

Multimedia Appendix 2: Details of included Apps

Note: ¹Whether or not an app allows for patient and health care practitioner collaboration; ² Other languages (Bulgarian, Czech, Finnish, French, German, Greek, Hungarian, Indonesian, Italian, Japanese, Korean, Malay, Polish, Portuguese, Romanian, Russian, Chinese, Spanish, Swedish, Thai, Turkish, Ukrainian, Vietnamese, Welsh); ³ Not recorded

Name of the app	Rare disease (age group)	Platform	Country	Affiliations	Participant involvement (Passive or Active)	Target audience (person/carer or both)	Collaboration Consumer facing only or collaborative ¹	Rating	Version	Last update	Cost
Narcolepsy Monitor	Narcolepsy (17+)	iOS Android	Netherlands	NGO University	Active	Person	Consumer-facing only	Hasn't received enough ratings or reviews to receive a summary	1.0.2	2020	Free
Cure SMA guide	Spinal muscular atrophy (12+)	iOS Android	USA	NGO	Both	Both	Consumers & HCPs can use independently	Hasn't received enough ratings or reviews to display a summary	2021.1	2021	Free
Cystic Fibrosis Manager	Cystic fibrosis (17+)	iOS	USA	Commercial	Both	Person	Collaborative	Hasn't received enough ratings or reviews to display a summary	10.8.0	2022	Free
Project Breathe/Breath RM	Cystic fibrosis (12+)	iOS Android	UK	Commercial	Active	Person	Consumer-facing only	Hasn't received enough ratings or reviews to	3.8.0	2022	Free

								display a summary				
RarePulse	Multiple rare diseases (all ages)	iOS Android	NR ³	NGO	Passive	Both	Consumers & HCPs can use independently	Hasn't received enough ratings or reviews to display a summary	1.1	2020	Free	
PatientMpowerment for CF	Cystic fibrosis (17+)	iOS Android	USA Europe	NGO	Active	Person	Collaborative	Hasn't received enough ratings or reviews to display a summary	1.7.0	2022	Free	
RareGuru	Multiple rare diseases (12+)	iOS Android	USA	NGO	Active	Both	Collaborative	Hasn't received enough ratings or reviews to display a summary	1.2.6	2021	Free	
MicroHealth Hemophilia	Haemophilia (17+)	iOS Android	NR	Commercial	Active	Both	Consumers & HCPs can use independently	Hasn't received enough ratings or reviews to display a summary	3.8.8	2022	Free	
Cystinosis & me	Cystinosis (12+)	iOS Android	USA	Commercial	Active	Person	Collaborative	Hasn't received enough ratings or reviews to display a summary	0.15.1	2022	Free	
Spina Bifida Association	Spina bifida (17+)	iOS Android	USA	NGO	Both	Person	Consumers & HCPs can use independently	Hasn't received enough ratings or reviews to	1.0.47	2020	Free	

								display a summary			
HaemActive™	Haemophilia (12+)	iOSAndroid	Denmark	Commercial	Active	Person	Collaborative	Hasn't received enough ratings or reviews to display a summary	1.3.3	2022	Free
PBC Health Storylines	Primary biliary cholangitis (all ages)	Android	Canada	NGO	Active	Person	Consumer-facing only	Hasn't received enough ratings or reviews to display a summary	5.4.4	2017	Free
ThalTracker	Thalassaemia (12+)	iOS	Canada	NGO University	Active	Person	Consumer-facing only	Hasn't received enough ratings or reviews to display a summary	Unknown	Unknown	Free
CANrecall	Rare cancers (17+)	iOSAndroid	Australia	Commercial	Active	Person	Collaborative	Hasn't received enough ratings or reviews to display a summary	2.2	2022	Free
THALIA app	Thalassaemia & sickle cell disease (17+)	iOSAndroid	International	Commercial	Active	Person	Consumer-facing only	Hasn't received enough ratings or reviews to display a summary	1.1	2021	Free
VASCERN app	Rare vascular diseases (all ages)	iOSAndroid	International	NGO	Passive	Both	Consumers & HCPs can use independently	Hasn't received enough ratings or	1.0.9	2022	Free

								reviews to display a summary				
ThlaliMe	Thalassaemia (all ages)	iOS Android	Canada	NGO	Active	Both	Consumer-facing only	Not stated	3.8.0	2019	Free	
Cystic Fibrosis Downhill	Cystic fibrosis (all ages)	Android	USA	Commercial	Active	Both	Consumer-facing only	Not stated	1.0	2016	Free	
Cystic Fibrosis: A Pocket Guide	Cystic fibrosis (all ages)	Android	UK	NGO	Passive	Both	Consumers & HCPs can use independently	3.8	1.0.3	2013	Free	
PH Aware	Pulmonary hypertension (4+)	iOSAndroid	NR	NGO	Passive	Both	Consumers & HCPs can use independently	Hasn't received enough ratings or reviews to display a summary	1.278.54 1.1101	2020	Free	
Haemophilia Pal	Haemophilia (all ages)	Android	NR	NGO	Active	Person	Collaborative	Not stated	1.8.3	2019	Free	
MyHemophiliaTeam	Haemophilia (17+)	iOS Android	USA	Commercial	Active	Both	Consumer-facing only	Hasn't received enough ratings or reviews to display a summary	12.0.8	2020	Free	
Autogenic Drainage	Cystic fibrosis (9+)	iOS Android	USA	Commercial	Active	Person	Consumer-facing only	Hasn't received enough ratings or reviews to display a summary	1.2	2015	Free	
Recognize Amyloidosis Disease	Amyloidosis disease (all ages)	Android	NR	Commercial	Passive	Both	Consumers & HCPs can use independently	Hasn't received enough ratings or reviews to display a summary	3.0.1	2019	Free	

Recognize Thalassemia Disease	Thalassaemia (all ages)	Android	NR	Commercial	Passive	Both	Consumers & HCPs can use independently	Hasn't received enough ratings or reviews to display a summary	3.0.1	2019	Free
Easy Diagnosis- Thalassemia	Thalassaemia (all ages)	Android	NR	Commercial	Both	Person	Consumer-facing only	Hasn't received enough ratings or reviews to display a summary	1.0	2021	Free
Narcolepsy Disorder	Narcolepsy (all ages)	Android	NR	NGO	Passive	Both	Consumers & HCPs can use independently	Hasn't received enough ratings or reviews to display a summary	Not stated	2017	Free
Hemophilia Disease	Haemophilia (all ages)	Android	NR	Commercial	Passive	Both	Consumer-facing only	Hasn't received enough ratings or reviews to display a summary	Not stated	2017	Free
Thalassemia Disease	Thalassaemia (all ages)	Android	NR	Commercial	Passive	Both	Consumer-facing only	Hasn't received enough ratings or reviews to display a summary	Not stated	2017	Free