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	Reference	Year	Country	Rare disease	Name of intervention/resource if applicable	Research or available		Needs/barriers to care	Details	e-resource	Language/s	e-resource details	Findings (if research only)
1	Ackbarali TA, et al. Assessing Patient and Provider Perspectives, Clinical Practice, Behaviors, and Knowledge on Hemophilia A Care. <i>Blood</i> ; 05 Nov2020. p. 24-5.	2020	USA	Haemophilia	a web-based joint educational initiative for patients/caregivers and HCPs	Research	Conference abstract	Management of severe haemophilia is rapidly evolving - patients, carers and HCPs alike unsure of new treatments but keen to learn		website active	Not given	1-hour online video-based CME activity for HCPs and 1-hour healthcare education activity for patients were created in June, 2020 to address identified practice and knowledge needs among HCPs, and knowledge, communication and self-efficacy behaviors among patients. Each activity consisted of slides, polling and live questions, and remains on-demand	
2	Aizawa R, et al. Status of narcolepsy-related information available on the Internet in Japan and its effective use. <i>Sleep and Biological Rhythms</i> . 2008;6(4):201-7.	2008	Japan	Narcolepsy	Existing internet resources	publicly available	Journal article	High quality web-based information can reduce time to diagnosis for people with narcolepsy	Useful, harmful information is low on search engine rankings.	website passive	Not given	Existing web-based resources	Patients were asking for info on the hereditary nature of the disease and ways to deal with their disease.
3	Al-Saleh H, et al. Beta testing of the "MY CF" smartphone/tablet app: In patients with cystic fibrosis. Conference Abstract presented at American Journal of Respiratory and Critical Care Medicine. Conference: American Thoracic Society International Conference, ATS; 2014.	2014	USA	Cystic fibrosis	MY CF	Research	Conference abstract	Complicated self-management	Difficulties keeping track of medications, test results and symptoms for adolescents or parents of younger children with CF.	App		Android OS for phone or tablet. The three most favored functionalities of the app were: Medication list, Symptom Diary, and Weight/Height/Body Mass Index monitoring. 32 invited to participate; of 23 who did, majority wanted to continue using it and would recommend it	
4	Armayones M, et al. APTIC: A social network to improve the quality of life of members of patients' associations. Conference Abstract presented at Orphanet Journal of Rare Diseases. Conference: 5th European Conference on Rare Diseases, ECRD; 2010.	2010	Spain	Rare diseases	APTIC	publicly available	Conference abstract	Fragmentation of information regarding rare diseases	Need for people to learn from one another, share experiences	social platform	Not given	Social networking platform that aims at enabling the individual members of patients' associations (mostly parents of children with chronic and rare diseases) to share experiences, information, advice	
5	Aznar J, et al. Telemedicine in Hemophilia: Virtual consultation for the hematologist at patient's home. <i>Haemophilia</i> ; July2012. p. 72.	2012	Spain	Haemophilia	domiciliary virtual consultation and virtual monitoring tools	Research	Conference abstract	Frequent hospital visits impact QoL	Domiciliary replacement therapy (DRT) ensures rapid infusion of lacking factors when any bleeding episode occurs and reduces hospital dependency of patients with hemophilia. However, these patients still have to visit the hospital frequently because the hematologist can prescribe general guidelines for home-replacement therapy but cannot adapt them to the bleeding evolution	telehealth	Not reported	Three interventions: (1) patient entered bleeding episode and self managed treatment; (2) virtual monitoring by ultrasound of haemarthroses, (3) Virtual consult	Successful in 45 patients which in turn may decrease dependency on hospital visits and by association QoL
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7	Badiu C, et al. Developing and evaluating rare disease educational materials co-created by expert clinicians and patients: the paradigm of congenital hypogonadotropic hypogonadism. <i>Orphanet Journal of Rare Diseases</i> . 2017;12(1)	2017	Europe	congenital hypogonadotropic hypogonadism (CHH) and the olfacto-genital (Kallmann) syndrome	Educational package	Research	Journal article	Need for high quality information/education on rare diseases	Important it is easy to read and engaging	website passive	20 languages	patient education materials	Appropriate reading level and accessibility
8	Balestri E, et al. 'F (accio) C (entro)': Project for a smartphone application to increase adherence to aerosol treatment in adolescents with cystic fibrosis. Conference Abstract presented at Italian Journal of Pediatrics. Conference: 25th Italian Congress of Cystic Fibrosis and the 15th National Congress of Cystic Fibrosis Italian Society. Milan Italy; 2020.	2020	Italy	Cystic fibrosis	Faccio Centro	Research	Conference abstract	Complicated self-management with decreasing adherence from adolescents	Patients with Cystic fibrosis have onerous therapy - respiratory physiotherapy, therapy by aerosol, oral, intravenous and physical activity. During adolescence the therapy adherence, that is undergoing treatments at the right time of the day, in the right sequence and dosage, considerably decreases with negative consequences in terms of: health status, quality of life and hospitalization	App		Mobile phone app - lists daily therapy, with instructions on order, progress tracking, alerts for when to start and when checks are needed. Also can email questions to HCP team.	
9	Barazani Brutman T, et al. New communication technologies improve hemophilia care. <i>Haemophilia</i> . 2017;23(Supplement 2):134-5.	2017	Israel	Haemophilia	WhatsApp social support group messaging	Research	Conference abstract	Parents with newly diagnosed children require immediate response when things happen		social platform	Not given	Social support groups of parents, patients and medical staff WhatsApp. Parents, patients and medical staff used the WhatsApp application installed on smartphone to provide immediate response to various issues: queries regarding bleeds (with relevant photos), queries regarding dosage/ frequency of therapy, queries about quality of life (QOL) and specific situations noted at school/ kindergarden, personal communication and general consult and support.	Extension of physical groups at the treatment centre.
10	Blackwell LS, et al. CFone: A social networking site for adolescents and young adults with cf. <i>Pediatric Pulmonology</i> . 2012;35):430.	2012	USA	Cystic fibrosis	CFOne	Research	Conference abstract	Transition from child to adult requires increased independence and self efficacy	Social support associated with better psychological wellbeing and better outcomes.	social platform	Not given	online peer support program for adolescents and young adults with CF	Social networking sites for adolescents and young adults with CF may be useful for increasing knowledge of disease management, increasing perceptions of social support and improving mental health and quality of life.
11	Boon M, et al. Use of a mobile application for self-management of pancreatic enzyme replacement therapy is associated with improved gastro-intestinal related quality of life in children with Cystic Fibrosis. <i>Journal of Cystic Fibrosis</i> . 2020;19(4):562-568	2020	Europe	Cystic fibrosis	MyCyFAPP	Research	Journal article	Complicated self (parental)-management for gastrointestinal distress in children	Most patients with cystic fibrosis (CF) suffer from pancreatic insufficiency, leading to fat malabsorption, malnutrition, abdominal discomfort and impaired growth. Pancreatic enzyme replacement therapy (PERT) effective but evidence-base on dosing still being built. This uses a new algorithm.	App	Dutch, English, Flemish, Italian, Portuguese, Spanish	App calculates individual PERT-doses for optimal fat digestion and includes a symptoms diary, educational material, and it is linked to a web tool allowing HCPs to view data and give feedback.	Increased GI QoL measures.
12	Breakey VR, et al. A feasibility study of "managing hemophilia online": An Internet-based self-management and transitional care program for teens. <i>Haemophilia</i> . 2012;3):207-8.	2012	Canada	Haemophilia	online self-management intervention	Research	Conference abstract	Adolescents have heightened educational needs as they learn to manage their disease and become self-sufficient in preparation for transition to adult health care.		website passive	English and French	Online course - not clear if it is interactive. Pilot - still working it out	

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13	Breakey VR, et al. A pilot randomized control trial to evaluate the feasibility of an internet-based self-management and transitional care program for youth with haemophilia. <i>Haemophilia</i> . 2014;20(6):784-93.	2014	Canada	Haemophilia	Teens Taking Charge: Managing Hemophilia Online'	Research	Journal article	Adolescents have heightened educational needs as they learn to manage their disease and become self-sufficient in preparation for transition to adult health care.		website active	English and French	8 week educational program on line with weekly telephone support from a trained Research Assistant.	Teens on the intervention arm showed significant improvement in disease-specific knowledge (P = 0.004), self-efficacy (P = 0.007) and transition preparedness (P = 0.046). There was a statistically significant improvement in knowledge in the intervention group when compared to the control group (P = 0.01). Overall, the teens found the website to be informative, comprehensive and easy to use and were satisfied with the program.
14	Breakey VR, et al. Feasibility study of a randomized control trial to evaluate an internet-based self-management program for adolescents with hemophilia: Preliminary results and observations. <i>Journal of Thrombosis and Haemostasis</i> ; July2013. p. 1058.	2013	Canada	Haemophilia	Teens Taking Charge: Managing Hemophilia Online'	Research	Conference abstract	Adolescents have heightened educational needs as they learn to manage their disease and become self-sufficient in preparation for transition to adult health care.		website active	English and French	8 week educational program on line with weekly telephone support from a trained Research Assistant.	Overall, these teens found the website to be informative, comprehensive and easy to use and were satisfied with the program.
15	Breakey VR, et al. The value of usability testing for Internet-based adolescent self-management interventions: "Managing Hemophilia Online". <i>BMC medical informatics and decision making</i> . 2013;13:113.	2013	Canada	Haemophilia	Teens Taking Charge: Managing Hemophilia Online'	Research	Conference abstract	Adolescents have heightened educational needs as they learn to manage their disease and become self-sufficient in preparation for transition to adult health care.		website active	English and French	8 week educational program on line. Course contained multimedia components (videos, animations, quizzes)	
16	Calvo-Lerma J, et al. Clinical evaluation of an evidence-based method based on food characteristics to adjust pancreatic enzyme supplements dose in cystic fibrosis. <i>Journal of Cystic Fibrosis</i> . 2020.	2020	Europe	Cystic fibrosis	MyCyFAPP	Research	Journal article	Complicated self (parental)-management for gastrointestinal distress in children	Most patients with cystic fibrosis (CF) suffer from pancreatic insufficiency, leading to fat malabsorption, malnutrition, abdominal discomfort and impaired growth. Pancreatic enzyme replacement therapy (PERT) effective but evidence-base on dosing still being built. This uses a new algorithm.	App	Dutch, English, Flemish, Italian, Portuguese, Spanish	App calculates individual PERT-doses for optimal fat digestion and includes a symptoms diary, educational material, and it is linked to a web tool allowing HCPs to view data and give feedback.	Improved fat absorption for those with poor baseline measures.
17	Calvo-Lerma J, et al. Change in nutrient and dietary intake in European children with cystic fibrosis after a 6-month intervention with a self-management mhealth tool. <i>Nutrients</i> . 2021;13(6)	2021	Europe	Cystic fibrosis	MyCyFAPP	Research	Journal article	People with CF have increased energy needs and a diet with a specific nutrient distribution. Nutritional status is an indicator of disease prognosis and survival. Self(parental)-management is complicated	App provided educational resources about nutrition and dietary advice for parents	App	Dutch, English, Flemish, Italian, Portuguese, Spanish	Food diary, nutrition follow-up (goals), symptoms diary (health diary), nutrition educational material (living with CF) and messages among other functions	Users had modest improvements towards the nutritional guidelines
18	Carr SB, et al. Children and adults Tai Chi study (CF-CATS2): A randomised controlled feasibility study comparing internet-delivered with face-to-face Tai Chi lessons in cystic fibrosis. <i>ERJ Open Research</i> . 2018;4(4)	2018	UK	Cystic fibrosis	NA	Research	Journal article	Maintaining exercise difficult for people with CF due to isolation.	8 lessons over 3 months, delivered face to face (n=22) or via internet (n=18) for 40 adults and children with CF.	telehealth	English	Lessons delivered over Skype; also had a DVD, booklet, stickers and t-shirts aimed at different ages to increase adherence.	Feasibility and safety were demonstrated. All participants showed significant improvements in self-reported sleep, cough (both daytime and night-time), stomach ache and breathing. No differences in lung function, health status, quality of life, sleep or mindfulness was shown before or after completing the lessons.
19	Carr SB, et al. Children and adults Tai Chi study (CF-CATS2): A randomised controlled feasibility study comparing internet-delivered with face-to-face Tai Chi lessons in cystic fibrosis. <i>ERJ Open Research</i> . 2018;4(4).	2018	UK	Cystic fibrosis	Internet delivered Tai-Chi class	Research	Journal article	Isolation yet needing tailored exercise	Maintaining an exercise regime can be difficult in cystic fibrosis: group classes risk potential infection, yet motivation is hard to maintain when alone.	telehealth	English	Comparison of F2F and internet classes	Improvements in sleep, cough, GI symptoms and breathing but no diff in lung function, health status and QoL. Findings same in both groups.

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20	Castro RA, et al. Exploring the Views of Osteogenesis Imperfecta Caregivers on Internet-Based Technologies: Qualitative Descriptive Study. J Med Internet Res. 2019;21(12):e15924.	2019	Canada	Osteogenesis Imperfecta (OI)	Exploring use of what's available online and what is needed	publicly available	Journal article	Multiple needs	(1) Distraction for children after surgery to promote rest and immobilization, or to distract from painful or frightening procedures etc; (2) Isolation from family or friends at a distance or in unsafe places for the child to visit; (3) Carers' self care; (4) Parents and carers feeling distressed by the disease and child's suffering; (5) Managing logistics of caregiving/ HCPs (6) Communication with HCP; (7) Facilitating care; (8) Information seeking; (9) social isolation (10) Updates on research and new treatments (11) Concern about quality, security (12) wishlist (13) caregivers desired child-friendly and age-appropriate (14) In their own language	other			(1) Games, videos, audio books have a calming affect to distract from boredom, pain or fear; (2) Social media platforms like FaceTime useful for staying in touch; (3) Can be a lot of waiting for appointments and then keeping the child quiet at home after surgeries etc. Yoga apps, games and ; (4) Watching inspirational videos of other children with OI doing well gave hope; (5) Booking online much easier and e-calendars useful to store all appointments; (6) Some allowed email or messaging (e.g., to SW or PT); (7) Some tools allowed carers to find local community and care resources - e.g., wheelchair accessibility of local shopping centre etc. Appropriately adapted sports programs; (8) Found via Google so not optimal (9) Social media specifically for OI - share day-to-day care information rather than using it for specific information on prognoses or treatments. Some caregivers were more interested in answering others' questions than in having their own questions answered. OI parents were the ones who know practical day-to-day care strategies, such as where to find adaptive clothing and winter boots that would fit her child's physique. Claimed to get faster information from a social media platform group rather than an HCP. (10) Access to information; (11) Concerned about web-based predators or cyberbullies or judgement from other parents. Often were confronted with worst-case scenarios that were not applicable to their own children. (12) Web-based home fracture-splinting videos with diverse techniques for every fracture possible • Web-based videos portraying OI patients before and after various
21	Cipriani D, Dulcan E. See and be seen: The CF community. Pediatric Pulmonology. 2017;52(Supplement 47):147-148.	2017	USA	Cystic fibrosis	BreatheCon	limited availability	Conference abstract	CF considered an invisible disease; social support limited by infection risk; niche information hard to find; mental health often impacted.	Lack of understanding of peers and family when the disease is "invisible." Desire to connect with people with the same disease (who "get it") but face-to-face not possible. telling your boss about CF as well as colleagues, classmates, friends, in-laws and other new family. The alienation of invisibility is compounded by uncomfortable, lonely, boring treatments. When life expectancy improves for a cohort of patients, little information about reproduction, family planning, safe sex practices, genetic	social platform	Not given	Online conferences for people with CF subdivided into adults, parents/children and young people.	
22	Colman AW, et al. Use of Quick Response (QR) coded bracelets and cards for the improvement of cortisol deficiency/Addison's disease management: An audit of quality of care of the management of steroid deficiency in acute illness. BMJ Innovations. 2018;4(3):115-22.	2018	UK (England)	Addison's disease	Quick response coded bracelet	Research	Journal article	Adrenal crisis is life-threatening and requires swift intervention but is very rare	Study of HCPs - clinically needed / useful?	website passive	Not given	Bracelet has a scannable QR code that links to emergency management information	Clinical need identified
23	Cox NS, et al. A web-based intervention to promote physical activity in adolescents and young adults with cystic fibrosis: protocol for a randomized controlled trial. BMC polim. 2019;19(1):253.	2019	Australia	Cystic fibrosis	ActivOnline	Research	Journal article	Tailored exercise program without risk of infection		website active	Not given	internet-based physical activity program for 12 weeks for adolescents and young adults	Protocol

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24	Cox NS, et al. Feasibility and acceptability of an Internet-Based program to promote physical activity in adults with cystic fibrosis. <i>Respiratory Care</i> . 2015;60(3):422-9.	2015	Australia	Cystic fibrosis	ActivOnline	Research	Journal article	Tailored exercise program without risk of infection		website active	Not given	internet-based physical activity program for 8 weeks for adults. Also fortnightly phone consult	Feasible and acceptable
25	Cummings E, et al. Enhancing self-efficacy for self-management in people with cystic fibrosis. <i>Studies in Health Technology and Informatics</i> . 2011;169:33-37.	2011	Australia	Cystic fibrosis				Complicated self-management	Health mentoring project with 3 groups: (1) Self-efficacy web-based program + mentor via phone, (2) mentor via phone + self-efficacy program +App, (3) usual care.	App	English	App consisted on Symptom diary plus optional feedback on progress	Results show the intervention was generally considered to be useful and allowed CF individuals to focus on changes in symptoms. Self-efficacy increased in subjects in both intervention groups, but it is unclear from the results if the application provided additional benefits beyond supporting the mentoring intervention.
26	D'Ambrosio C. Open versus closed social networking groups. <i>Haemophilia</i> . 2014;3:183.	2014	USA	Bleeding disorders in women	MyGirlsBlood	publicly available	Conference abstract	Little information for this group of women; social isolation	Debate over whether open or closed group better. Closed for safety discussing personal details but reinforces it as a "secret" and shuts out others who may help / get it on the research agenda.	social platform	Not given	Open group (not closed) on Facebook where people can ask questions or share experiences.	Having closed social networks are needed for groups that need privacy and security in their communications. WWBD need privacy to learn from one another and to solve intimate problems. However, when there are only closed groups, awareness ceases to exist across the larger multi-disciplinary and diverse worldwide community. Many would like to help, but would not be permitted in a closed group for WWBD.
27	Decker K, Meilleur C. CBDR and MyCBDR advancing hemophilia nursing practice in Canada. Conference Abstract presented at Haemophilia; May, 2018	2018	Canada	Haemophilia	MyCBDR (linked to Canadian Bleeding Disorder Registry (CBDR))	limited availability	Conference abstract	Complicated self-management	Better outcomes from new treatment regimes but requires detailed record keeping to accurately monitor bleeding episodes, factor usage and adherence to treatment regimens.	App	Not reported	Links to CBDR - app allows people with a bleeding disorder to add track infusions and symptoms. Data available to all Haemophilia Treatment Centres in Canada meaning greater integration for specialist services.	Useful tool that allows access to detailed information to the care teams and by implication, better treatment outcomes
28	Fidika A, et al. A web-based psychological support program for caregivers of children with cystic fibrosis: A pilot study. <i>Health and Quality of Life Outcomes</i> . 2015;13(1)	2015	Germany	Cystic fibrosis	WEP-CARE	Research	Journal article	Parents caring for a child with Cystic Fibrosis (CF) are at high risk for psychological distress and have limited access to psychological care.	Severe distress not unusual. Lack of appropriate and knowledgeable support.	website active	Not given	Web-based writing therapy - 9 sessions, tailored for the specific needs of caregivers. Written assignments that were given feedback within 48 hours. The intervention program was provided by two trained and supervised psychotherapists with expertise in psychosocial care for patients with CF and their families.	On average, the caregivers' symptoms of anxiety decreased statistically significant and clinical relevant about five points from an elevated (M=11.4; SD =2.6) to a normal level (M=6.7; SD =2.6; p < .001) between pre and post treatment. Fear of disease progression (p < .001) and symptoms of depression (p = .02) significantly decreased as well. Quality of life significantly improved (p = .01). The effects were maintained at the 3-months follow-up assessment.
29	Floch J, et al. Users' Experiences of a Mobile Health Self-Management Approach for the Treatment of Cystic Fibrosis: Mixed Methods Study. <i>JMIR mHealth and uHealth</i> . 2020;8(7):e15896.	2020	Europe	Cystic fibrosis	MyCyFAPP	Research	Journal article	Complicated self-management	Overall positive experience but food recording was seen as too complicated. Once people met their goals, lost motivation to continue using the app. HCPs also reported that information communicated by patients is more reliable and accurate. Normally, patients do not record data systematically. They forget details or get information mixed up. Empowering patients to record events at the time they occur, HCPs felt that the data they receive are more precise and better reflect the reality of patients' status	App	Dutch, English, Flemish, Italian, Portuguese, Spanish	Food diary, nutrition follow-up (goals), symptoms diary (health diary), nutrition educational material (living with CF) and messages among other functions	Patients and parents had different skills, requiring follow-up by HCPs in an introductory phase. HCPs valued obtaining precise information about the patients, allowing for more personalized advice. However, the tight follow-up of several patients led to an increased workload. Over time, as patient self-efficacy increased, patient motivation for using the app decreased and the quality of the reported data was reduced. They suggest focusing on patients with poor control using the app; all patients using it for the week before a consult. Introducing all the features of the app at once can be overwhelming - staged approach better. Personalising it with help from the HCP also useful.

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30	Gow J, et al. Participation in patient support forums may put rare disease patient data at risk of re-identification. <i>Orphanet Journal of Rare Diseases</i> . 2020;15(1)	2020	UK	Rare diseases	Social support groups generally for people with RD	publicly available	Journal article	Vulnerable to re-identification on social support platforms	Online social support groups may not have sufficient security to prevent malicious matching of health and personal data to re-identify anonymised data	social platform			
31	Grande SW, et al. Improving care for pediatric cystic fibrosis in Sweden using a successful mHealth patient support system. Conference Abstract presented at Pediatric Pulmonology; September, 2017.	2017	Sweden	Cystic fibrosis	Genia	limited availability	Conference abstract	Complicated self-management/tracking symptoms and treatments	Parents don't always recall symptoms and treatments for their child making it hard for HCPs to accurately assess the patient.	App	Not reported	Patients/parents record daily health observations and complete reports about symptoms, medications, and goals immediately prior to a clinic appointment. Data available to HCPs at the consult.	High uptake at the study hospital; HCP took QI approach to its implementation. Considered to have improved coordination and patient-provider consensus yet without greater HCP burden.
32	Gulliams JM, et al. Feasibility and usefulness of a mobile health exercise intervention in women with lymphangioleiomyomatosis. Conference Abstract presented at <i>Cardiopulmonary Physical Therapy Journal</i> ; July, 2021.	2021	Not given	Lymphangioleiomyomatosis (LAM)	Home based exercise program for women with LAM	Research	Conference abstract	Require tailored exercise program	Patients have reduced lung function and exercise tolerance; and a recent report indicates lower physical activity levels in LAM compared to patients with COPD and healthy populations.	App	Not reported	App on smartphone with interfacing wearable and home monitoring devices. Check in with Physio weekly.	12 wk trial. Initial findings indicate feasibility and usefulness of an mHealth home exercise program for LAM, including good patient adherence and satisfaction with the program.
33	Haik D, et al. The Online Support Group as a Community: A Thematic Content Analysis of an Online Support Group for Idiopathic Subglottic Stenosis. <i>Annals of Otolaryngology, Rhinology and Laryngology</i> . 2019;128(4):293-299.	2019	USA	Idiopathic subglottic stenosis (ISGS)	Living With Idiopathic Subglottic Stenosis (LwiISGS),	publicly available	Conference abstract	Access to information, sharing of experiences		social platform	Not given	Online community specifically for people with ISGS	Analysis demonstrated that communications primarily encompassed three major thematic elements: (1) information sharing; (2) emotional support, expression, and experience sharing; and (3) community building. Positively toned posts grossly overshadowed negatively toned posts by almost a factor of 3. A significant portion of group members requested information from their peers, suggesting a high level of trust toward the resources provided in this group, even those involving a surgical procedure or medication.
34	Ho G, et al. Metabolic Diet App Suite for inborn errors of amino acid metabolism. <i>Molecular Genetics and Metabolism</i> . 2016;117(3):322-327.	2016	Canada	Inborn errors of metabolism (IEM)	Metabolic DietAppSuite	publicly available	Journal article	Burden of daily adherence to complex and time-consuming medical diet to attain metabolic control and prevent organ damage	Diet is only one of a number of competing priorities for people with IEM, but one of the most onerous. Poor nutritional labelling on many foods - restricts diet further.	App	Not reported	Online tool for mobile phones and desktops for 15 different IEMs. Creates a personalised dashboard including specific nutrient goals. Food diary, nutrient counts and able to add your homemade recipes.	
35	Howard S, The All Wales Adult Cystic Fibrosis Centre (AWACFC) Virtual Instruction of Exercise with Technology to Enhance Care-VIEWTEC Programme. <i>Journal of Cystic Fibrosis</i> . 2014;2:S20	2014	UK (Wales)	Cystic fibrosis	VIEWTEC Programme	Research	Conference abstract	Patients live 2 and 3 hours away from treatment centre but benefit from tailored exercise programs	Group exercise is more motivating	telehealth	Not given	virtual exercise sessions with a CF Gym Instructor. Email invitations and delivered via Cisco Webex	Feasible and patients liked it.

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36	Huang X, et al. Developing and evaluating HE-APP: Acceptability and usability of a smartphone APP system to improve self-management in Chinese patients with haemophilia. Conference Abstract presented at Haemophilia; June, 2020	2020	China	Haemophilia	HE-APP		Conference abstract	Complicated self-management linked to outcomes	Outcomes linked to self management and accurate symptom-tracking.	App	Mandarin?	(1) recording of bleeding symptoms; (2) monitoring of treatment adherence; (3) education, training and support system; (4) accounting and analysing the use of the medicine; and (5) recording the economic cost.	Acceptability and usability levels high among patients and their parents. Small trial with 10 patients.
37	Ingravallo F, et al. Telemedicine with mobile internet devices for innovative multidisciplinary patient-centred care of patients with narcolepsy. Protocol of the randomized controlled trial TENAR (TElemedicine for NARcolepsy). European Journal of Neurology. 2020;27(Supplement 1):516.	2020	Italy	Narcolepsy	TENAR trial (Protocol)	Research	Conference abstract	disease burden is increased by the need for traveling for medical consultations, with high costs for patients and families.		telehealth			
38	Kauw D, et al. The Contribution of Online Peer-to-Peer Communication Among Patients With Adrenal Disease to Patient-Centered Care. J Med Internet Res. 2015;17(3):e54.	2015	The Netherlands	Addison's disease and Cushing's syndrome	online forum moderated by the Dutch Adrenal Society	publicly available	Journal article	Peer-to-peer information sharing		social platform	Not given	Public area and password protected area. Rules for posting e.g., posting medical information - must provide references. Moderated by volunteers.	Analysis of content: 81% asking for more info about the disease; 10% asking for emotional support; Answers mostly practical tips and sharing own experiences. Seen as an important information source. Social support in the form of experiential info and emotional support - not able to be obtained from HCPs.
39	Khair K, et al. Social networking for adolescents with haemophilia. Haemophilia. 2011;17(2):369.	2011	UK	Haemophilia	VivaSix	Research	Conference abstract	Adherence to treatment difficult for adolescent boys with severe haemophilia	Parents are often sole source of information outside of HCPs. Few know of other boys with haemophilia	social platform	Not given	Restricted social network for boys 11-18 years with severe haemophilia. Will include games and other features to promote sharing of self management skills.	
40	Khair K, et al. The role of social networking in haemophilia management. Haemophilia. 2010;4):129-130.	2010	UK	Haemophilia	hiFive	Research	Conference abstract	Adherence to treatment difficult for adolescent boys with severe haemophilia	Parental influence lessens. Potential for peer to peer transmission of self management skills	social platform	Not given	hiFive - small group for 11-19 year olds living with severe haemophilia. Closed to parents.	
41	Kirk S, Milnes L. An exploration of how young people and parents use online support in the context of living with cystic fibrosis. Health expectations. 2016;19(2):309-321.	2016	UK	Cystic fibrosis	Online forum for people with CF	Research	Journal article	Can be hard to find information and support for people with a rare disease or caring for a child with a rare disease		social platform	Not given	Participants exchanged experientially derived advice and views on how to manage treatments, emotions, relationships, identity and support from services. While parents sought information and support on managing specific therapies/services and ways of maintaining their child's health, the information and support young people desired appeared to be more directed at how to 'fit' CF into their everyday lives	Online support groups appear to supplement professional support in relation to self-management. They enable young people and parents to share experiences, feelings and strategies for living with long-term conditions with peers and develop the expertise to empower them in interactions with health-care professionals.
42	Kühnle L, et al. Development of a Social Network for People Without a Diagnosis (RarePairs): Evaluation Study. J Med Internet Res. 2020;22(9):e21849	2020	Germany	Undiagnosed rare diseases	RarePairs	Research	Journal article	Diagnostic delay is a regular feature of rare diseases	Diagnosis can be difficult with limited information and experience of rare diseases. This uses information from a database of 973 diagnosed people	social platform	German, English, Chinese, Portuguese, and Finnish	Social network platform with built in algorithm to match individuals with similar disease burden in the lead up to diagnosis.	

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43	Lassandro G, et al. EMO.TI.ON.: Technologies for the safety of children with hemophilia. Blood Transfusion; November 2017, p. s539.	2017	Italy	Haemophilia	EMO.TI.ON. system	Research	Conference abstract	Home care decreasing reliance on hospital	Diagnosing suspected bleeds into joints requiring hospital visit for diagnosis	telehealth	Not given	an ultrasound diagnostic solution using at home by parents or caregivers. Moreover, the system can transfer, live, images by world wide web to specialist physician creating a network. The solution will be achieved by attending the design related to familiarization processes. Other function of the system are: teleconsulting tools, semantic scientific search, recording data (i.e. clinical chart, infusional diary...).	Ongoing trial but results of parent use comparable to HCP use.
44	Lee Yeong J, et al. A Newly Developed Web-Based Resource on Genetic Eye Disorders for Users With Visual Impairment (Gene.Vision): Usability Study. J Med Internet Res. 2021;23(1):e19151.	2021	UK (England)	Genetic eye disorders	Gene.Vision	Research	Journal article	Educational web-based materials need to be accessible by people with low vision		website passive	Not given	Gene.vision web site on genetic eye disorders optimised for people with vision problems	
45	Lewis T. Improving quality of life in patients with cystic fibrosis with exercise: CF foundation impact grant update. Conference Abstract presented at Pediatric Pulmonology; October, 2019.	2019	USA	Cystic fibrosis	Exercise program via App	Research	Conference abstract	Require tailored exercise program in isolation	Deliver an at home exercise program to people with CF - indirect supervision by exercise physiologist.	App	English	Guided exercise program (3 levels to choose from) and assessment tasks. Supported by live recorded discussions and Q and A sessions.	Suggests it is feasible and could lead to improvements in QoL.
46	Lomotey RK, et al. Mobile self-management guide for young men with mild hemophilia in cases of minor injuries. Network Modeling Analysis in Health Informatics and Bioinformatics. 2014;3(1).	2014	Canada	Haemophilia	Hemophilia Injury Recognition Tool ("HIRT?")	limited availability	Journal article	Patients may be slow to recognise injuries if their disease is mild	People with mild haemophilia may only experience bleeds after a significant injury and so not recognise sequelae of milder events - not seek appropriate treatment.	App	English, French	Structured assessment of suspected bleeds plus appropriate first-aid if needed. If more help required, phone number of all Haemophilia Treatment Centres in Canada are given to enquire about further management.	High usability for all users whether tech savvy or not.
47	Manu-Pereira MM, et al. ENERCA: Towards a European Reference Network (ERN) in rare haematological diseases. British Journal of Haematology. 2016;173(Supplement 1):39-40.	2016	Europe	Rare and Congenital Anaemias	e-ENERCA (European Network for Rare and Congenital Anaemias (ENERCA))	Research	Conference abstract	Distance from specialist centres, lack of relevant information and need to share data with expert HCP.	European reference Networks - hub and spoke model for rare disease care	website active	Not given	3 separate platforms linked to the e-ENERCA website 1) e-Registry, a Pan European registry of RAs for epidemiological surveillance 2) e-Learning for the dissemination of knowledge, continuous medical education, and best practices awareness, and 3) Telemedicine, a platform to provide expertise, at distance, for complex cases.	
48	Moon H, Moon J. Comparative readability analysis of information on exercise for hemophilia patients. Haemophilia. 2021;27(SUPPL 2):57.	2021	South Korea	Haemophilia	Existing online exercise programs for Haemophilia	publicly available	Conference abstract	Tailored online exercise programs need to be understandable.	Readability and other access features not always present	website passive	Not given	Existing web-based resources	Sites had higher than recommended readability scores and came low down in search algorithm rankings making them hard to find.
49	Naik H, et al. Experience with a pilot skype internet support group for symptomatic patients with acute intermittent porphyria. Clinical Chemistry and Laboratory Medicine. 2013;51(5):eA10.	2013	USA	Acute Intermittent Porphyria (AIP)	Skype support group mediated by HCPs	Research	Conference abstract	Psychosocial and emotional isolation leading to poor mental health in this group	Life-threatening acute episodes - painful with sequelae - chronic symptoms. Poorly understood psychosocial needs.	social platform	Not given	Skype support group mediated by a porphyria expert physician, and the genetic counselor/coordinator of the porphyria clinic and an available psychologist with 4 women with AIP.	Participants reported that this was a very comforting experience, reducing the feeling of isolation and increasing their understanding of the disease.

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50	Nicholl H, et al. Internet Use by Parents of Children With Rare Conditions: Findings From a Study on Parents' Web Information Needs. <i>J Med Internet Res</i> . 2017;19(2):e51.	2017	Ireland	Rare diseases	Hypothetical	publicly available	Journal article	Recommendations for a consumer facing website	<ul style="list-style-type: none"> The content needs to be relevant, accurate, trustworthy, and up to date. The topics most frequently searched for (Table 5) need to be addressed. It should contain a Web-based forum or a social network component. The website should be integrated with social media and be mobile friendly. 	other				
51	Nilson J, et al. Are you HIRT? (Hemophilia Injury Recognition Tool): Perceptions of the mobile app on injury self-management from young men with mild hemophilia in Canada. Conference Abstract presented at Haemophilia; July, 2016.	2016	Canada	Haemophilia	Hemophilia Injury Recognition Tool ("HIRT?")	limited availability	Conference abstract	Patients may be slow to recognise injuries if their disease is mild	People with mild haemophilia may only experience bleeds after a significant injury and so not recognise sequelae of milder events - not seek appropriate treatment.	App	English, French	Structured assessment of suspected bleeds plus appropriate first-aid if needed. If more help required, phone number of all Haemophilia Treatment Centres in Canada are given to enquire about further management.	Increased confidence dealing with injuries but no change in self management	
52	Osara Y, et al. Development of newborn screening connect (NBS connect): a self-reported patient registry and its role in improvement of care for patients with inherited metabolic disorders. <i>Orphanet Journal Of Rare Diseases</i> . 2017;12(1):132.	2017	USA	Phenylketonuria (PKU), maple syrup urine disease (MSUD) or tyrosinemia (TYR)	Newborn Screening Connect (NBS Connect)		Research	Journal article	Patients/carers isolated by rareness of disease.	Linking patients/carers with information. Registries are generating useful data and contributing to the research agenda.	website active	Not given	Registry - patient initiated and enters data. Resources such as education materials, information on the latest research and clinical trials, recipes, interactive health tracking systems, and professional support tools	
53	Paglalanga A, et al. eHealth for patients with rare diseases: the eHealth Working Group of the European Reference Network on Rare Multisystemic Vascular Diseases (VASCERN). <i>Orphanet Journal of Rare Diseases</i> . 2021;16(1):164.	2021	Europe	Rare Multisystemic Vascular Diseases	Mobile app developed by VASCERN (European Reference Network on Rare Multisystemic Vascular Diseases); Pills of Knowledge YouTube channel	limited availability	Journal article	(1) Finding a suitable expert; (2) finding a patient support agency; (3) need for timely info about the patient in an emergency situation; (4) information needs of the patient	(1) In Europe can mean travelling across borders, languages - incurring time and money. Difficult to find appropriate RD expert. This RD is multisystem so may need several specialists; (2) Not always named after your disease / group of diseases (3) Paper records carried by the patient are common but may be lost and can only contain a limited amount of information; (4) High quality and easy to understand - combining patient and carer needs, HCP expertise and patient advocacy agency perspectives	App	Multiple European languages	However, further research is needed as digital patient passports may also pose new challenges, for example in terms of data management, patient privacy, informed consent, and control of shared data. In addition, digital passports may not necessarily fit the needs of every patient with the disease as, for example, people with limited digital skills and people not willing to use a smartphone to handle clinical issues might still prefer to use conventional paper documents. Issues about confidentiality and ethical rules in various EU countries, remain to be solved.		
54	Parrott H, et al. A digital solution for virtual consultation and sharing health data in adults with cystic fibrosis. <i>Journal of Cystic Fibrosis</i> . 2019;18(Supplement 1):S51	2019	UK	Cystic fibrosis	Virtual consults and remote monitoring		Research	Conference abstract	Frequent clinic visits are having a huge impact on the quality of life.	Also growing cohort of patients as they are living longer - concerns about Health system capacity	telehealth	Not given	Virtual clinics and spirometry done by patients at home	Considerable savings of time for both patients and clinicians. So far no issues. Patients like it.
55	Polineni D, et al. A stakeholder-informed feasibility study of tele-coaching to improve treatment adherence in patients with cystic fibrosis. <i>Pediatric Pulmonology</i> . 2017;52(Supplement 47):479.	2017	USA	Cystic fibrosis	Tele-coaching		Research	Conference abstract	Adherence to treatment not optimal	Proposed intervention= tele-coaching	telehealth			

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56	Richesson RL, et al. An automated communication system in a contact registry for persons with rare diseases: Scalable tools for identifying and recruiting clinical research participants. <i>Contemporary Clinical Trials</i> . 2009;30(1):55-62.	2009	USA	Rare diseases	Notifications of relevant new research projects	Research	Journal article	Patients have a lack of access to new trials; Researchers - hard to recruit patients	All related to rarity of the conditions	website passive	Not given	web-based automated system generates periodic and customized communications to notify registrants of relevant studies in the NIH Rare Diseases Clinical Research Network (RDCRN).	
57	Rits S, et al. Weekly patient webcasts: An adult CF center's response to the COVID-19 pandemic. Conference Abstract presented at Pediatric Pulmonology, October, 2020.	2020	USA	Cystic fibrosis	Webcasts on COVID	publicly available	Conference abstract	Urgent need for disease specific information during COVID pandemic	Plenty of information for the general public but not for people with a rare disease. Concerns from people with CF adequate infection control, access to care, medications and supplies, clinical outcomes as they relate to CF, employment status and disability, and overall mental health	other	Not given	Weekly webcasts on COVID made available Could ask questions through Google form. Email notification out to patients and carers.	
58	Rodman J, et al. Patient perspectives on electronic access to registry health records: An Irish-Slovene online survey. <i>Journal of Cystic Fibrosis</i> . 2016;15(Supplement 1):S36.	2016	Ireland and Slovenia	Cystic fibrosis	European CF Registry	Research	Conference abstract	Lack of patient access to their own medical records	Thought to be useful for self management	website active	Not given	Hypothetical access to the Register	Patients in favour of it but concerned about security
59	Rudolf I, et al. Assessment of a Mobile App by Adolescents and Young Adults With Cystic Fibrosis: Pilot Evaluation. <i>JMIR mHealth and uHealth</i> . 2019;7(11):e12442.	2019	Germany	Cystic fibrosis	Kinderhilfe Organtransplantation (KIOAPP)	publicly available	Journal article	Lung function decline in transition from 12 and 24 years.	Improving self management and independence from parents important for ongoing outcomes. Poor self management only slowly manifests itself.	App	?German	App contains a diary function for recording vital signs and personal observations, communication platform for sending information to the HCP, a medication plan, and medication reminder function. Age appropriate format	Perceived as useful and supportive overall. Most useful feature was the medication plan and reminders. Diary use became less frequent quickly at odds with its high usefulness rating.
60	Ruther DF, et al. Mobile app requirements for patients with rare liver diseases: A single center survey for the ERN RARE-LIVER. <i>Clinics and Research in Hepatology and Gastroenterology</i> . 2021;45(6).	2021	Europe	autoimmune liver diseases (AILD)	Hypothetical	Research	Journal article	Research into what consumers want in a Rare Liver disorder app		App	Not reported	Hypothetical	A substantial majority of patients expected to benefit from the app due to constant access to health data (81%), better overview of the course of the disease (80%), better understanding of the disease (70%) and faster detection of drug side effects (64%). only the minority of patients believed that an app could help to improve quality of life (21%), reduce fears associated with the disease (24%), reduce mistakes in taking medication (32%) or improve medication adherence (37%) (Fig. 3). Significantly desired features were information on new developments (93%), access to one's own medical records (89%), notifications to practitioner in case of concerns (84%), automatic ordering of follow-up prescriptions (81%), information on clinical trials (79%), disease information (79%) and recording of health concerns with symptom trackers (73%). In contrast, significantly undesired features were gamification or reward system (5%), networking (27%) and comparisons (35%) with other persons affected (Fig. 3). Did not all match with HCP responses.
61	Sottilotta G, et al. The HEMONLINE project: Preliminary results. <i>Haemophilia</i> . 2012;3:77.	2012	Italy	Haemophilia	HEMONLINE	Research	Conference abstract	Distance to treatment centre burdensome and results in expenses including loss of wages.		telehealth	Not given	Web-cam and internet connection provided to patients to allow them to contact HCPs in addition to in person home visits by the MDT	In progress but suggests better use of health services and patient satisfaction

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62	Stevenson Won A, et al. Assessing the Feasibility of an Open-Source Virtual Reality Mirror Visual Feedback Module for Complex Regional Pain Syndrome: Pilot Usability Study. <i>J Med Internet Res.</i> 2021;23(5):e16536.	2021	USA	Complex regional pain syndrome (CRPS)	Virtual Reality Visual Feedback Module	Research	Journal article	Few treatment options for CRPS.	Mirror visual feedback therapies promising. Can be delivered using VR but costly and not so far popular. Now cheaper and HCPs developing skills to deliver it	Website active	Not reported	HCP led VR sessions in a clinic with a view to extending it to home use. Provides therapy platform and information.	Did not improve pain but usability, feasibility and all good.
63	Storf H,et al. Vision and challenges of a cartographic representation of expert medical centres for rare diseases. <i>Studies in health technology and informatics.</i> 2014;205:677-81.	2014	Germany	Rare diseases	se-atlas	Research	Journal article	Difficult for people with rare diseases to find appropriate specialist centre in Germany		website active	Not given	Interactive map and list	
64	Timmer AM, et al. A Blended Physiotherapy Intervention for Persons With Hemophilic Arthropathy: Development Study. <i>J Med Internet Res.</i> 2020;22(6):e16631.	2020	Netherlands	Haemophilia	e-Exercise HA	Research	Journal article	Few PTs understand haemophilic arthropathy and so access to one is difficult for this common complication; Cost of specialist physio	most critical barriers to adhering to physiotherapy were the limited reimbursement by the health insurance, execution of boring exercises, and stubbornness of the patients to accept advice. The patients mentioned that a good relationship with their physiotherapist facilitated their adherence to the physiotherapy treatment.	website active	Not given	A 12-week blended intervention was developed, integrating face-to-face physiotherapy sessions with a web-based app. The intervention consists of information modules for persons with HA and information modules for physiotherapists, a graded activity program using a self-chosen activity, and personalized video-supported exercises. The information modules	
65	Verkleij M, et al. Development and evaluation of an internet-based cognitive behavioral therapy intervention for anxiety and depression in adults with cystic fibrosis (eHealth CF-CBT): An international collaboration. <i>Internet Interventions.</i> 2021;24.	2021	Netherlands	Cystic fibrosis	eHealth CF-CBT	Research	Journal article	Anxiety and depression in people with CF common and can affect adherence, health and QoL	Access to evidence-based mental health care can be limited adding to the cost and burden of care for people with CF.	website active	English and Dutch	Internet delivered CBT sessions guided by a therapist. Trialled with 16 people with CF	high levels of acceptability and usability
66	Verkleij M, et al. Development of a therapist-guided internet-delivered cognitive behavioral therapy intervention for anxiety and depression in adults with cystic fibrosis (e-Health CF-CBT): An international collaboration. <i>Pediatric Pulmonology.</i> 2019;54(Supplement 2):406-7.	2019	Netherlands	Cystic fibrosis	eHealth CF-CBT	Research	Conference abstract	Anxiety and depression in people with CF common and can affect adherence, health and QoL	Access to evidence-based mental health care can be limited adding to the cost and burden of care for people with CF.	website active	English and Dutch	Pilot Internet delivered CBT sessions guided by a therapist	
67	Verkleij M,et al. Development and evaluation of an internet-based cognitive behavioral therapy intervention for anxiety and depression in adults with cystic fibrosis: An international collaboration. <i>Pediatric Pulmonology.</i> 2020;55(SUPPL 2):267.	2020	Netherlands	Cystic fibrosis	eHealth CF-CBT	Research	Conference abstract	Anxiety and depression in people with CF common and can affect adherence, health and QoL	Access to evidence-based mental health care can be limited adding to the cost and burden of care for people with CF.	website active	English and Dutch	Internet delivered CBT sessions guided by a therapist. Trialled with 16 people with CF	High levels of acceptability and usability
68	Wagner B,et al. Establishing an online physical exercise program for people with hemophilia. <i>Wiener Klinische Wochenschrift.</i> 2019;131(21-22):558-66.	2019	Germany and Austria	Haemophilia	online exercise program	limited availability	Journal article	Distance to attend exercise program at the specialist centre not feasible		website passive	Not given	Online exercise lessons for adults and young people conducted by physician. Also have consultation hours (? Online) when you can speak to someone at the clinic about the program)	

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69	Walker KK. Cognitive and affective uses of a Thoracic Outlet Syndrome Facebook support group. 2014	2014	USA	Thoracic Outlet Syndrome (TOS)	Thoracic Outlet Syndrome (TOS) Awareness Facebook group	publicly available	Journal article	Finding reliable information difficult for people with a rare disease	HCPs may not be knowledgeable. Support from peers difficult due to rarity.	social platform	Not given	Facebook group for people with TOS	Analysis of cognitive needs indicated TOS patients used the site more to share information about their own TOS symptoms and journey with diagnosis than to seek information. Analysis of affective needs found patients were more likely to use the site to give support and encouragement to others than to express concerns and complaints. The complaints they did express were primarily related to their frustration with the general medical community's perceived inability to diagnose and understand their disease or to question a specific doctor's diagnosis/recommendation
70	Wittmeier K, et al. Analysis of a Parent-Initiated Social Media Campaign for Hirschsprung's Disease. J Med Internet Res. 2014;16(12):e288.	2014	Canada	Hirschsprung's Disease	Social media campaign "Shit happens"	publicly available	Journal article	Families of children with rare diseases can feel isolated and unsupported		social platform	English	Social media campaign to raise awareness and provide support for families dealing with Hirschsprung's disease. Facebook, Twitter, Blog posts and question and answer style postings. Very engaging for the community	Analytics showed 5400 views of the blog from 37 countries. Across platforms - within 2 hours of posting a question could get 143 views, 20 responses increasing to 30 responses within 5 hours.
71	Wood J, et al. A smartphone application for reporting symptoms in adults with cystic fibrosis improves the detection of exacerbations: Results of a randomised controlled trial. Journal of Cystic Fibrosis. 2020;19(2):271-276.	2020	Australia	Cystic fibrosis	Not given	Research	Journal article	Delayed reporting of symptoms can result in more severe exacerbations and worse outcomes.		App	Not reported	12 questions re symptoms associated with exacerbation that alert a nurse if respondents answer yes.	No change in IV antibiotic use. Number of courses of oral antibiotics increased and the median (IQR) time to detection of exacerbation requiring oral or IV antibiotics was shorter in the intervention group compared with the control group. No detectable change in lung function.
72	Wood J, et al. High usability of a smartphone application for reporting symptoms in adults with cystic fibrosis. J Telemed Telecare. 2018;24(8):547-552.	2018	Australia	Cystic fibrosis	Not given	Research	Journal article	Delayed reporting of symptoms can result in more severe exacerbations and worse outcomes.		App	Not reported	12 questions re symptoms associated with exacerbation that alert a nurse if respondents answer yes.	Study looked at HCP response to the app questions using 45 clinical scenarios. Excellent usability and near-perfect agreement interpreting the app responses.