

Chapter 4

Knowledge and Skills to Lead Effective Patient Organizations

ABSTRACT

The potential role of patients' organizations in healthcare, in order to be effective, needs to be sustained by appropriate knowledge and skills. The chapter has the scope to review the key requirements for the management of such organizations. After a background introduction about added value of patient capacity building, it proposes the 'antenna skill framework', a visual and practical illustration summarizing the necessary knowledge and skills for patient organizations' management. A generic patient organization is represented as an antenna progressively picking up many kinds of knowledge and skills: about the institutional framework, disease-related, technical, and managerial. Particular attention is devoted to management and administration, proposing a business model canvas tailored to patient organizations. In conclusion, the insightful tools proposed in the chapter can foster policymakers, universities, and other educational operators to conceive suitable training programs to form capable patient managers.

BACKGROUND

The contribution of patient organizations to health policies and healthcare R&D, as well as the educational role of patients' organizations to disseminate information from patients to other stakeholders (policy-makers, health authorities, mass media, scientific community, professional community)

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and vice-versa, require for these entities a strong attitude to internal capacity building and to strengthen their organizations and governance structures (Sienkiewicz & Van Lingen, 2017). Ideally, patients' organizations should assume the connotation of learning organizations, 'places' where people collectively learn how to learn, continually developing new patterns of thinking and the capacity to achieve desired results (Senge, 1990). Such organizations, whereas 'organizational learning' takes place (Rebelo & Gomes, 2011; Tsang, 1997) are also innovative and performing (Power & Waddell, 2004; Watkins & Marsick, 1993; 1999; Robinson *et al.*, 1997), because they are able to adapt to environmental changes (Armstrong & Foley, 2003). According to Watkins and Marsick (1993), seven dimensions connote learning organizations: continuous learning, dialogue and inquiry, team learning, embedded system, system connections, empowerment and leadership. More recently Marquadt (2011) identified five sub-systems in a learning organization: organization, learning, people, knowledge management, and technology. Each of them complements and is dynamically interrelated with the others: consequently, a scarce development in one (or more) of these subsystems has a compromising effect on the entire organizational system.

The above literature highlights how a holistic and systemic approach is needed to manage effective organizations. The scope of the present chapter is to propose a general framework summarizing the necessary knowledge and skills for patient organizations' management. In order to address this aim, the core categories of desired knowledge and skills are identified according to managerial and policy literature. Afterwards, the categories are 'exploded' into more specific areas and put together in the 'antenna skill framework', a visual and practical framework summarizing the necessary knowledge and skills for patient organizations' management. The notion of skills used in this chapter consists on *the ability to apply knowledge and use know-how to complete tasks and solve problems* (<https://ec.europa.eu/esco/portal/escopedia/Skill>). In some cases, the term 'skills' is paired with 'knowledge', to remark that some practical and technical applications require important achievements and advancements in one's cognitive sphere (about basic or specialist concepts and ideas) to be practiced systematically. When the term 'skills' is used alone, it is because the practical/technical component is prevalent in comparison with the - still present - epistemological one (for example in the case of communication skills).

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