Additional File 6 – Grey Literature Databases

1. General
   - SIGLE
   - Grey Literature Report (The New York Academy of Medicine)
   - Des Libris
   - GreyNet
   - Réseau de recherche en santé des populations du Québec
   - The Fraser Institute
   - PHRED Public Health Research, Education & Development
   - Canadian Women's Health Network
   - World Health Organization
   - OECD iLibrary
   - Grey Matters
   - Open DOAR
   - OAIster
   - The Joanna Briggs Institute
   - Virtual Health Library
   - RIAN (Pathways to Irish Research)
   - Lenus (The Irish Health Repository)
   - NARCIS - National Academic Research and Collaborations Information System (Netherlands)
   - Lenus (The Irish Health Repository)
   - INAHTA (International Network of Agencies for Health Technology Assessment)
   - Centre for Reviews and Dissemination (UK)
   - OpenAIRE
   - OpenGrey
   - Public health Grey Literature Sources (from OPHLA)

2. Conferences
   - Summer Institute 2017
   - POR Training Program Session 4: Innovative Methods for Patient-Oriented Res
     https://www.eventbrite.ca/e/por-training-program-session-4-innovative-methods-for-patient-oriented-research-part-1-identifying-tickets-30329570562?aff=erelexpmlt
   - Nova Scotia LGBTQ Health Research Conference June 2916
     https://www.dal.ca/diff/gahps/research-projects/improvinglgbtqhealth.htm
   - Challenges: the Patients' perspective; IRDiRC meeting, Dublin 2013

3. Training
   - https://www.mcmasterhealthforum.org/citizens/masterclass-patient-oriented-research
4. Organizations

Canadian Consumer Health Associations

- Allergy & Asthma Information Association
- Allergy & Asthma Information Association (ON)
- Alzheimer Society (PEI)
- Alzheimer Society of Canada (NF & LBR)
- Amyotrophic Lateral Sclerosis (ALS) Society
- Anaemia Institute
- Arthritis Society
- Arthritis Society (AB & NWT)
- Arthritis Society (BC & Yukon)
- Arthritis Society (PEI)
- Asthma Society of Canada
- BC Lung Association
- BC Persons with AIDS Society
- Canadian Arthritis Network
- Canadian Arthritis Patient Alliance
- Canadian Association for Independent Living Centres
- Canadian Breast Cancer Network
- Canadian Cancer Society
- Canadian Cancer Society—AB/NWT
- Canadian Cancer Society—NB
- Canadian Cancer Society—NS
- Canadian Cystic Fibrosis Foundation
- Canadian Diabetes Association—ON
- Canadian Diabetes Association (SK)
- Canadian Haemophilia Society
- Canadian Liver Foundation
- Canadian Liver Foundation—BC
- Canadian Liver Foundation—NB
- Canadian Liver Foundation—NS
- Canadian Mental Health Association (MB)
- Canadian Network for Asthma Care
- Canadian Prostate Cancer Network
- Canadian Treatment Action Council (CTAC)
BC persons with AIDS
• CARP, Canada’s Association for the 50 Plus
• Epilepsy Ontario
• Haemophilia Ontario
• Haemophilia Saskatchewan
• Heart & Stroke Foundation
• Heart & Stroke Foundation (PQ)
• Heart & Stroke Foundation (ON)
• Hepatitis C United Resource Exchange (Hep Cure)
• Hepatitis C Resource Centre (MB)
• Kidney Foundation of Canada
• Lupus Canada
• Multiple Sclerosis Society of Canada
• Osteoporosis Society of Canada
• Spina Bifida & Hydrocephalus Association
• Titz n Glitz Breast Cancer

Note: Above list is from (J. Pivik et al. / Health Policy 69 (2004) 253–268 257)
• Health Policy Citizen Council (Toronto)
• CADTH
• Canadian Institutes of Health Research (CIHR)
• Canadian Institute for Health Information (CIHI)
• Centre for health Economics and Policy Analysis (CHEHPA)
• Health Canada
• Health quality council of Ontario
• Institute for Clinical and Evaluative Sciences (ICES)
• Institute of Research and Public Policy

United States (US)
• Patient-Centered Outcomes Research Institute (PCORI)
• Kaiser Permanente
• National Health and Medical Research Council (NHMRC)
• National Institutes of Health
• Agency for Healthcare Research & Quality
• Centre for health Services and Policy Research
• National Guidelines Clearinghouse
• IOM Institute of Medicine
• NIHR National Institute for Health Research

United Kingdom (UK)
• INVOLVE
• Wellcome Trust
• National Health Service (NHS)
• National Institute for Health Research (NIHR)
• Mental Health Research Network (MHRN)
• Mental Health Foundation
• www.peopleinresearch.org/
• www.ukctg.nihr.ac.uk/pages/signup-page
• www.nihr.ac.uk/patients-and-public/
• www.hra.nhs.uk/resources/public-involvement-research/
• Medical Research Council
• Centre for Health Information Quality (UK)
• Consumers in NHS Research Support Unit
• United Patients’ Organisations of the Chronically Ill (WOCZ)
• Research Institute for Consumer Affairs (RICA) (1960’s ??)
• National Consumer Council
• Patients Association
• National Institute for Health and Clinical Excellence (NICE)
• James Lind Alliance
• SCH Scottish Health Services
• Medical Research Council
• Health Technology Assessment (HTA) Programme - NIHR

Europe
• Picker Institute Europe
• European patients forum
• European Medicines Agency (EMA) (Eligible patients and consumers organisations
• Cochrane Consumer network
• Julius Center for Patient-Oriented Research, Utrecht University Medical School, Utrecht, the Netherlands
• “Centre de sociologie de l'innovation” (Ecole des Mines, Paris, France)
• European Organisation for Rare Diseases (EURORDIS)
• The European Patient Voice
• AQUUMED German Agency for Quality in Medicine (Ärztliches Zentrum für Qualität in der Medizin)
• ECRIN EFGCP European Clinical Research Infrastructure Network European Forum for Good Clinical Practice
• EFSA European Food Safety Authority
• EGAN European Genetic Alliances Network
• EMA European Medicines Agency
• ENPCR European Network of Patients Partnering in Clinical Research
• EPF European Patients’ Forum
• EUNETHTA European Network for Health Technology Assessment
• EUPATI European Patients Academy on Therapeutic Innovation
- EURORDIS IAPO European Organization for Rare Diseases International Alliance of Patients’ Organizations
- VSOP Dutch Genetic Alliance

**Australia**
- ACSQHC Australian Commission on Safety and Quality in Health Care
- National Health and Medical Research Council (NHMRC)
- Cancer Voices Australia
- The Consumers’ Health Forum of Australia

**International Organizations**
- Cochrane Collaboration
- International Alliance of Patients’ Organizations
- ICPHR International Collaboration on Participatory Health Research
- ICPHR International Collaboration on Participatory Health Research