

Supplementary material 5: Article characteristics

Overview of identified articles including an evaluation of needs in rare diseases

Study characteristics	Number of included articles (N = 272)
Year of publication	
2006 – 2009	5
2010 – 2013	8
2014 – 2017	33
2018 – 2021	121
2022 – 2023	105
Geographical region	
Europe	135
US	44
Australia	12
Canada	5
Latin-America	3
Asia	8
Inter-continental	30
Unspecified	35
Study design	
Literature review	31
Qualitative methods	70
Quantitative methods	129
Mixed quantitative-qualitative methods	28
Other	14
Disease categorisation (ICD-11)	

Orphan but non-disease specific	56
Disease specific	213
ICD01 - Certain infection diseases	2
ICD02 - Neoplasms	13
ICD03 - Diseases of the blood or blood-forming organs	11
ICD04 - Diseases of the immune system	22
ICD05 - Endocrine, nutritional or metabolic diseases	62
ICD07 - Sleep/wake disorders	1
ICD08 - Diseases of the nervous system	31
ICD09 - Diseases of the visual system	1
ICD11 - Diseases of the circulatory system	3
ICD12 - Diseases of the respiratory system	4
ICD13 - Diseases of the digestive system	4
ICD14 - Diseases of the skin	6
ICD15 - Diseases of the musculoskeletal system or connective tissue	8
ICD16 - Diseases of the genitourinary system	2
ICD18 - Pregnancy, childbirth or the puerperium	1
ICD20 - Development anomalies	35
X - Extension Codes	7
Not specified	3

Summary of identified article characteristics including an evaluation of needs in rare diseases categorized according to method category

1. Literature based studies

Author (year)	Geographical region	Disease	Study design		NEED criteria
			Method	Objectives	
Review					
Wehrli (2023)	Unspecified	Osteogenesis imperfecta		Improved physical healthof paediatric and adult patients	- Improved mental health needs - Support in work and education
Choon (2023)	Unspecified	Generalised pustular psoriasis	Systematic literature review	Health-related Improved physical health	- Improved physical health - Improved mental health - Availability of Availability of treatments - Social support
Wechsler (2023)	Unspecified	hypereosinophilic syndrome and eosinophilic granulomatosis with polyangiitis		Unmet needs and evidence gaps	- Improved physical health - Availability of Availability of treatments - Timely and accurate diagnosis - Information needs
Fournier (2023)	Europe	Rare genetic skin diseases	Systematic literature review	Psychosocial implications	- Improved physical health - Improved mental health - Improved autonomy - Accessibility of healthcare - Social support - Support in work and education
Connolly (2023)	Australia	Sarcoma			- Improved physical health
Howley (2023)	Europe	Congenital athymia			- Financial stability - Improved mental health - Integrated, multi-disciplinary care - Information needs - Accessibility of healthcare - Timely and accurate diagnosis
Applequist (2023)	US	Orphan but non disease specific		Direct-to-Consumer recruitment methods	
Dabbous (2023)	Inter-continental	Orphan but non disease specific	Systematic literature review	Valuation of Availability of treatments of RD	- Improved physical health - Financial stability
McMullan (2022)	Unspecified	Rare diseases		Needs of informal caregivers	- Improved physical health - Financial stability
Sawad (2022)	US	Arginase 1 deficiency (ARG1-D)	Systematic review of case reports	Unmet needs of patients	- Improved physical health - Availability of treatments - Timely and accurate diagnosis
Trieste (2022)	Europe	Rare and complex connective tissue and musculoskeletal diseases (rCTDs)		Assessing Improved physical health	

Brandt (2022)	Inter-continental	Spinal muscular atrophy	<i>Systematic review of quantitative and qualitative data</i>	Psychosocial situation, caregiver burden and family needs	- Improved physical health - Financial stability - Integrated, multi-disciplinary care - Information needs - Social support
Hassall (2022)	Europe	Lysosomal storage disorders (LSDs)	<i>Systematic review and integrative sequential explanatory narrative synthesis</i>	Psychosocial impact of parenting a patient	- Improved physical health - Financial stability - Availability of treatments - Timely and accurate diagnosis
Camerini (2022)	Europe	Acromegaly	<i>Systematic review</i>	Clinical powerful instruments in Timely and accurate diagnosis and management	- Availability of Availability of treatments - Availability of Availability of treatments
Bardon (2022)	Inter-continental	Orphan but non disease specific	<i>Realist review of literature</i>	Development, evaluation and implementation of evidence-based group therapy	- Social support
De Heus (2021)	Europe	Rare cancer	<i>Systematic review</i>	Unmet supportive care needs	- Improved physical health - Timely and accurate diagnosis - Social support
Soeun (2021)	US	Immunoglobulin A nephropathy	<i>Systematic literature review</i>	Epidemiology, HRImproved physical healthand Financial stability	- Financial stability - Improved physical health - Improved mental health - Availability of treatments - Timely and accurate diagnosis
Seefried (2021)	Unspecified	X-linked hypophosphataemia	<i>Systematic literature review</i>	Improved physical health	- Improved physical health - Improved mental health - Improved autonomy - Availability of treatments - Accessibility of healthcare - Impact on work
Petros (2021)	US	Adult-onset Still's disease		Clinical manifestation, Timely and accurate diagnosis, Availability of treatments, and unmet needs	- Accessibility of healthcare - Timely and accurate diagnosis - Social support
Monga (2020)	Inter-continental	Mantle cell lymphoma	<i>Systematic literature review</i>	Real-world clinical, economic and humanistic burden data	- Financial stability - Improved physical health - Availability of treatments - Timely and accurate diagnosis
Lanar (2020)	Europe	Orphan but non disease specific		To identify all relevant PROMs	
Hill (2019)	Europe	Osteogenesis imperfecta	<i>Systematic review</i>	Experiences and psychosocial impact on families and caregivers	- Improved physical health - Financial stability - Improved mental health - Improved autonomy - Information needs - Accessibility of healthcare
Mackay (2019)	Unspecified	Prader-Willi syndrome		Describing health and well-being	- Improved physical health - Improved physical health - Impact on work

Meyer (2019)	Unspecified	Idiopathic inflammatory myopathies	<i>Narrative review Systematic literature search</i>	Unmet needs in clinical practice guidelines	- Accessibility of healthcare
Palikara (2018)	Unspecified	Williams syndrome		Educational needs	- Improved physical health - Improved autonomy - Information needs - Impact on work and education
Wheeler (2017)	US	Angelman syndrome	<i>Targeted literature review</i>	AS phenotype, epidemiology, diagnostic processes, Availability of treatments and burden	- Improved physical health - Improved mental health - Availability of treatments - Timely and accurate diagnosis - Social support
Yamaguchi (2017)	Asia	Inborn errors of metabolism		Difficulties in Daily Life and Associated Factors and Improved physical health	- Improved physical health - Improved mental health - Accessibility of healthcare - Financial stability
Pelentsov (2015)	Australia	Orphan but non disease specific	<i>Scoping review</i>	Supportive care needs of parents	- Improved physical health - Financial stability - Information needs - Accessibility of healthcare - Social support
Banerji (2013)	US	Hereditary angioedema	<i>Boolean search</i>	Burden of illness	- Improved physical health - Financial stability - Improved mental health - Improved autonomy - Accessibility of healthcare - Social support
Rajmil (2010)	Unspecified	Orphan but non disease specific	<i>Systematic review</i>	Available instruments of HRImproved physical health	
Gaite (2008)	Europe	Orphan but non disease specific		Needs assessment	- Improved physical health - Financial stability - Integrated, multi-disciplinary care - Information needs - Timely and accurate diagnosis - Social support

2. Quantitative studies

Author (year)	Geographical region	Disease	Study desgin			NEED criteria
			Population	Validated tool		
Survey/Questionnaire						
Schut (2023)	Europe	Desmoid- type fibromatosis (DTF)	-	Patients/patient organisations/patient representatives	- SQ20 - EORTC QLQ-C30	- Improved physical health - Integrated, multi-disciplinary care - Accessibility to healthcare
Landlust (2023)	Inter-continental	Phelan-McDermid syndrome (PMS)	-	Caregiver/parents	- Genetic Syndrome Stressors Scale (GSSS)	- Improved physical health
Taruscio (2023)	Inter-continental	Undiagnosed diseases	-	Multistakeholder		- Integrated, multi-disciplinary care - Information needs - Timely and accurate diagnosis
Goldfarb (2023)	US	Primary hyperoxaluria	-	Patients and caregivers	- Kidney Disease Quality of Life (KDIMPROVED PHYSICAL HEALTH-36™) - Wisconsin Stone Quality of Life (WISIMPROVED PHYSICAL HEALTH)	- Availability of treatments - Timely and accurate diagnosis
Skrobanski (2023)	Europe	tuberous sclerosis complex	-	Caregiver		
Moore (2023)	Inter-continental	Pelizaeus-Merzbacher Disease	-	Caregiver/parent		- Improved physical health - Availability of treatments - Timely and accurate diagnosis
Stubbs (2023)	US	juvenile localized and systemic scleroderma	-	Caregiver	- The Barriers to Care Scale (BACS)	- Availability of treatments - Integrated, multi-disciplinary care - Accessibility to healthcare - Timely and accurate diagnosis
Acaster (2023)	US	Hereditary transthyretin amyloidosis	-	Caregiver/parents	- EQ-5D-3L - Hospital anxiety and depression scale	- Improved physical health
Tkachuk (2023)	Latin-America	neuromyelitis optica spectrum disorders	-	Patients/patient organisations/patient representatives	- EDSS	- Accessibility to healthcare - Timely and accurate diagnosis
Alesci (2023)	Europe	Immune thrombocytopenia	-	Patients/patient organisations/patient representatives	- FACIT-F - BDI	- Improved physical health

				- Epworth Sleepiness Scale - STOP-BANG	
Ballesteros-Sayas (2023)	Europe	Dravet syndrome	- Caregiver/parents		- Timely and accurate diagnosis - Accessibility of healthcare - Support in work and education - Financial stability
Büttner (2023)	Europe	Hypoparathyroidism	- Patients/patient organisations/patient representatives	- HPQ-28	- Improved physical health - Information needs - Impact on work
Kerr (2023)	US	complex vascular anomalies	- Patients/patient organisations/patient representatives	- PROMIS Global Health Measure - PCC-Ca-36	- Improved physical health - Integrated, multi-disciplinary care - Information needs - Accessibility of healthcare - Social support
Chappell (2023)	Unspecified	mtDNA deletion syndromes	- Patient and caregivers	- MCN-PNS - ZBI-22	- Improved physical health - Financial stability - Integrated, multi-disciplinary care - Information needs
Mahic (2023)	Europe	myasthenia gravis	- HCPs	- WPAI - MG-Improved physical health-15r - EQ-5D-5L - VAS	- Improved physical health - Availability of treatments - Integrated, multi-disciplinary care
Pivonello (2023)	Europe	Cushing's syndrome	- HCPs		- Availability of treatments
Runacres (2023)	Australia	Motor neuron disease	- Patients	- ALSFRS-R - IPOS-Neuro questionnaire	- Improved physical health
Van Roessel (2023)	Europe	hypothalamic dysfunction	- Patients/patient organisations/patient representatives		- Improved physical health - Integrated, multi-disciplinary care - Timely and accurate diagnosis - Information needs - Financial stability
Weiss (2023)	Unspecified	antisynthetase syndrome	- Patients/patient organisations/patient representatives - HCP		- Timely and accurate diagnosis - Information needs - Impact on work
Schuster (2022)	Europe	Duchenne Muscular Dystrophy	- Patients & caregivers	- PUL-PROM - EQ-5D-3L	- Improved physical health - Availability of treatments
Pélissier (2022)	Europe	Non-disease specific	- Patients & caregivers		- Timely and accurate diagnosis
Strzelczyk (2022)	Europe	Dravet syndrome	- Patients & caregivers		
Gutenbrunner (2022)	Europe	Non-disease specific	- Patients/patient organisations/patient representatives	- ReGoS	- Improved physical health - Integrated, multi-disciplinary care - Accessibility to healthcare

Gimenez-Lozano (2022)	Europe	Non-disease specific	-	Patients & caregivers		-	Improved physical health - Availability of treatments - Accessibility to healthcare - Timely and accurate diagnosis
Valassi (2022)	Inter-continental	Cushing's syndrome	-	Patients & caregivers		-	Improved physical health - Availability of treatments - Integrated, multi-disciplinary care
Kramer-Golinkoff (2022)	US	Cystic fibrosis (CF)	-	Patients & caregivers		-	Improved physical health - Availability of treatments - Accessibility to healthcare
Kontogeorgos (2022)	Europe	Hypoparathyroidism	-	Patients/patient organisations/patient representatives	- SF-36 - EQ5D-VAS	-	Improved physical health - Accessibility to healthcare
Bonnekoh (2022)	Europe	Urticarial vasculitis	-	Patients/patient organisations/patient representatives		-	Availability of treatments
Johansen (2022)	Europe	Loeys-Dietz syndromes, vascular Ehlers-Danlos syndrome	-	Patients/patient organisations/patient representatives	- Standardized Nordic Questionnaire - FSS - HADS	-	Improved physical health - Integrated, multi-disciplinary care - Accessibility to healthcare
Rihm (2022)	Europe	Non-disease specific	-	Caregiver/parents	- DT-P	-	Improved physical health - Availability of treatments - Integrated, multi-disciplinary care
Scharping (2022)	Europe	Inherited metabolic diseases (IMDs)	-	Caregiver/parents	- PNS	-	Integrated, multi-disciplinary care - Accessibility to healthcare
Mancuso (2022)	Europe	Rare neurological diseases (RNDs)	-	HCP		-	Accessibility to healthcare - Timely and accurate diagnosis
Mahic (2022)	US	Myasthenia gravis	-	HCP		-	Improved physical health - Availability of treatments - Timely and accurate diagnosis
Al Mukaddam (2022)	Inter-continental	Fibrodysplasia ossificans progressiva	-	Patients & caregivers		-	Improved physical health - Availability of treatments - Accessibility to healthcare
Mesa (2022)	US	Systemic mastocytosis (SM)	-	Patients/patient organisations/patient representatives		-	Improved physical health
Mesa (2022)	US	Systemic mastocytosis (SM)	-	HCP		-	Improved physical health - Availability of treatments
Auchus (2022)	Inter-continental	Congenital adrenal hyperplasia	-	HCP		-	Improved physical health - Availability of treatments
Rispoli (2022)	Europe	Dystonia	-	Patients/patient organisations/patient representatives		-	Improved physical health - Integrated, multi-disciplinary care
Koto (2022)	Asia	Fabry disease	-	Patients/patient organisations/patient representatives	- SF-8	-	Improved physical health - Timely and accurate diagnosis
Atila (2022)	Europe	Central diabetes insipidus	-	Patients/patient organisations/patient representatives		-	Improved physical health - Integrated, multi-disciplinary care
Bogart (2022)	US	Orphan but non disease specific	-	Patients & caregivers		-	Improved physical health - Integrated, multi-disciplinary care - Timely and accurate diagnosis - Information needs

						- Accessibility of healthcare - Social support - Financial stability
Moretti (2021)	Europe	Non-disease specific	- Patients & caregivers	- Checklist For Children with Special Healthcare Needs		- Improved physical health - Accessibility to healthcare
Strober (2021)	NS	Generalized pustular psoriasis (GPP)	- HCP			- Availability of treatments
Bryson (2021)	Inter-continental	Non-disease specific	- Patients/patient organisations/patient representatives			- Improved physical health - Integrated, multi-disciplinary care
Drabbe (2021)	Europe	Non-disease specific	- Patients/patient organisations/patient representatives			- Integrated, multi-disciplinary care - Timely and accurate diagnosis
Lamy (2021)	Europe	Non-disease specific	- Patients/patient organisations/patient representatives			- Integrated, multi-disciplinary care - Accessibility to healthcare - Timely and accurate diagnosis
Rose (2021)	NS	relapsing polychondritis	- Patients & HCP	- SF-36 - MFI		- Improved physical health - Availability of treatments - Integrated, multi-disciplinary care - Timely and accurate diagnosis
McMillan (2021)	NS	Spinal Muscular Atrophy (SMA)	- Patients & caregivers	- EQ-5D-5L - CSI		- Improved physical health
Mendivil (2021)	Inter-continental	hereditary angioedema	- Patients/patient organisations/patient representatives	- AE-Improved physical health - SF-12v2 - AECT - HADS - WPAI		- Improved physical health - Availability of treatments
Langhinrichsen-Rohling (2021)	US	EhlersDanlos Syndrome (EDS)	- Patients/patient organisations/patient representatives			- Improved physical health - Integrated, multi-disciplinary care - Timely and accurate diagnosis
de Graaf (2021)	Europe	Non-disease specific	- Patients/patient organisations/patient representatives	- CarerImproved physical health-7D - WPAI - 5-D-Itch scale -		- Improved physical health - Availability of treatments - Integrated, multi-disciplinary care
Ruiz-Casas (2021)	Europe	progressive familial intrahepatic cholestasis	- Caregiver & HCP	- PedsQL™ - FIM - VSS - GMFC-MLD - HRIMPROVED PHYSICAL HEALTH - Family Functioning		

					Summary Scores	
					- Total Impact Score	
AmmannSchnell (2021)	Europe	severe neurological disorders, including Pontocerebellar hypoplasia type 2 (PCH2) and metachromatic leukodystrophy (MLD)	- Caregiver/parents			
Fasshauer (2021)	Europe	Primary immunodeficiencies	- Patients/patient organisations/patient representatives			- Improved physical health
Eichler (2021)	Europe	Gastrointestinal stromal tumours	- Patients/patient organisations/patient representatives	- EORTC QLQ-C30		- Improved physical health - Availability of treatments -
Depping (2021)	Europe	Non-disease specific	- Patients/patient organisations/patient representatives	- SCNS-SF34		- Improved physical health - Integrated, multi-disciplinary care
Cheung (2021)	Inter-continental	X-linked hypophosphatemia	- Patients & caregivers	- XLH Improved physical health		- Improved physical health - Availability of treatments - Integrated, multi-disciplinary care
Grant (2021)	US	mucopolysaccharidoses	- Family members			
Webb (2021)	Inter-continental	Non-disease specific	- Patients & HCP			- Timely and accurate diagnosis
Sestini (2021)	Europe	Inherited Metabolic Diseases	- Patient & caregiver			- Improved physical health - Integrated, multi-disciplinary care - Accessibility to healthcare
Qi X (2021)	Asia	Gaucher Disease	- Patient & caregiver	- PSQI - SG-36		- Improved physical health - Integrated, multi-disciplinary care - Accessibility to healthcare - Timely and accurate diagnosis
Abeni (2021)	Europe	Autosomal recessive congenital ichthyoses	- Patients/patient organisations/patient representatives -	- FDLQI - FBI tool		- Improved physical health - Financial stability
Bejarano (2021)	Unspecified	hATTR amyloidosis	- Patients/patient organisations/patient representatives	- IEXPAC questionnaire		- Integrated, multi-disciplinary care - Impact on work
Molnár (2021)	Europe	Pompe disease	- Patients/patient organisations/patient representatives	- Fatigue Severity Score - R-PAct-Scale - Rotterdam and Bartel disability scale - EQ-5D - SG-36		- Improved physical health - Information needs
Martins (2020)	Latin-Amerika	Phenylketonuria (PKU)	- Patients & caregivers			- Improved physical health - Integrated, multi-disciplinary care - Timely and accurate diagnosis

Painous (2020)	Europe	Four different groups of rare MDs were studied: group 1 included dystonia, paroxysmal dyskinesia and neurodegeneration with brain iron accumulation (NBIA) (group 1-DYS); group 2, ataxias and hereditary spastic paraparesis (HSP) (group 2-ATX/ HSP); group 3, atypical parkinsonism such as progressive supranuclear palsy, multiple system atrophy and corticobasal degeneration (group 3-AP); group 4 included Huntington's disease (HD) and other choreas (group 4-C).	- HCPs			- Availability of treatments - Accessibility to healthcare - Timely and accurate diagnosis
Dermer (2020)	Canada	Genetically determined leukoencephalopathies	- Caregiver/parents	- Parenting Stress Index–4th Edition		- Timely and accurate diagnosis
Izquierdo-García (2020)	Europe	Hereditary fructose intolerance	- Patients & caregivers	- EQ-5D-Y - ED-5D		- Improved physical health - Integrated, multi-disciplinary care - Accessibility to healthcare - Timely and accurate diagnosis
Bolte (2020)	Europe	Transthyretin familial amyloid polyneuropathy (ATTRFAP)	- Patients/patient organisations/patient representatives	- PROMIS-10 - WHODAS 2.0		- Improved physical health - Accessibility to healthcare
Xu (2021)	Asia	Gaucher Disease	- Caregiver	- SF- 36 - SAS - SDS - Multi-dimensional Scale of Perceived Social support		
Boettcher (2020)	Europe	Non-disease specific	- Caregiver/parents	- Improved physical health - ULQIE - BSI - CHIP - OSSS-3 - FAM		

Fjermestad (2020)	Europe	neurofibromatosis 1 (NF1) and hereditary spastic paraparesis (HSP)	-	Patients/patient organisations/patient representatives	-	Integrated, multi-disciplinary care
Saglio (2020)	Europe	Narcolepsy and idiopathic hypersomnia	-	HCP		
Cook (2020)	Inter-continental	Pigmented villonodular synovitis	-	Patients/patient organisations/patient representatives	-	Improved physical health - Availability of treatments - Integrated, multi-disciplinary care - Accessibility to healthcare - Timely and accurate diagnosis
Dinur (2020)	Inter-continental	Gaucher disease	-	Patients/patient organisations/patient representatives	- GD1-PROM	Improved physical health - Availability of treatments
Kodra (2020)	Europe	Cri du Chat syndrome (CdC)	-	Patients & caregiver		Improved physical health - Availability of treatments -
Kuman (2020)	Europe	- homozygous familial hypercholesterolemia	-	Patients/patient organisations/patient representatives	- SCL-90-R	Improved physical health
Valero-Moreno (2020)	Unspecified	- Primary ciliary dyskinesia	-	Patients/patient organisations/patient representatives	- BIEPS-J - HADS-A	Improved physical health
Khair (2019)	Europe	Inherited bleeding disorders	-	Caregiver/parents	- PNS-RD	Integrated, multi-disciplinary care
Lagaea (2019)	Europe	Dravet syndrome (DS)	-	Patients/patient organisations/patient representatives		Improved physical health - Availability of treatments - Accessibility to healthcare
Efthymiadou (2019)	Europe	Non-disease specific	-	Patients/patient organisations/patient representatives		Integrated, multi-disciplinary care
Courbier (2019)	Inter-continental	Non-disease specific	-	Patients & caregivers		Integrated, multi-disciplinary care
Conner (2019)	US	Mucopolysaccharidosis	-	Caregiver/parents		Improved physical health - Availability of treatments - Accessibility to healthcare
Nagamatsu (2019)	Asia	malignant pleural mesothelioma (MPM)	-	Patients/patient organisations/patient representatives		Improved physical health - Availability of treatments - Integrated, multi-disciplinary care - Accessibility to healthcare
Morrison (2019)	Europe	Mucopolysaccharidosis type VII	-	Patients/patient organisations/patient representatives		Improved physical health - Improved physical health - Timely and accurate diagnosis - Social support - Support in work and education
Godoy Torres (2018)	Latin-Amerika	Chronic kidney disease (CKD) in children	-	Caregiver/parents	- CBS - BDI - BAI	Improved physical health - Accessibility to healthcare
Ebert (2018)	Europe	anorectal malformations (ARM) and the exstrophy-	-	Patients/patient organisations/patient representatives		Improved physical health

		epispadias complex (EEC)				
Fischer (2020)	Europe	spinal muscular atrophy	-	Patients/patient organisations/patient representatives	- SWLS - RSES - PANAS - USER-P - BPNSFS	- Improved physical health - Availability of treatments
Efthymiadou (2018)	Europe	Non-disease specific	-	Patients/patient organisations/patient representatives		- Improved physical health
Pinto (2018)	Europe	hemophilia (PWH)	-	Caregiver/parents	- Sociodemographic and Clinical Questionnaires - Improved physical healthActivity Questionnaire - A36 Hemophilia-Improved physical health:15 - CHO-KLAT - HAL - PedHAL - PROMIS-Anxiety and Depression - IPQ-R	- Improved physical health
Majoer (2017)	Europe	Fibrous dysplasia (FD)	-	Patients/patient organisations/patient representatives	- EQ-5D	- Improved physical health
van Walsem (2017)	Europe	Huntington's disease	-	Patients/patient organisations/patient representatives	- EQ-5D-3L - NPCS - UHDRS	- Improved physical health - Availability of treatments
Lakhani Jindal (2017)	Canada	Hereditary angioedema	-	Patients/patient organisations/patient representatives	- SF-36v2	
Dzemaili (2017)	Inter-continental	congenital hypogonadotropic hypogonadism (CHH)	-	Patients/patient organisations/patient representatives	- MMAS - SDS - IPQ-R	- Improved physical health - Availability of treatments - Integrated, multi-disciplinary care - Accessibility to healthcare - Timely and accurate diagnosis
Wolin (2017)	US	Neuroendocrine Tumors	-	Patients/patient organisations/patient representatives		- Improved physical health - Availability of treatments - Integrated, multi-disciplinary care - Timely and accurate diagnosis - Accessibility of healthcare - Impact on work - Financial stability

Angelis (2016)	Europe	Juvenile idiopathic arthritis (group of different rare disorders)	-	Patients & caregivers	-	EQ-5D Barthel Index	
Molster (2016)	Australia	Non-disease specific	-	Patients & caregivers			- Integrated, multi-disciplinary care - Accessibility to healthcare - Timely and accurate diagnosis
Landfeldt (2016)	Europe	Duchenne muscular dystrophy (DMD)	-	Caregivers/parents			
Silibello (2016)	Europe	Non-disease specific	-	Caregivers			- Improved physical health - Integrated, multi-disciplinary care
Pelentsov (2016)	Australia	Non-disease specific	-	Caregivers/parents			- Integrated, multi-disciplinary care - Accessibility to healthcare
Pelentsov (2016)	Australia	Non-disease specific	-	Caregivers/parents			
Siden (2015)	Canada	Non-disease specific	-	Patients & caregivers			- Improved physical health
Chevreur (2015)	Europe	Systemic sclerosis	-	Patients & caregivers	-	EQ-5D-5L	
Fang (2015)	Asia	Primary cutaneous amyloidosis	-	Patients/patient organisations/patient representatives	-	DLQI SF-36	- Improved physical health
Garcia (2015)	Europe	Orphan but non disease specific	-	Patients/patient organisations/patient representatives			- Timely and accurate diagnosis - Information needs - Social support - Financial stability
Kocova (2014)	Europe	Spinal muscular atrophy	-	Patients & caregivers	-	PedsQL Neuromuscular Module Scales	- Integrated, multi-disciplinary care
Anderson (2013)	Australia	Non-disease specific	-	Patients & caregivers	-	HUI- II IOF RAHC-MOF	- Improved physical health - Accessibility to healthcare - Timely and accurate diagnosis
Guillevin (2013)	Europe	Pulmonary arterial hypertension		Patients & caregivers			- Improved physical health - Improved physical health - Information needs - Social support - Impact on work
Morad (2007)	Canada	ocular genetic eye disease	-	Patients/patient organisations/patient representatives			- Integrated, multi-disciplinary care - Accessibility to healthcare
Database analysis							
Bell (2023)	US	Eosinophilic granulomatosis with polyangiitis	-	Patients/patient organisations/patient representatives			
Benito-Lozano (2023)	Europe	Orphan but non disease specific	-	Patients/patient organisations/patient representatives			- Improved physical health - Timely and accurate diagnosis - Social support - Support in work and education
Strobel (2022)	Inter-continental	Rare Eosinophil-Driven Diseases					- Improved physical health - Accessibility to healthcare

				-	Timely and accurate diagnosis
Tisdale (2021)	US		- Patients/patient organisations/patient representatives	-	Improved physical health - Accessibility to healthcare - Timely and accurate diagnosis
Hilker (2021)	Europe	Sarcoidosis or Boeck's disease	-	-	Integrated, multi-disciplinary care
Burke (2021)	US	Hemophilia B	- Patients/patient organisations/patient representatives	-	Improved physical health
Carbone (2020)	Europe	Primary sclerosing cholangitis	- Patients/patient organisations/patient representatives	-	Integrated, multi-disciplinary care
Meng (2019)	Europe		- Patients & caregivers	-	Integrated, multi-disciplinary care - Accessibility to healthcare - Timely and accurate diagnosis
Pujades-Rodriguez (2018)	Unspecified	hypertrophic cardiomyopathy	- Patients/patient organisations/patient representatives	-	Improved physical health - Availability of treatments
Registries					
Palladini (2023)	Europe	light chain (AL) amyloidosis	- Patients/patient organisations/patient representatives	-	Availability of treatments - Timely and accurate diagnosis
Senn (2023)	Europe	Inclusion Body Myositis	- Patients/patient organisations/patient representatives	-	Improved physical health - Integrated, multi-disciplinary care
Van Geest (2023)	Unspecified	MCT8 Deficiency	- Patients/patient organisations/patient representatives	-	Integrated, multi-disciplinary care - Timely and accurate diagnosis
Duffy (2021)	US	WAGR syndrome	- Patients/patient organisations/patient representatives	-	Improved physical health

Duda (2020)	Europe	Hemophilia	-	Patients/patient organisations/patient representatives	
Kolbin (2020)	Europe	Spinal muscular atrophies	-	Patients/patient organisations/patient representatives	
Tilson (2013)	Europe	Cryopyrin-Associated Periodic Syndromes (CAPS)	-	Patients/patient organisations/patient representatives	
MCDA					
Gasol (2022)	Europe	Non-disease specific	-	Multistakeholder	
Cross-sectional studies					
Burgevin (2022)	Europe	Silver-Russell syndrome	-	Patients/patient organisations/patient representatives	- Improved physical health - Social support
Clairman (2021)	Unspecified	Juvenile dermatomyositis	-	Patients/patient organisations/patient representatives	
Witt (2019)	Europe	achondroplasia	-	Patients & HCP	- Improved physical health - Integrated, multi-disciplinary care

3. Qualitative studies

Author (year)	Geographical region	Disease	Study design		NEED criteria	
			Population	Objective		
Focus group discussions						
Snijders (2023)	Europe	Autoimmune hepatitis	Multistakeholder		-	Integrated, multi-disciplinary care
Witt (2023)	Unspecified	Orphan but non disease specific	Multistakeholder		-	Information needs
Beirne (2023)	Europe	Hyperemesis Gravidarum	Patients		-	Obstacles and barriers in route to psychosocial care
Dreyer (2022)	US	Kallmann syndrome	Patients & caregivers		-	Healthcare experience
Pignolo (2022)	Inter-continental	Fibrodysplasia ossificans progressive	Multistakeholder		-	Improved mental health
					-	Accessibility of healthcare
					-	Social support
					-	Financial stability
					-	Timely and accurate diagnosis
					-	Social support
					-	Availability of treatments
					-	Integrated, multi-disciplinary care
					-	Information needs

					- Accessibility of healthcare - Timely and accurate diagnosis - Social support
Petracca (2021)	Europe	Type A Hemophilia	Multistakeholder	Input for app improvement	
Kleinendorst (2020)¹	Europe	16p11.2 deletion	Patients & caregivers	Impact on life and information provision	- Improved physical health - Financial stability - Improved mental health - Improved autonomy - Integrated, multi-disciplinary care - Information needs - Social support
Aiyegbusi (2020)	Europe	Renal transplant recipients and primary sclerosing cholangitis patients	Patients & HCP	Impact of rare disease on patients	- Future public health trends - Improved physical health
Pak (2020)	Unspecified	Acromegaly	Patients	Patient perceptions of primary to tertiary care	- Integrated, multi-disciplinary care - Information needs - Social support
O'Mahony (2018)	Global	Haemophilia	Multistakeholder	Patient impacts	- Improved physical health - Accessibility of healthcare
Ogunsanya (2018)	US	Cutaneous lupus erythematosus	Patient/patient organisation/representatives	Improved physical health	- Improved physical health - Improved mental health - Availability of treatments - information needs - Social support
Swezey (2018)	Unspecified	Osteogenesis imperfecta	Patients/patient organisation/representatives	Key health issues, gaps in knowledge, research priorities	- Improved physical health - Improved mental health - Availability of treatments - Integrated, multi-disciplinary care - Social support
De Freitas (2017)	Inter-continental	Congenital Disorders of Glycosylation	Multistakeholder	Public and patient involvement in needs assessment	- Improved physical health - Financial stability - Improved mental health - Integrated, multi-disciplinary care - Accessibility of healthcare - Timely and accurate diagnosis - Social support
Pelentsov (2016)	Australia	Orphan but non disease specific	Patients & caregivers	Supportive care needs	- Improved physical health - Financial stability - Integrated, multi-disciplinary care - Information needs - Timely and accurate diagnosis
Interviews					
Loesken (2023)	Europe	Primary sclerosing cholangitis	Patients/patient organisations/representatives	Patient perception	- Improved physical health - Improved mental health - Integrated, multi-disciplinary care - Information needs

					- Timely and accurate diagnosis - Social support
Respondek (2023)	Global	Progressive supranuclear palsy	Multistakeholder	Patient experiences	- Improved physical health - Improved mental health - Integrated, multi-disciplinary care - Information needs - Timely and accurate diagnosis
Kleitsch (2023)	US	Dermatomyositis	Patients/patient organisations/representatives	Improved physical health and emotional impact	- Improved physical health - Improved mental health - Availability of treatments - Social support
Raspa (2023)	US	Severe combined immunodeficiency (SCID)	Parents & caregivers	Uncertainties experienced by patients	- Improved physical health - Information needs - Accessibility of healthcare - Timely and accurate diagnosis
Witt (2023)	Unspecified	Orphan but non disease specific	Patients & caregivers	Experiences/needs with medical and psychosocial care	- Improved physical health - Improved mental health - Improved autonomy - Integrated, multi-disciplinary care - Timely and accurate diagnosis - Information needs - Social support - Support in work and education
Potter (2023)	Inter-continental	Men diagnosed with breast cancer (MBC)	Patients/patient organisations/representatives	Patient experiences	- Improved physical health - Improved mental health - Improved autonomy - Availability of treatments - Integrated, multi-disciplinary care - Information needs - Social support
Bauskis (2022)	Australia	Orphan but non disease specific	Parents & caregivers	Diagnostic odyssey	- Improved physical health - Availability of treatments - Integrated, multi-disciplinary care - Social support
Ciesluk (2022)	US	Nuclear protein in testis (NUT) carcinoma	Patients & caregivers	Patient experiences	- Improved physical health
Olischläger (2022)	Unspecified	Orphan but non disease specific	Patients & HCP	Patient experiences & needs	- Integrated, multi-disciplinary care - Information needs - Accessibility of healthcare
Randall (2022)	US	Classic galactosemia	Patients & caregivers	Disease burden & daily challenges	- Improved physical health - Improved mental health - Improved autonomy - Social support
Garcia-Diaz (2022)	Europe	Lysosomal Storage Diseases	Patients & HCP	Disease impact	- Improved physical health - Improved mental health - Improved autonomy - Patient experience - Information needs

					- Accessibility of healthcare - Timely and accurate diagnosis - Social support
Smits (2022)	unspecified	Orphan but non disease	Caregiver	Needs	- Improved physical health - Improved mental health - Integrated, multi-disciplinary care - Information needs - Accessibility of healthcare - Social support
Ashtari (2022)	US	Ehlers-Danlos syndrome	/	Effectiveness of online peer support groups	- Improved mental health - Availability of treatments - Information needs - Accessibility of healthcare - Social support
Hill (2022)	Unspecified	Osteogenesis imperfecta	Multistakeholder	Patient experiences and needs	- Improved physical health - Improved mental health - Availability of treatments - Integrated, multi-disciplinary care - Accessibility of healthcare - Social support - Impact on work - Financial stability
Simpson (2021)	Europe	Orphan but non disease specific	Patient & caregivers	Impact on patients and their carers	- Financial stability - Integrated, multi-disciplinary care - Accessibility of healthcare
Cardão (2021)	Europe	Congenital disorders of glycosylation	Parents & caregivers	Patient experience	- Improved physical health - Financial stability
Skrobanski (2021)	Inter-continental	Aromatic l-amino acid decarboxylase (AADC) deficiency	Caregiver	Impact of caring for a patient	- Improved physical health - Financial stability
Maxfield (2021)	Unspecified	Disorder of the corpus callosum	/	Patient experience	- Integrated, multi-disciplinary care - Social support - Support in work and education - Impact on work
Strugnell (2020)	Australia	Rett syndrome	Patients & caregivers	Aspects of life that are satisfying or challenging	- Improved physical health - Improved mental health - Improved autonomy - Integrated, multi-disciplinary care - Social support
Hiltrop (2020)	Europe	Male breast cancer patients (MBCPs)	Patients/patient organisations/representatives	Return-to-work experiences	- Financial stability - Improved physical health
Brod (2020)	US	Hypoparathyroidism	Patients & HCP	Patient experience	- Improved physical health
Verrecchia (2020)	Europe	Alpha-mannosidosis	/	Caregiver's and physician's perspectives	- Integrated, multi-disciplinary care - Timely and accurate diagnosis
Oladapo (2019)	Unspecified	Congenital (Hereditary) Thrombotic Thrombocytopenic Purpura	Patients/patient organisations/representatives	Patient experiences	- Improved physical health - Improved mental health - Improved autonomy

Baumbusch (2019)	Canada	Orphan but non disease specific	Parents & caregivers	Parent experiences	- Financial stability - Improved mental health - Integrated, multi-disciplinary care - Information needs - Social support
Wu (2019)	Asia	Epidermolysis bullosa	Caregiver	Family caregivers' experiences	- Improved physical health
Mooney (2019)	Unspecified	Rare rheumatic condition	/	Impact on patients and informal carers	- Improved physical health - Financial stability - Improved physical health - Improved mental health
Babac (2018)	Europe	Orphan but non disease specific	Multistakeholder	Patient, relatives and HCP needs	- Improved mental health - Information needs - Social support
Ruijin (2018)	Asia	Adrenoleukodystrophy	Caregiver/parents	Parents' experience	- Improved physical health - Integrated, multi-disciplinary care - Timely and accurate diagnosis
Adams (2018)	Europe	Lipodystrophy	Patients/patient organisations/representatives	Impact on body image	- Improved mental health - Timely and accurate diagnosis - Information needs - Social support
Sibeoni (2018)	Europe	Neuroendocrine tumors	/	Patients and physicians perspectives	- Improved mental health
Beynon (2015)	Europe	Primary cutaneous T-cell lymphoma	Patients/patient organisations/representatives	Patient experiences, attitudes and approaches to coping	- Improved physical health - Improved mental health - Availability of Availability of treatments - Timely and accurate diagnosis - Social support - Financial stability
Montali (2011)	Unspecified	Primary biliary cirrhosis	/	Patient experiences	- Integrated, multi-disciplinary care - Social support
Henderson (2009)	US	Niemann-Pick disease	Patients & caregivers	Psychosocial aspects of patients	- Improved physical health - Improved mental health - Information needs - Social support
Griffiths (2007)	Europe	Rarer cancers	Patients/patient organisations/patient representatives	Patient needs	- Improved physical health - Improved mental health - Integrated, multi-disciplinary care - Accessibility of Availability of treatments/care - Social support
Lowton (2006)	Europe	Cystic fibrosis	Patients/patient organisations/representatives	Patient experiences	- Financial stability - Integrated, multi-disciplinary care - Information needs
Report					
Mease (2023)	Unspecified	Orphan but non disease specific	/	Patient experiences	- Improved physical health - Improved mental health

					- Availability of treatments - Timely and accurate diagnosis - Impact on work
Gross (2017)	Inter-continental	Disease(s)-specific	/	Unmet needs	- Timely and accurate diagnosis - Accessibility of healthcare - Social support - Support in work and education
Mixed qualitative methods					
Foster (2023)	US	Orphan but non disease specific	Multistakeholder	Self-efficacy managing by parent	- Improved physical health - Availability of treatments
Hartford (2023)	US	Generalized myasthenia gravis	Patients & HCP	Patient experience	- Improved physical health - Availability of treatments
Bingaman (2023)	Inter-continental	GM1-gangliosidosis	Parents & caregivers	Disease burden	- Improved physical health - Financial stability - Improved autonomy - Availability of treatments - Social support
Martin-gomez (2023)	Europe	NKX2-1-related disorders	Patients & caregivers	Preferences and information needs of patients and caregivers	
Golden (2023)	US	Niemann-Pick disease type C	Patients & caregivers	Patient experience	- Improved physical health - Improved mental health - Improved autonomy - Integrated, multi-disciplinary care - Timely and accurate diagnosis - Social support
Engler (2022)	Europe	Life-limiting illness	Multistakeholder	Needs for palliative care	- Accessibility of healthcare
Teare (2022)	Europe	Central diabetes insipidus	Patients & HCP	Challenges and improvement needs	- Financial stability - Availability of treatments - Integrated, multi-disciplinary care - Timely and accurate diagnosis - Social support
Hanbury (2021)	Europe	Aromatic l-amino acid decarboxylase	Multistakeholder	Needs	- Improved physical health
Jimenez-Moreno (2021)	Inter-continental	Neuromuscular diseases	Patients & caregivers	Patient preferences	- Improved physical health - Improved mental health - Availability of treatments - Impact on work
Güeita-Rodriguez (2020)	Europe	Rett syndrome	Parents & caregivers	Access to health and social care resources	- Financial stability - Availability of treatments - Integrated, multi-disciplinary care - Information needs - Accessibility of healthcare - Timely and accurate diagnosis - Social support
Khanna (2019)	Inter-continental	Systemic sclerosis	/	Patient perception of disease burden	- Timely and accurate diagnosis - Social support

Both (2018)	Europe	Tuberous sclerosis complex	Patients & caregivers	Concerns and care needs of young adults	- Financial stability - Improved physical health - Improved mental health - Improved autonomy - Information needs - Accessibility of healthcare - Social support
Litzkendorf (2018)	Europe	Orphan but non disease specific	Multistakeholder	To develop an information portal on RD	- Information needs
Simoës (2017)	Europe	/	Patients/patient organisations/representatives	Patient expectations	- Integrated, multi-disciplinary care - Information needs
Pauer (2016)	Europe	Orphan but non disease specific	Patients & caregivers	Patient information needs	- Information needs

4. Mixed-method studies

Author (year)	Geographical region	Disease	Study design			NEED criteria
			Methods	Population	Objective	
Kocher (2023)	Europe	Systemic sclerosis	- Survey - Interviews - Focus group discussion	Patients/ Patient organisations / Patient representatives	To describe the current state of chronic illness care and HRIImproved physical healthfrom the patient perspective	- Improved physical health - Integrated, multi-disciplinary care - Information needs
Hoenig (2023)	Europe	Non-tuberculous mycobacteria (NTM)	- Survey - Interviews	Patients/ Patient organisations / Patient representatives	Eliciting Patient Insights on the Burden of Nontuberculous Mycobacterial Lung Disease	- Improved physical health - Availability of treatments - Integrated, multi-disciplinary care - Timely and accurate diagnosis
Antoniadou (2023)	Europe	Orphan but non-disease specific	- Survey - Interviews	Multistakeholder	To identify the parameters that matter for patients, professionals and policymakers in the context of rare diseases	- Improved physical health - Accessibility of healthcare - Social support
Hughes (2023)	US	generalized myasthenia gravis	- Survey - Interviews	Patients and Caregivers	To characterize how SDOH barriers impact individuals from diverse racial, ethnic, educational, and socioeconomic	- Improved physical health - Information needs - Accessibility of healthcare - Social support - Financial stability

					backgrounds living with gMG		
Müller (2023)	Unspecified	tuberous sclerosis complex	- Survey - Interviews	Patients	To understand the impact of tuberous sclerosis complex through the development and validation of the TSC-PROM		
Marinello (2022)	Europe	Rare and complex rheumatic tissue diseases (rCTDs)	- Survey - Focus group	Patients/ Patient organisations / Patient representatives	Exploring patient's experience and unmet needs on pregnancy and family planning in rare and complex connective tissue diseases	- Improved physical health - Integrated, multi-disciplinary care - Information needs	
McMullan (2022)	Europe	Orphan but non-disease specific	- Survey - Focus group		To gain an understanding of carer reported experiences derived specifically from persons caring for someone with a rare disease	- Improved physical health - Financial stability - Information needs - Social support	
Spencer-Tansley (2022)	Europe	Orphan but non-disease specific	- Survey - Interviews	Patients and caregivers	To explore the impact on mental health of living with a rare condition, and experiences of health service support	- Improved physical health - Integrated, multi-disciplinary care - Accessibility of healthcare - Social support	
Marcinkowska (2022)	Europe	Tuberous Sclerosis Complex	- Survey - Interviews	Patient and caregiver	Identifying the needs and difficulties of patients with Tuberous Sclerosis Complex	- Improved physical health - Support in work and education	
Yang (2022)	US	Neurofibromatosis Type1 (NF1) and Plexiform Neurofibroma (PN)	- Survey - Interviews	Patients and caregivers	To gain understanding in the burden Among Caregivers of Pediatric Patients with Neurofibromatosis Type 1 (NF1) and Plexiform Neurofibroma (PN)	- Improved physical health - Financial stability - Improved physical health	
Godfrey (2021)	US	Cystic fibrosis	- Survey - Focus group	Patients, HCP and caregivers	To determine the educational needs and preferences	- Social support	
Long (2021)	Australia	Mitochondrial Respiratory Chain Disorders (MRCDs)	- Survey - Focus group	Patients and caregivers	Identifying the perspectives of people and parents of children concerning disease management after Timely and accurate diagnosis	- Integrated, multi-disciplinary care - Information needs - Accessibility of healthcare - Social support	

Depping (2021)	Europe	neurofibromatosis type 1; primary sclerosing cholangitis; pulmonary arterial hypertension; and Marfan syndrome	- Survey - Focus group	Patients/patient organisations/patient representatives	The development of a self-care intervention for patients with rare diseases	- Improved physical health - Accessibility of healthcare - Social support
Applebaum (2020)	US	Erdheim–Chester disease	- Survey - Interviews	Caregivers and parents	Understanding the burden of caregivers	- Improved physical health - Financial stability
McMullan (2020)	Europe	Orphan but non disease specific	- Survey - Interviews	Patients/patient organisations/patient representatives	Identifying which improvements are required to further support people living with a rare disease	- Improved physical health - Information needs - Social support
Porter (2020)	US	Mucopolysaccharidosis type III (MPS III, Sanfilippo syndrome)	- Survey - Focus group	Patient and caregivers	Identifying the unmet Availability of treatments needs	- Improved physical health - Availability of treatments - Information needs - Accessibility of healthcare - Social support
Inhestern (2020)	Europe	Orphan but non disease specific	-		Developing best practice recommendations on management concepts in healthcare for rare diseases	
Ragusa (2020)	Europe	Prader-willi	- Survey - Interviews	Patients and caregivers	Gaining insights in the needs of patients and caregivers	- Improved physical health - Timely and accurate diagnosis
Kocher (2019)	Europe	Systemic sclerosis	- Survey - Interviews	Patient, HCP and caregivers	Gaining insights into the chronic illness care and disease management	- Integrated, multi-disciplinary care
Noël (2019)	Europe	Fabry Disease	- Survey - Interviews	Patients/patient organisations/patient representatives	Identification of Availability of treatments needs and expectations	- Availability of treatments
Svernlung (2019)	Europe	Locked-in syndrome	- Database analysis - Interviews	Patients/patient organisations/patient representatives	Assessment of the Improved physical health	- Improved physical health - Integrated, multi-disciplinary care - Social support
Erbis (2018)	Europe	Autoinflammatory diseases	- Survey - Focus group	Patients and caregivers	Evaluating the patient perspective of the unmet needs in AID	- Improved physical health - Financial stability - Improved physical health - Information needs - Accessibility of healthcare - Timely and accurate diagnosis - Social support
Hiremath (2018)	US	Eosinophilic gastrointestinal disorders (EGID)	- Survey - Focus group	Patients and caregivers	Identification of the unmet medical needs and barriers in patients with EGID	- Improved physical health - Integrated, multi-disciplinary care - Accessibility of healthcare

						- Social support
Tejada-Ortigosa (2017)	Europe	Rare metabolic diseases	- Survey - Interviews	Patients and caregivers	Identification of the health and socio-educational needs	- Improved physical health - Financial stability - Improved physical health - Integrated, multi-disciplinary care - Accessibility of healthcare - Timely and accurate diagnosis - Social support
Kasparian (2015)	Australia	Von Hippel–Lindau disease	- Survey - Interviews	Patients and caregivers	Eliciting the experiences and unmet medical needs of patients their families and caregivers	- Improved physical health - Integrated, multi-disciplinary care - Information needs - Timely and accurate diagnosis - Social support
Van Groenendaal (2015)	Europe	Alstrom syndrome	- Survey - Interviews	Patients and caregivers	Analyzing the effectiveness of the MDC	- Integrated, multi-disciplinary care
Behan (2016)	Europe	Primary ciliary dyskinesia	- Survey - Interviews	Patients/patient organisations/patient representatives	To investigate the patients' perspectives on Timely and accurate diagnosis between	- Timely and accurate diagnosis - Information needs - Social support
Dwyer (2014)	Europe	Congenital hypogonadotropic hypogonadism	- Survey - Focus group	Patients/patient organisations/patient representatives	Identifying the unmet health needs of patients	- Improved physical health - Integrated, multi-disciplinary care - Information needs - Social support