

### **Additional File 3 – Possible Search Terms**

#### **Patients**

- patient, patient's, patients, patients'
- consumer, consumer's, consumers, consumers'
- public, publics, public's, publics
- citizen, citizens, citizen's, citizens'
- stakeholder, stakeholders, stakeholder's, stakeholders'
- caregiver, caregiver's, caregivers, caregivers'
- carer, carers, carer's, carers'
- community
- client
- user
- service user
- lay
- parents
- guardians
- disabled people
- organizations (represent those using services)
- patient advocates
- patient representatives

#### **Clinician**

- Physician
- Nurse
- Social Worker
- Allied Health professional
- Physiotherapist
- Occupational therapist

#### **Decision Maker**

- decision making
- health care management
- health care planning
- health care policy
- health care quality
- participatory management
- policy maker
- policy making
- public policy

## **Role**

- Engage engages engaged engaging engagement
- Deliberate deliberates deliberated deliberating deliberation
- Participate participates participated participating participation
- Involve involves involved involving involvement
- Collaborate collaborates collaborated collaborating collaboration
- Input
- eliciting
- Partner partners partnered partnering partnership
- Consult consults consulted consulting consultation
- Empower empowers empowered empowering empowerment
- Dialogue dialogues
- Perspective
- Inform
- Shared decision making
- Patient centeredness
- Patient activation

## **Patient oriented research**

Patient oriented research

Patient-outcome research

Patient, person, family, consumer centred care

Patient, person, family, consumer centred medicine

Personalized care

Practiced based research

Clinical research

Translational research

Community participation research

## **Research (Social, biomedical, medical, health, animal)**

- Health services research (HSR)
- health systems research
- health policy and systems research (HPSR)
- medical or biomedical research
- basic science
- bench research
- bench science
- applied research
- pre-clinical research
- clinical research
- basic medical research
- translational research
- Consultation (seeking the view of the public on components of research)

- Collaboration (partnership between researchers & public during research)
- Publicly led (public designs and leads research – researchers invited by public)
- “study design” “trial design” “research design”
- Prioritize prioritizes Priority priorities prioritization priority-setting “priority setting”
- “resource allocation” “allocation of resources”
- Priority setting
- Policy, policy-making
- “topic selection” “selecting topics”
- agenda
- Translate translating Translation
- Disseminate disseminating Dissemination
- Systematic reviews
- Guidelines
- Health technology assessments
- Clinical trials
- Reviews
- Observational studies
- Protocols
- Question development
- Research outcomes
- Implementation plan
- Structures
- Mechanisms
- Evaluation
- Input into organisational governance (organisation wide committee member)
- Fundraising
- Disseminate research information
- Individual research project committee member
- Identify research needs
- Prioritise research
- Input into acceptability of proposed research and likelihood of participation
- Recruit participants
- Other (ethics committee member)
- Assist the development of research funding applications
- Assist the development of research tools e.g. participant surveys or information sheets
- Gather/facilitate research data collection
- Member of research grant review panel
- Contribute to the formulation of research policy such as funding guidelines
- Other (felt laboratory research was not applicable)
- Other (planning to in future)
- Other (provide community talks)
- generating topics, topic generation,

- prioritiz\*,
- selecting topics, topic selection, voice
- “Public involvement in the systematic review process is defined as the involvement of the public in one or more of the following review activities:
  - Topic identification, prioritization and commissioning
  - Refinement of review question
  - Development of review protocol (including
  - search strategy and inclusion/exclusion criteria)
  - Literature search
  - Appraisal of the literature, including assessment of study relevance, data extraction and evidence synthesis
  - Initial drafting of findings
  - Interpretation of findings
  - Final report writing
  - advisory board, advisory committee, citizen board, citizen council, citizen jury, focus group, graphic elicitation,
  - grounded theory, ethnography, health experience research, mixed methods research, interview, participatory action research, participatory health research, observation, phenomenology
  - photovoice, photo elicitation
  - patient board, patient council, patient panel, people board, people council, people panel, public board, public council , public panel,
  - questionnaire, social science methods, survey,
  - verbal elicitation,
  - visual elicitation

### **French**

- Consommateurs, patients, publique
- choisir, choix, consultation, consulter, sélection, sélectionner, participation, participer
- la décision médicale partagée, recherche clinique orientée patient, soins orientée patient, sujets de recherche