

### Search string Ovid: Medline, Embase, Psycinfo

rare disease.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, an, ui, sy, tc, id, tm, mh]

OR

(narcolepsy or primary biliary cholangitis or Fabry disease or cystic fibrosis or h\*emophilia or spinal muscular atrophy or retinal dystrophy or X-linked hypophosph\*emia or urea cycle disorders or pulmonary arterial hypotension or cerebral adrenoleukodystrophy or hereditary angioedema or AA amyloidosis or Cushing's syndrome or mitochondrial respiratory chain disorders).mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, an, ui, sy, tc, id, tm, mh]

AND

"Quality of Life"/ or "Delivery of Health Care"/ or Patient Advocacy/ or Patient Participation/ or patient education.mp / or Self-Help Groups/ or Health Resources.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, an, ui, sy, tc, id, tm, mh]

AND

Mobile Applications/ or Cell Phone/ or Smartphone/ or Social Media/ or Internet/ or Social Networking/ or Patient Portal.mp/ e-health [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, an, ui, sy, tc, id, tm, mh]

Limit to English language

### Hand search of Orphanet Journal of Rare Diseases

Electronic resources/ or e-health/ or m-health/ or apps/ or mobile/ or telehealth/ or virtual

### Hand search of Journal of Medical Internet Research

Rare dis\*/ narcolepsy/ or primary biliary cholangitis/ or Fabry disease/ or cystic fibrosis/ or h\*emophilia/ or spinal muscular atrophy/ or retinal dystrophy/ or X-linked hypophosph\*emia/ or urea cycle disorders/ or pulmonary arterial hypotension/ or cerebral adrenoleukodystrophy/ or hereditary angioedema/ or AA amyloidosis/ or Cushing's syndrome/ or mitochondrial respiratory chain disorders.