patient choice can only be achieved if favourable conditions at the provider and health care system-levels allow patients to make truly informed health-related choices.

To achieve this, the services and the information that health care professionals provide to patients must be adequate and consider the different levels of literacy and health literacy. In addition, information must be based on appropriate sources of information (e.g., evidence-based guidelines). Patients and service users should know which patient and consumer organizations to contact with their questions, even if these organizations currently have limited operational resources. Because informing and educating patients and service users is time-consuming, initial efforts in this area may incur additional costs. However, these additional costs are expected to be offset by the savings that would result from better, more informed decisions in the long run.

4. Focus and method of this report

Summary

This chapter explains the methodology of this working paper. 9 projects of the NRP 74 have addressed aspects linked to patient participation and provide evidence in several specific areas. These findings, the insights gained in extensive exchanges with NRP 74 project leaders and relevant stakeholders as well as the information gathered by consulting the current scientific and grey literature in Switzerland are placed into a conceptual framework used as guiding support for this synthesis report.

This framework has been inspired by Michie et al. (2011)'s capability, motivation, opportunity, and behaviour system (COM-B) and behaviour change wheel. It demonstrates practical and research implications at the patient / service user level, health care professional level, and health system level of the projects synthesized in this report have. Further, it recognizes how these three levels interact and influence each other as mediators of patient participation.

Thus, it becomes possible to broadly outline where the NRP 74 projects can contribute novel insights to current discussions and developments in the respective context of patient participation and offer policy-orientation.

The recommendations that are brought forward in this report were developed by the synthesis team over 1.5 years in a process that included extensive exchanges with the relevant NRP 74 project leaders and with stakeholders from the field. In addition to the NRP 74 research findings, the Synthesis Team has taken into account the current scientific and grey literature in Switzerland.

4.1 Methods used

This working paper draws on a variety of methodologies. Evidence was collected through informal, semi-structured interviews with researchers, primarily those working on the relevant NRP74 projects, and patient representatives. Insights were also gained through extensive exchanges with key stakeholders to discuss the project results and the implementability of the recommendations derived from them by the synthesis team, as well as through a review of pertinent scientific publications, unpublished documents (conference presentations, reports, etc.) resulting from NRP74 projects, and selection of current literature on patient participation. Prior to finalizing this report, the project's principal investigators (PIs) were invited to review the synthesis.

Both the discussions held with key stakeholders during a dialogue event in October 2021 (see section 6.1 for details) and the feedback gathered from NRP 74 researchers and experts in occasion of the final NRP 74 programme conference in November 2021 (see section 6.2 for details) corroborated the terminological considerations discussed in previous sections and led the synthesis team to opt for use the term *patient participation* rather than *patient choice* throughout this synthesis working paper.

4.2 Research perspective

Nine projects of the NRP 74 address aspects linked to patient participation and provide evidence in several specific areas. It is important to underscore the different ways these nine projects operationalize the notion *patient participation*: Some are not concerned with patients *per se*, but rather focus on healthy individuals seeking preventive services or on individuals navigating the health system. Others do not necessarily study participation or choices, but focus on patient preferences, satisfaction, decisions, or experiences. Annex I (p. 50) gives a detailed description of the individual projects.

Given that there were two distinct groups of actors (patients and health care professionals) whose behaviours, perspectives, and experiences were examined by the nine projects we synthesize, we provide a summative table (Table 1) of the projects in which we indicate the health-related choice each study examined and briefly describe the data collected in regard to patients' and/or health care professionals' capabilities, opportunities, and motivations as influencers of the health choice/behaviour in question.

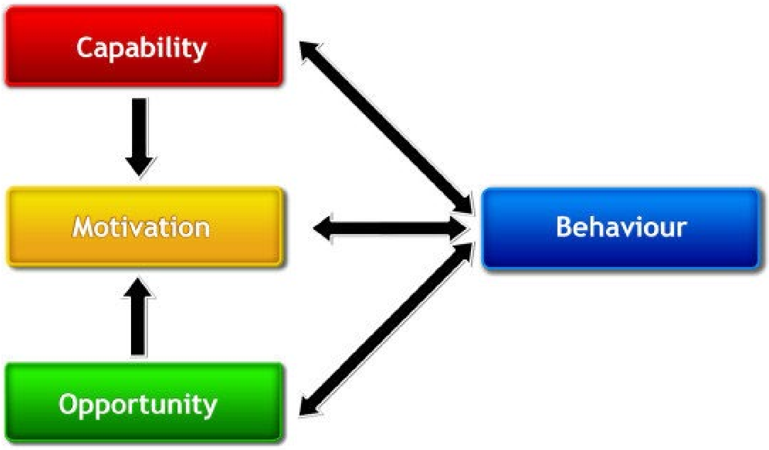
Table 1: NRP 74 Projects related to patient participation (NRP 74)

NRP74 Project	Study Population	Study Setting	Health Related Choice	Capabilities	Opportunities	Motivations
1. Learning from migrant women's experiences and improving healthcare services (Abel)	Migrant women	Community setting	Experiences with accessing healthcare and with the healthcare system	Health literacy, language, knowledge about the health system and how to navigate it, health status	Financial situation, stigmatization, social capital (resources through informal/personal/social/community networks)	*Not applicable: Did not collect information on this.*
2. Promoting participatory medicine in colorectal cancer screening (Auer)	General practitioners	Out-patient; primary care setting	Colorectal cancer screening options offered: (1) colonoscopy, (2) Fecal Occult Blood Test (FOBT)	Use of decision aids, conduct shared decision-making, tailored communication	Decision aid available, discussions with colleagues through quality circles	Peer influences from colleagues, provide evidence-based care to patients
4. Social inequalities in the provision of in-patient healthcare in Switzerland (Bayer-Oglesby)	(1) Patients with chronic diseases and a hospital stay within the previous 3 months (2) Professionals: health, social work, etc.	In-patient; hospital setting	Recent hospital stay related choices regarding: (1) admission, (2) treatment, (3) discharge	*Data collection is ongoing*	*Data collection is ongoing*	*Data collection is ongoing*
5. Using case management to remove burden on emergency departments (Bodenmann)	(1) case management teams (emergency care specialists, toxicologist, psychiatrists, social workers/case managers, etc.) (2) visitors to emergency departments	Emergency department	Care and treatment offered through triage in emergency departments	(2) health literacy, knowledge about the health system and how to navigate it, health status	(1) resources (material, personnel, etc.), perception that the hospital/emergency department isn't overburdened, changing the case management process is an additional burden (2) case management offered or not	(1) better allocation of resources, better working conditions

8. Cost-effectiveness of home treatment for acute mental illness (Crivelli)	Acute mental illness patients who had chosen home treatment	Patients’ homes	Preferences for the setting of acute mental illness treatment (home or in-patient care)	Ability to manage home visit (i.e. power dynamics/role reversal when welcoming healthcare professionals into one’s home)	Offer of choice for home treatment, interactions with healthcare professionals, social capital (resources through informal/personal/social/community networks)	Being at home (comfort, organizing one’s life, pets/children at home), avoiding stigmatization associated with in-patient mental health treatment, etc.
17. Diagnosing dementia: cantonal policies and ethical issues (Lucas)	Policy makers and healthcare professionals	Not applicable	Perspectives on early diagnoses of dementia	*Not applicable: Did not collect information on this.*	*Not applicable: Did not collect information on this.*	Ethical considerations for early diagnosis: (1) the desire to know, (2) the consequences of the diagnosis on individuals’ lives, (3) no current treatment in case of diagnosis
22. Optimising medication with electronic decision-making assistants in patients with multiple chronical illnesses (Streit)	(1) General practitioners (2) Older patients with multimorbidity and polypharmacy	Out-patient, primary care setting	Medication optimization	(1) Use of clinical decision support tool/system, shared decision-making, tailored communication *(2) data collection ongoing*	(1) Clinical decision support tool/system available *(2) data collection ongoing*	(1) Provide evidence-based care to patients, reduce adverse drug events *(2) data collection ongoing*
25. Long-term care choices in the older population (Santos-Eggimann)	Older adults living at home	Community setting	Long term care preferences: (1) nursing home, (2) assisted living facility, (3) living at home	*Not applicable: Did not collect information on this.*	Social capital (resources through informal/personal/social/community networks)	Severity of disability presented in vignette (i.e. hypothetical ability to care for oneself)
28. Vaccine-sceptical patients and doctors in Switzerland (Tarr)	(1) Physicians), practitioners of complementary/alternative medicine, (2) Parents and caregivers, (3) Youth	Out-patient, primary care setting	Vaccination preferences and decisions	(1) Communication training, (2) and (3) Health literacy	(1) Information sources on vaccination, (2) and (3) Social capital (resources through informal/personal/social/community networks), offer of vaccination choice	(1) Provide evidence-based care to patients, engage in shared decision-making (2) Protect one’s child(ren) (3) Protect oneself

Source: NRP 74 (Jungo/Deml)

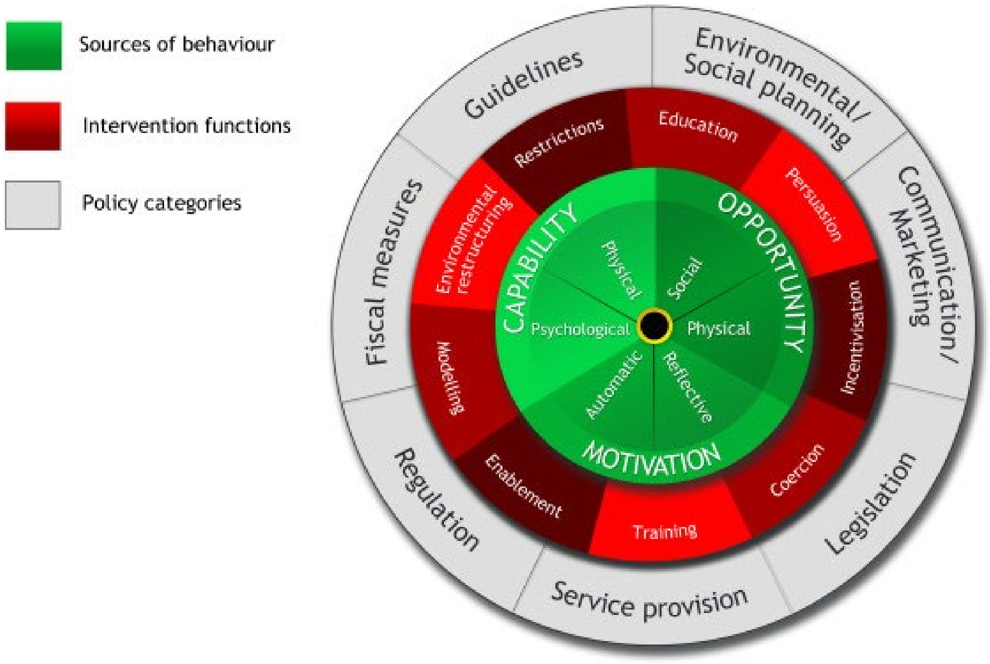
Figure 1: The COM-B-system, a framework for understanding behaviour



Source: Michie et al. 2011, p.4.

This summative table is theoretically grounded in Michie et al. (2011)'s capability, opportunity, motivation, and behaviour system (COM-B) (Figure 1) and behaviour change wheel (Figure 2). In this model, behaviour is at the centre and is influenced by individual capabilities, motivations, and opportunities. Table 1 details how each project specifically engaged with these three categories. Moving outwards from the centre of the wheel, there is a range of intervention functions (in red) potentially influencing the COM-B factors at the centre. The outermost part of the wheel, the grey zone, indicates policy categories that can have an impact on both intervention functions and the COM-B factors at the centre. Having identified specific elements of this COM-B model, this framework allows us to identify different points of entry for future recommendations in relation to patient participation outcomes. This brings added value to the synthesis report because it provides ways forward for formulating health policy, practice, and research recommendations.

Figure 2: The Behaviour Change Wheel



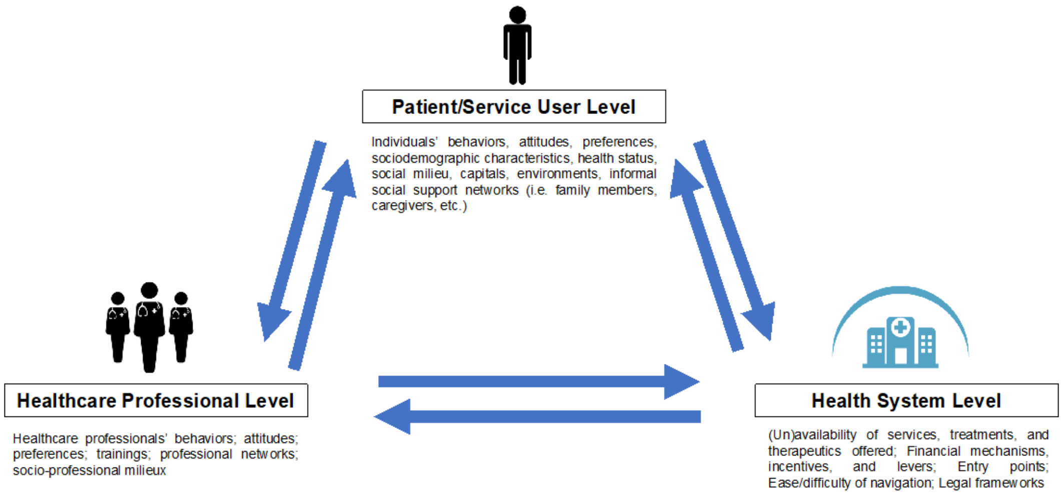
Source: Michie et al. 2011, p.7

The nine projects covering topics relevant to patient participation conducted research or intervened on three interrelated levels acting as mediators of patient choice:

1. the patient/service user level,
2. the health care professional level, and
3. the health system level.

By focusing on these three levels within a conceptual framework recognizing how they interact with and influence each other (Figure 3), we synthesize the nine projects in a way that takes into account the complex nature of patient participation as facilitated by individuals' own characteristics and social settings (i.e. behaviours, attitudes, preferences, sociodemographic backgrounds, health status, social milieu, capitals, etc.), the influences of health care professionals (health care professional behaviours, attitudes, preferences, trainings, professional networks, and socio-professional milieu), and interactions with the health system (un/availability of services, treatments, and therapeutics; financial mechanisms, incentives, and levers; entry points; ease/difficulty of navigation; legal frameworks, etc.).

Figure 3: Interrelated Mediators of Patient Participation



Source: NFP 74 (Jungo/Deml)

Thus structured, the following synthesis chapters demonstrate how the nine projects focused on a combination of:

1. patients/service users,
2. health care professionals, and
3. both patients' and health care professionals' interactions with the health system in relation to a particular health-related choice.

This framing also finds support from ecosocial theory (Krieger, 2011) and structure-agency dialectics (Abel and Frohlich, 2012). Simply put, such theoretical frameworks can help us understand how individuals interact with, shape, and are shaped by health systems and their social environments. Conceptually, these models are useful for identifying and demonstrating different entry points for interventions that can be implemented for changes related to patients' participation in decisions related to their health.

5. NRP 74 research with a view of enhancing patient participation

Summary

This chapter gives describes and discusses the contribution of specific NRP 74 research projects to the topic of patient participation, including their background, methods used, results and conclusions for implementation.

Of a total of 34 NRP 74 projects, nine specifically addressed aspects linked to patient participation on three distinct levels:

Patient/Service User Level (section 5.1)

- *Project no. 1,* Enhancing migrant women's agency (Abel)
- *Project no. 4,* Addressing social inequalities in the provision of health care (Bayer-Oglesby)
- *Project no. 8,* Cost-effectiveness of home treatment for acute mental illness (Crivelli)
- *Project no. 25,* Exploring long-term care choices for an elder population (Santos-Eggimann)

Health Care Professional Level (section 5.2)

- *Project no. 2,* Participatory medicine for informed decisions (Auer)
- *Project no. 22,* Optimising medication with the help of electronic devices (Streit)
- *Project no. 28,* Vaccine sceptical patients and doctors (Tarr)

Health System Level (section 5.3)

- *Project no.5,* Case management to relieve emergency services (Bodenmann)
- *Project no. 17,* Diagnosing Dementia: cantonal policies and ethical issues (Lucas)

Five other projects (no. 6, 21, 30, 31, 32), although not predominantly centered on patient participation, contributed valuable insights (see section 5.4)

For more details on all these projects, see Annex I, page 50.

5.1 Patient/Service User Level

Among the nine projects of the NRP 74 addressing aspects linked to patient participation, several had a stronger methodological and topical focus on health choices made at the patient/service user level, including, but not limited to, individuals' behaviours, attitudes, preferences, sociodemographic characteristics, health status, social milieu, and individual resources. Such factors also include resources available to individuals through their environment and social support networks, such as those available to them through family members. Although we have chosen to include the following projects within the patient/service user level category, we recognize, in line with the above-mentioned conceptual understanding, that within these projects there are overlaps and interactions between the patient/service user and the health care professional and health system levels.

5.1.1 Enhancing migrant women's agency

Project no. 1, led by Prof. Thomas Abel, aimed at learning more about the Swiss health system from the experiences of women with chronic illness and migration experience by qualitatively examining their interactions with the health care system. This brought added value to the research results since these processes cannot be adequately established by analysing available quantitative data nor by looking at health records or insurance documents. By taking this perspective, researchers were able to highlight women's *agency*, or ability to act, choose, and enact change, while navigating the health care system. The researchers explicitly chose to structure their study design around Amartya Sen's capability approach (described in further detail here: Abel and Frohlich (2012)).

This project considers migrant women from Portugal, Turkey, and Germany and compares them to Swiss women not hampered by language barriers or other "migrant" context conditions. In total, the researchers conducted qualitative semi-structured interviews with 48 women and 12 professionals from the health system, including family physicians, specialists, and social workers (Frahsa et al., 2020b). Two focus group discussions with 15 women were held to triangulate analyse and discuss the interview results and collect the women's views on issues to be discussed further. In a transdisciplinary approach, the participants then joined a series of stakeholder dialogues with actors working in the field of health insurance, the Swiss Red Cross, the Federal Office of Public Health (FOPH), self-help groups, and other professional stakeholders. The first dialogue focused on patients' needs, including their own competences and comprehension/shared understanding of the service system. The second dialogue focused on existing resources and strategies and on how to optimize health care processes to improve quality. The final dialogue presented a preliminary set of recommendations on how to improve access to care and the quality of care based on the study and dialogue findings. This set of recommendations was then discussed, adapted, and agreed upon as relevant and transferrable into routine services (Frahsa et al., 2020a).

Learning to "read" the system

The results of project 1 point to different processes women go through in their interactions with the health system. The researchers refer to these lessons learned as *learning careers,* i.e. the process of learning to "read" the system. These learning careers were characterized by certain barriers, such as language, system knowledge, the complexity of the system, reservations about discussing health issues with doctors, especially due to apprehension about the doctor's ability to understand the complexity of the health issue at hand, finding the proper doctor or health care provider, financial considerations and hardships, difficulties to navigate health insurance processes, the roles doctors played in the health insurance reimbursement process, and dealing with perceived prejudice and stigmatization from actors in the health system treating migrant women as if they were looking to live off of the state. The learning careers were also defined by facilitators, such as activating informal social networks, e.g., neighbours or community groups that can assist with finding providers or properly submit a health insurance claim; discussing the health system with one's family; and finding a trustworthy provider or doctor who can then serve as a point of contact and mediator to help women navigate the complexities of the Swiss health system.

As participants were heterogeneous in terms of age, length of stay in Switzerland, socio-economic and educational situation, type of illness and medical history, the findings can shed light on obstacles inherent to the health care system that could be improved by considering patient experiences. Among the innovative and novel aspects of the project was the idea that patients should be involved in health systems research, not just as data providers, nor simply as helping health practitioners and researchers in implementing interventions. On the contrary, project participants defined the problem in the early stages of the project, with researchers viewing them as experts of their own experiences of accessing the health care system to manage their chronic conditions.

In publishing the study approach and findings, the research group also presents recommendations for improvement based in six areas: 1) reduce barriers to access health services, 2) promote trust between health professionals and patients, 3) improve the involvement of patients and their resources in treatment decisions, 4) improve cooperation between health care professions, 5) promote non-medical support environments, such as self-help groups and community-based approaches, and 6) improve education and training opportunities, particularly for transcultural health care and chronic disease management (Frahsa et al., 2020b).

5.1.2 Social inequalities in the provision of health care

Led by Dr. Lucy Bayer-Oglesby, project no. 4 examined social inequalities in the provision of in-patient health care in Switzerland. The main study in this project sought to fill gaps by analysing a database of nationwide inpatient data and linking it with Swiss census data. The results of this quantitative research allowed researchers to understand whether and how social factors affect in-patient hospital care. They examined patients hospitalized for chronic conditions, the treatments they received in hospital, and the outcomes of hospital treatments. The analyses included variables from medical statistics complemented by variables on social factors, such as highest educational attainment, household type, labor market integration, and migration status.

However, the quantitative dataset lacked information about patients’ motivations deciding to seek in-patient treatment. This prompted the researchers to organize focus group discussions with patients with chronic conditions (including various cancers, cardiovascular diseases, respiratory diseases, musculoskeletal diseases, and mental disorders) in German-speaking Switzerland who had hospitalized three months prior to participating in the qualitative sub-study. By conducting the qualitative data collection, the researchers aimed to gather further information about patients’ choices, experiences, and preferences regarding (1) hospital admission, (2) treatment during hospitalization, and (3) discharge from hospital.

Allowing patients to speak in their own words

The sample for the qualitative sub-study was varied in terms of social characteristics and included individuals from different educational, economic, and migration backgrounds. Analysis of the focus group interviews revealed a general desire among chronically ill patients for continuous and constant professional support beyond medical treatment. Patients with medium/high social status expect to be informed about diagnoses and to be able to participate in treatment decisions and processes, while patients with a migrant background (and low social status) wish to be accompanied to medical appointments, to be supported by interpreters, and to have access to information, i.e., support that ensures their access to medical and social assistance.

An innovative aspect of this project is its focus on how social factors and social inequalities impact patients' choices and options, particularly patients in precarious situations. There is added value in complementing quantitative medical and social data with a qualitative approach that allows patients with chronic conditions to speak in their own words about their in-patient experiences and perspectives.

5.1.3 Cost-effectiveness of home treatment for acute mental illness

Project no. 8, led by Prof. Luca Crivelli, consists of a quasi-experimental study on a geographic basis in which researchers compared clinical outcomes of people with acute mental disorders treated in a psychiatric hospital with those of similar patients who received treatment at home. The project aimed to evaluate a pilot home treatment intervention and was limited to a specific geographical area in southern Switzerland (Bellinzona and Valleys).

Researchers worked on a qualitative sub-study aiming at understanding patients' and their family members' experiences with home-based care and the nature of their interactions with health care professionals in this particular care setting. The qualitative study began after the end of the quasi-experimental portion. Patients were asked to participate in a semi-structured interview and to indicate a family member willing to discuss their experiences with the researcher team. Patients were recruited at discharge from home treatment, while the interview was conducted several days later. In total, 29 out of 176 patients agreed to participate. Seven of them could not be encountered. Thus, the final sample is composed of 22 patients and 11 family members. The patient sample is diversified in terms of gender, age and mental disorders, while the family member sample is diversified in terms of family relationship with the patient. The researchers also conducted four focus group discussions and were able to gather the impressions of the home treatment team composed of 13 professionals, including psychiatrists, psychiatric nurses, and a psychologist.

Here also, researchers preferred the term “patient participation” to “patient choice", emphasising that patients were involved in all decisions and steps of the care process in this setting. This allowed them to negotiate personalized choices throughout the entire home care process.

Challenges inherent to the home setting

Patients and health care providers face three main challenges when interacting in the context of the home care setting. The first stems from the reversal of power dynamics between patients and professionals. In the home setting, patients act as the “mater of the house” and negotiate the aspects associated with hosting professionals in their home environment. On the other hand, professionals act as guests and regulate the way they use the patients’ private spaces. It is therefore important to acknowledge the reciprocal roles and to build a climate of trust. Another challenge is the level of intimacy that patients share with their guests. In the home setting, patients cannot control what information they disclose about themselves, which increases their vulnerability and creates an unbalanced relationship that requires an effort on the part of the health professionals in terms of reciprocity. A third challenge relates to the fact that home care eliminates some of the standardized procedures and protocols that would be expected for psychiatric care and treatment in a hospital setting. The home setting is therefore characterized by a lower level of formal regulation and a high degree of uncertainty in terms of interactions. Both the patient and the health care professional tend to adopt personalized behaviours dictated by circumstances and their specific personalities. At the same time, they negotiate their behaviours with the entire health care team to maintain the coherence of the clinical intervention.

Respect and reciprocity

An innovative approach of this project is its focus on the perspective of those involved in home-based treatment. Many of the studies on this topic to date have been quantitative and do not provide such detailed description or insight into what patients and health care professionals can expect in a home setting for acute psychiatric therapy. The lessons learned from the qualitative study will be used to improve home-based treatment and the training of psychiatric teams called to work in home-based settings in the future. The study also provides useful input for health care professionals working in traditional hospital settings. The delicacy, respect and reciprocity that the home context requires, and fosters is indeed important for any caregiver and should be promoted in other care settings as well. The evaluation of the study has led to a temporary extension of the intervention, which means that home treatment will become a stable offer for patients in the Bellinzona and Valleys region, and even be extended to the Lugano area.

5.1.4 What long-term care choices for an elder population?

In the context of *Project no. 25, led by Prof. Brigitte Santos-Eggimann,* researchers published a study aimed at quantitatively understanding older adults' perspectives on the most appropriate long-term care options in specific settings (Santos-Eggimann and Meylan, 2017). To this end, a vignette survey was mailed to a population-based sample of 3,133 individuals aged 68 years or older and living at home. Participants were presented with 10 different vignettes, each asking them to consider their situation as if they were (1) living with an able-bodied spouse and (2) living alone or with a spouse who could not help them. For each vignette (20 in total), respondents were asked to select whether, in that particular situation, their long-term care option would be to live (1) at home, (2) in assisted living ("sheltered housing"), or (3) in a nursing home.

The wish to live at home

Overall, the results indicate a strong preference for living at home as a long-term care option. Preferences for assisted living or nursing home settings notably varied notably by gender, the presence of a spouse able to assist with care, education, number of chronic conditions, ability to walk, Bristol Activities of Daily Living Scale (BADLS) scores, cognitive ability, and urine (in)continence. The strengths of the study result from the large sample of individuals aged 68 years and older, the high participation rates, and the wide array of options provided by the vignettes offering a better understanding of the conditions that might prompt persons in this age group to opt for different long-term care options. However, as the study population was geographically limited it may not be representative of the entire Swiss population. Only participants living in community settings (i.e. at home) were included, and the sample did not comprise persons in assisted living or nursing home settings. As with other vignette studies, the decisions reported by the participants may not reflect the actual decisions they would make when confronted with the same choice in a real-life setting.

The added value of this study is to provide a large data set of older individuals and their preferences for long-term care options and thus a valuable decision basis for health policy makers exploring long-term scenarios for ageing populations.

5.2 Health Care Professional Level

Several projects focused particularly on the role of health care professionals in mediating patient participation. These projects either collected data on the behaviour, attitude, preferences, training, professional networks and socio-professional milieu of health professionals or interacted with them with a view to intervene on these factors. This focus recognizes the importance that health care professionals can play in influencing patient participation, both through enabling and mediating the participation of individual patients and through their position within the health care system.

5.2.1 Participatory medicine for informed decisions

Project no. 2, led by Prof. Reto Auer, investigated the behaviour of general practitioners (GPs) regarding recommendations for colorectal cancer (CRC) screening in patients aged 50-75 years. In this context, the term patient refers to individuals who are eligible for colorectal cancer screening. Clinical guidelines recommend that primary care physicians (PCPs) offer their patients a choice between colonoscopy and fecal immunochemical testing (FIT) for colorectal cancer screening. In practice, however, most patients in Switzerland are screened by colonoscopy, whereas screening ratings with the use of FIT remain low (Martin et al., 2019b).

Communication is key

In the first part of the study, researchers conducted a cross-sectional study to assess the proportion of patients aged 50-75 who were screened for colorectal cancer by either FIT or colonoscopy in the past 10 years. Data were collected through the Sentinella network. The results show a significant variation in colorectal cancer screening practices among general practitioners in Switzerland. Very often, GPs only offer colonoscopies. While about 50% of patient were behind with their screening, 40% had received a colonoscopy in the 10 years prior to data collection, and 4% had received a FIT (Braun et al., 2019). The data collection form also captured patient refusal of CRC screening, a critical aspect of patient participation. They found that 25 % of patients declined CRC screening and that more patients refused screening when physicians only offered colonoscopy as a screening option rather than additionally offering fecal occult blood testing (FOBT) as a screening option (Martin et al., 2019a).

The second part of the project consisted of two randomized controlled trials (RCT) with general practitioners. In the first RCT, physicians in the Sentinella network who had participated in an initial data collection in 2017 were randomized into an intervention and a control group. Physicians in the intervention group were mailed a package of patient decision aids to support shared decision making, a two-page evidence summary on colorectal cancer screening, an immunological FOBT sample kit, and individualized performance feedback based on their past CRC screening practices. Both groups were then asked to repeat the data collection to measure outcomes. Results from the 109 physicians who participated in the data collection showed an increase in the number of primary care physicians who prescribed at least one FOBT to their patients in the intervention group and a significant increase in primary care physicians' intentions to perform a FOBT. This suggests that the intervention increased the likelihood that patients were tested using their preferred method.

Quality circles – an effective tool

In the second RCT, the team invited existing quality circles of primary care physicians to participate in a multilevel CRC screening intervention promoting shared decision-making (SDM) for CRC screening decisions. Quality circles went through two plan-do-check-act (PDCA) quality improvement cycles, one year apart. The quality circles in the intervention group started PDCA right away; the control group waited 12 months. In the first PDCA cycle, the team summarized the evidence for primary care physicians, provided them with communication material enabling SDM about CRC screening and asked them to collect data from 40 consecutive patients to measure their current practice. The data collected allowed for performance feedbacks with group discussions about their processes of care. The PDCA cycle was repeated in the intervention group after 12 months and the intervention group’s outcomes were compared to those of the control group at the start of the intervention.

The main outcome was the CRC screening rate (colonoscopy in the past 10 years or FOBT in the past 2 years) 12 months after the start of the intervention. The secondary outcome was the prescription of at least one FOBT in 40 consecutive patients per primary care physician. Of the 120 quality circles invited, 9 participated in the study (5 intervention group; 4 control group). A total of 63 primary care physicians (32 intervention group; 31 control group) from these quality circles collected data on 2114 patients (1132 intervention group; 982 control group; mean age 61.5 years, 53% women) 12 months after the start of the trial. The proportion of patients tested for CRC within the recommended intervals was higher in the intervention group than in the control group. However, the proportion of primary care physicians who had screened at least one patient screened with FOBT did not differ between intervention and control groups. In conclusion, a multilevel intervention promoting shared decision making for colorectal cancer screening in quality circles of primary care physicians significantly increased CRC screening rates at 12 months. This increase, however was not due to more primary care physicians prescribing FOBT.

This participatory project enabled the collection of important information on physician behaviour through data collection tools developed by the physicians themselves. Methods to change practice behaviour were also developed and tested. However, the study focused on data collected from physicians and did not collect data on patient preferences on these issues.

During the preparatory phase of the trial, patients were involved in the development of the decision aid used during the study. Patients were also included as partners and paid members of the research team throughout the research project (Selby et al., 2021b). The project’s principal investigator described this as an important and innovative aspect of the project and recommended that patients be more systematically involved and rewarded for their efforts in future research endeavours.

5.2.2 Optimising medication with the help of electronic devices

Project no. 22 of the NRP74, led by Prof. Sven Streit, is a cluster-randomized controlled trial (called the OPTICA trial) involving older adults with multimorbidity and polypharmacy in Swiss primary care settings. The trial's aim was to compare the use of a new electronic clinical decision support tool, called 'Systematic Tool to Reduce Inappropriate Prescribing', to usual care. The main outcome is medication appropriateness. Secondary results of the trial are other clinical and patient-reported outcomes (e.g., quality of life, etc.).

The 'Systematic Tool to Reduce Inappropriate Prescribing' is a web-based clinical decision support system to help customize medication reviews. It is based on the validated criteria of the 'Screening Tool of Older Person's Prescriptions' (STOPP) and the 'Screening Tool to Alert doctors to Right Treatment' (START) to identify potentially inappropriate prescriptions. The intervention also consisted of a shared decision-making process between general practitioners and patients in which discussions triggered by the tool were reviewed and, if applicable, implemented. Patient preferences are thus a key feature of the OPTICA trial and its intervention. The general practitioners who participated in the intervention part of the study received instructions on how to conduct shared decision making. The one-year follow-up of the trial ended in February 2021.

Obstacles to shared decision-making

Apart from the main trial analyses, there are several OPTICA sub-studies, which combine both quantitative and qualitative evidence. One of them, a mixed-methods study, investigated the use of the tool by the general practitioners in the intervention group during the trial and the subsequent shared decision-making. It found that only a small percentage of the recommendations generated by the tool were presented to patients and then implemented in the shared decision-making process.

Some of the reasons for this low implementation were that

1. Patients did not desire a change in their medication,
2. The condition of the patient was stable and did not warrant any medication change,
3. The perception that the medication in question had a health benefit,
4. Negative experiences with deprescribing in the past,
5. The treatment had been prescribed by another specialist, and
6. The irrelevance of a medication change in view of the current health status of the patient, in a e.g., palliative situation (Jungo et al. unpublished manuscript).

Although these explanatory findings were context-dependent, they are crucial for the future implementation of electronic clinical decision support systems in the Swiss primary care setting.

Another OPTICA sub-study investigates patients' experiences and expectations regarding polypharmacy, medication review during consultations, and deprescribing. This is a qualitative study in which patients in the OPTICA intervention group were interviewed. It is ongoing at the time of writing this report.

In terms of patient participation in clinical research, the project team was able to show that it is possible to recruit older adults with multimorbidity and polypharmacy for a clinical trial in primary care (Jungo et al., 2021). . Patients were included in the trial's data safety and monitoring board. Questionnaires were piloted with patients during the preparatory phase of the study. This is an important finding in a context where older patients and patients with chronic conditions are commonly excluded from clinical trials and numerous barriers exist to recruiting and retaining them in clinical studies.

5.2.3 Vaccine-sceptical patients and doctors

Project no. 28, led by Prof. Philip Tarr, is an observational study on vaccine hesitancy and under-immunization examining vaccination practices and perspectives of parents, adolescents/young adults (15-26 years of age, hereafter referred to as youth), and health care providers in Switzerland. The study focuses on patient preferences and patient-provider interactions related to vaccination. A key element of the study was the inclusion of complementary and alternative medical (CAM) providers as participants and project collaborators in the study design, as CAM use is associated with vaccine hesitancy and under-immunization, and CAM use is widespread in Switzerland and integrated into the Swiss health care system.

The study employed a mixed-methods approach, consisting of a qualitative and a quantitative component (Deml et al., 2019a). The qualitative component included semi-structured interviews and observations of vaccination consultations with parents (Deml et al., 2021), youth, biomedical health care providers (Deml et al., 2020) and complementary medicine providers (Deml et al., 2019b). Qualitative interviews and consultation observations allowed researchers to gain deeper insights into the vaccination decision making of parents and youth, and patient–provider interactions in general practice settings related to childhood and HPV vaccines.

In the study's quantitative component, parents of children, youth, and physicians were surveyed on diverse vaccine-related topics. The quantitative part of the study was to investigate the determinants of vaccine hesitancy and under-immunization with pediatric and human papillomavirus vaccines (HPV) in Switzerland. In total, 1,256 parents, 1,001 youth, and 112 providers responded to various versions of a quantitative questionnaire. The ultimate aim of the study was to design an evidence-based intervention to improve vaccine-related communication between patients and providers.

Unmet patient needs at the core

The study shows that vaccine hesitancy and under-immunization often reveal an unmet patient need (e.g., better patient-provider communication is needed to build and maintain trust, which is a key component of successful vaccination consultations). The qualitative findings indicate that choice is crucial for vaccine hesitant parents. When parents feel that they do not have a choice in the matter, tension can arise between parents and providers. Results also show that biomedical providers appear to follow vaccination-related guidelines more strictly than CAM providers. Therefore, from the perspective of hesitant patients, biomedical providers were perceived of as giving patients/parents less leeway in making vaccine-related decisions. For some parents, this may in turn complicate vaccination decision making and increase vaccine hesitancy. Complementary and alternative medicine providers, on the other hand, generally allowed patients/parents to voice more their own interests, concerns, questions about vaccination during consultation.

Quantitative analyses show an association between under-immunization of children and vaccine hesitancy among parents and providers. Overall, the study findings indicate that changing provider communication techniques related to vaccination may allow patients to take a more central role in decision making and adequately address vaccine hesitancy during vaccination consultations. This, in turn, may increase vaccination rates and reduce vaccine hesitancy by creating long-lasting, trusting relationships between parents and their children's health care providers.

This study has the advantage of combining both quantitative and qualitative evidence. The results are specific to Switzerland but provide important information on patient and provider attitudes toward vaccination. However, the recruitment strategy for the qualitative and quantitative components of the study was not representative of the Swiss population; rather, but rather allowed researchers to link patients' perspectives and practices regarding vaccination to the views of their providers. The study's findings are of great importance to infectious disease prevention efforts in the Swiss setting, particularly in the current context of the ongoing COVID-19 vaccine rollout.

5.3 Health System Level

Certain projects had a particular emphasis on the health system as a key mediator of patient participation. At the health system level, we identified projects centred on the following factors facilitating and/or hindering patient participation:

- Availability or unavailability of certain services, treatments, or therapeutics;
- Financial mechanisms, incentives, and levers;
- Entry points into the health care system;
- Ease and/or difficulty to navigate the health system;
- Policy and legal frameworks or legislation.

5.3.1 Case management to relieve emergency services

Led by Prof. Patrick Bodenmann, Project no. 5 justified and contextualized the fact that Swiss emergency departments are often overloaded, which in part is due to some patients visiting emergency departments with higher than average frequency (Bieler et al., 2012). The study aimed to implement a case management intervention in emergency departments in French-speaking Switzerland, evaluating both the implementation process and the clinical trajectories among patients who received the intervention.

Case management specifically seeks to improve the care of patients who visit the emergency department five or more times a year and to empower them to gain ownership of their care decisions. These patients are typically affected by multiple somatic, psychological and social problems (Bieler et al., 2012). At the core, case management centres on a patient-provider relationship that focuses on the patient's specific needs and priorities. Case management teams generally include nurses, physicians, social workers and/or psychologists.

In this study, qualitative and quantitative methods were used to assess implementation effectiveness as well as process and clinical trajectories among patients who received the intervention at implementation sites (e.g., quality of life, emergency department use, etc.).

A potential to scale-up

Semi-structured interviews conducted with patients receiving the intervention documented that most of them rated the intervention positively. In particular, the holistic evaluation offered by case management and the quality of the relationship with the case manager were cited as the two most important positive differences compared with usual care. The relationship with the case manager was seen as the key mechanism that enabled positive change. Participants highlighted three main outcomes resulting from the intervention: (1) increase in motivation, (2) improvement of their relationship with the health care system, and (3) an increase of their health literacy. Although less common, a few participants noted some negative aspects of the intervention, such as the case manager's lack of time and the negative impact of COVID-19 on the organization of the intervention. These promising qualitative results were corroborated by quantitative findings which showed a significant decrease in emergency department visits and a significant improvement in patients' quality of life after the intervention. Together with previous research findings (Althaus et al., 2011, Bodenmann et al., 2017), the results confirm that such case management interventions are a promising way to address the specific needs of these patients.

This study tested an innovative new case management intervention to improve patient self-determination in the emergency department setting. By implementing a new model of case management in emergency departments, this project demonstrated how changes in the health care system itself, through proper coordination and training of health care professionals working on case management teams, can have a mediating influence on the options available to patients visiting hospital emergency departments for health issues that might be more appropriately addressed in other departments. A survey assessing the need for and interest in a broader implementation of this intervention in Swiss emergency departments found that health care providers often encounter challenges in assisting these patients and generally find the intervention useful. The results indicate that case management interventions could be rolled out to other emergency departments in Switzerland.

5.3.2 Diagnosing dementia: cantonal policies and ethical issues

In Project no. 17, led by Prof. Barbara Lucas, researchers conducted a systematic public policy analysis by examining the concrete implementation of dementia diagnosis in Switzerland, mapping the diversity of cantonal diagnosis strategies, and identifying the main ethical dilemmas faced by professionals in their practice of dementia diagnosis.

The researchers used a multilevel study design based on qualitative and quantitative methods. First, they reviewed the relevant literature on ethical issues associated with dementia diagnosis. Second, they carried out extensive desk research to map the 26 cantonal diagnostic policies and networks. Third, they conducted an online survey of specialized institutions identified during the mapping process. Fourth, the team developed four case studies in the cantons of Ticino, St. Gallen, Zurich, and Vaud to formulate a public policy analysis and explore practical and ethical dilemmas reported by health and social care professionals in diagnosis clinics. The fifth step consisted of a multilevel comparative analysis integrating the theoretical study results.

Reasons for early diagnosis

The national online survey with a 58% response rate yielded 113 responses. Based on these, the researchers were able to determine that there is widespread support for promoting early detection among facilities offering dementia diagnosis. However, the answers point to potential tensions between reasons for and against early diagnosis. The most frequently cited argument *in favour of* early diagnosis (69% of respondents) was “reducing stress and uncertainty for patients/their families", while another 60% see the “risk of negative emotions for patients/their families” as one of the top three reasons *against* early diagnosis. Researchers emphasized the importance of examining and considering the extent to which patients with dementia can retain or regain their autonomy and self-determination after diagnosis, particularly in terms of their interactions with health care professionals.

The second most frequently cited reason supporting early diagnosis (59% of respondents) is the ability to “take appropriate legal action (for instance advanced directives, or testaments)”. However, the extent to which patients are involved in diagnostic decisions remains ambivalent with over 90% of respondents indicating that patients’ family members are always involved in the decision to proceed with the diagnostic process after the initial consultation, but only 77% of respondents believe that patients themselves should always be involved. In addition, 60% indicate that the diagnosis is always communicated to the patient first. A fundamental ethical consideration in these discussions was the paradox inherent in a health care professional giving a patient an early dementia diagnosis when there is no curative treatment option; for 45% of respondents one of the main reasons against early diagnosis is it's being “of little use in the absence of effective treatment.”

Cantonal borders can determine participation

Research results showed great heterogeneity in terms of cantonal strategies on dementia, with only 50% of Swiss cantons having explicit dementia strategies in place in 2019. Of the cantons with explicit dementia strategies, the researchers conducted four case studies that revealed the different types of governance for dementia diagnosis throughout Switzerland, with models structured by cantonal dementia policies, different degrees of cantonal centralization, the specific characteristics of specialized actors’ networks, the coordination logic of the curative and care systems, as well as some of the aforementioned debates on dementia diagnosis. Thus, Ticino stood out for its community-based early diagnosis model, Vaud for its delegated and centralized early diagnosis model, Zurich for its urban diagnosis model of integrated care, and Saint Gallen for its decentralized, uncoordinated diagnosis model. Patient participation in dementia diagnoses (including the final step of establishing post-diagnosis support) appears to be contingent on the canton in which health care services are sought.

The researchers also identified specific ethical questionings and dilemmas experienced by professionals that have implications for patient participation. A major issue in the four cantonal case studies revolved around access to diagnosis. It had to do with the reluctance of some primary care physicians to refer patients for early diagnosis and with the insufficiently recognized potential of Spitex staff for dementia screening.

Another important dilemma concerned first consultations and decisions further dementia-related screening. This boiled down to the following questions:

1. Should screening continue in the absence of a request or if the patient declines it?
2. Should screening continue with biomarker assistance?
3. how should professionals manage tensions between patients and their families regarding possible dementia diagnoses?

A further salient dilemma involved the issue of organizing care pathways for patients and their families, particularly in terms of their social needs in the context of insufficient care and social services. These discussions also raise questions about advance directives, which can be uncertain terrain if the patient does not request them.

Political and professional perspectives matter

In this context, and with regard to early diagnosis, it is difficult to make general recommendations for or against early diagnosis. Rather, the researchers recommend ensuring that early dementia diagnosis can be conducted in a person-centred manner to identify potential alignments and divergences of interest. This can be achieved by means of a specific set of questions, used as a tool for decision-making at the individual and collective level, when diagnosis first becomes possible.

An original an innovative feature of this research arises from its focus on the political and professional perspectives related to (early) dementia diagnoses. Systematically establishing these perspectives is fundamental to further understanding how the health care system is designed in relationship to these individuals and in addressing diagnostic practices and their implications.

5.4 Other NRP74 Projects with elements of patient participation

At the final NRP74 Programme Conference, several additional NRP74 projects with interesting patient participation components, were brought to our attention. We briefly describe them below.

Project no. 30, led by Prof. Sabina De Geest: This project investigates a new model for integrated community-based care for home-dwelling older people. There is patient participation throughout all steps of the implementation of this nurse-led care model in two care regions in the Canton of Basel-Landschaft.

Project no. 31, led by Dr. Heidi Kaspar focusing on the development of caring communities for long-term care at home, adopts participatory research approach and encourages the inclusion of members from the local care community, local politicians, patients, relatives and the civil society.

Project no. 32, led by Prof. Joachim Marti: This project aims to improve care coordination for people with chronic conditions in Switzerland. Among the data sources used there is a survey designed to measure patient preferences. According to Prof. Marti the participation of patients was crucial, as it would not have been possible otherwise to collect some of the elements crucial to better understand the needs of the Swiss population with regard to health care coordination.

This project, as well as several others (Project no. 21, led by Prof. Dr. Gerold Stucki as well as Project 22, led by Dr. med. Sven Streit) included patients in their advisory boards. Project no. 22 and Project no. 6, led by Dr. Anne Niquille moreover highlighted the challenges for the involvement of patients with cognitive impairment. In these situations, involving relatives appears to be even more crucial.

For more details on all these projects, see Annex I, page 50.

6. Stakeholders' views on topics for policy recommendations

Summary

In order to obtain feedback on the relevance and focus of the policy recommendations proposed in chapter 7, a dialogue event with key stakeholders was held in autumn 2021. This chapter summarizes the feedback provided, not least with regard to factors liable to hinder or facilitate their implementation.

The event was attended by a diverse panel of experts, representing the federal and cantonal Swiss health authorities, the medical profession, clinical research, health leagues, patient organisations and organisations promoting health literacy in care professions as well as among the general public.

While the stakeholders did not question the general relevance and interdependence of the raised topics, they expressed a number of concrete reservations as to their realization or effectiveness.

Key observations:

- The health care system should be made inclusive by default.
- Increased patient involvement should be part of health professionals' training and continuing education.
- The need of an independent entity promoting patient health literacy and providing quality assistance in navigating available information sources and advisory services.

Put in place incentive mechanisms and minimal guidelines to include patient perspectives in research.

Within the framework of a dialogue event, held in Bern on October 22, 2021, the synthesis team presented three main thematic fields resulting from the synthesis work (1. Give patients a voice, 2. Provide information to promote health literacy, 3. Devise mechanisms to integrate patients' experiences into research) as well as a first draft of policy recommendations derived therefrom. The aim was to obtain feedback on the relevance and focus of these policy options and to discuss their implementation in the Swiss health care system. The event was attended by a diverse panel of experts, representing the federal and cantonal Swiss health authorities, the medical profession, clinical research, health leagues, patient organisations and organisations promoting health literacy in care professions as well as among the general public.

The presentations and discussions focused on the five following topics:

- Increase patient engagement and the skills necessary to promote and ensure that it is part of health professionals' training.
- How to enable patient participation, i.e. promote the health literacy of patients.
- How to provide reliable sources of information.
- How to create standardized (financial) incentive mechanisms for the inclusion of patient perspectives in research
- Guidelines for participatory research.

While the stakeholders did not question the general relevance and interdependence of the raised topics, they expressed a number of concrete reservations as to their realization or effectiveness. The attendees criticized that most of the proposed policy options lack a clearly designated recipient and do not indicate with precision in which settings or by means of which specific incentive mechanisms they should be implemented. This, according to the stakeholder panel, implies the risk that none of the actors of the health care system need to feel responsible and compelled to act. Another point the panel found insufficiently acknowledged is the influence of patients' family environment and the significant role family members (or other close persons) can play in providing care and effective psychological and emotional support.

6.1 Central insights

The health care system should be made inclusive by default

The stakeholders pointed out that enhancing patient participation and promoting "health literacy" should in no way be an excuse for a health care system getting so complex that patients or health care professionals become incapable of explaining it to their patients without specialist training. Such a system would be non-inclusive by definition. Instead, the experts advocate for a health care system designed in such a way that, in every care situation, adequate patient-oriented information is available and involvement is made possible by default. They emphasize that the cantons and the federal government have an obligation to provide guidance in this regard.

Another central conclusion is that, in order not to reiterate well-known concerns without proposing concrete solutions, realistic policy options should be formulated and backed up by research results (as provided by various NRP 74 projects provide, e.g., the implementation science project “INTERCARE – Nurse-led model of care in Swiss nursing homes: improving interprofessional care for better resident outcomes”) presenting evidence-based strategies to enhance patient participation. Finally, the stakeholder panel advises to take advantage of the development of specific framework conditions permitting a firmer entrenchment of notions such as transparent information and increased patient participation. Examples of such developments cited by the panel are the establishment of the federal quality commission, the national quality agreements or the new rules pertaining to the passing on of discounts governed by the revised Therapeutic Products Act (TPA).

Increased patient involvement should be part of health professionals' training and continuing education

This, together with the next recommendation (enabling patient participation) is seen as the most relevant issue by the stakeholders – and one that, in many ways, is already addressed in the training of health care personnel today. In this context, the importance of co-education and interprofessionalism are repeatedly emphasized as well as the need to provide training that is practice-oriented, co-designed with the direct input of patients, and always considers patients' socio-cultural backgrounds. The Swiss Cancer League provides communication skill trainings for oncology nurses based on such principles that have been found to substantially improve patient-centred communication. Trainings of this nature exist but should be accessible to all health professionals and part of the curriculum right from the start. Science communication training should also be provided to researchers who need to be able to explain the results of clinical studies in lay terms.

In general, the challenge pertaining to the training of health care workers is that it is provided by a multitude of different institutions in various settings such as universities, universities of applied sciences for basic training or health leagues such as the Swiss Cancer League. Continuing education on the other hand is mostly organized by physician and health care professional networks – the stakeholders therefore are more optimistic about the possibility to implement changes here.

As to the applicability of enhanced patient involvement in everyday practice, stakeholders point out that the Tarmed tariff structure hardly allows for the time needed to adapt content (e.g., hospital discharge reports) to the audiences health professionals wish to address (e.g., specialist colleagues or patients). Time resources are scarce which is not conducive to better communication or participatory decision-making. In this sense, stakeholders stress that education and training are necessary but not sufficient if the framework conditions for implementation are missing.

Promote patients' health literacy

Patients (or better: all citizens, even before they are ill and in need of treatment) need access to understandable, updated, and accurate information with regard to prevention, specific diseases, treatment and post treatment options. While the stakeholders do not dispute the relevance of this point, they also stress that it would be unfair to put the onus solely on the patients: not all of them can be expected to find their way around the health system or to acquire a sufficient level of health literacy. The system must be accessible for persons with little education or knowledge of the local language as well (or else provide the necessary assistance).

The use of the Electronic Patient Record (EPR) is expected to facilitate access to information, to help patients play a more active role in the treatment process and increase their ability to participate in decisions concerning their health, while at the same time promoting patients' health literacy. But stakeholders are critical of the lack of an independent entity providing quality assistance and pointing patients to available advisory services (e.g., on how to ask for a second opinion). The necessary resources are missing, the existing patient organizations chronically underfunded, relying on donations and volunteer work and thus limited in their action.

Provide reliable information

The importance of providing a reliable, easily accessible one-stop source of objective and accurate information in an easily understandable form and targeting the needs of different population groups is undisputed. Stakeholders agree that there can be no valid patient participation if patients do not have access to reliable sources of information. But they also raise different problematic issues. First and foremost, there certainly is no lack of information sources and so no need to add more information. Quality is not the problem either. In fact, there is a wealth of quality information constantly available, not least online. The crucial point, according to the stakeholder panel, is how patients can find the right information, how they perceive it, by whom it is conveyed and who helps them to process it. The problem thus, according to the panel, is not the source, but the channel. Trusted (digital) platforms, set up under the impetus of the federal government (e.g., the State Secretariat for Education, Research and Innovation) or by the Cantons could play a central role here, while health associations, patient organisations and NGOs such as the Red Cross could provide the necessary credibility. The Swiss Medical Association (FMH) and the Foundation "Dialog Ethik" provides a guideline on quality criteria for patient information materials, published in 2018.

Incentive mechanisms to include patient perspectives in research

The inclusion of patients in research ensures its patient-centeredness and quality in terms of answering questions that are relevant to patients. This, according to the stakeholder panel, is generally accepted and patient participation a prerequisite for a growing number of research grants. The SCTO has published a guideline for researchers to address patient and public involvement (PPI) in clinical trials.

But, as that guideline states, PPI should be more than a simple box-ticking-exercise to receive research grants. Stakeholders agree that if patients are put in a position to participate in a meaningful way, e.g., by acquiring a basic understanding of clinical research, their contribution to optimizing health care can be considerable, not least in the area of health services research focusing on care pathways and the performance of the entire system.

Stakeholders see the following critical points and questions in connection with PPI:

- Missing resources for PPI in research settings (although the SNSF and Innosuisse provide some funding).
- Who can guarantee the representativity of patient panels?
- Who protects and defends the patients' interests and independence? (patient organizations need more funding if they are to play this role)

Guidelines for participatory research

Guidelines or, rather, “best practices” for participatory research are therefore seen as a necessity. As a minimal requirement, they should standardise the fair and equal remuneration of patients and experts acting as partners in research and research-related activities.

6.2 NRP Programme Conference: Clarifying some notions

On November 15, 2021, the final Programme Conference of the NRP74 took place. It included a “World Coffee" providing an opportunity to discuss the first draft of the recommendations with the research teams involved in the NRP 74.

One of the points discussed related to the change of the title of this synthesis from "patient choice" to "patient participation", deemed to much more appropriately reflect the broad range of the interactions of patient/service users with health care providers, health care institutions, as well their role as stakeholders in various health-related processes (e.g., receiving information, voicing their values, participating in shared decision-making processes).

The researchers present also felt that more the term "patient" used in the title of this synthesis report needed to be clarified. It was felt to be important to note that "patient" explicitly refers not only to people who are undergoing medical treatment for an illness, but in a broader sense to any health service users.

Other issues raised by the NRP 74 research community:

- Funding for patient and public involvement should not only allow for reimbursing participants for their time, but also cover the costs of organizing meetings (e.g., funding for coffee breaks, transportation, etc.).
- Much like the stakeholder panel, participants insisted that the crucial role played by relatives and informal caregivers should be more widely acknowledged, particularly in the context of patients with cognitive impairment, and that this should be prominently featured in the final recommendations.

7. Conclusion: Policy options for improving patient participation

Summary

The NRP 74 aims to strengthen the base of evidence for decision-making in the Swiss health care system. As shown in the last chapter, its results can contribute to this in the area of patient participation, on varying levels. In this chapter we discuss and present policy options derived from these results as well as from extensive exchanges with stakeholders and the researchers involved in NRP 74.

These policy options or recommendations are discussed at three interconnected levels:

- patient/service user level,
- healthcare professional level,
- health system level

The main conclusions are four overarching policy options:

1. **Patients as care team members:** Patients and service users, as well as their families, should be involved by clinicians in decisions about their own health according to their preferences and considered as members of the care team.
2. **Provide curated high-quality information:** Patients, service users, communities, and populations should be enabled to access and discuss reliable and appropriate information from health care providers to support their health decisions and help them navigate different health care settings.
3. **Strengthen patient organizations:** Patient and service user organizations should be strengthened, professionalized and their funding secured.
4. **Guidelines to involve patients in research:** Patients and service users should be invited and supported by researchers, policy makers, and clinicians to participate in patient-centred research.

This synthesis working paper has shown that research, policy, and practice efforts to better understand and promote patient participation are multifaceted, employing a variety of methodological, theoretical, and conceptual approaches, and varying over time and by context. Although our synthesis has assigned projects to three levels of mediating factors influencing patient participation (i.e. patient/service user level, health care professional level, and health system level), it is important to point out that these three levels should not be viewed as separate entities, but interact with, influence, and shape one another.

More specifically, grounding our synthesis in the COM-B (capability, motivation, and opportunity) system as well as the behaviour change wheel from Michie et al. (2011) we can highlight how future research, policy, and practice efforts for change on patient choice and participation can be mediated at different entry point levels (patient, health care professional, and health system). In effect, this conceptual model recognizes that the behaviour of service users and health care professionals can influence and be influenced by interventional functions and policy categories (refer to Figure 2, “The Behaviour Change Wheel”) that serve as determinants of the capabilities, opportunities, and motivations of these actors.

Four important overarching recommendations

Given the summative and focused nature of this synthesis, the recommendations we propose are based on an unsystematic review of the literature on patient participation. They are also limited by the methods used to collect data from the projects summarized above. The recommendations are therefore based upon our professional assessment and interpretation of the data we have synthesized. They were further adjusted on the basis on the stakeholder dialogue and the final NRP 74 programme conference as presented in Chapter 6.

We would like to acknowledge that although the issues we highlight in this section are not new, they have been underscored as highly relevant in the context of the NRP74.

Although recommendations are made at three levels in the following subchapters this synthesis allows us to formulate four important overarching policy options related to patient participation.

Four policy options for improving patient participation

1. **Patients as care team members:** Patients and service users, as well as their families, should be involved by clinicians in decisions about their own health according to their preferences. They and their family members should be viewed by clinicians as members of the care team, with varying degrees of involvement based on their preferences, values, and abilities. To enable this, health professionals should be appropriately trained. For more information, see section 7.1.2.
2. **Provide curated high-quality information:** Patients, service users, communities, and populations should be enabled to access and discuss reliable and appropriate information from health care providers to support their health decisions and help them navigate different health care settings (e.g., hospital, home care, transitions from one setting to another, etc.). It is important to distinguish between information provided to patients/service users already in contact and familiar with the health care system and those who are not (e.g., with regard to prevention and health promotion activities in general), as these different groups of patients may not be reached through the same channels. As part of this effort, patient and service user associations should be encouraged to work with health professionals, health systems, and academic institutions to provide this information in a form that is accessible and understandable to patients/service users, with a special focus on marginalized groups. Providing information to patients and service users is not sufficient in and of itself. Rather, such health information must be tailored to the needs and level of knowledge of patients.
3. **Strengthen patient organizations:** Patient and service user organizations should be strengthened. This entails professionalizing them and securing their funding so that they become independent and strong. It also means that adequate training must be imparted to patients and service users who are patient representatives and/or involved in participatory research.
4. **Involve patients in research:** Patients and service users should be invited and supported by researchers, policy makers, and clinicians to participate in patient-centred research. For example, they should be encouraged to participate in the development of research questions and to help design appropriate research approaches. Guidelines and best practices should be available to assist researchers with patient/service user participation issues in research. For more information, see Section 7.1.1.

7.1 Discussion

7.1.1 Patient/Service User Level

For health policy recommendations to have meaningful impact for patients and service users, it is essential that researchers, clinicians, and policymakers fully understand their needs by engaging patients and service users in implementation actions that are designed to benefit them. This includes conducting research aimed at understanding and meeting patients and service users where they are and subsequently designing interventions reflecting these situations.

For a more systematic inclusion of patients/health service users in early-stage study designs, the NRP74 steering committee can recommend best practices for future health service research through the Swiss National Science Foundation. Building on already existing documents, (e.g., the PPI fact sheet published by the SCTO), this could include establishing guidelines and best practices for researchers and clinicians this could include establishing guidelines and best practices for researchers and clinicians to follow when involving patients and health service representatives at various stages of their research and for compensating them for their participation as representatives of patients or health service users. Funding for PPI must cover not only reimbursement for participants' time, but also funding for meetings with patients and service users (e.g., funding for coffee breaks, etc.).

Building on this, researchers should involve patients/service users more systematically in the design of research studies and health service interventions. This should include writing study protocols and summaries in lay language. In addition, funders of health services research (SNSF, hospitals, foundations, donors, etc.) should provide incentives for researchers to systematically involve patients/service users in the various phases of a research project.

7.1.2 Health care Professional Level

Health professionals should be better trained in communication and interpersonal skills to have the appropriate skills to build trust-based patient-provider relationships and to discuss patient choices in clinical practice. Opportunities for this training include basic (“Ausbildung”), advanced (“Weiterbildung”), and continuing education (“Fortbildung”). This may include instruction on decision aid tools, software, and other communication resources. Training for health care workers should not be theoretical only, but as hands-on as possible. Medical school, nursing schools, and allied health schools, as well as professional associations and health care institutions, should develop and deliver these trainings, as they are involved in the various stages of health care professional education. Quality circles also provide an opportunity for such training.

Researchers and clinicians should question blanket statements that uncritically emphasize only the positive benefits of maximizing patient participation.

In practice, health professionals should favour and support the individual interaction of patients, service users (or their representatives) and relatives with care teams and encourage their involvement in a shared decision-making process consistent with their wishes, needs, and values.

Clinician fees should be revised to provide financial incentives for encouraging patient participation and for offering appropriate compensation for consultation time.

7.1.3 Health System Level

Stakeholders from health services research, health service delivery, and patient advocacy can work together to propose a more clearly defined approach to patient participation and clearly outline desired goals for practice.

Patients and service users can be more systematically encouraged to use PREMs and PROMs during health care visits and consultations in order to provide better data for the health care system and future health service interventions. Appropriate questionnaires and data collection tools should be made available by health care providers.

Future health services research and intervention efforts addressing patient participation issues could use the conceptual framework we propose in order to provide a broader understanding of the interrelated mediators of patient choice at the level of (1) the individual patient, (2) health care professionals, and (3) the health system. Combined with Michie et al.'s (2011) COM-B system and behavior change wheel, researchers and clinicians could be encouraged to identify different entry points for interventions that meaningfully impact patient participation outcomes.

As a result of this synthesis work, regulations, interventions, and policies should be developed and implemented to promote greater and direct involvement of patients and service users in the governance of the health system. This should occur at multiple levels, including micro, meso, and macro, and include a focus on health promotion and preventive initiatives.

In the context of the stakeholder dialogue, the idea of working toward the adoption of a law that would provide an appropriate legal basis (e.g., the Patient Information Act or "Patienteninformationsgesetz" in German) was discussed. This law could, for example, provide a regulatory framework for training health professionals to improve their competencies in the area of patient participation, train patient representatives and provide funding for patient organizations.

8. Outlook

There are many dimensions to the question of what framework conditions and structures are needed to take greater account of patients' needs and wishes in health care and to enable them to be involved in health-related decision-making processes. Research can contribute to an answer by investigating certain aspects.

This working paper provides a synthesis of the research results pertaining to patient participation the scientific community involved in the NRP 74 has gained in five years of research. The nine projects dealing with patient participation have analysed actual "real-life" processes, always considering the specifics of the Swiss health care system as a constitutive framework. Discussions among the wider community of researchers involved in NRP 74 and with key stakeholders in health care and health policy have provided further valuable insights about possible courses of action. All this has been condensed into policy options to promote patient participation in Switzerland.

This synthesis working paper is one of a total of six syntheses, covering one of six overarching and essential issues facing the Swiss health care system today. Taken together, the six syntheses working paper establish a unique overall picture and constitute the basis for the final synthesis report, ambitioning to show in concrete terms how to overcome the lack of integration and the multiple interrelated barriers in order to improve the care of an ageing population with multiple chronic conditions, improve coordination to better deploy existing resources and deliver appropriate health care services to patients and their caregivers.

Bibliography

ABEL, T. & FROHLICH, K. L. 2012. Capitals and capabilities: Linking structure and agency to reduce health inequalities.

AGORITSAS, T., HEEN, A. F., BRANDT, L., ALONSO-COELLO, P., KRISTIANSEN, A., AKL, E. A., NEUMANN, I., TIKKINEN, K. A., WEIJDEN, T. V. D., ELWYN, G., MONTORI, V. M., GUYATT, G. H. & VANDVIK, P. O. 2015. Decision aids that really promote shared decision making: the pace quickens. *BMJ : British Medical Journal,* 350**,** g7624.

ALTHAUS, F., PAROZ, S., HUGLI, O., GHALI, W. A., DAEPPEN, J. B., PEYTREMANN-BRIDEVAUX, I. & BODENMANN, P. 2011. Effectiveness of interventions targeting frequent users of emergency departments: a systematic review. *Ann Emerg Med,* 58**,** 41-52.e42.

BFH. 2021a. PIONEERS - Pioniere eines neuen Paradigmas in der psychiatrischen Pflege und Betreuung an der Berner Fachhochschule, Fachbereich Gesundheit [Online]. Available: https://www.bfh.ch/en/research/research-projects/2015-302-286-970/ [Accessed May 12, 2021].

BFH. 2021b. Systematischer Einbezug der Perspektive von Patientinnen und Patienten sowie deren Angehörigen in die Gesundheitsforschung und -lehre an einer Hochschule [Online]. Available: https://www.bfh.ch/en/research/research-projects/2018-629-101-502/ [Accessed May 12, 2021].

BIELER, G., PAROZ, S., FAOUZI, M., TRUEB, L., VAUCHER, P., ALTHAUS, F., DAEPPEN, J. B. & BODENMANN, P. 2012. Social and medical vulnerability factors of emergency department frequent users in a universal health insurance system. *Acad Emerg Med,* 19**,** 63-8.

BODENMANN, P., VELONAKI, V. S., GRIFFIN, J. L., BAGGIO, S., IGLESIAS, K., MOSCHETTI, K., RUGGERI, O., BURNAND, B., WASSERFALLEN, J. B., VU, F., SCHUPBACH, J., HUGLI, O. & DAEPPEN, J. B. 2017. Case Management may Reduce Emergency Department Frequent use in a Universal Health Coverage System: a Randomized Controlled Trial. *J Gen Intern Med,* 32**,** 508-515.

BOSISIO, F. & BARAZZETTI, G. 2020. Advanced Care Planning: Promoting Autonomy in Caring for People with Dementia. *Am J Bioeth,* 20**,** 93-95.

BRAUN, A. L., PRATI, E., MARTIN, Y., DVOŘÁK, C., TAL, K., BILLER-ANDORNO, N., BULLIARD, J. L., CORNUZ, J., SELBY, K. & AUER, R. 2019. Variation in colorectal cancer testing between primary care physicians: a cross-sectional study in Switzerland. *Int J Public Health,* 64**,** 1075-1083.

CITIZENSCIENCECENTERZURICH. 2021a. *Citizen Science Center Zurich Homepage* [Online]. Available: https://citizenscience.ch/en/ [Accessed December 6, 2021].

CITIZENSCIENCECENTERZURICH. 2021b. *Criteria* [Online]. Available: https://citizenscience.ch/en/start/criteria [Accessed December 6, 2021].

COOK, N. S., CAVE, J. & HOLTORF, A. P. 2019. Patient Preference Studies During Early Drug Development: Aligning Stakeholders to Ensure Development Plans Meet Patient Needs. *Front Med (Lausanne),* 6**,** 82.

DEML, M. J., BUHL, A., HUBER, B. M., BURTON-JEANGROS, C. & TARR, P. E. 2021. Trust, affect, and choice in parents' vaccination decision-making and health-care provider selection in Switzerland. *Sociology of Health & Illness,* n/a**,** 1-18.

DEML, M. J., BUHL, A., NOTTER, J., KLIEM, P., HUBER, B. M., PFEIFFER, C., BURTON-JEANGROS, C. & TARR, P. E. 2020. 'Problem patients and physicians' failures': What it means for doctors to counsel vaccine hesitant patients in Switzerland. *Social Science & Medicine,* 255**,** 112946.

DEML, M. J., JAFFLIN, K., MERTEN, S., HUBER, B., BUHL, A., FRAU, E., METTRAUX, V., SONDEREGGER, J., KLIEM, P., CATTALANI, R., KRÜERKE, D., PFEIFFER, C., BURTON-JEANGROS, C. & TARR, P. E. 2019a. Determinants of vaccine hesitancy in Switzerland: study protocol of a mixed-methods national research programme. *BMJ Open,* 9**,** e032218.

DEML, M. J., NOTTER, J., KLIEM, P., BUHL, A., HUBER, B. M., PFEIFFER, C., BURTON-JEANGROS, C. & TARR, P. E. 2019b. “We treat humans, not herds!”: A qualitative study of complementary and alternative medicine (CAM) providers’ individualized approaches to vaccination in Switzerland. *Social Science & Medicine,* 240**,** 112556.

DOCCOM. 2021. *Die Lernplattform für Kommunikation im Gesundheitswesen* [Online]. Available: https://doccom.iml.unibe.ch/startseite/ [Accessed May 12, 2021].

EUPATI. 2021. *EUPATI Switzerland* [Online]. Available: https://ch.eupati.eu/ [Accessed May 12, 2021].

FMH 2018. Qualitätskriterien für Patienteninformationsmaterialien und Entscheidungshilfe am Beispiel des interprofessionellen, sektorenübergreifenden Behandlungspfads Kolorektalkarzinom. Bern, Switzerland.

FOPH. 2018. *Gesundheit2020 - Health2020 - a comprehensive health care strategy* [Online]. Available: https://www.bag.admin.ch/bag/en/home/strategie-und-politik/gesundheit-2020/eine-umfassende-strategie-fuer-das-gesundheitswesen.html [Accessed May 12, 2021].

FOPH 2019. Statistique de l’assurance-maladie obligatoire 2017: Statistiques de l’assurance-maladie. *Report***,** 1-198.

FOPH. 2020. *Right of Free Choice* [Online]. Available: https://www.bag.admin.ch/bag/en/home/medizin-und-forschung/patientenrechte/rechte-arzt-spital/3-freie-wahl-gesundheitsfachperson.html [Accessed April 19, 2021].

FOPH. 2021. *The Federal Council’s health policy strategy 2020–2030* [Online]. Available: https://www.bag.admin.ch/bag/en/home/strategie-und-politik/gesundheit-2030/gesundheitspolitische-strategie-2030.html [Accessed November 30, 2021].

FOTAKI, M. 2006. Choice is yours: A psychodynamic exploration of health policymaking and its consequences for the English National Health Service. *Human Relations,* 59**,** 1711-1744.

FRAHSA, A., ABEL, T., CATTACIN, S., FARQUET, R., MEYER, S. & SAKARYA, S. 2020a. Améliorer les soins pour les femmes atteintes de maladies chroniques: considérer les effets de la migration. *SocioBrief,* 3b.

FRAHSA, A., FARQUET, R., BAYRAM, T., DE ARAUJO, L., MEYER, S., SAKARYA, S., CATTACIN, S. & ABEL, T. 2020b. Experiences With Health Care Services in Switzerland Among Immigrant Women With Chronic Illnesses. *Frontiers in Public Health,* 8.

GURTNER, S., HIETSCHOLD, N. & VAQUERO MARTÍN, M. 2018. Do patients value a hospital's innovativeness reputation? A multi-method approach to assess the relative importance of innovativeness reputation in patients' hospital choice. *Health Serv Manage Res,* 31**,** 138-153.

HEPPRICH, M., DONATH, M. Y. & HEMKENS, L. G. 2020. Patient involvement to inform the design of a clinical trial in postbariatric hypoglycaemia. *BMC Medical Research Methodology,* 20**,** 290.

HUG. 2021. *PATIENTS PARTENAIRES, QU'EST-CE QUE C'EST ?* [Online]. Available: https://www.hug.ch/patients-partenaires/approche-patients-partenaires-qu-est-ce-que-c-est [Accessed May 12, 2021].

ISREC. 2021. *Patient and health care provider experience in adoptive cell therapies: An experience-based co-design study* [Online]. Available: https://www.isrec.ch/en/the-research/other-research-projects/details-other-research-projects/news/detail/news/patient-and-health care-provider-experience-in-adoptive-cell-therapies-an-experience-based-co-design-study [Accessed November 30, 2021].

JUNGO, K. T., MEIER, R., VALERI, F., SCHWAB, N., SCHNEIDER, C., REEVE, E., SPRUIT, M., SCHWENKGLENKS, M., RODONDI, N. & STREIT, S. 2021. Baseline characteristics and comparability of older multimorbid patients with polypharmacy and general practitioners participating in a randomized controlled primary care trial. *BMC Family Practice,* 22**,** 123.

KERN, H., CORANI, G., HUBER, D., VERMES, N., ZAFFALON, M., VARINI, M., WENZEL, C. & FRINGER, A. 2020. Impact on place of death in cancer patients: a causal exploration in southern Switzerland. *BMC Palliative Care,* 19**,** 160.

KOLLER, A. & COSTA, G. 2021. *La médecine pour et avec les patientes* [Online]. Available: https://pulsations.hug.ch/article/la-medecine-pour-et-avec-les-patients [Accessed May 12, 2021].

KRIEGER, N. 2011. Epidemiology and the people's health: theory and context, Oxford University Press.

MARTIN, Y., BRAUN, A. L., BILLER-ANDORNO, N., BULLIARD, J. L., CORNUZ, J., SELBY, K. & AUER, R. 2019a. Screening Refusal Associated with Choice of Colorectal Cancer Screening Methods. A Cross-sectional Study Among Swiss Primary Care Physicians. *J Gen Intern Med,* 34**,** 1409-1411.

MARTIN, Y., BRAUN, L. A., JANGGEN, M.-A., TAL, K., BILLER-ANDORNO, N., DUCROS, C., SELBY, K., AUER, R. & ROHRBASSER, A. 2019b. Offering patients a choice for colorectal cancer screening: a quality improvement pilot study in a quality circle of primary care physicians. *BMJ open quality,* 8**,** e000670-e000670.

MICHEL, G., GIANINAZZI, M. E., EISER, C., BERGSTRAESSER, E., VETSCH, J., VON DER WEID, N. & KUEHNI, C. E. 2016. Preferences for long-term follow-up care in childhood cancer survivors. *Eur J Cancer Care (Engl),* 25**,** 1024-1033.

MICHIE, S., VAN STRALEN, M. M. & WEST, R. 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science,* 6**,** 42.

O'HAGAN, P., DEDERICHS, J., VISWANAD, B., GASSER, M. & WALDA, S. 2018. Patient preference for a maintenance inhaler in chronic obstructive pulmonary disease: a comparison of Breezhaler and Respimat. *J Thorac Dis,* 10**,** 5727-5735.

OECD 2017. RECOMMENDATIONS TO OECD MINISTERS OF HEALTH FROM THE HIGH LEVEL REFLECTION GROUP ON THE FUTURE OF HEALTH STATISTICS: Strengthening the international comparison of health system performance through patient-reported indicators. 1-87.

PMLIVE. 2011. *What is NHS patient choice?* [Online]. Available: http://www.pmlive.com/pharma_news/what_is_nhs_patient_choice_347686 [Accessed April 19, 2021].

POINTOFCAREFOUNDATION. 2021. *EBCD: Experience-based co-design toolkit* [Online]. Available: https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/step-by-step-guide/1-experience-based-co-design/ [Accessed November 30, 2021].

PRO-SALUTE.CH. 2021. *Pro-salute.ch* [Online]. Available: https://www.pro-salute.ch/ [Accessed May 12, 2021].

ROSCA, A., KRONES, T. & BILLER-ANDORNO, N. 2020. Shared decision making: patients have a right to be informed about possible treatment options and their risks and benefits. *Swiss Medical Weekly,* 150.

SAMW 2016. Patienten und Angehörige be-teiligen Einbezug. *Swiss Academies Communications,* 11.

SANTOS-EGGIMANN, B. & MEYLAN, L. 2017. Older Citizens' Opinions on Long-Term Care Options: A Vignette Survey. *Journal of the American Medical Directors Association,* 18**,** 326-334.

SCAPE. 2021. *Swiss Cancer Patient Experiences* [Online]. Available: https://www.scape-enquete.ch/ [Accessed November 30, 2021].

SCTO. 2021. *Publications: Fact Sheets* [Online]. Available: https://www.scto.ch/en/publications/fact-sheets.html [Accessed December 6, 2021].

SELBY, K., AUER, R. & CORNUZ, J. 2017. Shared decision making in preventive care in Switzerland: From theory to action. *Z Evid Fortbild Qual Gesundhwes,* 123-124**,** 91-94.

SELBY, K., CARDINAUX, R., METRY, B., DE ROUGEMONT, S., CHABLOZ, J., MEIER-HERRMANN, V., STOLLER, J., DURAND, M.-A. & AUER, R. 2021a. Citizen advisory groups for the creation and improvement of decision aids: experience from two Swiss centers for primary care. *Research Involvement and Engagement,* 7**,** 37.

SELBY, K., CARDINAUX, R., METRY, B., DE ROUGEMONT, S., CHABLOZ, J., MEIER-HERRMANN, V., STOLLER, J., DURAND, M. A. & AUER, R. 2021b. Citizen advisory groups for the creation and improvement of decision aids: experience from two Swiss centers for primary care. *Res Involv Engagem,* 7**,** 37.

SNSF. 2021. *Clinical research: patients and the public have their say* [Online]. Available: https://www.snf.ch/en/7GJ99FdMjxpeGkc1/news/clinical-research-patients-and-the-public-have-their-say [Accessed November 30, 2021].

SOUZA, D. L. B., OLIVERAS-FABREGAS, A., MINOBES-MOLINA, E., DE CAMARGO CANCELA, M., GALBANY-ESTRAGUÉS, P. & JEREZ-ROIG, J. 2021. Trends of multimorbidity in 15 European countries: a population-based study in community-dwelling adults aged 50 and over. *BMC Public Health,* 21**,** 76.

UN. 2019. *World Population Ageing 2019* [Online]. Available: https://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2019-Report.pdf [Accessed May 12, 2021].

WASTESSON, J. W., MORIN, L., TAN, E. C. K. & JOHNELL, K. 2018. An update on the clinical consequences of polypharmacy in older adults: a narrative review. *Expert Opin Drug Saf,* 17**,** 1185-1196.

WELDRING, T. & SMITH, S. M. S. 2013. Article Commentary: Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). *Health Services Insights,* 6**,** HSI.S11093.

ZOLKEFLI, Y. 2017. Evaluating the Concept of Choice in Health care. *The Malaysian journal of medical sciences : MJMS,* 24**,** 92-96.

Annex I: NRP 74 research projects related to Patient Participation

Projects discussed in the working paper

NRP Project no. 1: Patient experiences help improve health care for migrant women (Prof. Dr. Dr. Thomas Abel, Universität Bern, Institut für Sozial- und Präventivmedizin)

NRP Project no. 2: Promoting participatory medicine in colorectal cancer screening (Prof. Dr. med. Reto Auer, Universität Bern, Berner Institut für Hausarztmedizin (BIHAM))

NRP Project no. 4: Social inequalities in the provision of in-patient healthcare in Switzerland (Dr. sc. nat. Lucy Bayer-Oglesby, Fachhochschule Nordwestschweiz, Hochschule für Soziale Arbeit)

NRP Project no. 5: Case management reduces the number of ED visits and promotes patients' quality of life in frequent users, (Prof. Patrick Bodenmann, Université de Lausanne, Policlinique médicale universitaire)

NRP Project no. 8: Cost-effectiveness of home treatment for acute mental illness (Prof. Dr. Luca Crivelli, Scuola universitaria professionale della Svizzera italiana)

NRP Project No. 17: Diagnosing dementia: cantonal policies and ethical issues (Prof. Dr. Barbara Lucas, Haute école spécialisée de Suisse occidentale)

NRP Project No. 22: Optimising medication with electronic decision-making assistants in patients with multiple chronical illnesses (Dr. med. Sven Streit, Universität Bern)

NRP Project No. 25: Older adults express their choices to guide the long-term care policy (Prof. Dr. Brigitte Santos-Eggimann, CHUV Centre hospitalier universitaire vaudois, Institut Universitaire de Médecine Sociale et Préventive)

NRP Project No. 28: Vaccine-sceptical patients and doctors in Switzerland (Prof. Dr. med. Philip Tarr, Medizinische Universitätsklinik, Infektiologie und Spitalhygiene Kantonsspital Baselland)

Other projects mentioned in the working paper

NRP Project no. 6: Interprofessional quality circles improve medication in nursing homes (Dr. Anne Niquille**,** Policlinique Médicale Universitaire Lausanne)

NRP Project no. 21: Standardised assessment and reporting system for functioning information supports quality reports and individual rehabilitation (Prof. Dr. Gerold Stucki, Schweizer Paraplegiker-Forschung, Nottwil)

NRP Project no. 30: Integrated community-based care for home-dwelling older people (Prof. Dr. Sabina De Geest, Institut für Pflegewissenschaft, Universität Basel)

NRP Project no. 31: Development of caring communities for long-term care at home (Dr. Heidi Kaspar, Berner Fachhochschule, Partizipative Gesundheitsversorgung)

NRP Project no.32: How to improve care coordination for people with chronic conditions in Switzerland? (Prof. Dr. Joachim Marti, Institut Universitaire de Médecine Sociale et Préventive – IUMSP, CHUV et Université de Lausanne)

Glossary

The following definitions have been borrowed from the United States National Library of Medicine, the Cochrane Library, the British Medical Journal (BMJ), Centre for Evidence-Based Medicine, the Centres for Desease Control and Prevention, the WHO, the Swiss Clinical Trial Organisation and the Federal Office of Public Health.

Ageing population: Complementary health insurance: It represents the insurance for co-payments, meaning that it insures the difference in price of a health service, covered by the compulsory health insurance, and the full price of the service.

Grey literature: Refers to documents and other research-based material issued in limited amounts outside formal channels of publication and distribution. Examples include scientific and technical reports, government documents, doctoral theses and unpublished material.

Health literacy: Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others. *Organizational health literacy* is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Health policy: A formal statement or procedure within institutions (notably government) which defines priorities and the parameters for action in response to health needs, available resources and other political pressures.

Informal caregivers: An informal caregiver, often a family member, provides care, typically unpaid, to someone with whom they have a personal relationship. Informal caregivers are a critical resource to their care recipients and an essential component of the health care system, yet their role and importance to society as a whole have only recently been appreciated.

Inpatient /stationary: An individual who has been admitted to a hospital or other facility for diagnosis and/or treatment that requires at least an overnight stay.

Managed care: Managed care is a health care plan that integrates the financing and delivery of health care services by using arrangements with selected health care providers to provide services for covered individuals.

Multiple medication: The use of multiple medicines, commonly referred to as polypharmacy is common in the older population with multimorbidity, as one or more medicines may be used to treat each condition. Polypharmacy is associated with adverse outcomes including mortality, falls, adverse drug reactions, increased length of stay in hospital and readmission to hospital soon after discharge

Multimorbidity: Multimorbidity is the coexistence of multiple health conditions and a growing public health challenge.

Patient and public involvement: PPI in clinical research can be defined as research carried out with or by patients and members of the public rather than to, about, or for them. This means that patients and members of the public become actively involved in shaping the goals, design, and evaluation of research projects by sharing their specific experience with a disease.

Randomized controlled trial: A trial in which participants are randomly assigned to two or more groups: at least one (the experimental group) receiving an intervention that is being tested and another (the comparison or control group) receiving an alternative treatment or placebo. This design allows assessment of the relative effects of interventions.

Tarmed: Tarmed (tarif médical) is the nationwide fee-for-service tariff system in Switzerland. It has been used since 2004 for the invoicing of all out-patient medical services, both in doctors' practices and in hospitals throughout Switzerland.

Abbreviations and acronyms

ANQ – Swiss National Association for Quality Development in Hospitals and Clinics

CAM – Complementary and Alternative Medicine

COM-B – Capability, opportunity, motivation, and behavior system

CRC – Colorectal Cancer

EHCL – Emerging Health Care Leaders (

EPR – Electronic Patient Record

FIT – Fecal Immunochemical Testing

FMH – Foederatio Medicorum Helveticorum (The Swiss association of physicians)

FOBT – Fecal occult blood test

FOPH – Federal Office of Public Health

GP – General practitioner

HMO – Health Maintenance Organization

NRP – National Research Programme

OECD – Organization for Economic Cooperation and Development

PCP – Primary Care Physician

PDCA – Plan-Do-Check-Act

PI – Principal Investigator

PPI – Patient Public Involvement

PREM – Patient reported experience measurements

PRO – Patient reported outcome

PROM – Patient reported outcome measurements

RCT – Randomized Controlled Trials

SAMS – Swiss Academy of Medical Sciences

SCTO – Swiss Clinical Trial Organization

SDM – Shared Decision Making

SNSF – Swiss National Science Foundation

WHO – World Health Organization