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Patient and healthcare professional eHealth literacy and needs for systemic sclerosis support: a mixed methods study

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ABSTRACT

Objectives We engaged patients with systemic sclerosis (SSc) and healthcare professionals to assess electronic health (eHealth) literacy and needs relating to web-based support using internet-based information and communication technologies (ICT).

Methods We employed an explanatory sequential mixed methods design. First, we conducted a cross-sectional survey in patients (n=101) and professionals (n=47). Next, we conducted three focus groups with patients, family members and professionals (n=17).

Results Of patients, 89.1% used ICT at least weekly for private communication. Patients reported relatively high comprehension of eHealth information ($\bar{x}$ =6.7, 95% CI: 6.2 to 7.3, range 1–10), yet were less confident evaluating information reliability ($\bar{x}$ =5.8, 95% CI: 5.1 to 6.4) and finding eHealth apps ($\bar{x}$ =4.8, 95% CI: 4.2 to 5.4). Patients and professionals reported little experience with web-based self-management support. Focus groups revealed 'considering non-ICT-accessible groups' and 'fitting patients' and professionals' technology' as crucial for acceptability. In relation to understanding/appraising eHealth, participants highlighted that general SSc information is not tailored to individual's disease course. Recommendations included 'providing timely, understandable and safe information' and 'empowering end-users in ICT and health decision-making skills'. Professionals expressed concerns about lacking resources. Patients were concerned about data security and person-centredness. Key eHealth drivers included 'addressing end-user perceptions' and 'putting people at the centre of technology'.

Conclusions Patients and professionals need education/training to support uptake of eHealth resources. Key elements include guiding patients to timely/reliable information and using eHealth to optimise patient–provider communication. Design that is responsive to end-users' needs and considers individuals with limited eHealth literacy and/or ICT access appears to be critical for acceptability.

Key messages

What is already known about this subject?

- Internet-based information and communication technologies have become increasingly important for chronic disease management and hold promise for rare disease patients who are geographically dispersed.
- In systemic sclerosis, little is known about electronic health (eHealth) literacy or how patients and providers use eHealth to inform clinical practice and make health decisions.

What does this study add?

- Quantitative findings reveal patients have difficulty appraising the quality of eHealth information and both patients and professionals rarely use online information for health and care decisions.
- Qualitative findings indicate patients and professionals lack experience with eHealth support (eg, apps, online forums, self-help groups) and desire support/guidance in appraising eHealth resources.

How might this impact on clinical practice or future developments?

- Involving stakeholders early in the eHealth development process is important for user-centred design, supporting equity and producing high-quality eHealth resources that are responsive to patient/provider needs and complementary to face-to-face care/support.

BACKGROUND

Internet-based information and communication technologies (ICT) have become increasingly recognised in healthcare as a means to improve health—termed eHealth.[1] In the light of this trend, the Chronic Care Model (a reference model for chronic care improvement) was amended in 2015 to include ICT approaches.[2] Broadly, the updated model aims to improve health outcomes through empowering patients and healthcare professionals by introducing web-based solutions to support self-management,

delivery system design, clinical decision support, clinical information systems and eHealth education. Notably, eHealth literacy is a fundamental prerequisite for empowerment within such care models.

eHealth literacy is defined as people's knowledge, motivation and competence to 'access', 'understand', 'appraise' and 'apply' health information from electronic sources to address or solve a health problem[3 4]: 'Access' refers to the ability to seek, find and obtain health information, 'understand' refers to the ability to comprehend information, 'appraise' refers to interpret and evaluate information and 'apply' describes the ability to use health information to make informed decisions. Greater eHealth literacy is associated with better access to healthcare, more proactive health/self-management behaviours and improved health-related outcomes.[5] Similarly, provider eHealth education and attitudes toward ICT use have considerable impact on eHealth implementation.[6] Therefore, it is crucial to assess eHealth literacy of patients and professionals eHealth literacy and their respective needs to ensure uptake and sustainability of eHealth services.

Prior research on rare multisystemic, autoimmune connective tissue disease such as systemic sclerosis (SSc) and systemic lupus erythematosus (SLE) has primarily focused on patient general health literacy and barriers to ICT use.[7 8] There is a paucity of evidence on eHealth literacy among rheumatologic providers. In regard to SSc/SLE eHealth support, web-based resources are often of low quality, have inadequate readability and limited functionality.[9–11] Several studies demonstrate that patients with rare connective tissue diseases and their providers are interested in web-based education and support.[12–14] However, few online programmes focus on critical concepts of health equity, patient engagement and empowerment. The Lupus Interactive Navigator is a web-based self-management programme for SLE with high patient ratings of content, usability and acceptability.[15] In SSc, several studies have shown that appropriate eHealth interventions can support high-quality care through reliable disease information, self-management support and disease monitoring.[16–19] Despite such promising results, little is known about patient with SSc and health professional eHealth literacy or how eHealth is applied to inform clinical practice and daily life decisions. In particular, patients affected by rare diseases, such as SSc, often have limited access to health information and care. Thus, it is important to explore how web-based technologies can best facilitate access to high-quality, coordinated SSc care. Similarly, understanding stakeholder eHealth literacy, needs and perspectives is important for developing targeted, user-centred interventions that are accepted.[20]

The *MANagement Of Systemic Sclerosis (MANOSS)* project aims to fill existing gaps in SSc care by developing an eHealth-enhanced rare disease chronic care model for patients with SSc in Switzerland.[21] Part of the MANOSS project involves conducting a contextual analysis with stakeholder involvement to inform user-centred design.

This explanatory mixed methods study aimed to describe eHealth literacy of patients and healthcare professionals as well as perspectives and needs for web-based chronic care support. The quantitative phase assessed how patients with SSc and professionals access, understand, appraise and apply web-based health information and technologies for aspects of chronic care. The quantitative results informed the subsequent qualitative phase that aimed to deepen our understanding of how eHealth literacy, perspectives and needs explain eHealth use and can be incorporated into user-centred eHealth solutions within a new model of care.

METHODS

Study design

We employed an explanatory sequential mixed methods design[22] involving multiple centres providing SSc care (figure 1). The first phase utilised quantitative data from a cross-sectional survey of Swiss patients with SSc and healthcare professionals. Analyses informed the qualitative inquiry consisting of three focus groups with Swiss/international patients and professionals. The qualitative findings were used to explain quantitative findings.

Patient and public involvement

Involvement of patient research partners and relevant stakeholders is strongly recommended for developing web-based technologies.[23 24] Key stakeholders in this study were the Swiss League against Rheumatism, a patient research partner and the Swiss Scleroderma Association. Additionally, the European Alliance of Associations for Rheumatology (EULAR) study group, dedicated to improving and standardising non-pharmacological management of connective tissue diseases (CTDs), supported recruitment of participants for the qualitative inquiry.

Quantitative data collection

Sample and setting

We targeted a convenience sample of 100 adult patients (>18 years) spanning a range of SSc disease severity/experiences and 50 healthcare professionals with varied levels of experience in treating SSc. We recruited German-speaking and French-speaking participants (patients and professionals) from all Swiss University hospitals (Basel, Bern, Geneva, Lausanne, Zurich), one regional (state) hospital (Lucerne), rheumatology outpatient clinics, and the Swiss scleroderma patients' association (www.sclerodermie.ch) according to the MANOSS study protocol.[21]

Variables and measurement

Validated patient-reported outcome measures for rare diseases such as SSc are scarce. Moreover, given the rate of technologic advances, available eHealth literacy measures do not adequately cover current technological developments.[25–27] Hence, we constructed a set of pragmatic

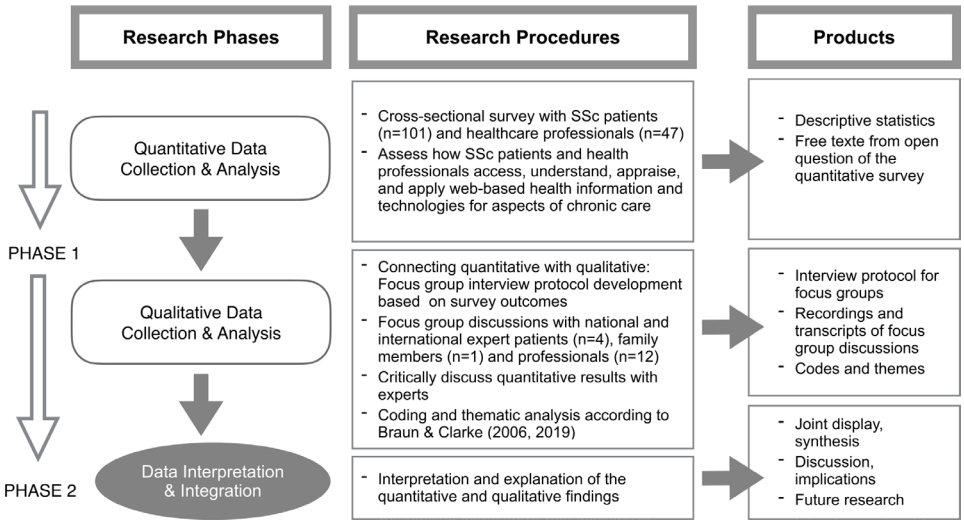

Figure 1 Study diagram for the explanatory, sequential mixed methods design. eHealth, usage of ICT for health; ICT, information and communication technologies; SSc, systemic sclerosis.

items tailored to SSc, including dimensions of instruments developed by Halwas *et al*[28] and Vanhoof *et al*.[29] Item selection was guided by the dimensions of eHealth literacy including 'access', 'understand and appraise' and 'apply' ICT/eHealth services (table 1). Participants were invited to provide open-ended, free text comments at the end of the questionnaire. Participants were given the option to complete the questionnaire online or in paper-pencil format (professionals online only).

Quantitative data analysis

We performed descriptive statistics (frequencies/percentages or means/medians with 95% CI and IQRs) to summarise quantitative survey data and sociodemographic characteristics (R, V.4.0.4). To compare groups (ie, sex, age groups, education, patient–professionals), we computed standardised mean differences (SMD) which are identical to Cohen's *d*, using the tableone package for R. Compared with *p* values, SMD is more appropriate for calculating effect size estimates in small, uneven datasets—such as the ones analysed in this study.[30] A SMD ≥0.2, ≥0.5 and ≥0.8 depict small, medium and large differences between groups, respectively. We calculated 95% CIs for means to facilitate visual comparison between ratings. Differences between groups were defined as means with distinct, non-overlapping CIs.

Qualitative data collection

Sample and setting

We used a purposeful sampling strategy to recruit 12–18 participants with expertise in SSc care/management. We defined participants with expertise as individuals with several years of experience with (1) SSc as a patient or (2) family member and/or (3) professional experience in chronic care, implementation science and/or health policy. Purposeful sampling focused on individuals with varied expertise in national or international care settings, across disciplines (eg, physicians, nurses, physiotherapists, occupational therapists and patient experts). Swiss professionals were recruited from Swiss University Hospitals (Bern, Lausanne, Zurich) and the Swiss League against Rheumatism (Rheumaliga Schweiz). International participants were recruited via the EULAR non-pharmacological management of CTDs study group.

Focus group discussions

The quantitative study results informed questions for focus group discussions. Due to the COVID-19 pandemic, focus groups were conducted using an online video conferencing system. With participant consent, focus group discussions were recorded. Briefly, findings of our systematic literature review and the quantitative study findings were provided to orient participants. Findings were discussed using open-ended prompts to elaborate quantitative results (ie, What is important/surprising? What fits your experiences? What is contradicting to your clinical experiences? What are important aspects that should be taken into account when improving chronic care for SSc patients?). Subsequently, primary care needs and problem areas for care were discussed for national (focus groups 1 and 2) and international contexts (focus group 3).

Qualitative data analysis

Focus group transcriptions and free text comments from the quantitative survey were analysed using reflexive thematic analysis.[31 32] In brief, analysis was a recursive process that started with familiarisation with the data and coding of the text. Subsequently, codes were collated to build initial inductive themes (ie, patterns of shared meaning across all participants) and mapped to the corresponding eHealth literacy dimension. Finally, themes were refined and named based on original data (ie, quotes, codes).

Mixed methods data integration

As noted, quantitative data informed the structure of the qualitative study. Subsequently, the qualitative data were used to explain the quantitative findings. Importantly,

Table 1 Quantitative variables and measurements

Dimension	Questionnaire	Variables and measurement: *Patient questionnaire*	*Provider questionnaire*	Response options
Access *ICT possession*	Possession and use of modern information and communication technologies[29]	Possession of cell phone; smartphone; desktop, laptop or tablet computer; fitness tracker or smartwatch. Internet access; subscription for smartphone; subscription at home. Download speed: >50.0 Mbit per second; 20.0–50.0 Mbit; <20.0 Mbit	Possession of cell phone; smartphone; desktop, laptop or tablet computer; fitness tracker or smartwatch.	Patients: yes/no/ don't know Providers: employer's device/ own device/no device
Understand and appraise *Confidence using ICT*		I feel confident using my smartphone, tablet, laptop and/or desktop computer. I feel confident using the internet; the internet makes my everyday life easier		Not at all/ not true/ neither/applies/fully applies
Confidence using eHealth	eHealth literacy[28]	I understood health information on the internet, which I have already used well; eHealth offers (online health offers) have raised my medical knowledge; I know where I can find suitable eHealth offers for my health issues; I know how to find suitable applications (apps) for my healthcare; I know how to use health apps; the offers on the internet are useful for making decisions about my health; Feeling safe making decisions based on online information and/or offers; I can differentiate reliable from unreliable online information and/or offers	Online offers (eg, training programmes) have raised my medical knowledge; I know how to find suitable apps for the healthcare of my patients; The offers on the internet are useful for making decisions about the health of my patients; Feeling safe making decisions based on online information; I can differentiate reliable from unreliable online information and/or offers	10-point Likert scale: 'I totally disagree' to 'I totally agree'
Apply *General ICT usage*	Possession and use of modern information and communication technologies[29]	Frequency of internet-use: to send and/or receive emails; to read news (eg, online magazine or newspaper); for social networking (eg, Facebook); to communicate (eg, chat, Skype, Facetime, WhatsApp); to download mobile apps; use mobile apps on the smartphone (eg, train timetable, weather); watch films; use a fitness tracker (eg, record pulse, speed, distance) or a smartwatch	Frequency of internet-use to: send and/or receive emails	Never/several times a year / several times a month/several times a week/daily
eHealth usage	eHealth usage questionnaire[28]	Do you use apps which support you in a healthy lifestyle? If yes, which ones? (open text) Which of the devices do you prefer to use to search for information on the internet? (Smartphone, tablet, portable or desktop computer)	Do you use apps in your private life which support you in a healthy lifestyle? Do you recommend apps to your patients that support them in a healthy lifestyle?	Yes, no
		Frequency of internet-use to: contact a physician or another health professional via email; search for health information (eg, on illness, symptoms, therapies); search for a medical specialist; download and store health information (eg, brochures, pictures, videos); read a health issue related blog; discuss with other patients in an online forum; participate in a self-help group; remind you of a doctor's appointment (eg, SMS or email); other health-related purposes (eg, online database)	Frequency of internet-use to: contact patients via email; search for information (eg, on diseases, therapies); communicate with patients (eg, SMS, Skype, Facetime, WhatsApp); discuss with patients in an online forum; make appointments with patients; remind patients of an appointment (eg, SMS or email)	Never/several times a year / several times a month/ several times a week/daily

ICT, information and communication technologies.

the mixed methods approach provides deeper insight for model development than either method in isolation.[22] We present our quantitative results first, followed by a joint display including key quantitative findings and qualitative in-depth themes for each eHealth literacy dimension. The resulting synthesis of quantitative and qualitative findings identified key targets for further model development and user-centred design.

RESULTS

Participants' characteristics

The quantitative survey was completed by 101 patients and 47 professionals (table 2). In total, 17 individuals (n=12 professionals; n=4 SSc patients; n=1 family member) participated in focus group discussions. All four patient participants were active members of a patient organisation and three had a medical and/or scientific background.

Quantitative survey

The quantitative results are reported according to the described eHealth literacy dimensions (ie, 'access', 'understand/appraise', 'apply').

Access

Survey results indicate both patients and professionals have adequate access to ICT (table 3). The overwhelming majority of patients (91/101, 90.1%) had access to the internet. Professionals were commonly equipped with devices—yet smartphones, tablets and smartwatches were seldom used for clinical purposes.

Understand and appraise

The majority of patients felt confident using a smartphone/tablet (70/101, 69.3%) and/or portable/desktop computer (71/101, 70.3%). Patients indicated few problems comprehending health-related information on the

Table 2 Participant characteristics (quantitative survey and qualitative focus groups)

Patients		**Quantitative (n=101)**	**Qualitative (n=4)**
Sex (n (%))	Female	77 (76.2)	4 (100)
	Not reported	4 (4)	–
Age (years) (median (IQR))		60 (50–68)	–
Country of healthcare provision (n (%))	Switzerland	101 (100)	3 (75)
	UK		1 (25)
Disease subset, self-reported (n (%))	lcSSc	31 (30.7)	2 (50)
	dcSSc	36 (35.6)	2 (50)
	Other rare rheumatic disease	3 (3.0)	–
	Don't know	25 (24.8)	–
Disease duration (years) (median (IQR))		8 (5–15)	32 (17–40)
Questionnaire (n (%))	Online survey	43 (42.6)	–
	Paper survey	58 (57.4)	–
Country of origin (n (%))	Switzerland (German region)	79 (78.2)	2 (50)
	Switzerland (French region)	22 (21.8)	–
	Germany	–	1 (25)
	UK	–	–
Marital status (n (%))	Single	13 (12.9)	–
	Married/cohabiting	68 (67.3)	–
	Divorced, separated or widowed	16 (15.9)	–
	Not reported	4 (4)	–
Highest educational degree (n (%))	Tertiary level	37 (36.7)	–
	Upper secondary	48 (47.5)	–
	Compulsory	13 (12.9)	–
	No completed education	1 (1)	–
	Not reported	2 (2)	–
Employment (n (%))	Employed	50 (49.5)	–
	Full time (80%–100%)	22 (21.8)	–
	Part time (<80%)	28 (27.9)	–
Reasons for non-employment (n (%))	Retired	30 (29.7)	–
	On disability or sick leave	10 (9.9)	–
	In training/student	7 (7)	–
	Looking for work	4 (4)	–
Family members			**Qualitative (n=1)**
Sex (n (%))	Female	–	1 (100)
Country of healthcare provision (n (%))	Germany	–	1 (100)
Healthcare professionals,		**Quantitative (n=47)**	**Qualitative (n=12)**
Sex (n (%))	Female	40 (85.1)	10 (83.3)
Age (years) (median (IQR))		41 (31–51)	

Continued

Table 2 Continued

Healthcare professionals,		Quantitative (n=47)	Qualitative (n=12)
Country of workplace (n (%))	Switzerland	47 (100)	6 (50)
	Austria		2 (16.7)
	Belgium		1 (8.3)
	Sweden		1 (8.3)
	USA		2 (16.7)
Working experience (years) (median (IQR))		13 (7–23)	–
Rheumatology experience (years) (median (IQR))		6 (3–12)	–
Number of SSc patients per year (patients) (median (IQR))		15 (5–29)	–
Position (n (%))	Registered nurse	13 (27.2)	
	Physiotherapist	10 (21.3)	2 (16.7)
	Rheumatologist	9 (19.2)	2 (16.7)
	Occupational therapist	9 (19.2)	4 (33.3)
	Advanced practice nurse	2 (4.3)	3 (25)
	General practitioner	1 (2.2)	–
	Psychologist	1 (2.2)	–
	Social worker	1 (2.2)	–
	Health policy	–	1 (8.3)
	Not reported	1 (2.2)	–
Working setting (n (%))	University hospital	36 (76.6)	–
	Non-university hospital	7 (14.8)	–
	Private outpatient clinic	2 (4.3)	–
	Rehabilitation clinic	2 (4.3)	–

lcSSc, limited cutaneous systemic sclerosis; dcSSc, diffuse cutaneous systemic sclerosis.

internet ($\bar{x}$ =6.7, 95% CI: 6.2 to 7.3, range: 1–10). No notable differences were found in relation to sex or age. However, patients with less education (ie, compulsory education only) reported poorer understanding ($\bar{x}$ =4.5 vs 7.1; SMD=0.81). Patients reported relatively limited ability to appraise eHealth information related to their health issues ($\bar{x}$ =5.8, 95% CI: 5.1 to 6.4), find health apps ($\bar{x}$ =4.8, 95% CI: 4.2 to 5.4) and other eHealth offerings ($\bar{x}$ =5.5, 95% CI: 4.9 to 6.2). Patients did not perceive that online resources increased their medical knowledge ($\bar{x}$ =4.3, 95% CI: 3.7 to 4.9) or helped them making informed health decisions ($\bar{x}$ =3.9, 95% CI: 3.4 to 4.5). Younger patients (<45 years) trended towards greater understanding of eHealth information ($\bar{x}$ =7.8 vs 6.6; SMD=0.48) and more confident decision-making based on online information ($\bar{x}$ =5.1 vs 3.8; SMD=0.43).

Compared with patients, healthcare professionals (figure 2) reported greater ability to assess reliability of online information ($\bar{x}$ =7.2 vs 5.8; SMD=0.55) and that eHealth resources increased their medical knowledge ($\bar{x}$ =6.3 vs 4.3; SMD=0.70). Similar to patients, professionals reported limited benefit of online information for health decision-making ($\bar{x}$ =5.0, 95% CI: 4.3 to 5.6) and lacking knowledge in finding health apps ($\bar{x}$ =5.5, 95% CI: 5.0 to 6.1).

Apply

Notably, most patients (90/101, 89.1%) used the internet weekly—primarily for personal, private purposes (eg, communication, mobile applications, online news) (figure 3) but not for health purposes (figures 4 and 5). Similarly, almost all healthcare professionals had used the internet at least weekly for email communication (45/47, 95.7%), nevertheless only 19/47 (40.4%) used email weekly for patient communication. Both patients and professionals indicated relatively limited experience with web-based self-management support. Most patients had never used an online support group (70/92, 76.1%) or forum (75/90, 83.3%), while 45/46 (97.8%) of healthcare professionals had never participated in an online patient forum. Only 14/101 (13.9%) patients had used apps to improve their health compared with 20/47 (42.5%) professionals. In total, only 14/47 (29.8%) healthcare professionals had recommended eHealth apps to their patients.

Table 3 Patient and healthcare professional access to ICT

	Patients (n=101)	Professionals (n=47)	
		ICT for patient communication	
ICT technology	Own ICT	*Equipment of employer*	*Own device*
Cell phone	24 (23.8%)	25 (53.2%)	2 (4.3%)
Smartphone	81 (80.2%)	2 (4.3%)	13 (27.7%)
Tablet	49 (48.5%)	9 (19.2%)	3 (6.4%)
Portable computer (laptop)	63 (62.4%)	38 (80.9%)	4 (8.5%)
Desktop computer	46 (45.5%)	40 (85.1%)	1 (2.1%)
SmartWatch	7 (6.9%)	0 (0.0%)	0 (0.0%)
Internet access	91 (90.1%)		
Home-based internet, download speed:			
>50.0 Mbit/sec	20 (19.8%)		
20.0–50.0 Mbit/sec	26 (25.7%)		
<20.0 Mbit/sec	8 (7.9%)	n/a	n/a
Download speed unknown	29 (28.7%)		
No contract	12 (11.9%)		
Not reported	6 (6.0%)		
Mobile internet, download data volume:			
Limited data volume	34 (33.7%)		
Unlimited data volume	34 (33.7%)		
Data volume unknown	6 (5.9%)	n/a	n/a
No contract	21 (20.8%)		
Not reported	6 (5.9%)		

ICT, information and communication technologies.

Qualitative results

Patient/professional eHealth perceptions and needs (ie, eHealth literacy and services) are described in six themes: 'considering non-ICT-accessible groups'; 'fitting patients' and professionals' technology'; 'providing timely, understandable and safe information'; 'empowering end-users in ICT and health decision-making skills'; 'addressing perceptions of end-users' and 'putting people at the centre of technology'. These themes are described and illustrated (ie, participant quotes) in a joint display with key quantitative findings for each eHealth literacy dimension (table 4).

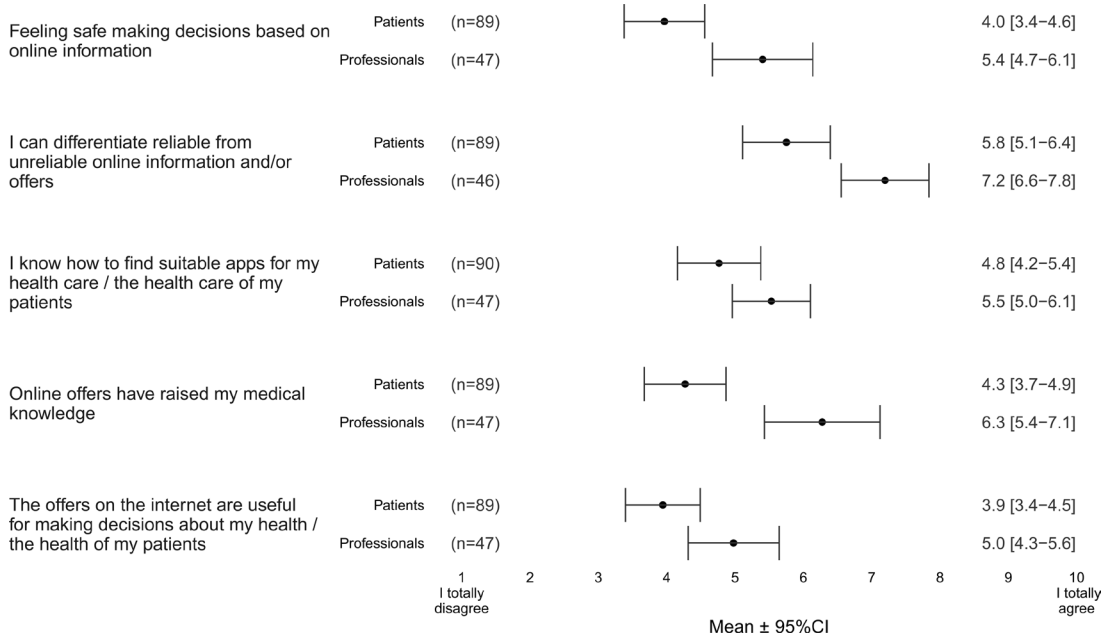

Figure 2 Patient and healthcare professional perceived understanding and appraising of eHealth (mean and 95% CI).

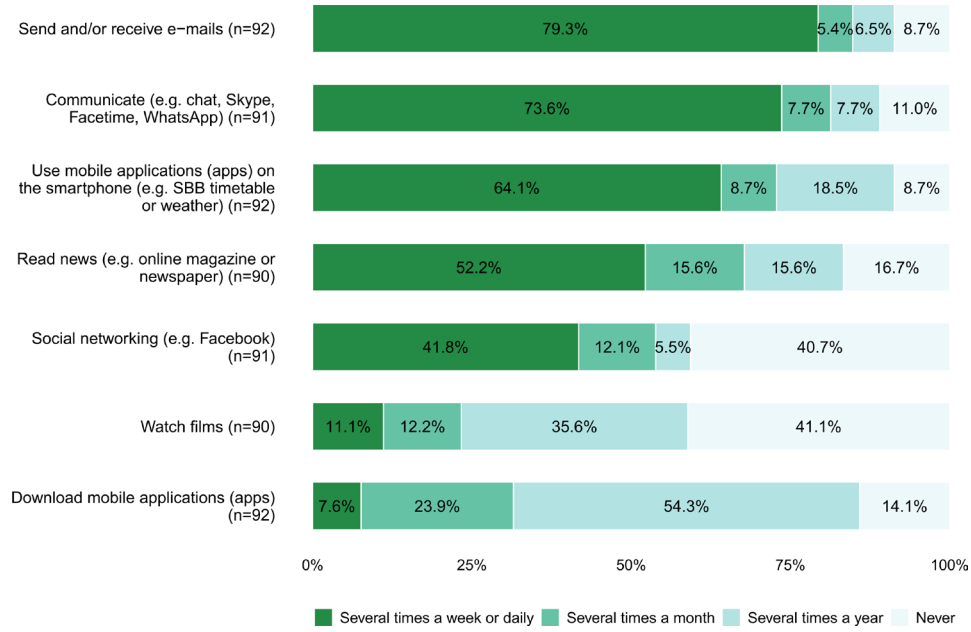

Figure 3 Internet use of patients for private purposes.

Synthesis of quantitative and qualitative findings on eHealth literacy domains

Access

Patients and healthcare professionals seem to be well equipped with hardware to access ICT and eHealth. However, our findings indicate it is important to consider those who are lacking ICT access when developing new eHealth services. Additionally, we need to consider interoperability to ensure that applications are fully supported by both patients' and professionals' devices and operating systems.

Understand and appraise

While patients and professionals feel confident using familiar technologies, they express needing guidance in understanding and appraising ICT/eHealth information. Valid, reliable information is key for empowering end-users to make high-quality decisions (ie, informed and aligned with values and preferences) for themselves or with their patients.

Apply

Most patients and professionals lacked experience with eHealth support (eg, apps, online forums, self-help groups), causing uncertainty and a variety of concerns. Involving stakeholders early in the development process is important for achieving user-centred design and supporting successful integration of onsite care and patient supports.

DISCUSSION

This explanatory mixed methods study examined patient with SSc and healthcare professional eHealth literacy

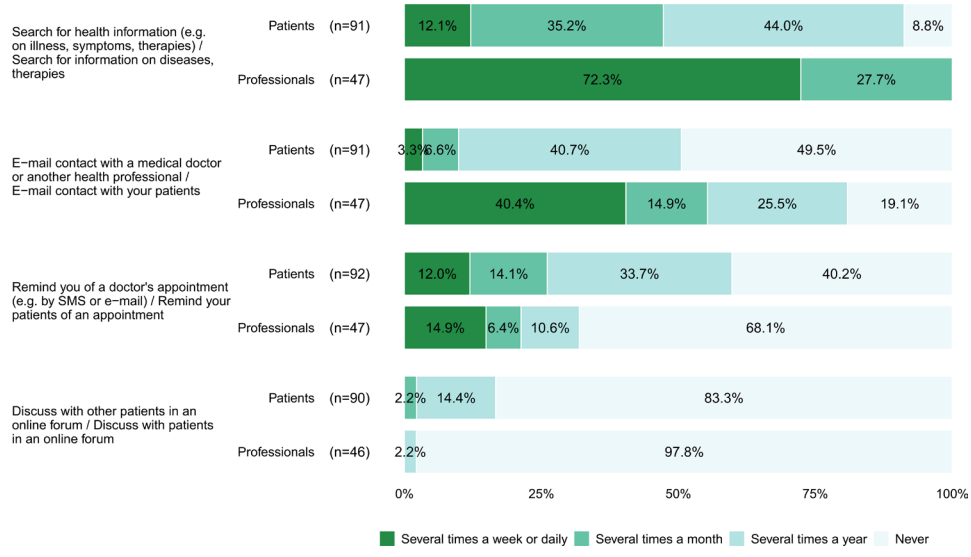

Figure 4 Internet use of patients and professionals for healthcare.

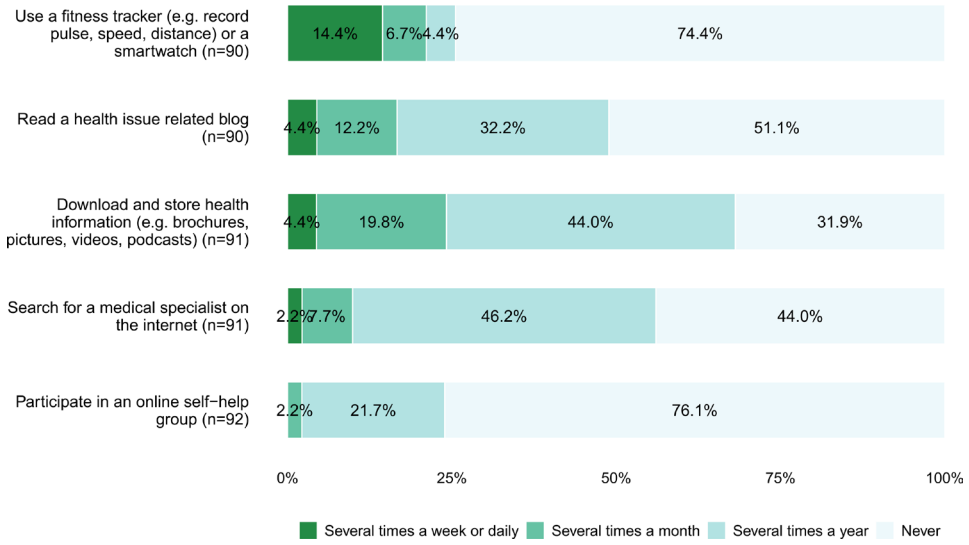

Figure 5 Internet use of patients for healthcare.

providing a deeper understanding of perspectives and needs for integrating web-based chronic care support. Notably, while technology is omnipresent in daily life, patients and professionals alike reported problems of interoperability of technology and indicated the need for education to effectively use eHealth applications. Additionally, the problem of equity in access was highlighted.

In respect to access, 89.1% of patients with SSc reported using the internet at least weekly—primarily for communication. These results mirror increasing numbers of people, especially older people, gained access to ICT/eHealth.[33] In Switzerland, more than 90% of people use the internet—including more than half of people 75 years and older.[34] However, our qualitative findings indicate the need for inclusive systems that are accessible to people with and without ICT access. In line with our findings, a European evaluation of more than 180 eHealth programmes/applications supporting integrated care for individuals with multiple morbidities highlighted eHealth barriers including insufficient ICT infrastructure and interoperability problems.[35]

We found that understanding and appraisal of eHealth in SSc are complicated by two interrelated factors—low-quality online information (as reported by focus group participants) and lack of confidence in using eHealth information for health decisions (as indicated by survey findings). We identified relatively low levels of perceived competency among patients with SSc and healthcare professionals in decision-making based on online information. These observations are similar to studies in patients with cancer.[28 36] Patients with cancer as well as SSc indicated difficulties in locating valid, reliable internet content to support decision-making. Evaluation of online information is complicated by the low quality and sometimes false, frightening information on the web. Similarly, the variable disease trajectory of SSc and the many healthcare specialists involved can make it challenging for individuals to apply information to their specific SSc concerns. Participants in the present study echo challenges faced by rare disease patients worldwide,[37 38] underscoring the importance of providing valid, reliable information that relates to an individual's disease course and health decision-making needs (ie, patients and healthcare professionals). Importantly, our findings indicate that patients with SSc and professionals who care for them need guidance and support to better understand and appraise eHealth information/technologies. The eHealth-enhanced chronic care model recognises eHealth education as a critical component for chronic disease management[2]; yet theory-driven programmes to enhance end-users eHealth literacy are frequently lacking.[35 39] Melchiorre *et al*[35] evaluated eHealth within integrated care programmes and found that half of programmes provided healthcare professional training—yet few addressed patient training needs. Thus, recommendations guiding eHealth services are needed to generate a shared understanding of disease impact and self-management support.[40] eHealth should be built on a scaffold of resources and information to support a shared illness perception and high-quality decision-making for patients and professionals alike.[41] Key relational functions of eHealth applications include facilitating patient–provider communication, supporting shared decision-making and assuring productive technology-based interactions.[2 24]

In respect to apply, the present study highlights application as a critical roadblock to eHealth implementation for patients and professionals. Patients cited ethical, legal and social concerns (ie, data security, dependence on ICT, loss of interpersonal interactions) while providers noted logistical barriers (ie, lack of personnel, resources, time). Such concerns have been identified as factors limiting end-user acceptability and engagement sustainability of eHealth services.[6 42] Nevertheless, our focus group discussions conducted during the quarantine imposed by the COVID-19 pandemic revealed positive attitudes about the utility of

Table 4 Joint display of key quantitative and qualitative findings for each eHealth literacy dimension

Main quantitative results	Description of qualitative themes	Representative quotes
Access	*Theme 1. Considering non-ICT-accessible groups*	
Patients ▶ High level of internet access (90.1%) ▶ Devices to go online available (eg, 80.2% smartphone). Health professionals ▶ Equipped by their employers with laptops (80.9%) or desktop computers (85.1%), rarely smartphones (4.3%)	▶ Experts were surprised about the high level of access to ICT. In their perception, access or internet connection is often problematic. Mainly patients >75 years old or some not interested or capable are discussed to be insufficiently equipped and literate to use ICT. ▶ Experts emphasised that the needs of the non-ICT-accessible group of patients must be taken into account when developing a model of care.	▶ *«I am now surprised that many are already so well equipped with the internet. That (MANOSS results) surprised me a lot. Because of the COVID situation the feedback I got was obviously different. But I can't verify that, it's just a subjective impression.»* (Nurse, national expert group) ▶ *«In our (…) project, we notice the cut in accessibility, which is around 80 years old. Those up to 75 are very accessible online, (…). But it's like this, you mustn't forget the others. At some point during this Corona period, we also realised that.»* (Physiotherapist, national expert group)
	Theme 2. Fitting patients' and professionals' technology	
	▶ Experts explained that patients' smartphones often do not have the capability to do video conferencing. ▶ Experts discussed that professionals are limited by ICT available at workplace and do not want to use their private devices for communication with patients. ▶ Experts agreed that for good acceptance, new eHealth solutions need a good fit with both patients' and professionals' devices (provided by the hospital).	▶ *«And (…) some phones do not have the capability to do visual.»* (Occupational therapist, international expert group) ▶ «We have the same experience, email works great. Resistance would certainly exist with technology that is not available from the hospital. Almost everyone here has an iPhone, but they are not willing to use it for patient (contacts). These are the technical hurdles, which would have to be overcome by professional devices.» (Nurse, national expert group)
Understand and *appraise* Patients ▶ Relatively high rating of comprehension of eHealth information (mean=6.7, 95% CI: 6.2 to 7.3). ▶ Less confident evaluating reliability of eHealth (mean=5.8, 95% CI: 5.1 to 6.4) and finding health apps (mean=4.8, 95% CI: 4.2 to 5.4). ▶ Online offers seldom raised their medical knowledge (mean=4.3, 95% CI: 3.7 to 4.9) or helped for making health decisions (mean=3.9, 95% CI: 3.4 to 4.5). Health professionals ▶ Felt able to assess reliability of eHealth (mean=7.2, 95% CI: 6.6 to 7.8), which improved their knowledge (mean=6.3, 95% CI: 5.4 to 7.1) ▶ Do not feel very confident in finding health apps for their patients (mean=5.5, 95% CI: 5.0 to 6.1) ▶ Rarely use online information for making decisions about the health of their patients (mean=5.0, 95% CI: 4.3 to 5.6)	*Theme 3. Providing timely, understandable and safe information*	
	▶ Experts discussed that because of patients' diversity a range of information offers (technology based and not) need to be accessible. ▶ Experts explained that due to the variable SSc progress and course, online information and pictures can be frightening for patients. Experts described patients' difficulties of navigating appropriate and safe information over time. In particular for SSc self-management, pragmatic and practical information is rare. ▶ Experts stated that patient organisations are good information sources for professionals as well, especially for people who do not know much about SSc. ▶ Experts agreed patients need information tailored to their understanding of SSc and self-management. The information provided should encourage people's coping of living with a rare condition by taking down the medicalisation of the disease. Professionals could guide patients to find appropriate information, but need to be educated about patient information themselves.	▶ *«When we developed our self-management program, (…) we did ask them what kind of format would they like, and very surprising for us, because we thought that everybody wanted an internet program, what a lot of people wanted was a book. (…), some people find it easier and we didn't really see that this was depending on age. That was kind of interesting.»* (Occupational therapist, international expert group) ▶ *«That (Google search) is still really frightening. (…) The information is better than it was, but I think it is still horrifying for people.»* (Patient, international expert group) ▶ *«Side effects of medicines: are often not bad but annoying. What can I do then? A visit to the doctor would often not be necessary but there is no information source/reference book especially for systemic sclerosis where I can find out what can be done about it. Doctor visits could be saved.»* (Patient, quantitative, open text) ▶ *«One of the ways we tried to overcome the fear factor was the Wikipedia page on the rare condition that I work on. It is actually managed by the head of the patient organization. (…) And we found that really helped change peoples' perceptions in the last couple of years. We partner with him (patient) to make sure that the information and data is updated regularly. But we found that was very helpful for kind of taking down the medicalisation of it and really thinking of it as a human experience of living with a rare condition.»* (Nurse, international expert group)
	Theme 4. Empowering end-users in ICT and health decision-making skills	
	▶ Experts discussed that patients who are afraid to learn how to use new technologies, but also professionals with a low affinity towards ICT can be limiting for eHealth implementation and use. ▶ Disease information—even if it is easy understandable—still needs explanation for patients. Not everything is going to happen to everybody and some decisions are easier if shared by patients and professionals. ▶ Experts agreed that user empowerment is crucial for sustainable ICT implementation. Furthermore, (shared) health decision-making competences need to be trained—by patients and professionals and integrated systematically in technological approaches.	▶ *«I do not feel able to familiarise myself with the new technologies and learn how to use them.»* (Patient, quantitative, open text) ▶ *«How open am I (to ICT), how affine am I, also in counselling, what experiences have you had yourself, how accessible do you experience it, what impression do you have of the quality? It's very difficult to cut that out. And if I don't have any affinity at all, then it becomes more difficult.»* (Physiotherapist, national expert group) ▶ *«What we would say to new patients, don't read a section if it doesn't involve you. You know, not everything is going to happen to you.»* (Patient, international expert group) ▶ *«Many times we talk about shared decision making, but we never talk about how to do it. There are several tricks, ways to do it. (…) how we could improve it this kind of shared decision making, because it should not stay with a principle.»* (Physician, international expert group)

Continued

Table 4 Continued

Main quantitative results	Description of qualitative themes	Representative quotes
Apply Patients ▶ Used the internet primarily for private purposes (eg, communication, mobile applications). ▶ 8.8% of internet-users never used it to search for health information, respectively, 44% only a few times a year. ▶ Indicated relatively little experience with web-based self-management support. Online support groups and forums were rarely (21.7%, 14.4%) or never (76.1%, 83.3%) used. Health professionals ▶ Used the internet at least weekly to send and/or receive e-mails (95.7%) or search for information on diseases/therapies (72.3%). ▶ Used email weekly for patient communication (40.4%) ▶ Rarely used the internet weekly for reminding patients of an appointment (14.9% weekly) and for discussing in online forums with patients (2.2% several times a year) ▶ Rarely used either eHealth apps in their private life (42.5%) and recommended them to their patients (29.8%)	*Theme 5. Addressing perceptions of end-users* ▶ Experts reported that patients and professionals have little experience with the use of eHealth services such as apps and internet programmes. They can hardly imagine how those technologies are supposed to work in their clinical practice. ▶ Out of this uncertainty experts formulated end-users concerns, such as lacking human, financial and time resources. Especially the patients concerned about data security and becoming dependent on ICT. ▶ Experts agreed that eHealth services need to be well planned and adjusted to the existing clinical procedures but also to the personal and financial conditions. To achieve this, end-users' worries need to be taken into account by engaging stakeholders in the development process.	▶ *«I mean what I do personally, I communicate a lot with patients by email and that works. That works. But on the other side now, if we're just talking about communication, exactly, you can ask yourself, do you have the resources through an app or is there a person in charge then? How do you want that to work?»* (Rheumatologist, national expert group) ▶ *«If you ask the rheumatologists, they fear the workload that is associated with it (…) Certainly, every stakeholder sees the potential, but every stakeholder has some fears or requirements.»* (Rheumatologist, international expert group) ▶ *«I am still wary of too much data shared with the health insurance companies.»* (Patient, quantitative, open text) ▶ *«The most powerful uptake of this (fears), is to engage stakeholders in the development process, so including patients in the development process and also to underscore that this is going to help relieve workload for healthcare providers, and try to extend their care rather than replace it.»* (Nurse, international expert group)
	Theme 6. Putting people at the centre of technology ▶ Experts emphasised the fears of patients and professionals loosing interpersonal interaction and relationship because of ICT use. ▶ During the COVID-19 pandemic they realised that online contacts are working and relieving—even if they did not know each other before. ▶ Experts discussed that eHealth programmes and onsite care need to be closely linked (eg, contents of eHealth programmes to be taken up in clinical visits). ▶ Experts agreed that eHealth is an additional way of giving care, not a replacement of all or most of the visits. Optimally it is closely linked and coordinated with onsite care for example in SSc symptom management.	▶ *«I am against any digitalisation - a personal relationship with a professional is/would be important in the recovery process. Today's tendency to digitalise everything is extremely annoying and I hope that this will not progress even more in the health sector.»* (Patient, quantitative, open text) ▶ *«Corona has probably also pushed the whole thing a bit. As a high-risk patient, I wasn't allowed out and they weren't allowed to receive patients either, so it was partly via video conference or telephone. This wasn't bad at all. I simply have to reserve this hour and I don't have to stay there for 1.5 hours and then come back.»* (Patient, national expert group) ▶ *«The most important findings were, that this (eHealth) is seen as an additional way of giving care, intermittent and mainly patient-driven, when patients feel the need for additional questions, additional topics to be discussed, and not as kind of replacement of all or most of the visits.»* (Physician, international expert group) ▶ *«We know from SCQM (ie, Swiss registry for inflammatory rheumatic diseases) that it is very much hoped, especially when it comes to symptom tracking, which can also be a part of dealing with the disease, that it would be quite decisive that in the consultations, really what people have followed over a certain period of time, that this is taken up. That the doctors look at it with the patients and if they were in a nursing consultation or physiotherapy/occupational therapy, that someone looks again at what was during this time, what they have monitored.»* (Physiotherapist, national expert group)

ICT, information and communication technologies; SSc, systemic sclerosis.

online support. Respondents expressed surprise about the quality of the online contact—even if they had not met the other person. Congruently, data from patients with chronic lung diseases show that experience using eHealth can demystify ICT and is associated with more positive attitudes about the usefulness of eHealth resources.[43] Thus, providing patients with SSc and healthcare professionals with more ICT/eHealth experiences may help create more positive attitudes and beliefs—especially in relation to peer-led support groups. Lack of knowledge about what happens at support

group meetings and not having reliable transportation to attend meetings are common barriers for patients with SSc.[44] One way to surmount such barriers is to utilise online groups to overcome geographic distance. Indeed, existing literature supports the notion that rare disease patients can benefit from online peer-to-peer support and mentorship.[45] Shaping patients' and healthcare professionals' attitudes may foster eHealth implementation. Specifically, providing guidance for using eHealth, as well as data supporting its utility for improving outcomes, can shift current perspectives and proper uptake of eHealth interventions.[46]

Additionally, our qualitative inquiry revealed user-centredness and equity as critical elements in developing eHealth-enhanced models of care. Participants highlighted the need to link eHealth and onsite care to ensure that resources are equitably accessible by individuals who lack ICT, have limited digital literacy (eg, less educated patients) and/or are geographically dispersed. For example, digital care for older adults may be most effective using a hybrid format (ie, combination of digital and in-person presence).[47] It is worthwhile to note that video-conferencing (eg, for home-based groups) is feasible even for those with limited eHealth literacy as long as appropriate ICT infrastructure and eHealth training are provided.[48] Importantly, eHealth may not directly reduce staff and costs[49] and is intended as a complement to care rather than a means to replace current practices.[50]

Relative strengths of this study include diverse data sources (ie, quantitative and qualitative) from a range of stakeholders that were geographically diverse (ie, within Switzerland and Europe/USA) and spanned a range of experience with SSc. It merits mention that some expert patients had professional backgrounds including health policy, medicine, nursing and/or biomedical research, thus may not be representative of all patients with SSc. A limitation of the quantitative survey is the Swiss sample, making it difficult to broadly generalise our results internationally. The international focus group largely supported our findings. However, only one patient participated in the international focus group so caution is warranted in generalising findings more widely. Furthermore, we did not include general practitioners and non-rheumatology specialists in the focus groups what limits conclusions that can be made regarding multiprofessional management. Further research is needed to better understand and improve eHealth literacy and multiprofessional support in patients with SSc. Importantly, such work could include the European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases (ERN ReCONNET) to increase generalisability.[51] Moreover, measuring eHealth literacy is challenging as validated instruments have not been updated to fully address the current state of platforms (ie, social media) and internet use patterns.[26 27] While rare disease populations have been considered internet 'power users', no tools specifically address the unique ways that rare disease patients use the internet to learn about their condition and crowdsource solutions.[52] Future research may focus on eHealth literacy in broader rare disease populations to determine if findings are SSc-specific or representative of experiences of rare disease patients more broadly. Additional investigation may focus on the active role of patients with SSc in designing eHealth-enhanced care (ie, co-creating solutions).[53] It would be important to know the optimal model of care to empower and support active involvement of patients and coordinate disease management across multiple healthcare professionals involved in the care pathway.

CONCLUSIONS

To develop an eHealth-supported model of care, the interoperability of patient and provider technology is foundational. Both patients and healthcare professionals could benefit from structured, systematic eHealth guidance and training to help them identify valid, reliable and pertinent patient information. A key aspect of eHealth-supported models of care is to facilitate patient–provider communication to support shared decision-making and self-management. To ensure equity, design must also consider those individuals who have limited eHealth literacy and/or lack access to ICT.

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