Patient Engagement Processes

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REDELSA EXCHANGE
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Our Programs and Services

**DRUG REIMBURSEMENT RECOMMENDATIONS**
- CADTH Common Drug Review (CDR)
- CADTH pan-Canadian Oncology Drug Review (pCODR)

**HEALTH TECHNOLOGY MANAGEMENT PROGRAM**
- Rapid Response Service
- Health Technology Assessment Service
- Optimal Use Service
- Environmental Scanning
- Horizon Scanning

**OTHER PROGRAMS AND SERVICES**
- Scientific Advice

**KNOWLEDGE MOBILIZATION AND LIAISON OFFICERS**
- Located in jurisdictions across Canada
- Understand the needs and priorities of local decision-makers
- Provide advice and tools to help turn evidence into policy and practice
Why Is Patient Input Important for CADTH?

- HTA recommendations will ultimately affect patients for whom the technology is intended.
- Only patients and their family/caregivers have:
  - day-to-day lived experience with the disease or condition
  - direct experience with currently available treatments (if applicable) and possibly experience with the technology being reviewed.
- Patients and their caregivers can provide their perspectives on the most important considerations and outcomes for a new technology.
DRUG REIMBURSEMENT RECOMMENDATIONS

- CADTH Common Drug Review (CDR)
- CADTH Pan-Canadian Oncology Drug Review (PCODR)
Patients Tell Us About…

- Standarized questionnaire/template
- Impact of health condition
- Experience with current therapy
- Unmet need
- Impact on caregivers
- Expectations for new technology
- Experience with new technology
Patient Group Input

CADTH Review Team
Patient input used to inform protocol & report

Expert Committees (CDEC, pERC)
Patient input presented, used in deliberations & reflected in recommendations

Public Drug Plans
Shared with plans and shared at www.cadth.ca
Patient Input to Pharmaceutical Reviews

Many groups answer multiple calls for patient input

532 patient input submissions from 137 patient groups

June 2010 – June 2016
Patient Input Template Revisions

• Based on analysis how input is used, comments from patient groups, CADTH reviewers and committee members
• Common wording and expectations
• Greater focus on potential benefits and risks of treatment than on description of condition
• Caregivers perspectives more consistently collected
• Identical conflict of interest declaration
Patient Group Input
• Tailored templates with specific prompts related to policy / research question asked by Therapeutic Review
• 1 month to complete

Patient groups provide feedback on
• Proposed project scope
• Included studies
• Draft science report
• Draft recommendations
CCAN Patient Engagement Navigator

- Collaboration of the Canadian Cancer Action Network (CCAN) and CADTH
- Funded by the Canadian Partnership Against Cancer, with in-kind funding provided by CADTH and CCAN, to develop, identify and support opportunities for patient and caregiver involvement with the pCODR program
CCAN Patient Engagement Navigator

• Promote patient awareness of pCODR and their role in the HTA process.

• Work directly with patient groups to identify and collect data as well as to prepare the submissions.

• Expand the breadth and improve the quality of resources available to patients.
Patient Community Liaison Forum

- Build understanding among forum members
- Help to identify priorities for patient engagement activities
- Facilitate the gathering of feedback on new patient engagement processes

Members:
- Canadian Cancer Action Network
- Canadian Organization for Rare Disorders
- Best Medicines Coalition
- Health Charities Coalition of Canada
- CADTH

www.cadth.ca/cadth-patient-community-liaison-forum
Expert Committees

Present patient group input to other committee members

**CDEC**: 2 public members  
Frank Gavin, Allen Lefebvre

**pERC**: 3 patient members  
Valerie Macdonald, Jo Nansen, Carole McMahon

**HTERP**: 1 public member  
Jeremy Petch
Patients’ perspectives can be integrated in health technology assessments: an exploratory analysis of CADTH Common Drug Review

Sarah Berglas1*, Lauren Jutai2, Gail MacKean3 and Laura Weeks1
Patient insights identified and tracked

- Summary of patient input
- CDR assessment protocol
- CDR assessment report
- CDEC recommendation
CADTH ASKED PATIENT GROUPS: what are the important outcomes for drug assessment?

- Health-related quality of life
- Symptom relief
- Cost
- Fewer side effects of treatment
- Avoid hospitalization
- Ease of adherence
- Avoid further disease
- Alternative treatment
- Fewer treatment supports
- Target root cause
- Treatment duration
- Independence in psychosocial quality of life

Based on patient input for 30 drugs reviewed by the CADTH Common Drug Review, with recommendations published between March 2013 and June 2014.
Use of Patient Input in CADTH CDR

- Patient Input Summaries: 119 things that matter to patients
- CADTH Review Protocols: 89 / 119 included, 75%
- Clinical Trials: 61 / 119 included, 50%
- CDEC Recommendation & Reasons: 67 / 119 included, 56%
HEALTH TECHNOLOGY MANAGEMENT

- Rapid Response Service
- Health Technology Assessment
- Optimal Use
Medical Device Assessments

- Patient interviews to validate key outcomes at protocol development
- Systematic review of patient preferences and values
- Patient groups provide feedback on draft report and recommendations

Optimal Use Reports to date:
- dMMR testing for patients with colorectal cancer
- Monitoring atrial fibrillation in cryptogenic stroke patients
- Interventions for obstructive sleep apnea
- Dialysis modalities for end-stage kidney disease
What is going well?

• Expert committee recognizes value
  • Unique evidence
  • Meeting demand for inclusion of patient perspectives
• Methodological rigor
  • Parallels to clinical systematic review
• Useful to inform deliberations and recommendations
  • Context and meaning of clinical results
  • Frame rationale to support recommendation
  • Identify implementation considerations
Some of the Challenges

• Too much or not enough studies
  • Sometimes difficult to infer relevance to Canadian setting
• Poor reporting of study attributes and quality criteria
• Ideal methods versus what is feasible
  • HTA timelines
• Integrating with other HTA components
• Specialized:
  • Resources
  • Research skills
OTHER PROGRAMS AND SERVICES

• CADTH Scientific Advice Program
CADTH Scientific Advice Program

- Established January 2015

- Advice on early drug development plans from a Canadian health technology assessment (HTA) perspective

- Voluntary, fee-for-service, confidential, non-binding
Engaged as Experts

- Process developed with members CADTH Patient Community Liaison Forum
- Non-disclosure agreement & paid honoraria
- Use known patient groups to find individual with:
  - Personal, long-term experience with disease
  - Has tried multiple therapies to deal with disease
  - Is aware of other’s experiences: moderated a chat group, answered help lines, led patient group
Patient Involvement

• 1 hour interview; standardized questions
• Written summary of interview included in the record of scientific advice

Experience to date:

• Patient perspectives have been most important in the development of advice regarding outcomes and quality of life measures
What is Next?

- Well supported approach to involving patients in all steps of the HTM process
- Addressing the need for tangible support to be confident partners
- Measuring impact
Contact Patient Engagement

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