

Supplemental Table 1: Affiliation Search Terms

patient	community partner
advisor	community co-researcher
patient author	community co-author
patient contributor	association
patient expert	organi*ation
patient representative	foundation
patient advocate	international
patient advocacy	federation
patient partner	caregiver
patient co-researcher	citizen
patient co-author	parent
family advisor	alliance
family partner	consortium
unaffiliated	platform
independent advisor	network
independent contributor	coalition
independent expert	confederation
independent representative	group
independent advocate	forum
independent partner	trust
independent co-researcher	fund
independent co-author	support
private advisor	council
private author	society
private contributor	
private expert	
private representative	
private advocate	
private partner	
private co-researcher	
private co-author	
public advisor	
public author	
public contributor	
public expert	
public representative	
public advocate	
public partner	
public co-researcher	
public co-author	
community advisor	
community author	
community contributor	
community expert	
community representative	
community advocate	

Supplemental Table 2: Ovid Search

#	Query
1	(patient\$ adj (advisor or advisory or author or authors\$ or contributor or expert or federation or forum or representative or advocate or advocacy or association or organi?ation or partner or co-researcher or co-author)).in.
2	(family adj (advisor or advisory or partner\$)).in.
3	Unaffiliated.in.
4	(Independent adj (advisor\$ or author or authors\$ or contributor or expert or representative or advocate or partner or co-researcher or co-author)).in.
5	(Private adj2 (advisor\$ or author or authors\$ or contributor or expert or representative or advocate or partner or co-researcher or co-author)).in.
6	(Public adj (advisor\$ or author or authors\$ or contributor or expert or representative or advocate or partner or co-researcher or co-author)).in.
7	(Community adj (advisor\$ or author or authors\$ or contributor or expert or representative or advocate or partner or co-researcher or co-author)).in.
8	(association or organi?ation or foundation or international or federation or caregiver or citizen or parent or alliance or consortium or platform or network or coalition or confederation or group or forum or trust or fund or support or council or society).in.
9	"rare disease* ".ab,kf,kw,nc,od,sh,ti.
10	(article or journal article or article in press).pt.
11	English.lg.
12	(9 and 10 and 11) not (conference abstract or chapter).pt.
13	(caregiver or citizen or parent).in.
14	exp Consumer Participation/ or "Patient Acceptance of Health Care"/ or exp Attitude to Health/ or *exp consumer satisfaction/ or patient preference/ or cooperative behavior/ or exp self efficacy/ or self-efficacy.ti,ab. or exp Adaptation, Psychological/ or exp health education/ or patient education as topic/ or exp attitude to health/ or health knowledge, attitudes, practice/ or *"Quality of Life"/ or "Quality of Life"/px or Personal Autonomy/ or self concept/ or consumer advocacy/ or freedom/ or Needs Assessment/ or Patient Advocacy/ or Self-Help Groups/ or Life Change Events/ or Attitude to Death/ or Patient-Centered Care/ or exp Professional-Patient Relations/ or Self Care/ or focus groups/ or narration/
15	(((((patient or consumer*) adj3 (participat* or decis* or decid*)) or patient-focused or (patientcentred or patient-centered) or (patient adj3 (attitude? or preference))).ti,ab. or "patient satisfaction".ti. or coping.ti,ab. or ("self perception" or "self concept").ti,ab. or self-efficacy.ti,ab. or exp Consumer Participation/ or "Patient Acceptance of Health Care"/ or exp Attitude to Health/ or *exp consumer satisfaction/ or patient preference/ or cooperative behavior/ or exp self efficacy/ or self-efficacy.ti,ab. or exp Adaptation, Psychological/ or exp health education/ or patient education as topic/ or exp attitude to health/ or health knowledge, attitudes, practice/ or *"Quality of Life"/ or "Quality of Life"/px or Personal Autonomy/ or self concept/ or consumer advocacy/ or freedom/ or Needs Assessment/ or Patient Advocacy/ or Self-Help Groups/ or Life Change Events/ or Attitude to Death/ or Patient-Centered Care/ or exp Professional-Patient Relations/ or Self Care/ or focus groups/ or narration/ or ("informed choice" or "shared decision making").ti,ab. or empowerment.ti,ab. or ("focus group*" adj3 (patient* or parent* or famil* or spouse*)).ti,ab. or (QoL or "Quality of life").ti. or self-management.ti. or ((patient* or consumer* or parent* or famil* or spouse*) adj (attitude* or involvement or desir* or perspective* or activation or view* or preference*)).ti,ab. or "expert patient*".ti,ab. or "focus group*".ti,ab. or qualitative.ti.
16	exp Decision Making/ or exp Communication/ or Stress, Psychological/ or Emotions/ or vignette*.ti,ab.
17	exp Patients/px or patient*.ti. or consumer*.ti.
18	16 and 17
19	14 or 15 or 18
20	12 and 19

Supplemental Figure 1: Article Selection

