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# Self-help organisations as patient representatives in health care and policy decision-making

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## ABSTRACT

A crucial question about participation is who is legitimised, willing and capable of representing particular collectives. Social insurance health care systems tend to focus on representation by patient organisations. Self-help organisations (SHOs), as one type of 'health consumer and patient organisation', often take over this role. Research findings indicate that participation by SHOs is accompanied by high expectations, but also by concerns about the risks of instrumental abuse, overload and professionalisation. However, there is a dearth of in-depth knowledge about both potential and risks of participating for the SHO.

To tackle this research gap, a qualitative study design was used to investigate fifteen SHOs in Austria. Data were generated by expert interviews with SHO representatives and documentary analysis of SHO websites. Content analysis was applied.

SHOs in Austria advocate for patients' interests, participate in invited spaces and have various forms of cooperative relations with the health care system. Thereby, they draw on the experiential knowledge of their members without, however, systematising it. Experiences with professionalisation and instrumental use are ambiguous, whereas overload is prevalent.

SHOs need resources for reflection in order to define their position vis-à-vis the health system and to realise their potential as patient representatives. Deepening co-operation with the health care system might lead to new participatory practices acknowledging differences in culture and the resources of both sides.

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## 1. Introduction

Public and patient participation is high on the health policy agenda of many countries [1–5]. However, a comprehensive participation strategy is often lacking [4]. As participation is a complex and multidimensional phenomenon, its realisation beyond mere rhetoric remains challenging. Marent et al. [6] define participation as 'gaining influence on decisions that are taken by established stakeholders legitimized by expertise and/or legal authority and over which those who are affected usually have very little control'. Thereby, they point to several crucial questions that have to be dealt with when participation is planned, implemented and evaluated: What are the aims of participation (Why?), which issues are offered for participation (about what?), which role perspectives should be included (Who?), and how is the process of participation structured socially, factually and temporally (How?) [6].

In this article, we focus on the question of 'Who is representing patient/user perspectives in health care and policy decision making?' We do this by using empirical research from Austria where health policy increasingly draws on self-help organisations (SHOs) when patient perspectives are to be involved in health care and policy decision-making. This corresponds to what health policy analysts have found out: Different types of health care systems are inclined to include different perspectives and actors. In social insurance systems, such as Austria (or the Netherlands or Germany), patient/user-perspectives are generally sought [3,5,7,8] while in centralistic market-based systems (e.g. UK), there is a trend towards public or citizen participation. The perspective of patients or users of services [9,10] relates to the specific interests of certain groups and is informed by its 'experiential knowledge' [11] while the perspective of the general public or the citizenry is assumed to be oriented towards the 'common good' [12] and informed by lay knowledge and general democratic values. According to empirical studies, this dualism is in practice less distinct because the general public as well as users are not homogeneous [13]. Recent research [13] has shown that the role perspective of collectives of users may oscillate between particularistic and public interests.

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**Table 1**  
Initial sampling plan and ultimate sample.

	Initial sampling plan		Ultimate sample	
	Indication-specific SHO	Umbrella SHO	Indication-specific SHO	Umbrella SHO
National level	4	2	4	3
Provincial level	4	2	4	4

Who represents public or patient interests is also a question of who is capable of and willing to engage in participatory endeavours. Different selection procedures have different implications for the investment of money and effort, for the inclusion/exclusion of certain groups or the accessibility of representatives for the groups represented [14]. Patient/user perspectives are often represented by 'Health consumer and patient organisations' (HCPO) [15,16]. Among them SHOs play a prominent role.

SHOs are indication-specific, member-governed, voluntary associations building upon local self-help groups (SHGs) where those affected by a specific condition are engaged in mutual exchange and support. SHOs mediate between their members (read: patients) and the health care system [17,18]. SHOs strive to influence health care decision-making, to improve treatment conditions for patients and to enhance patient orientation. Their legitimacy to represent patients is founded on democratic elections of chairpersons [19] and the experiential knowledge of their members, which is accumulated more or less systematically [11,20,21]. This knowledge allows for the identification of common problems of patients using services. The integration of this experiential knowledge into health care decision-making is expected to lead towards improvements of services and the enhancement of patient orientation and is brought forward as the key argument for collective patient participation [3,11,20,21].

In Austria, a federal republic with a fragmented social-insurance type health care system, there are approximately 1700 health-related SHGs/SHOs. As self-help is self-organised and voluntary, there is a huge variety in aims, functions, organisational structure and reach of these groups/organisations [5]. The Austrian self-help field is composed of many local SHGs, more highly organised, indication-specific SHOs, and umbrella organisations at both provincial and national levels. Forster et al. [22] identified three main functions of SHGs/SHOs: sharing of experiences and mutual support, individual counselling and representation of interests. As the latter depends on a higher organisational structure, it is mainly found in SHOs. The main resources of SHOs are the voluntary work of members and the accumulated knowledge of those managing their disease/disability in everyday life. A core problem for their work in general and for participation in particular is the lack of resources, which may explain the discrepancy identified between participation as an aim of Austrian SHOs and participation taking place in practice [23].

Many stakeholders (e.g. Austrian Medical Association, Austrian Social Insurance) claim to represent patient interests in Austria. So far, patient advocates, ombudsman-like institutions, are considered to be the institution closest to patient interests. Direct patient participation in health care is just beginning to be established. The selection of patient representatives for participation usually relies on SHOs who are offered a seat (mostly in a consultative role) at the table of a few policy boards at both the provincial and the national levels. But so far, there are hardly any incentives and support for patient representatives nor is there a profound legal basis for collective patient participation [5].

As mentioned, the practice of involving SHOs in participatory practices is also common in countries other than Austria. Research findings conclude that SHOs have high potential as patient representatives. However, risks for SHOs may accompany this potential:

As SHOs are multi-functional organisations, participation might distract them from other functions. Furthermore, participatory involvement might result in instrumentalisation for the interests of others, e.g. medical industries or health professionals. Their involvement might become merely token [3,5]. Professionalisation of representatives is often considered as a possible counterstrategy. But it also constitutes a risk [3,5,24–26] as it implies the availability of additional resources and competences, such as e.g., the acquisition of formal knowledge [3,21]. This might result in alienation from the ordinary members due to a gap of information and power. Another risk discussed in the literature is overload of patient representatives due to an imbalance of participation opportunities and available resources [3,5].

In a nutshell, there is little and ambiguous empirical evidence about the experiences of SHOs when participating. It was our aim to reduce this gap and to deepen the understanding of the potential of and the risks for SHOs acting as patient representatives in the health care and health policy context.

## 2. Material and methods

The findings reported in this article are based on a larger qualitative study, which investigated the participatory practices and associated struggles of SHOs in Austria.

This study included only SHOs declaring representation of interests as one of their aims on their websites. SHOs were purposely sampled in accordance with the structure of the Austrian self-help field by organisational structure (indication-specific and umbrella organisations) and range of action (national and provincial level). For each SHO on national level, a corresponding SHO on provincial level was selected. Initially our sampling plan included twelve SHOs (c.f. Table 1). Selected SHOs were contacted via e-mail and asked to take part in the study. Only one of the intended SHOs could not be reached. It was replaced by another one and supplemented by an umbrella SHO on national and provincial level. Furthermore, one umbrella SHO on provincial level could not decide on its participation and was replaced by another one, but in the end also took part. Finally, fifteen SHOs participated in the study.

All but one SHO on provincial level were registered associations. SHOs on national level and umbrella organisations have existed for a shorter period of time than SHOs on provincial level. Indication-specific SHOs on the provincial and national level dealt with somatic (n=4) and mental (n=2) diseases as well as single-disability (n=2). The indication-specific SHOs on national level all had about ten member associations. Those on provincial level had five to ten SHGs and usually above 100 individual members. Umbrella SHOs on national level had ten to 40 member associations, on provincial level all but one had above 100 SHGs as members. Eleven of the fifteen SHOs had an office and employees.

Data were gathered by analysing the websites of the selected SHOs using an extraction scheme focussing on SHOs' participatory activities and associated struggles, if applicable, and through interviews with board members and, if existing, the chief executive officer of the SHO. Between July and December 2014, the first author conducted seventeen interviews (13 individual interviews and four with two representatives of the SHOs) after the representatives gave their formal consent.

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