

**STAKEHOLDERS IN SUPPORT SYSTEMS FOR SELF-CARE FOR  
CHRONIC ILLNESS: THE GAP BETWEEN EXPECTATIONS AND  
REALITY REGARDING THEIR IDENTITY, ROLES AND  
RELATIONSHIPS**

Journal:	<i>Health Expectations</i>
Manuscript ID	HEX-2015-2135.R1
Manuscript Type:	Original Research Paper
Keywords:	Chronic illness, Self-care, Self-management support, Stakeholders, Patient-centred care, Cross-national research

**Abstract**

**Background and objective** The spread of self-care holds the promise of containing chronic illness burden. Falling within the framework of a FP7 collaborative research project, this paper reports the views of key informants from six countries regarding who the main stakeholders are at different levels in the support system for self-care for patients with chronic illness (SSSC) and how they accomplish their role and collaborate.

**Methods** 90 Interviews with purposefully selected key informants from Bulgaria, Greece, Netherlands, Norway, Spain, and United Kingdom, were conducted. Interviews involved government and local authorities, politicians, academics, health professionals and private sector representatives. Interviewers followed an expert opinion-based guide. Analysis involved a cross-country examination with thematic analysis and Framework Method techniques.

**Results** Key informants described the ideal SSSC as inclusive, interdependent and patient-centred. The following main stakeholders in SSSC were identified: patients, governments, healthcare professionals, associations, private companies and the media. In the current SSSCs, collaboration among stakeholders within and across different levels was said to be lacking. Patients were seen as playing a passive subordinate role based on the following: their own attitudes; the paternalistic and medicalised attitudes of the healthcare professionals; their misrepresentation by patient associations; and their exposure to the damaging influences of media and industries.

**Conclusions** Making SSSC patient-centred constitutes the greatest challenge for European authorities. Strategies must be revised for promoting patient participation. They should undergo changes so as to promote industry and media social responsibility and patient association advocacy capacity.

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3 **Keywords** Chronic illness, self-care, self-management support, stakeholders, patient-centred  
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For Peer Review

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3 **STAKEHOLDERS IN SUPPORT SYSTEMS FOR SELF-CARE FOR CHRONIC ILLNESS: THE GAP**  
4 **BETWEEN EXPECTATIONS AND REALITY REGARDING THEIR IDENTITY, ROLES AND**  
5 **RELATIONSHIPS.**  
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9 **Background**  
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13 Fast-moving social and demographic changes in recent years have imposed great  
14 challenges on health systems. A critical example of this is the enormous and rising prevalence  
15 of chronic illness which, according to the World Health Organisation (WHO), could account for  
16 57 per cent of the global burden of disease by 2020.<sup>1</sup> Because such a burden would be  
17 overwhelming and posing a threat to the sustainability of health systems, new strategies for  
18 tackling chronic illness are emerging. Among the latter is self-care, which can be understood  
19 as *“the care taken by individuals towards their own health and wellbeing [that] comprises the*  
20 *actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological*  
21 *needs; to care for their long-term condition; and to prevent further illness or accidents”*.<sup>2</sup>  
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35 Evidence suggests that the main intermediate objective of self-care, sustainable  
36 behaviour change, can be better attained through multilevel approaches (individual,  
37 community, organisational, and systemic levels) that address processes involved in illness  
38 management at different systemic levels.<sup>3,4</sup> This is not surprising because findings from  
39 qualitative research have revealed that to engage in self-care tasks, patients feel the need for  
40 different types of support, stemming from a variety of sources (e.g. Instrumental,  
41 psychosocial and relational support from healthcare professionals, relatives and peers).<sup>5</sup> The  
42 corollary is that the development and deployment of self-care strategies require the  
43 involvement and coordination of multiple stakeholders at different systemic levels.  
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3 Moreover, this has implications for the design of support systems for self-care for  
4 patients with chronic illness (SSSC), an endeavour that policy makers and governments across  
5 Europe have gradually incorporated into the broader agenda of public health, health  
6 promotion and patient-centred care.<sup>6,7</sup> In particular, the main implication is that SSSC should  
7 adopt a social-ecological approach that supports patients and their capacity for self-care by  
8 addressing not only individual factors but also environmental influences spanning macro-,  
9 meso-, and micro-contextual levels. Indeed, environmental influences such as governance  
10 arrangements within welfare and healthcare systems (macro level), services provided by  
11 voluntary and community organisations (meso level) and patient domestic and employment  
12 context characteristics (micro level) have been identified as influencing self-care support.<sup>6,8</sup>  
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28 The operationalisation of this social-ecological SSSC is challenging. While research  
29 abounds in terms of how support for self-care is influenced by individual factors,  
30 understanding the impact of environmental influences remains scarce.<sup>9</sup> This makes it difficult  
31 to establish which environmental aspects should be prioritised in the design of SSSC and who  
32 could and should be involved and held responsible for their management.  
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40 **In summary,** it is necessary to broaden our understanding regarding how support for  
41 self-care is influenced by environmental factors in order to facilitate the design of SSSC, thus  
42 allowing for the implementation of informed initiatives relevant in the everyday life of  
43 individuals. To accomplish this general aim across selective settings in Europe, a project  
44 funded under the EU's 7th Framework Programme, entitled EU-WISE (Self-Care Support for  
45 People with Long Term Conditions, Diabetes and Heart Disease: A Whole System Approach)<sup>10</sup>,  
46 included an exploration of the influence of the broader socio-economic and policy  
47 environment on the capacity of **self-management**. More specifically, this investigation  
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3 included the identification and examination of views expressed by key informants in relation  
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5 to: (1) emerging policies and practices regarding type 2 diabetes and self-care; (2) impact of  
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7 macro and meso level influences on the SSSC for type 2 diabetes; and (3) roles, division of  
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9 labour and relationships of stakeholders on the micro-, meso- and macro-level of the SSSC for  
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11 patients with chronic illness and type 2 diabetes.  
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16 Most relevant findings related to the views expressed by key informants on policy  
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18 practices and meso-level influences on type 2 diabetes and self-care have been reported  
19  
20 elsewhere.<sup>9,11</sup> This paper focuses on reporting the findings related to the views of key  
21  
22 informants from six European countries regarding who the main stakeholders are at different  
23  
24 levels in the SSSC and how they should ideally participate and interact among one another.  
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26 Key informants' perspectives on the actual levels of coordination and collaboration between  
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28 these stakeholders are also examined.  
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### 32 33 **Methods** 34

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37 The EU-WISE exploration of the roles, division of labour and relationships of  
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39 stakeholders in the SSSC for patients with chronic illness and type 2 diabetes involved  
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41 interviews with key informants from a range of socio-economic, institutional and healthcare  
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43 contexts that could influence the organisation of and experiences with SSSC. These contexts  
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45 were the EU-WISE project partner countries: Bulgaria (BG), Greece (GR), Netherlands (NL),  
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47 Norway (NO), Spain (ES), and United Kingdom (UK). Each partner country obtained ethical  
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49 approval for the project from their pertinent Ethics Committee. **A pan-European approach to  
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51 study the issue was preferred as it can provide more robust insight into context-dependent  
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53 phenomena than single studies and it accelerates the generation, accumulation and transfer  
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3 of knowledge across countries. Furthermore, it offers the opportunity to identify a basic set of  
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5 networking structures and practices that suggest suitability for different contexts, and thus,  
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7 can enrich the development of supra national strategies and policies directed at  
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9 strengthening SSSCs.  
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13 The selection of key informants was purposeful and aimed at maximising variation and  
14  
15 expert sampling. A special effort was made to include a wide variety of participants from  
16  
17 different fields who had first-hand inside knowledge regarding policy, structures and practices  
18  
19 related to self-care support for chronic illness and type 2 diabetes. These participants  
20  
21 included government representatives and local authorities, as well as politicians, academics,  
22  
23 health professionals (i.e., general practitioners, specialist physicians, nurses, pharmacists and  
24  
25 dieticians) and representatives of the private sector (i.e. drug, technology, food and insurance  
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27 companies). Patients were not included because although they could offer a different  
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29 perspective on the issues under study, their opinions would not be based on expertise in  
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31 terms of informing, shaping and spreading the uptake of practices and policies related to  
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33 health programmes.  
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41 Potential key informants were identified through personal knowledge of project team  
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43 members, snowballing techniques, and examination of policy statements and organisational  
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45 websites in each partner country. Once identified, potential key informants were approached  
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47 via telephone calls or emails and given a brief explanation of the project and interview topics.  
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49 Further information and a consent form were emailed through a second contact, after which  
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51 approval to participate was obtained and interviews were scheduled.  
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3 Table 1 presents details on the backgrounds of the 90 key informants interviewed (15  
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5 per partner country).  
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9 Table 1. (INSERT HERE)  
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12 Interviews were conducted face to face or via telephone by project team members or  
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14 thoroughly trained interviewers who followed an interview guide based on expert group  
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16 discussions. As summarised in table 2, the latter was adapted to each partner country and  
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18 included questions reflecting the main interview topics. Interviews lasted between 30 and 90  
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20 minutes.  
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25 Table 2. (INSERT HERE)  
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29 Interviews were audio recorded and transcribed verbatim into Bulgarian, Greek, Dutch,  
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31 Norwegian, Spanish and English. Some of the Dutch interviews were not audio recorded. The  
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33 latter were analysed on the basis of detailed summaries typed immediately after each  
34  
35 interview. Anonymity of key informants' contributions was maintained in the presentation of  
36  
37 the data.  
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41 The analysis of the transcripts involved a three-stage cross-country examination guided  
42  
43 by thematic analyses and techniques from the Framework Method.<sup>12, 13</sup> Each partner country  
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45 provided a preliminary analysis of a set of interviews that were examined together so that  
46  
47 consistent themes and topics could be identified across countries, leading to the emergence  
48  
49 of a common thematic framework. Following the reading of the transcripts and field notes,  
50  
51 each partner country undertook a thematic and textual intra-country analysis that led to the  
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53 identification of recurring themes and subthemes. Selected quotes illustrative of these  
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55 themes were translated into English to allow for discussion among partner countries in two  
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3 comparative cross-cultural data analysis clinics and for supplementary discussions with  
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5 individual partners. The initial coding of each country's dataset was subjected to an adapted  
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7 comparative method to identify convergent and divergent themes across topics. Project team  
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9 members from each country accounted for cross-cultural differences in the datasets while  
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11 working towards shared meanings to reach a consensus on the meanings of key topics.  
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## 14 15 16 **Findings**

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19 Two main themes emerged in relation to the roles, division of labour and relationships  
20  
21 of stakeholders in the SSSC for patients with chronic illness and type 2 diabetes. The first  
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23 theme, "Identity of stakeholders in the SSSC", reflects the views expressed by key informants  
24  
25 regarding who the main stakeholders are at different levels in the SSSC and how they should  
26  
27 ideally operate and interact. The second theme, "Attitudes and collaboration of stakeholders  
28  
29 in the SSSC", reflects the perceptions of key informants concerning how these stakeholders  
30  
31 actually recognise the roles assigned to them and how they are currently acting, coordinating  
32  
33 and collaborating to support self-care. Therefore, the second theme abandons the  
34  
35 descriptions of the key informants' expectations on how the SSSC should operate to focus on  
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37 their perceptions of the actual state of affairs.  
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### 44 **Identity of stakeholders in the SSSC**

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46 According to the key informants, if new chronic illness and type 2 diabetes strategies  
47  
48 (and subsequently self-care) are to be promoted, multiple stakeholders should intervene in a  
49  
50 complementary and coordinated manner. Among these stakeholders, key informants cited  
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52 patients, governments, healthcare professionals, professional, scientific and patient  
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54 associations, private companies (such as drug, technology and food companies) and the  
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3 media. As presented in figure 1, these different stakeholders belong to and operate at  
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5 different SSSC levels, including the micro-, meso- and macro-levels.  
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9 Figure 1. (INSERT HERE)  
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12 Key informants described different functions for each of these stakeholders that, far  
13  
14 from being hermetic, are complementary and interdependent and thus prescriptive of a  
15  
16 particular pattern of interactions within the SSSC. The optimal relationships among  
17  
18 stakeholders in the SSSC for patients with chronic illness and type 2 diabetes as described by  
19  
20 key informants are presented in the left diagram of figure 2.  
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25 Figure 2. (INSERT HERE)  
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29 As illustrated in the left diagram of figure 2, key informants from the six countries were  
30  
31 consistent in stating that the SSSC should be patient-centred. In this arrangement, all efforts  
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33 and resources for self-care are organised around patients who, given their central position,  
34  
35 become empowered to establish active and direct relationships with health professionals and  
36  
37 patient associations. These relationships are expected to give patients a means by which to  
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39 make an impact not only on their own care but also on general standards of care, health  
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41 services designs and health policies. Ultimately, key informants expressed that patients'  
42  
43 empowerment and participation, aside from being desirable to themselves, are necessary for  
44  
45 meeting the demand for increasing the responsibility of patients in their own health  
46  
47 management and decision-making. While key informants from the UK and ES linked this  
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49 demand with the need to contain burdens on the health care sector, Norwegian key  
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51 informants linked it with a process of increased democracy.  
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3 From the key informants' perspectives, in the ideal SSSC, healthcare professionals  
4 should serve as some of the closest partners of the patients at the micro-level (See left  
5 diagram of figure 2). Healthcare professionals are expected to focus on helping patients  
6 increase their autonomy to the maximum extent possible, thus allowing an effective  
7 implementation of self-care.  
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16 Patient associations were described as the most important instruments for patients for  
17 influencing the health policies and practices of health professionals. They should maintain a  
18 close relationship with patients, advocating for patient aspirations and needs in terms of care  
19 and self-care, and at the same time they need to maintain ties and collaborate with  
20 healthcare professionals, professional associations and healthcare planners.  
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29 According to key informants, the input of patient associations and professional  
30 associations should help authorities at different levels to fulfil their roles in developing and  
31 maintaining the SSSC. These roles include the development and enforcement of self-care,  
32 chronic illness and type 2 diabetes policies; the organisation of health systems; the allocation  
33 and distribution of resources; and regulating and overseeing the environment wherein the  
34 SSSC is framed. This includes the regulation of industry (especially the pharmaceutical and  
35 food industries) and the media to protect the public from unhealthy environmental  
36 influences.  
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49 Key informants charged industry and the media with the duty of collaborating with  
50 health professionals and organisations so as to share accurate information about chronic  
51 illness and self-care with the public, break myths associated with chronic illness and self-care,  
52 and increase health literacy. More importantly, key informants highlighted the need for  
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3 industry and the media to self-regulate, fulfilling their social responsibility of avoiding  
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5 environmental impacts that endanger public health.  
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9 In addition to being consistent about how the SSSC should be characterised as patient-  
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11 centred and inclusive, key informants also agreed that this idealised model is far from the  
12  
13 current reality that is depicted by the right diagram in figure 2.  
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### 16 17 **Attitudes and collaboration of stakeholders in the SSSC**

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19 Within the theme regarding the current roles of the stakeholders, coordination and  
20  
21 collaboration, three sub-themes emerged highlighting the perceived deviations from the ideal  
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23 model of SSSC, as observed by the key informants: (1) Distortions in micro-level stakeholder  
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25 attitudes and relationships; (2) Distortions in meso-level stakeholder attitudes and  
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27 relationships with stakeholders at the micro level; and (3) Distortions in macro-level  
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29 stakeholder attitudes and relationships with stakeholders at the micro level.  
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### 33 34 ***Distortions in micro-level stakeholder attitudes and relationships***

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38 As presented in the right diagram of figure 2, key informants were in agreement that the  
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40 central role of patients in the SSSC that had been urged had not been developed or put into  
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42 practice. Instead, patients were seen as playing a passive and subordinate role due to  
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44 influence from the media and the private sector, and considered to be under the dominance  
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46 of paternalistic healthcare professionals.  
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51 According to the key informants, the subordinate relationship with healthcare  
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53 professionals was accepted and even promoted by large sectors of patients. For example, key  
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55 informants from GR and ES stated that elderly people are used to having a paternalistic  
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57 relationship with healthcare professionals and thus may not have the cultural inclination,  
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3 experience, skills or health literacy to participate in decision-making processes that affect  
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5 their health and self-care. Key informants from the UK noted that younger patients were also  
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7 having problems taking on a proactive role in self-care due to a lack of basic skills required to  
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9 undertake simple self-care tasks such as cooking. This may result in an increase in patient  
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11 preferences for medicalised care that relies on expert instructions and control.  
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16 For type I diabetes things are different because the patients are young. In type II  
17 (...) it's extremely difficult to persuade someone that their health does not solely  
18 rely on the doctor's decision on the units of insulin they take in the doctor's office,  
19 but that they too have to do something. To a large extent it shifts the doctor-  
20 patient relationship from how it had been previously established (GR1;  
21 Epidemiologist and internist)  
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24 People prefer more a paternalistic doctor that tells them what they have to take  
25 and what they have to eat (...) this demands from them less suffering and anxiety  
26 than having to learn to manage things for themselves, and it requires less effort  
27 on their part (...) I think this is a problem created by the doctor-patient culture in  
28 this country, where people are used to that "Mr Doctor says I have to take these  
29 pills and I take them, and I don't want to know" (...) it also depends on the type of  
30 population: now there are younger people who tend more to seek information  
31 themselves, but the average diabetic patient who finds themselves in this area of  
32 Endocrinology is over 70, and has had diabetes for 30 years now, and has always  
33 done whatever he was told to do, so it's hard for them to make their own  
34 decisions (ES6; Endocrinologist and academic)  
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38 There's also a lot of concerns about how as a nation, I'm not just talking Scotland  
39 here, I'm talking UK, is for how many people no longer even have very basic  
40 cooking skills and actually think that being able to cook means that you can do  
41 things like put something in a microwave (UK7; Academic)  
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44 Nevertheless, key informants explained that the subordinate position of patients is also  
45  
46 perpetuated by healthcare professionals. Key informants stated that while healthcare  
47  
48 professionals' attitudes towards promoting patient autonomy and self-management are  
49  
50 noticeably improving, their practice is still dominated by paternalism. This was mainly  
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52 attributed to the over-exposure of healthcare professionals to medicalised paradigms and to  
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3 existing practical barriers for implementing patient-centred approaches, such as insufficient  
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5 time, training, incentives, autonomy, and multi-professional human resources.  
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9 The way doctors behave is paternalistic and condescending and preserves their  
10 status quo (...) It is necessary to change the consciousness of patients, the training  
11 of doctors, to alter the behavioral model of medical personnel and it is important  
12 to start with the education at the medical universities (BG10; Academic)  
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15 Doctors are so much under time pressure to see so many patients that writing a  
16 prescription is a lot easier than taking that extra 5 minutes to find them the  
17 proper service (UK13; Drug company representative)  
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20 The satisfaction felt by the patients due to the rendering of services which they  
21 would not otherwise have, is the only incentive that I see (...) In England recently,  
22 8 years ago, financial and personal incentives regarding quality of life were given  
23 (...) and after 5 years there was some improvement in health indicators (GR7;  
24 General practitioner)  
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27 You don't have an agent for the implementation of those recommendations, you  
28 have an agent for the implementation of all the drug recommendations – they're  
29 called doctors (...) Where are all these behaviour change experts? (UK9; Social  
30 policy campaigner and academic)  
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33 More encouragingly, key informants from the UK and ES observed that nurses seem  
34 more inclined to participate in the development of less patronising and more egalitarian  
35 relationships with patients and thus to support and pioneer the implementation of new self-  
36 care strategies. Nurses' professional ethos and the opportunity that the spread of self-care  
37 presents for the expansion of their professional role were highlighted as the reasons for  
38 nurses to take such a favourable stance.  
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47 ***Distortions in meso-level stakeholder attitudes and relationships with stakeholders at***  
48 ***the micro level***  
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51 Key informants stated that patients are disempowered and relegated to a minor passive  
52 role in the SSSC, not only by their own attitude and their healthcare professionals'  
53 paternalistic and medicalised attitudes but also because they are misrepresented in patient  
54 associations. As presented in the right diagram of figure 2, in most countries (especially BG  
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3 and ES), the patient association sector is small, fragmented and immature. Their own needs  
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5 for development and survival lead them to focus on delivering services to patients rather than  
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7 on advocating for them.  
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11 Look how many patients' organizations there are and each one lobbies for its own  
12 interests, but they are not interested in educating the patients and defending  
13 their rights (BG10; Academic)  
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16 They always saw themselves as advisory and then (...) the only way to grow was to  
17 deliver services (...) you've now got a not for profit organisation that has spun off  
18 to deliver self-management and indeed commercial organisations who now say  
19 we can do it better than you (UK9; Social policy campaigner and academic)  
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22 In addition, their financial needs lead patient associations to strive for partnerships with  
23 stakeholders, such as professional and consumer associations and private companies. This has  
24 given rise to a shift in the agendas of patient associations from patient-centred to one driven  
25 by the interests of industry and professionals.  
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32 It isn't the patients the ones who represent themselves, but the consumers.  
33 Traditionally, the perspectives of consumers and patients are radically different,  
34 consumers are generally supporting the government stance at all times, and the  
35 patients, obviously, are more aggressive in demanding what they consider they  
36 need (...) Nowadays, the patients don't have a great influence on diabetes or on  
37 any other illness (ES4; Drug company representative)  
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41 They're very (...) one sided because it seems like they work very closely with  
42 medical professionals so everything they worked on was related to health care  
43 professionals so there wasn't much going on in terms of (...) health psychology or  
44 other areas where there is research being done (UK8; Academic and policy  
45 advisor)  
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48 In the UK, where the patient association sector appears to be more advanced, key  
49 informants noted that truly patient-driven associations tend to be single-issue campaigns  
50 without the ability and interest in promoting and seeing the bigger picture, and as a result,  
51 they are disregarded and marginalised.  
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3 There is this other charity (...) which was set up to campaign against human insulin  
4 which they believed caused cancer and is a true patient organisation (...) they're  
5 not quite as mad. It's a very, very small group and they're marginalised as being  
6 nutty. I think they probably are the foundation for a proper patient group but  
7 they're minor, minor, tiny, tiny, considered nutty (UK4; Academic and policy  
8 advisor)  
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11 The corollary of the failure of patient associations to fulfil their role of representing  
12 patients' interests and views to the authorities is that the influence patients have over health-  
13 related policies was considered to be rather marginal.  
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19 ***Distortions in macro-level stakeholder attitudes and relationships with stakeholders at***  
20 ***the micro-level***  
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23 Remarkably, stakeholders that should be placed in the most distant position from  
24 stakeholders at the micro-level were identified by key informants as the ones that find ways  
25 to establish direct contact with them (See right diagram of figure 2). For example,  
26 pharmaceutical companies were said to strive for establishing direct contact with both  
27 professionals and patients by means of financing the training and research of professionals or  
28 by getting involved in patient associations and educational activities. In most of the  
29 participant countries (UK, BG, ES, GR), this was said to occur despite existing regulations  
30 restricting these relationships.  
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43 There is a company which teaches patients how to take their insulin at home.  
44 Now, no company has been contracted with official bodies which provide such  
45 assistance (GR1; Epidemiologist and internist)  
46

47 Most of the pharmaceutical companies take part together with the medical  
48 experts in training modules for patients, the most active participants being the  
49 companies producers of insulin (BG15; Internist)  
50  
51

52 Key informants representing pharmaceutical companies alleged that their activities with  
53 professionals and patients are only intended to contribute to the SSSC while adding value and  
54 differentiating their products in the marketplace. However, the rest of the key informants  
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3 reiterated that pharmaceutical companies have ulterior motives for their formation of close  
4  
5 relationships with professionals and patients. For example, by organising training and  
6  
7 educational activities, pharmaceutical companies have the opportunity to introduce  
8  
9 informational biases that help reinforce the culture of medicalisation most favourable to their  
10  
11 organisational interests: maximising medication consumption and sales.  
12  
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16 There is now more of a tendency in some spheres to actually put people on type 2  
17 diabetes with insulin a bit earlier on (...) obviously general practitioners base their  
18 clinical decisions on guidelines but to some extent the guidelines are informed by  
19 the evidence (...) and unfortunately the evidence base that is currently available is  
20 predominantly driven by the pharmaceutical companies (...) there are lot more  
21 agendas at play than we might want to think (UK7; Academic)  
22  
23

24 I just see their role very much as funding the kind of research that ensures that  
25 their products get on to patient prescriptions in order to maximise profit (UK7;  
26 Academic)  
27

28  
29 One Spanish interviewee explained that pharmaceutical companies, unlike IT or  
30 insurance companies, have not understood the importance and irreversible character of  
31 recent changes to health systems, and thus, they have committed a strategic error by failing  
32  
33 to identify a new market niche.  
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38  
39 In the last forty years the pharmaceutical industry has not cured hardly anything.  
40 What it has done is to turn loads of patients into chronic patients. The drugs that  
41 are now out there pull in the same direction (...) An interesting thing that may  
42 happen to them is that they are launching products that they are not going to be  
43 able to sell because the market is changing. They don't understand that their  
44 customer organisation is going to be very different from the organisation they  
45 used to sell to. A company should divert its attention to the payer who is in  
46 control (ES10; Academic and policymaker)  
47  
48

49  
50 IT, telecare and telehealth companies were better regarded by key informants; they  
51 explained that their interests are more aligned with the philosophical underpinnings of  
52 chronic illness and self-care strategies. Thus, despite their incipient development and  
53  
54 marginal impact on the SSSC, telecare and telehealth companies were welcomed into the  
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3 system with less suspicion. Nevertheless, some key informants highlighted that the potential  
4  
5 for telecare and telehealth strategies to enhance the system of support for self-care would be  
6  
7 missed if their focus on the design and development of their products shifted from a patient-  
8  
9 focused approach to a healthcare professional-focused approach. Indeed, telecare and  
10  
11 telehealth products that are commercialised only as tools for the convenience of  
12  
13 professionals and to save them time could perpetuate paternalism in the relationships  
14  
15 between professionals and patients.  
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19  
20 The mobile phone intervention has a lot of potential but you've got to be very  
21  
22 careful how you organise it because the classic model is send your information to  
23  
24 the healthcare professional and they'll tell you whether you have a problem.  
25  
26 That's totally disempowering and that's a very common telehealth model  
27  
28 currently practiced (...) which was designed to be for the convenience of the  
29  
30 physicians (UK9; Social policy campaigner and academic)

31  
32 Finally, food companies and the media were noted as the least compromised in the  
33  
34 advancement of SSSC. According to key informants, food companies' sales strategies and false  
35  
36 advertising practices (i.e., presenting their products as almost medicinal) and media  
37  
38 sensationalism are harmful to people's eating behaviours and to the public's image of chronic  
39  
40 illness and type 2 diabetes.  
41

42  
43 You go to X supermarket and there is the trick: there is something like a "healthy  
44  
45 best-offer" but there is still the offer of unhealthy food that creates diabetics and  
46  
47 obese people (ES10; Academic and policymaker)

48  
49 The labelling here (...) is ludicrous. Low fat. What does low fat mean? One or 2  
50  
51 kilocalories below the full fat version but still 5 times higher than having a piece of  
52  
53 fruit (UK9; Social policy campaigner and academic)

54  
55 Some news coverage are little 'bombs' that go off, to do this that or the other (...)  
56  
57 all undermine our work a lot, because misinforming is very dangerous. As for the  
58  
59 Internet, they come to my office having already decided what their therapy  
60  
relationship should be. It's tiring and it leads to mistakes and it undermines the doctor-patient  
relationship (GR9; General practitioner and internist)

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3 Type 2 diabetes has had a focus in the media and it has been a biased focus upon  
4 overweight and perspectives – well one eats too much and doesn't move; that's  
5 why you have got diabetes type 2. It is obviously a stigmatising situation for those  
6 with diabetes type 2 (NO8; Nurse, professional association leader and  
7 policymaker)  
8

9  
10 The responsibility for the negative relationships between the industries, the media and  
11  
12 the public was laid on the industries and media but also on the authorities. While private  
13  
14 companies were accused of lacking social responsibility and refusing to self-regulate,  
15  
16 authorities were charged with failing to adequately regulate and oversee the environment of  
17  
18 the SSSC.  
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23 Other industries have somewhat started to self-regulate, but it is the agri-food  
24 industry which needs to do something serious about sugar and salt (ES10;  
25 Academic and policymaker)  
26

27  
28 The media do not reflect on their educational role (...) Most of them told us: "This  
29 is not our work. Our work is not educating or training people. This is your work.  
30 Our work is just to inform about whatever happens thanks to our freedom of  
31 press" (ES10; Academic and policymaker)  
32

33  
34 It is a problem that the government and the Ministry of Health do not control  
35 food and nutrition supplements advertisements (BG4; Patient association  
36 manager)  
37

38  
39 Enough pressure is not being put on producers and markets (...) you can see all  
40 sorts of conflicts of interest, you just have to look at the Olympics (...) we're trying  
41 to promote healthy activity and all our major sponsors are McDonalds and Coke  
42 (...) you allow advertisers to make those sort of false links in people's mind  
43 between healthy activity and McDonalds (UK10; Academic and policymaker)  
44

## 45 46 47 **Discussion** 48

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51 This study exposes the desires of the key informants for both reconfiguration and the  
52  
53 creation of new modes of functioning within the SSSC as well as their views on the current  
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55 state of affairs. While the SSSCs are at different developmental stages in the participating  
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57 countries, various issues could be observed that were common to all of them. First, key  
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3 informants from the six partner countries described the ideal SSSC as inclusive (in that it  
4  
5 demands the participation of multiple stakeholders at the micro-, meso- and macro-levels),  
6  
7 interdependent and patient-centred. This archetype, presented in more detail in the left  
8  
9 diagram of figure 2, emphasises the importance of a range of interactions between  
10  
11 stakeholders at the micro- and meso-levels in the SSSC as proposed in the Chronic Care Model  
12  
13 for chronic care improvement.<sup>14</sup> This demonstrates the great impact that the Chronic Care  
14  
15 Model has had on European stances in the battle against chronic illness.  
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21 Furthermore, key informants from all of the participating countries described practical  
22  
23 realities that are far from the ideal SSSC. In particular, the difficulty in bringing patients to the  
24  
25 centre of the system was observed across all of the participants' settings. The study identified  
26  
27 attitudinal and practical barriers to implementing patient-centred approaches such as  
28  
29 professionals recurring to paternalistic practice when confronted with a lack of resources, or  
30  
31 the variability in patient willingness to be involved in decision-making when they lack previous  
32  
33 experience, skills or health literacy. These barriers had been previously identified in studies  
34  
35 exploring perspectives regarding self-care strategies of other populations such as healthcare  
36  
37 professionals and patients.<sup>5, 15-17</sup> The fact that the same sources of paternalistic attitudes and  
38  
39 practices towards caring for chronic illness had been consistently identified as a deterrent for  
40  
41 self-care from a variety of perspectives reinforces the grounds for suggesting that actions  
42  
43 directed at addressing latent causes of patient disempowerment could be sound and  
44  
45 acceptable for enhancing SSSC and consequently, for spreading the practice of self-care.  
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52 Study findings also suggest that patient relegation to a minor role in the SSSC is also  
53  
54 perpetuated by the lack of capacity, representativeness and independence of patient  
55  
56 organisations for serving as the means for patients to influence health professionals' practices  
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3 and healthcare policies. Concerns regarding the capacity of European patient organisations to  
4  
5 advocate for patients have been raised before, but not in terms of its impact on the  
6  
7 configuration of SSSCs.<sup>17</sup> Thus, this study provides novel evidence to bring to light an  
8  
9 important area for intervention if SSSC is to be redesigned as patient-centred and to be truly  
10  
11 supportive of self-care strategies.  
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16 Another finding observed across the studied settings is the distortion in macro-level  
17  
18 stakeholders' practices and the relationships with stakeholders at the micro-level. The  
19  
20 inability of industry and the media to self-regulate and reconcile their interests with society's  
21  
22 health interests has been denounced previously and it appears to constitute an enduring  
23  
24 problem requiring genuine attention from authorities.<sup>19-21</sup>  
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29 Thus, the cross-country examination carried out in this study suggests that there are  
30  
31 common enduring barriers to enacting changes in health systems which must be addressed to  
32  
33 implement new strategies for tackling chronic illness, such as self-care. Study key informants  
34  
35 assigned the ultimate responsibility for addressing these barriers to governments and  
36  
37 authorities, who should strive for truly enacting patient-centred care by strengthening their  
38  
39 strategies to address the latent factors behind the inclination of professionals and patients  
40  
41 towards paternalistic and medicalised approaches to care; and the marginalisation of patient  
42  
43 capacity to influence health services and policies. In other words, authorities were said to be  
44  
45 responsible for promoting industry and the media social responsibility, as well as, patient  
46  
47 associations' growth (so they can become more independent and focus on advocating for  
48  
49 patients).  
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3 The traditional strategies of governments for encouraging corporate social  
4 responsibility, namely, ministerial leadership in identifying and allocating risks, development  
5 of public-private partnerships, subsidy of corporate social responsibility activities and  
6 organisations, and development of soft regulation, have shown limited effectiveness.<sup>22</sup>  
7  
8 However, recent evaluations of public-private partnerships aimed at improving corporate  
9 social responsibility have provided valuable insight into what can be done to improve the  
10 strategies for engaging companies and producing environmental gains for public health. In  
11 particular, their effectiveness could be improved if they evolve, becoming evidence-based,  
12 measurable and widespread, open to public and formal scrutiny, and supported by both  
13 appealing incentives (i.e. opportunities for improving organisational reputation) and sanctions  
14 for lack of commitment.<sup>23,24</sup>  
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30 Moreover, to bolster the patient associations' independent growth and advocacy  
31 capacity, researchers and patient associations have often recommended that governments  
32 increase funding and facilitate access of patient associations to decision-making structures.  
33 However, this governmental interference is not without disadvantages: patient associations  
34 may find it difficult to maintain patient agenda when facing the need for meeting criteria  
35 attached to subsidies; to oppose government proposals; or to use non-institutional or activist  
36 oppositional strategies to influence decision-making. For this reason, recent literature  
37 proposes that governments create less constrained subsidies that "come with fewer strings  
38 attached", last longer periods of time, and respond to public expenditure account systems  
39 that take into account a broad set of metrics that also evaluates their activities in terms of  
40 relevance for their members.<sup>25</sup>  
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3 In this research, the involvement of a range of countries with different socio-economic,  
4 institutional and healthcare contexts posed major advantages for improving the trans-  
5 European understanding of how SSSCs should be characterised and transformed. However, it  
6 also posed challenges for data collection and analysis that required attention so as to  
7 preserve the trustworthiness and dependability of the findings. Among them, the lack of  
8 equivalence of key concepts and the variability in the composition of the samples between  
9 the participating countries stood out. Attention to conceptual nuances was maintained in the  
10 adaptation of the interview guides and in the development of the common thematic  
11 framework and cross-cultural data analysis clinics. The research team members had  
12 knowledge of the structural and cultural aspects of different countries so that interpretation  
13 errors stemming from cultural misunderstandings could be avoided. Moreover, efforts were  
14 made to minimise variability across samples that do not respond to national particularities  
15 that need to be accounted for in the development of intra-country relevant samples. For  
16 example, sampling biases associated with snowballing techniques for identifying potential key  
17 informants were prevented by complementing the sampling process with a review of policy  
18 statements and organisational websites in each partner country.  
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## 41 **Conclusion**

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45 Further development and spreading of new strategies for tackling chronic illness such as  
46 self-care should be carried out if the chronic illness pandemic is to be contained and the  
47 sustainability of health systems is to be guaranteed. To achieve this, SSSCs should be  
48 reoriented to truly support a patient-centred approach to caring that facilitates the effective  
49 involvement and coordination of multiple stakeholders at different levels. This requires a  
50 change in the persisting paternalistic and medicalised attitudes among patients and  
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3 professionals, the growth and maturation of patient associations, and an increase in the social  
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5 responsibility of both media and industry. European authorities play a critical role in creating  
6  
7 environments that support public participation. They should develop and introduce enhanced  
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9 public-private partnerships to improve industry and the media social responsibility and to  
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11 offer less constrained subsidies and modes of participation for patient associations so they  
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13 can be more capable of advocating for patients.  
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For Peer Review



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Table 1. Key informants' background\*

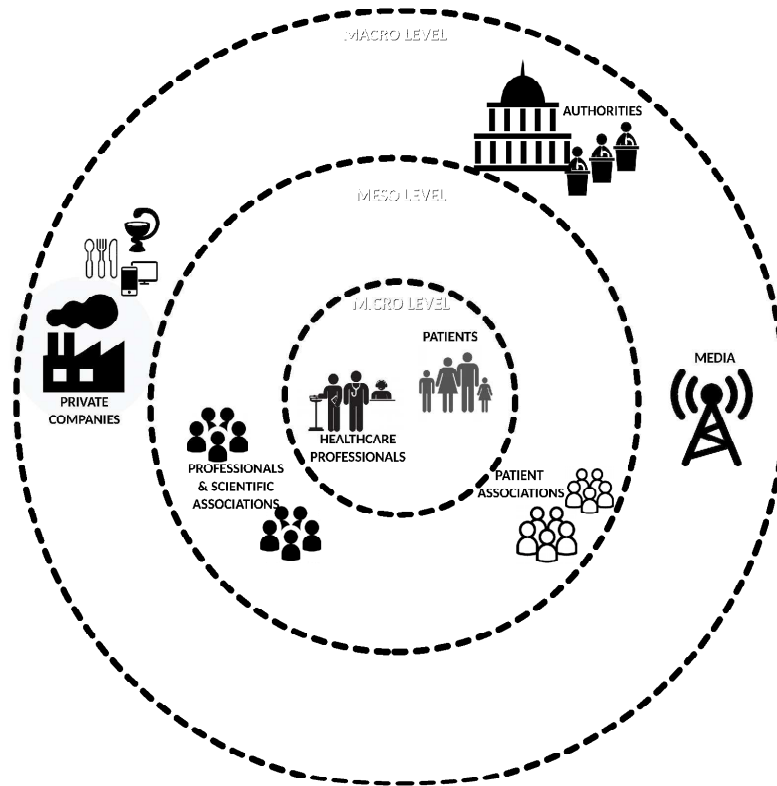
	Health professional			Policymaker/ Politician	Academic	Industry representatives (Drug/ Tech) / Health facilities managers
	General practitioner/ Specialist	Nurse	Other (Pharmacist, dietician)			
Bulgaria	11	1	3	5	5	5
Greece	6	2	7	3	3	3
Netherlands	2	2	11	6	3	1
Norway	5	4	6	7	2	2
Spain	5	3	7	6	7	3
UK	6	1	8	3	9	3

\*15 key informants per country who, in many cases, could be described under different categories

Table 2. Interview guide (questions adapted to each partner country)

- What are the key changes, policies, innovations in self-care support and diabetes type 2 over the last 10 years? Why have these been the most important ones? What changes have these led to?
- Why do you think policy has changed in the way that it has?
- Who are the most important stakeholders in this area? How have they influenced the agenda around self-care support?
- What is the role of drug companies nationally/ internationally? Do you have a view of current policy around the role of drug companies or how they influence the agenda in this area?
- What is the role of telecare companies?
- What is the involvement of other private companies in self-care support?
- How is the broader healthcare system organised?
- What are the public attitudes to self-care support and diabetes type 2?
- What are the media constructions of the epidemic of diabetes type 2 and who is at risk?

Figure 1. Stakeholders at different levels in the SSSC

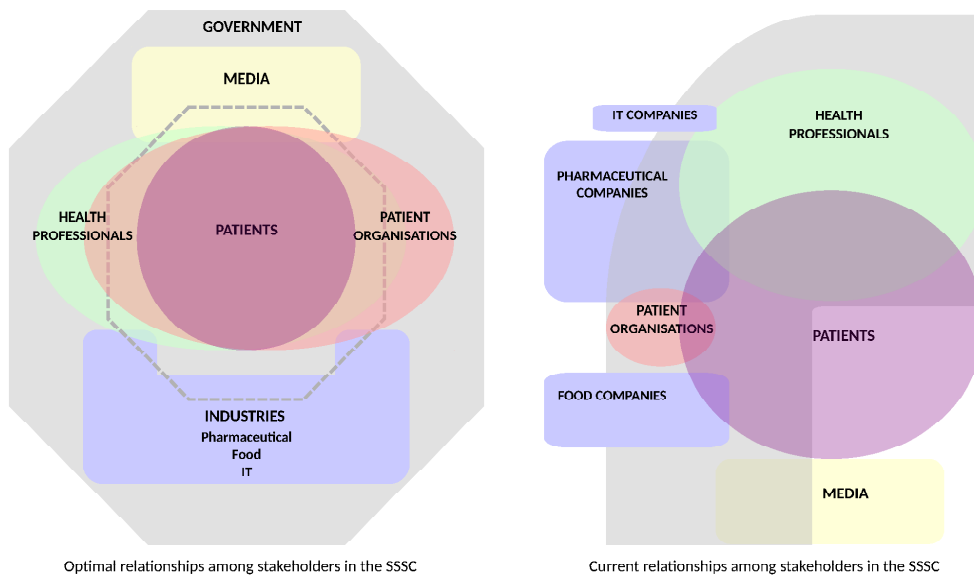


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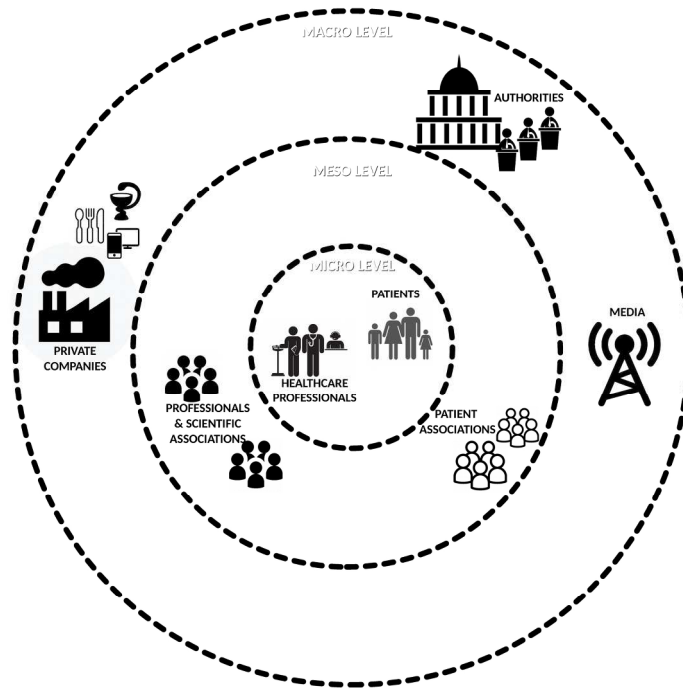
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Figure 2. Optimal and current relationships among stakeholders in the SSSC as described by key informants



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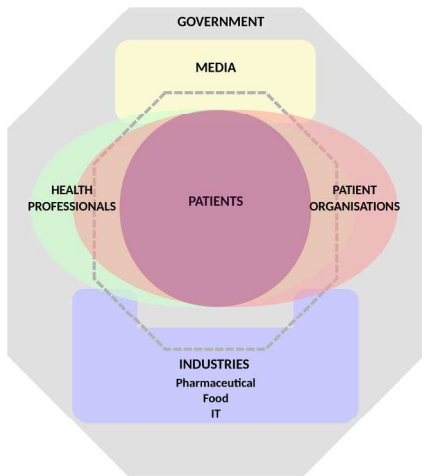
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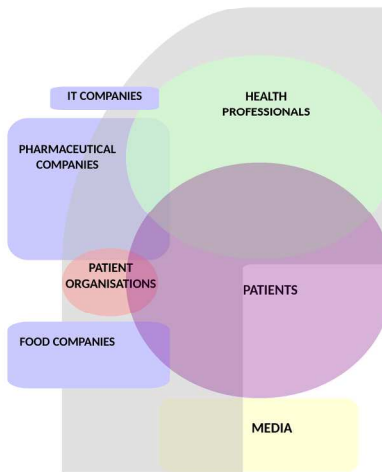
209x148mm (300 x 300 DPI)

Review

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Optimal relationships among stakeholders in the SSSC



Current relationships among stakeholders in the SSSC

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Review