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2 Engaging at all levels

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3 "Nothing about us without us"

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Engaging with patients at all levels

Patient engagement is an important challenge, and one that the FOPH is keen to support. There are various ways of engaging with patients and their relatives, ranging from the micro level, where professionals and patients hold one-to-one discussions, through to the macro level, where patients and their families may be asked to provide input for new draft legislation, for example.

Patient engagement – i.e. involving patients and their families in healthcare provision – is becoming increasingly important at global level. Engagement has been called the “Holy Grail of healthcare provision” or the “blockbuster drug of the decade”. While these claims are doubtless exaggerated, professionals all agree that involving patients and their families is important. Without greater patient engagement, it will be difficult to streamline our healthcare system and gear it more effectively to people’s needs.

Patient engagement is a subject that is constantly cropping up at the FOPH. One of the things that set the ball rolling was the Federal Council’s Health2020 strategy, which explicitly places people at its centre, stating that “The health system needs to continue to develop around them and their needs”. Engaging with health insurance policyholders and patients is essential in delivering a successful outcome to health policy reforms.

There are various reasons for stepping up engagement with patients and their families. One is that engagement increases the efficacy of treatment and improves care, as the Chronic Care Model demonstrates. Developed in the 1990s, the model provides an efficient way of delivering high-quality care to chronically ill patients. It comprises five elements, one of which is self-management support for patients. The aim is not to tell them what they have to do, but to help them take responsibility for their own health. It is important for patients to be informed of their illness so that they can make decisions autonomously. Furthermore, self-management has been shown to be cost-efficient when combined with care from the patient’s GP.

The question now is how to increase patient engagement in our healthcare system? How can professionals work more “with” rather than “for” patients? The Montreal model, developed at the University of Montreal’s Faculty of Medicine, delivers answers to these questions.

Levels of patient engagement

The first level of engagement is information – when a professional informs a patient about the treatment, for example. There is little dialogue at this level, which is a paternalistic form of engagement. The next level is consultation, where the

professional solicits the patient’s views and the patient has an opportunity to ask questions. At this level of engagement, patients assume a more active role by participating in decisions. At the partnership level, patients are aided in recognising their own capacities and using them for the benefit of their health.

The idea now is not to automatically turn every engagement into a partnership. A partnership-based approach does not make sense in all cases, all levels of involvement will continue to be legitimate in the future. However, a growing number of patients will want partnership-based involvement. This may also impact future treatment. For example, a study of patients with cardiac arrhythmia revealed that the patients who were involved in decision-making opted for fewer invasive procedures.

The introduction of electronic patient records (EPRs) in Switzerland may also affect engagement, in addition to exemplifying the shift towards a more active role for patients. In the past, the profes-

sionals held all the data and patients were granted access to it. EPRs will change that. Instead, patients will have control of their own records and will grant professionals access to them.

Organisational levels

The diagram not only shows the continuum of patient engagement, but also the levels at which it can occur. These start with the micro level, at which there is face-to-face dialogue between patients and professionals. The next level encompasses healthcare facilities such as hospitals and care homes. Here patients can contribute to improving everyday hospital processes or the quality of communications, updating care home recommendations or providing input for the training given to healthcare professionals. To make this a reality, a growing number of Swiss hospitals are setting up Patient Advisory Boards. Efforts to involve patients and their families in the planning, implementation and evaluation of health promotion projects can be seeded at this level.

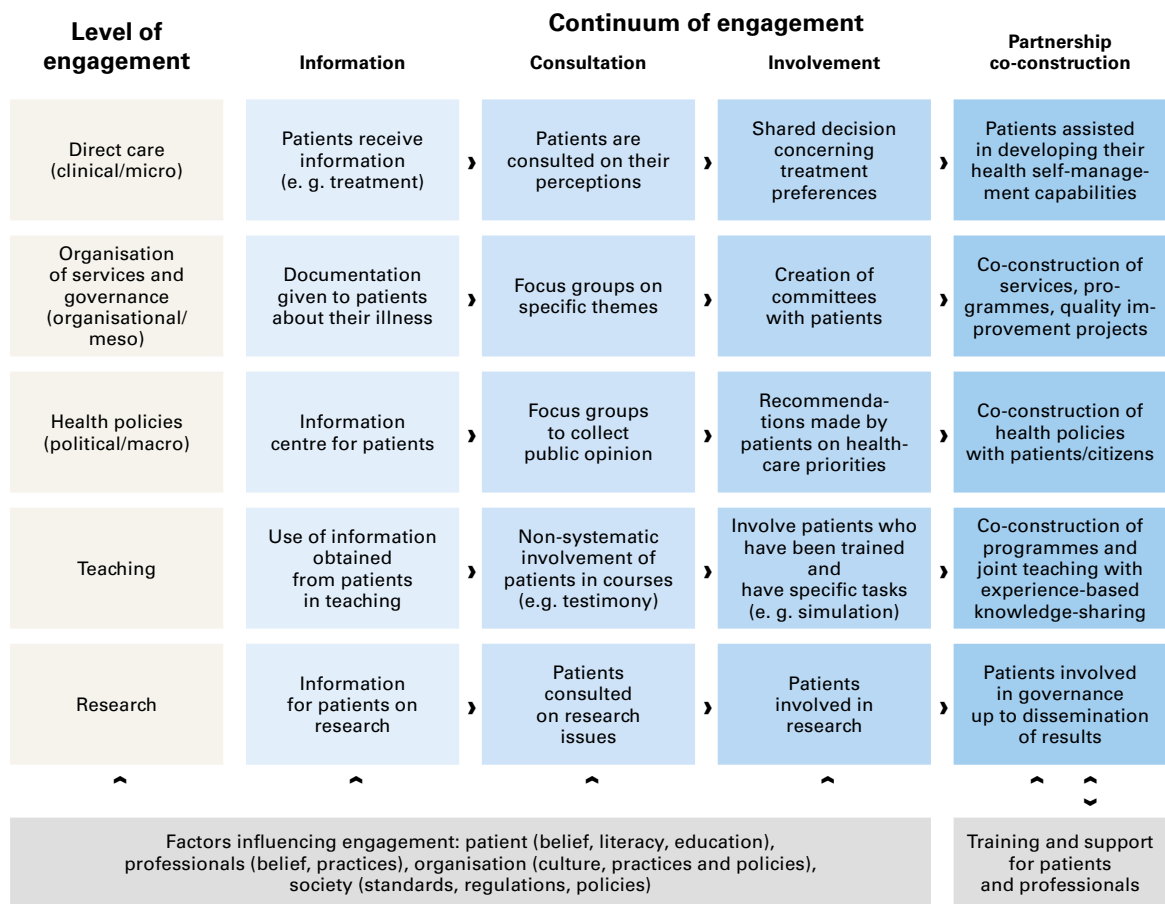
The macro level aim is to engage patients at communal, cantonal and national level in improving health laws or helping determine how resources are allocated.

Engaging with patients and their families at the FOPH

While the FOPH does not systematically engage with patients and their families, this edition of spectra does show that a number of initiatives are underway. Proposals for the “Prevention in healthcare provision PHP” project will be scrutinised to ensure that the projects chosen for funding provide for patient engagement. Furthermore, self-management has been designated within the PHP projects as an area requiring priority action (priority intervention area). In addition, the FOPH also works directly with people who are personally affected and/or their families on other projects – such as female genital mutilation or suicide prevention – or ensures during the award process that projects include engagement.

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Theoretical framework for continuum of patient engagement based on Carman et al. (2013): The Montreal model shows the continuum of patient engagement and the possible levels of participation. However, it takes little account of health promotion and prevention, both of which are important elements from the FOPH’s perspective. Patient engagement should not be limited to the treatment phase.

“Nothing about us without us”

A Patient and Family Advisory Board has been set up to support further implementation of the “Promoting self-management in non-communicable diseases, addiction and mental illness” project. This step reflects the project’s philosophy of “Nothing about us without us.”

A very special meeting took place at the FOPH in Bern on 18 June 2019: the first gathering of the seven-member Patient and Family Advisory Board (PFAB). One of the Board members is office worker Anna Troelsen, who was diagnosed with juvenile idiopathic arthritis – a severe inflammatory disease – at the age of 14. Since then she has been searching for the right treatment. On top of this, she also has scoliosis and cortisone-induced osteoporosis. Also on the Board is Martin Stucky, who was placed in foster care as a child and later developed a borderline personality disorder. While the seven members may have travelled different paths, they all have one thing in common: each is either affected by disease themselves or has had equivalent first-hand experience as the relative of someone with a disease. As part of its “Promoting self-management in non-communicable diseases, addiction and mental illness” project (see box), the FOPH invited these Board members to contribute their perspectives and experiences as patients and family members. Between them, the seven members cover all of these areas.

Nadine Stoffel-Kurt, FOPH project manager and co-initiator of the

PFAB, had this to say about the first meeting: “Everyone was very motivated and keen, and the discussion was wide-ranging and enriching for us all. We let our work be guided by our ‘Nothing about us without us’ slogan.” This slogan is intended to express the idea that professionals should always encounter patients and their families on an equal footing, and that expert theory should never be implemented without involving real-world experts.

Engaging with patients and their families in this way is still more of an exception at the FOPH. There are various reasons for this. Firstly, it is not always easy to find people who have been affected, and secondly, the FOPH has traditionally tended to work with health organisations and associations rather than with individuals with first-hand experience. Furthermore, processes like this often create a substantial amount of extra work. People need to be recruited and a communication flow has to be established and maintained between all stakeholders. And running a board of this kind is time-consuming.

Nevertheless, all the work pays off. “It’s definitely worthwhile”, says Stoffel-Kurt. “After all, we want interventions to be effective, which

means they have to be adapted to their target groups. Those of us working in the field benefit from a different perspective, one that we may not have been aware of before.” The members of the PFAB also benefit by helping to bring about tangible improvements and sharing their experiences with professionals in the field.

What needs to be borne in mind when engaging with patients and their families? “The important thing is to acknowledge the contribution that patients and their families make, for example by paying them an attendance fee for meetings.” The professionals represent their particular institution and contribute to boards and committees as part of their work – a task for which they receive compensation. This is generally not the case with patients and their families, who take part out of personal commitment and do the work associated with membership in their free time. “So payment represents an important way of recognising their work.”

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At first hand



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Improving care by engaging with patients and their families

Health policy measures should always be geared not only to the requirements of the people affected by them, but also to their needs. That is why the FOPH is endeavouring to include these people in the process of developing strategies and action plans right from the outset.

This issue of spectra is about engaging with patients, health insurance policyholders and local residents. There are many ways that people in Switzerland can help improve healthcare provision. As a patient, for example, I can play an immediate and active role in treatment decisions. However, patient or health organisations can also advocate my views in health policy processes and I can express my preferences myself by voting.

To be able to contribute actively to treatment decisions, however, we first have to have some understanding of the illness affecting us. The electronic patient records (EPRs) that are due to be rolled out throughout Switzerland from spring 2020 will give us, as patients, new ways of finding out more. With the arrival of EPRs, not only will professionals be able to consult our medical history wherever and whenever they need it, but, for the first time ever, we will be able to do so ourselves.

If I have an illness or accident, it not only affects me, it also affects my family. Family members can play a crucial role in my recuperation, either by offering emotional support or by actively helping with household chores or caring for me. To ensure that family carers do not get overburdened, they have been put at the centre of the research projects being undertaken as part of the “Relief services for family carers” promotional programme.

Everything we do as public health professionals should be guided by patients and their families.

Working together as equals

Strengthening self-management among patients and their relatives is one of the measures in the NCD strategy. The measure will be implemented in three steps. In the first step, a reference framework was created to promote a shared conceptual approach and mindset among stakeholders. The second step involved setting up a stakeholder platform as a forum for dialogue among stakeholders. During this step, it became clear that patient engagement is crucial in ensuring that the SELF platform can fulfil its tasks correctly. Implementing measures (step 3) without patient engagement is unthinkable in self-management promotion, which is why preparations to set up the PFAB were set in motion.

Organisationally, the PFAB is on the same (operational) level as the core team. It has the same powers and tasks as the core team, including annual planning, designing the platform event and communication resources, etc. To ensure communication flow between the core team and PFAB, one person from the PFAB communicates input from the board within the core team. Moreover, as an important indicator of commitment to participation, one person from the PFAB is a member of the steering group, the platform’s highest management level. This type of organisation is completely new and a first step to greater patient engagement. Experience will indicate where adjustments need to be made.



“Our experience is very positive”

Five questions for Denise Schwegler from the female genital cutting prevention unit at Caritas Switzerland. The unit assists and supports “multipliers” – key individuals in the communities from countries where cutting is practised. The unit partners with the multipliers to organise awareness events and counselling. By doing so they help protect at-risk girls and women.

1 Why is Caritas Switzerland working with volunteers in its efforts to prevent female genital cutting?

We refer to these people as multipliers, not volunteers, because we sign a contract with them and pay them for the work they do. There are around fifty men and women working with us in their communities to put an end to female genital cutting. They are essential to our efforts because they are the only way we can access the Somalian, Eritrean and Ethiopian populations, which often exist in isolation. The multipliers have the same background and speak the same language. Very often, they themselves are affected. Because they enjoy a high level of acceptance within their communities, they can address the often taboo issue of female genital cutting, and, in the best-case scenario, begin the process of bringing about a change in values.

2 How do you go about finding your multipliers?

In 2006, Caritas Switzerland set up a central counselling unit dedicated to preventing female genital cutting, most of the funding for which comes from the Federal Office of Public Health. Since then we have been running annual training courses for both male and female migrants as well as writing to interpreter referral services. Existing multipliers’ personal networks are also extremely important as a channel for motivating acquaintances and relatives to get involved too.

3 How do Caritas Switzerland and its multipliers divide up the work?

We support and coach our multipliers. Before they start their work, we give them a basic knowledge of the issue and brief them on the counselling services we provide. We also give them regular training once they are out in the field be-

cause we want to be sure that we are providing prevention counselling sessions and information events of the right quality. When multipliers organise awareness events, they decide where they should take place and invite people to attend. They also act as facilitators at the event and interpret if a specialist from the anti-cutting network speaks to the audience.

4 What experience have you had with this partnership? What works well and what are the challenges?

All in all, our experience has definitely been positive. The multipliers are helping us achieve our goals. We want to prevent girls being cut, but we also want to make sure that everyone in Switzerland has access to healthcare where possible. Because a lot of the women we meet at our events are unfamiliar with the Swiss system and often vulnerable too, they do not know that all forms of female genital cutting are a criminal offence in this country. They are frequently also unaware that they can get medical help or free advice. One of the major challenges facing our multipliers is the exposure within their community that the role inevitably involves. They need courage to counter the critics who accuse them of portraying the community in a bad light. For those of us who work in the cutting prevention unit, the challenge stems from the extreme heterogeneity of the multipliers, not only in terms of engagement and activities, but also in terms of education and familiarity with electronic media. Some do not even have an e-mail address.

5 Does Caritas Switzerland partner with volunteers in other areas too?

Yes, we do. We feel the model is a successful one and use it in other projects. We benefit greatly from partnering with volunteers because the work they do helps to create social cohesion.

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High rates of female genital cutting are found in the following countries in particular: Somalia, Eritrea, Sudan, Egypt, Guinea, Sierra Leone, Mali and Djibouti. Globally, more than 200 million girls and women are affected by genital cutting.

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