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Analysis of patient organizations' needs and ICT use – The APTIC project in Spain to develop an online collaborative social network

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Abstract

Background The purpose of this first part of the APTIC (Patient Organisations and ICT) project is to design and run an online collaborative social network for paediatric patient organizations (PPOs).

Objective To analyse the needs of PPOs in Spain to identify opportunities to improve health services through the use of ICT.

Setting and participants A convenience sample of staff from 35 PPOs (54.68% response rate) participated in a structured online survey and three focus groups (12 PPOs).

Results Paediatric patient organizations' major needs are to provide accredited and managed information, increase personal support and assistance and promote joint commitment to health care. Moreover, PPOs believe in the Internet's potential to meet their needs and support their activities. Basic limitations to using the Internet are lack of knowledge and resources.

Conclusion The discussion of the data includes key elements of designing an online collaborative social network and reflections on health services provided.

Introduction

The starting point of this article is Toiviainen *et al.*'s[1] definition of a patient organization (PO) as a registered nationwide organization formed around a specific, officially accepted disease or disability and whose members are sick people and/or their relatives. POs work to inform about the disease and its treatments; provide social and psychological assistance; improve quality of life of patients and their families; and perform numerous tasks such as organizing training or leisure activities, encouraging research and doing outreach and social awareness actions. Therefore, organizations strictly for health professionals are not included. A unified directory of POs does not yet exist in Spain and even less so for paediatric patient organizations (PPO). Thus, the reference used was an *ad hoc* directory to guide families to the appropriate organization in their area of residence. This directory, based

on a previous directory from the regional government[2] and a national directory created by the pharmacological industry,[3] was compiled by the patient organisations area of Sant Joan de Déu Paediatric Hospital (HSJDbcn), a paediatric hospital of reference in Spain. This PO area is an innovative initiative with a patient-centred strategy designed to cope with PPOs' difficulties in collaborating with hospitals[4] and help PPOs to develop their activities. It consists of a physical space, run by the hospital, where PPOs can meet, provide information and support patients and their families using the hospital's resources and facilities.

This article aims to analyse the needs of PPOs in Spain to identify opportunities to improve health services through the use of ICT. This analysis is the first step in an online service inside the hospital: APTIC Patient Organisations and ICT, a research project that follows the indications of the International Alliance of Patient Organisations (IAPO)[5] and the paradigm of participatory action research[6] because it has a patient-centred perspective designed to address patients' need in an appropriate and cost-effective way. APTIC's objective is to design and run a collaborative social network for PPOs within the Patient Organisation Area of the HSJDbcn. Thus, it becomes another health service tool. POs are a source of additional help for family caregivers (by giving information, mutual support, advice, etc.); thus, a supportive collaborative social network will enhance synergies between the hospital and organizations, improving health-care services.

Patient organizations and ICT

Involvement in POs and the structure of their activities promote the use of ICT because they favour membership and involvement in online health communities,[5,7] thus enhancing disclosure of sensitive topics. A PO provides a sense of community and hope for the future, reduces feelings of stress, enhances knowledge, favours preparedness and reassurance and boosts coping strategies and feelings of empowerment.[8–10] Thus, online health communities could lead to an extension of POs' range of action and a chance to set new goals.[11]

Online health communities have been studied as an opportunity for health-care organizations. Many hospitals include running an online health community in their catalogue of services as a way to expand and ensure customer loyalty.[12,13] They create virtual spaces with communicative and informational tools for patients, POs and professionals. In some cases, they even create communities of practice to promote collaborative knowledge creation among lay users and professionals.[13] These online communities have been used by patients and POs for informational purposes rather than for communicating and exchanging experiences.[12] They seem to have a positive impact on patients, enhancing relationships with the organization[13] and promoting a sense of satisfaction with the health organization and the services it provides.[14]

The study of health-related online communities has also been approached by observing the needs people try to meet through participation.[15] Among them, information about the disease and symptom management is usually identified as fundamental pillars in the research.[15–19] In health-related online communities, patients and caregivers (and/or health professionals) are more interested in sharing knowledge and personal experiences,[20] and do so regularly, than in sharing emotional support.[14] Moreover, considerable online health-related information is created and maintained through the mediation of individuals other than health professionals (e.g. other patients),[21] developing an online collaborative social network. Another perspective for studying online health communities stems from their impact and effectiveness. Thus, the WHO recognizes the positive impact on the quality of care and quality of life of patients who use the Internet, either through virtual communities or other Web 2.0 tools. In recent years, studies have indicated that participation in online health communities increases users' empowerment.[22] While no findings show that

participation can be detrimental, studies fail to find robust evidence of any health benefits,[16,17] despite positive effects through indirect mechanisms[23,24].

POs and ICT in Spain

Few studies have specifically analysed POs and ICT. In Spain, there have been two such studies: one by a pharmaceutical company[3] and another commissioned by the regional Department of Health (PIC Research Project)[25]. Although they do not provide segmented data on PPOs and therefore cannot serve as a clear reference for the present study, one of their main conclusions is that ICT is considered complementary to off-line communication methods, and the main objective is to use them unidirectionally to provide information to members, rather than facilitate collaboration.

A more recent study led by a pharmaceutical company in Spain[26] considered the role of POs as a source of health information on the Internet. Although information found on POs' websites was considered helpful, these sites were rarely consulted, which may be related to previous studies showing that for health issues, chronic patients (such as PO members) turn to different actors to meet their needs.[13,27] For health information, professionals are the reference used, rather than POs.

Online health communities provide new opportunities for POs. However, their mere use is not sufficient, as they must be employed in an efficient and meaningful way. Thus, the first phase of the APTIC project was to consult POs and explore their perspectives on desirable and important characteristics of an online health community designed to be run as an online collaborative social network to support coping with chronic paediatric illnesses. Opportunities and obstacles to the implementation of ICT in the PPOs' practice were sought and explored. In 2011, the APTIC project was included in the Web 2.0 strategy of the HSJD[28]. Therefore, this paper presents an analysis based on data gathered between 2008 and 2009.

In conclusion, the purpose of this paper is to analyse the needs of PPOs in Spain and explore how ICT can meet them. A sample of PPO staff were interviewed and surveyed about their current activities, their uses of ICT and their expectations about them. Data are discussed, concluding with some guidelines for designing an online collaborative social network for these organizations.

Methods

Participants

A convenience sample of PPO staff from the PPO directory compiled by the PO area of the HSJDbcn was used. In these organizations, staff members are also family caregivers of paediatric patients. A total of 35 PPOs participated in the study (35 of 64 PPOs contacted; response rate of 54.68%), 32 through an online survey and 12 through focus groups conducted at the hospital facilities. The 66.7% (8 of 12 PPOs) who participated in the focus groups also answered the online survey.

Participation was voluntary, and there were no incentives to participate, apart from a final report at the end of the project.[29]

Survey instrument

An online survey, adapted from a survey used in a previous study in Catalonia, Spain[25] and available in both Catalan and Spanish (co-official languages), was sent to the staff of the PPOs.

This survey contained 48 multiple-choice questions in two sections. The first section ('organization and disease data') requests information about the PPO's characteristics (number of affiliates, geographical coverage, age of the organization, members' ages, etc.) and the diseases it addresses. The second section ('the organization's activities and use of ICT') asked about ICT use for the PPO's ends. In this section, questions refer to the use of Internet, email, face-to-face or phone contacts for the organization's activities (information,

support, research). When the PPO had its own website, staff also had to report on its characteristics and resources available to manage the web. Finally, the staff was asked about expectations (pros and cons) regarding ICT use for their organization.

The survey was available online from December 2008 to March 2009. A copy of the survey in PDF format was sent to participants upon request.

Focus groups

Focus groups provide rich descriptions of phenomena and enhance understanding of the context in which these phenomena occur.[30] Three focus groups were run during December 2008 at the PO area of the HSJDbcn. Groups ranged from 4 to 9 participants, all of whom were staff in their respective PPOs, besides being family caregivers of a paediatric patient. A facilitator conducted each of the focus groups, together with two other members of the project. Discussions were organized around the following three elements: (i) presentation of the APTIC project; (ii) discussion of the PPO's ICT needs and uses; (iii) discussion of a pilot online community for caregivers and its applications (this community was similar to the APTIC project under development). Each session lasted from 120 to 150 min, and participants were asked for their consent to make an audio recording. The facilitator and collaborators also took field notes.

The Ethics Committee of the Universitat Oberta de Catalunya approved the study.

Analysis

All the quantitative analyses of the data obtained from the survey were performed using the statistical package IBM SPSS Statistics for Windows, Version 19.0, 2010 (IBM Corp., Armonk, NY, USA). First, a descriptive statistical analysis of PPOs was performed. Second, a description of PPOs' activities and Internet use is provided. This analysis uses parametric and nonparametric tests regarding the nature of the variables (comparisons of the confidence interval – IC-95% and chi-square test).

Discussions from the focus groups were transcribed *verbatim* by a research assistant and reviewed by the facilitator. Finally, a thematic analysis was made to identify themes emerging from the data.[31] Independently, two judges categorized the content of the focus groups. Discrepancies were resolved by consensus. They refined the code definitions and developed new categories as new topics emerged, to capture the major themes. Coding system reliability was determined by a complete and independent analysis of each transcription (Cronbach's alpha = 0.89).

Results

Results are organized in two sections: quantitative data from the survey and results from the analysis of the focus groups.

Survey results

Description of the paediatric patient organizations

Table 1 summarizes the data from the 32 PPOs that responded to the questionnaire. Most of the PPOs (55.2%) were established between 1991 and 2000, and they were not very large (69% had <500 members). The geographical scope was regional (58.6%) and national (41.4%). Members were mostly *family caregivers* (82.2%). All the PPOs had volunteer members working. The data showed that 72.4% of PPOs had a broad scope and dealt with between 1 and 5 different diseases. Diseases covered were congenital and chromosomical abnormalities (35.7%), physical diseases affecting different body systems (nervous, circulatory, digestive, musculoskeletal, endocrine, eye and ear diseases) (46.4%), mental and behavioural disorders (14.3%) and neoplasms (3.6%).

Another interesting finding displayed in Table 1 is the low participation of members in activities promoted by PPOs; in 67% of the cases, the participation rate was below 43%.

Table 1 Description of paediatric patient organizations

Year the PO was created		Geographical coverage	
Before 1990	17.2% (5)[1]	National scope	41.4% (12)
Between 1991 and 2000	55.2% (16)	Regional scope	58.6% (17)
After 2000	27.6% (8)		
Members' profiles (n = 56 responses)[2]		**Number of members**	
Professionals	5.4% (3)	8–100	31.0% (9)
Family caregivers	82.2% (46)	101–500	38.0% (11)
Others	12.5% (7)	501–1000	20.7% (6)
		>1000	10.3% (3)
Age of members			
Between 31 and 45 years old	53.3% (16)		
Between 46 and 60 years old	46.7% (14)		
Number of paid staff		**Number of volunteers**	
0 people	46.7% (14)	<6 volunteers	33.3% (10)
1 people	13.3% (4)	6 to 10 volunteers	33.4% (10)
>1 people	40.0% (12)	>10 volunteers	33.3% (10)
Range of diseases treated		**Participation rate of members**	
1 diseases	43.8% (14)	<10% regular participants	33.3% (9)
3 to 5 diseases	24% (7)	10% to 43% regular part.	33.4% (9)
> 5 diseases	27.6% (8)	>43% regular participants	33.3% (9)
Have website?		**Who designed the website**	
Yes	96.0% (1)	Volunteers	54.2% (13)
No	4.0% (24)	External professional	25% (3)
		Internal professional	4.2% (1)
		Others	16.7% (7)
Has the Website accreditation?		**Regularity of website updates**	
Accredited by *Web Medica*[3]	4.2% (1)	Daily	20.8% (5)
Other accreditations	8.3% (2)	Weekly	37.5% (9)
No accreditation	58.3% (14)	Monthly	25% (6)
Don't know	29.2% (7)	Yearly	8.3% (2)
		Never	4.2% (1)
		Don't know	4.2% (1)

[1]The % and (n) are calculated in base of valid cases in each answer.
[2]Multiresponse question.
[3]*Web Medica Acreditada* is a quality seal from the *Colegio Oficial de Médicos* [official college of doctors].

Thus, PPOs' members do not regularly participate in activities promoted by the organization.

Of the websites studied, 96% had a homepage, 54.2% of which were designed by volunteers. The web pages contained limited up-to-date content, as 83.3% of PPOs updated their sites less than once a month. 29.2% did not know whether their website was accredited, although this issue did not seem to concern them.

Table 2 shows a breakdown of the websites' contents. This information emerged from a

Table 2 Description of website contents

Website contents [1](*n* = 100 responses)	
Information for the general public about the disease	22%
Information about the activities of the PPO	22%
Information about the disease for professionals	15%
Information about social aid and grants	14%
Information about health resources	13%
Private area for communication between members	6%
Information about facilities in the local neighbourhood	2%
Private area containing profiles of each member	1%
Other	5%

[1]Multiresponse question.

multiresponse question; answers focused mainly on *information for the general public about the disease* (22.2%) and *information about the PPO's activities* (22.2%).

The PPO's activities and its Internet use

Face-to-face vs. online activities. Table 3 provides a summary of the PPOs' activities and the way they are carried out. The first column shows the importance of each activity to the organization, and the second and third columns show the degree to which these activities are performed online (Internet and email) or face-to-face (in person and by phone). The percentages reflect the total responses of *quite* or *very important* for the importance of each item (i.e. PPO's activity) or *often*/*very often* for the extent to which they use online or face-to-face communication for each. The final column presents a comparison of the confidence interval (CI) (95%) for the degree to which they use these two media (online vs. face-to-Face).

All the PPOs' activities were considered very important, with rates between 100% and 81%, with the exception of *information about treatments* (63%). There were no statistically significant preferences for doing activities online or face-to-face. However, there was a slight tendency to prefer doing activities related to psychological support through face-to-face meetings (62.5%) rather than online (40.6%), although the difference was not statistically significant.

Expected improvements due to ICT and limitations of use

The PPOs were asked how the Internet could improve different aspects of their activities, and the limitations of using the Internet (Table 4 expected uses and limitations of use,

Table 3 Activities of the PPO and means of carrying them out.

	Activities of the PO[1] (%)	Internet [2](%)	Face-to-face[2](%)	Significance[3]
Information about resources	96.3	65.5	62.5	n.s.
Information about the health condition	100	65.6	59.4	n.s.
Information about treatments	63	37.5	37.5	n.s.
Links to other sources of information	81.5	71.9	62.5	n.s.
Increase society's awareness of the disease	96.3	68.8	53.1	n.s.
Psychological support	85.2	40.6	62.5	n.s.
Promotion of scientific Research into the disease	81.5	34.4	21.9	n.s.
Information about the Organization	92.6	78.1	68.8	n.s.
Information about specialists	88.9	46.9	59.4	n.s.

[1]The percentages represent the total number of responses of *quite* or *very important* to every item.
[2]The percentages represent the total number of responses of *often* or *very often* to each item.
[3]Comparison of percentages for *online* vs. *face-to-face* comparing CI.

respectively). To highlight the most valued aspects, we compared the response distribution for each item (grouping responses into three categories – disagree/indifferent/agree) with a null hypothesis of equiprobability (equidistribution) using the nonparametric chi-square test. Table 4 highlights that the use of ICT can improve the knowledge of members and the general population about the disease and enhance the disease management and autonomy of patients and their families. Furthermore, ICT use for paediatric associations was considered an opportunity to improve relationships with the community and health professionals. However, improvements in the caregivers' own health or in relation to the pharmaceutical sector are not expected. Regarding limitations of using the Internet, the most important barriers were the associations' lack of computer skills and limited economic resources. PPO staff considered that a lack of qualified personnel, member Interest or use and knowledge about the Internet were not clear limitations to using ICT in associations. Finally, PPOs believed that ICT use can coexist with other useful tools (face-to-face contacts, telephone, email).

Focus group results

This section includes qualitative results from the thematic analysis of the focus groups. The issues are listed according to the most significant categories, and an example is included for each.

Tool for communication and information

Participants pointed out the potential of a website as a communication tool and a facilitator of information: newsletters, scientific papers, mailing lists, etc.

> ["ordinària entre nosaltres per reunions i així... i funciona molt bé. I ara... i a més a més, amb els socis, que som molt dispersos, si no tinguéssim internet, seria molt costós, perquè per correu ordinari és molt costós el paper...i el segell". (F181208)]

> Regular meetings between us and so... and works very well. And now... and also, with members, who are widely scattered, would be very costly without the Internet because mail is very expensive, paper, stamps...

Also, a PPO's website should provide users with information that is accessible, filtered, validated, rigorous, labelled, not excessive, specific

Table 4 Expected improvements and limitations

Expected improvement	Disagree (%)	Indifferent (%)	Agree (%)	Significance[1]
Improve knowledge about the disease	0	0	**100**	$P < 0.001$
Improve relationship with the community	12.5	0	**87.5**	$P < 0.001$
Improve relationship with health professionals	4.2	8.3	**87.5**	$P < 0.001$
Improve relationship with the health problem	4.2	12.5	**83.3**	$P < 0.001$
Improve personal health	30.4	43.5	26.1	$P = 0.57$ n.s.
Improve knowledge of and relationship with the pharmaceutical sector	25	29.2	45.8	$P = 0.42$ n.s.
Improve patient autonomy and of the people close to him/her	8.3	8.3	**83.3**	$P < 0.001$
Limitations of use				
Lack of funding	12.5	29.2	**58.3**	$P = 0.02$
Lack of computer skills	20.8	8.3	**70.8**	$P < 0.001$
Lack of qualified personnel	20.8	25	54.2	$P = 0.09$ n.s
Lack of members' interest	45.8	33.3	20.8	$P = 0.32$ n.s
Lack of members' use and knowledge	29.2	33.3	37.5	$P = 0.88$ n.s
Availability of other more useful tools	**62.5**	29.2	8.3	$P < 0.01$
Not limited	33.3	45.8	20.8	$P = 0.32$ n.s

[1]Comparison of the distribution of each item with the null hypothesis of equiprobability using the nonparametric chi-square test.
If there are statistically significant differences, the most frequent value is noted in bold.

and linked to the needs of individuals. It should reach people in a direct, centralized and personalized manner.

> [Tu no has de buscar la informació, la informació t'ha de venir i ha de ser una informació personalitzada... (F181208)]

> You don't have to search for information; the information has to come to you and be tailored...

Moreover, a website would be a way to increase members' involvement while making the organization more visible: it can explain who they are, their activities and how to contact them.

> [...nosaltres ara començarem a tenir una web i al menys així farem una mica de difusió. (F181208)]

> We will have a web and, at least, we could start spreading information.

Help people

In general, the reason for creating each PPO was to help people. With the incorporation of ICT, this objective is still valid. PPOs contend that members should be more active than ever, which means breaking time–distance barriers to get closer to members. ICT appears to be the best choice to meet individuals' different needs at different times.

> [...ja hem creat la pàgina web, també amb la idea de poder ajudar des de la web i dir: nosaltres estem aquí i et podem ajudar perquè vivim aquesta situació. (F151208)]

> ...we have already created the website, also with the idea to help from the web and say: we are here and we can help this situation because we live with it.

Along these lines, ICT is seen as a tool for developing skills that improve everyday life, beginning with members' quality of life.

> [Nosaltres no pretenem informar sobre les "cardiologies" congènites, per a això hi ha els metges i hi ha els hospitals que tenen les seves funcions. Nosaltres, en el que som especialistes és sobre les repercussions d'aquestes cardiologies congènites en la vida quotidiana. (F181208)]

> We do not intend to report on congenital 'cardiology; for this purpose, there are doctors and hospitals that have their functions. We are specialists in the implications of these 'congenital cardiology' [congenital cardiac diseases] in everyday life.

Compass, not a watch

First, goals should be set based on the characteristics of the PPO and its members, their needs and interests. With constraints regarding time, training, user availability, etc., rather than a time-keeper, a compass is needed to check the map and coordinates along the journey.

> [... tecnologies de la informació ehh, no són una finalitat en sí mateixes són un mitjà, i això moltes vegades no ho entenem, no sabem distingir entre unes coses i unes altres. Llavors com a mitjà té molta potencialitat, només cal saber com explotar allò que tens davant per millorar la teva situació i saber cap on has d'anar. (F151208)]

> ...information technology ehh, not an end in itself, they are a means, and this is something we don't understand so often, we do not know to distinguish between one thing and another. So as a medium has a lot of potential, you just need to know how to exploit what you have in front of you to improve your situation and know where you need to go.

Promote ICT use

Paediatric patient organizations perceive computers as strange and unfamiliar. Although using ICT means that regular contact can be maintained more easily, the difficulties with using these technologies complicate the issue. Therefore, PPOs need training in the use of ICT and a more personal technology, where users feel empowered and can be motivated. Consequently, Web 1.0 cannot satisfy users' demands or needs.

> [Perquè si hi és, has de saber com...Si no saps com...no pots fer-ho servir. (F151208)]

> Because if there is, you have to know how… If you don't know how…then you cannot use it.

Towards new time management

Paediatric patient organizations indicated a need for technology to help with time management, optimize resources more effectively and incorporate automated processes. Technology and the Internet are viewed as opportunities for better time management.

> […sense internet no funcionaríem… la major part de contactes, al marge de les reunions físiques, les hem hagut de reduir perque no hi ha temps material per fer-ho, no es podrien fer si no tinguéssim internet. (F151208)]

> … without the Internet we couldn't manage… most of our contacts, apart from face-to-face meetings, we have had to reduce them because there is not enough time to do them. We couldn't hold our meetings if we did not have Internet.

How to make members more involved

Participants conveyed their concern about members' lack of involvement.

> […però clar, és el que ell diu, és que falta gent per fer això…fal…falten voluntaris que vulguin fer-ho. (F151208)]

> …but of course, it's what he says, there aren't enough people to do this…there is a lack of volunteers willing to do it.

As the PPO's main engine is the volunteer, lack of commitment can be a serious problem, even putting the PPO's survival at risk. The interviewees trust that the information and communication provided by the website will increase members' involvement and personal commitment.

In Fig. 1 we can see the importance PPOs give to each category, as in a cloud tag image. Ideas mentioned less often are shown in smaller font, and the horizontal line delimits positive (above) and negative (below) categories regarding ICT use, highlighting that ICT elicits more positive attitudes than negative ones in PPOs. The most frequent categories deal with positive aspects (source of information, helping people, etc.), while the less frequent aspects are related to limitations of ICT for PPOs (little member involvement, data protection, etc.).

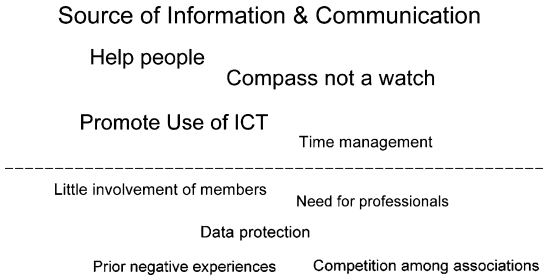

Figure 1 Basic aspects of the relation between PPOs and Internet use.

The need for professionals

The need for time management was referred to quite often and directly associated with something that might seem only causally linked – the need for professionals in the daily work of PPOs, especially in management processes. Professionals cannot only improve time management in the PPO, but they can also increase the level of expertise. Volunteers can offer time but not expertise, and they do not provide consistency or what is sometimes really required.

> [Tú eso imagínate…Vosotros tenéis profesionales…trabajando en la asociación. Nosotros no tenemos ninguno…nadie. O sea, somos todos, voluntarios… (F171208)]

> You imagine it… You have… professionals working in the organisation. We do not have any… anyone. That is, we are all volunteers.

Discussion

The purpose of this paper is to identify and discuss the ICT needs of PPOs and ICT incorporation in the APTIC online community design. Therefore, considering the results from both the survey and the focus groups, we have identified the major ICT needs of PPOs: to provide accredited and managed information, increase personal support and assistance and promote joint commitment to health care.

Moreover, we discuss key elements to take into account in designing an online community for health-care services.

Need for accredited and managed information

Along with advocacy, the main PPO activities have informational purposes (about the health condition, resources and their activities). However, previous research has found that PPOs have moved from being directly oriented towards information about the disease to covering broader interests.[32] Our data show that volunteers currently provide information about the disease, while paid staff work on other social, technical and economic issues, expanding the PPO's activities and engaging in *lobbying*.[33]

In line with previous research, PPOs search for health information online and assess it,[22,34–36] although they turn to personal referents for its validation and experiential elements. They seek information management tools and specific, accredited resources to check online information, and they consider it necessary to create a resource bank accessible to members, non-members and professionals. These specific resources are linked to general information about the disease, emphasizing information about the PPO and providing less information about health problems and treatments. Previous data about online communities sponsored by health organizations stress the importance of informational resources and state that an effort should be made to ensure that people reach the appropriate information.[12]

Personal support and assistance

Our data show that, although PPOs expect the Internet, and specifically health-care institution websites, to provide more information than social support, great hopes are placed in the Web as a space to find support, as found previously in the literature.[10,14] The website is considered a communication tool; at the same time, it includes information linked to the needs of the association and its members (mostly caregivers).

Personal support is an important PPO activity; however, only 6% of the websites have a forum for communication. Quite possibly, they give this personal support via email, even though face-to-face support is preferred.

Moreover, technology is needed to help people with time management and break time–distance barriers, so that Internet becomes a tool for improving everyday life. Finally, we suggest that web pages unrelated to the experience of illness and care should also be created to facilitate the recognition of personal identity beyond the caregiver role, allowing users to have positive experiences both in their own care and in displaying social relations with other users living under common conditions.

Joint commitment to health care

Our study shows that PPOs highlight the importance of involving different actors when providing information about health issues, so that each contributes specific skills in a complementary way, with little or no overlap. This patient-centred approach[5] is consistent with recent Pew Research Centre reports stating that patients turn to different actors for their specific health-care-related needs.[37–39] However, PPOs clearly state the need for professionals in order to increase the level of expertise and improve time management.

Although there is competition among PPOs to achieve greater visibility, representation and funding, our participants stressed the need for collaboration with other PPOs, patient alliances, health-care services and even research centres. However, working with pharmaceutical companies is seen as problematic, as in previous studies.[1,40,41] due to the perception of economic interests and the fear that the relationship would be oriented only by these interests.

In general, collaborations with other organizations are seen by society as quality indicators. PPOs are stakeholders that share information and resources in a network made

up of patients, researchers and health professionals.[21] where distinct health agents participate in order to involve people in the knowledge, promotion and/or care of a particular health situation. Curiously, although this is the PPOs' objective, our data show a very low rate of member involvement, which seems to be common across European POs.[40]

The PPOs stated that ICT would improve joint commitment to health care by increasing information about the disease and promoting patients' and relatives' relationship with the health problem, the health-care professional and the community. Therefore, it would change the roles of professional and non-professional users by encouraging engagement, which implies a continuous personal commitment.

The Internet: fears and high hopes

Almost all the PPOs had a website run by a volunteer and used to provide unidirectional information about the disease and the PO, but it was rarely updated and not a priority for staff. PPOs openly admitted having inadequate computer skills for the creation and management of the website; therefore, they considered training in these skills to be fundamental.

All the PPOs believed in the Internet's usefulness for health care, and almost all of them reported positive experiences in this regard. However, the PPOs studied also expressed a distrust of Internet information, not only regarding the quality of the information available, but also regarding information security and data privacy, which organizations explicitly demand, as described earlier in the literature.[42]

Furthermore, PPOs expressed some reservations about providing health care online. However, if used as a complementary resource, the Internet is welcome. In this regard, it has been recognized that limited Internet experience feeds prejudices about using web tools.[43]

As mentioned above, for PPOs, ICT is supposed to provide visibility, enhance health knowledge, improve relationships with community and professionals and promote autonomy. Despite currently having a web mainly for informational purposes, PPOs do not have other more useful web tools to deliver their activities. Therefore, a social network like APTIC would be a valuable complementary resource for them. Additionally, it would help them to increase member involvement, one of their major problems.

In the following section, we draw some guidelines for designing an online collaborative social network for PPOs.

Conclusion

Designing an online collaborative social network for PPOs

Table 5 shows a few key elements in designing a collaborative social network, based on the major needs discussed in the previous section. Both the technical and human issues displayed in the table reflect examples of suitable ways to use ICT to improve health services for PPOs.

Given that a PPO's web should be linked to its needs, the possibility of customizing the user profile and desktop (for access to information, specific resources and applications) seems important. This could be done by allowing different privacy levels (due to security concerns) and different levels of access to information (through *mash-ups* with different tools and social media, especially mobile devices). Appropriate information must be made available to users by incorporating an easy-to-use browser, a clear information hierarchy and rating systems that can help to identify the best

Table 5 Key elements to design a collaborative social network

Technical issues	Human issues
Customization	Facilitator
Structured and accessible information	Social and health professionals
Levels of privacy	Technical assistance
Scalability	Peer support
Ease of use	
Usability	
Communication tools	

information. As the PPOs displayed inadequate computer skills, ease of use (fast and effective, a friendly and intuitive design), usability and technical assistance would also be important.

Moreover, different actors would be involved in the network. First, to promote the involvement of the PPO's members, keep online exchanges flowing smoothly and ensure successful experiences with the Internet, there should be a facilitator to improve the network's adoption and use.

As mentioned in the discussion section, personal support and assistance would be necessary to ensure that PPOs and their members meet through specific resources in the network, thus promoting a satisfactory user experience. Peer support should be ensured by providing spaces for sharing, support spaces or spaces for joint construction. Identifying which professionals should be involved, how often, with what kind of contributions, and whether instant feedback is required or an asynchronous model is feasible would enhance joint commitment to health care.

Both technical and human issues would be taken into account to develop a scalable network to better meet the varying needs of PPOs, their members and organizations involved in health care. Finally, by providing each PPO with a common pool of free resources, rivalry can be diminished, and health care can be improved.

The findings, focusing on strengths rather than difficulties, identify some opportunities to improve the quality of health-care services. These opportunities would foster care beyond hospital walls and better meet users' needs (children, families and PPOs). Thus, promoting the successful use of the Internet by PPOs and families is seen as an interesting strategy, and proof of this is the launch of the Web 2.0 Strategy (H2O strategy) at the HSJDbcn. This strategy involves APTIC, a pilot online health community devoted to PPOs and families.

APTIC is integrated within the hospital's functioning in the sense that it can be recommended to families by paediatricians and the PO area of the hospital. Therefore, APTIC should be mediated by the PPOs themselves, even though some professionals participate continuously in it. It is hosted on the hospital server to give it an air of greater legitimacy and counteract initial misgivings about safety and quality. Consequently, APTIC could become a powerful tool to promote a positive change in health practices.

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Conflict of interest

The authors declare that they have no conflict of interests concerning this article.

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