Canadian Primary Care Research Network
Réseau canadien de recherche en soins primaires

Practice based research and learning:

Lessons learned about engagement from the Patient-Reported Indicator Surveys (PaRIS) OECD project

What is the project?

TIMELINE

2020-21 Phase 1 — **Instrument consistency & testing**

- Develop survey instruments in English
- Develop study protocol and operations manual
- Engage national stakeholders
- Develop country specific national roadmaps

2022-23 Phase 2 — **Field trial**

- Implement field trial (18 countries)
- Identify national project managers
- Engage national stakeholders
- Host collaborative working group meeting between technical experts and patient advisors
- Evaluate based on the field trial

2023-24 Phase 3 — **Main survey, analysis, & reporting**

- Roll survey out in 20 participating countries
- Analyse data and prepare for international and national-level reports
- Engage national stakeholders
- Host collaborative working group meeting between technical experts and patient advisors
- Disseminate results

High level of patient engagement

- Revision of the original PaRIS questionnaire
- Relational equity through health literacy
- People-centered care data literacy
- Learning health systems and practise-based research learning Network (PBRLN)

Supports recruitment and retention through a sense of belonging, trust and collaboration.

Objective for Canada

Compare nationally equivalent health outcomes and experiences of patients with chronic conditions treated in primary care to identify areas of excellence and improvement.

Study design

PaRIS-Survey in Canada is a two-phase cross-sectional study (field trial and main study).

Surveys

Providers

2 domains:

1. Practice characteristics (location, type of practice, funding model, computerized system, team composition)
2. Services provided (type of chronic condition treated, care coordination, self-management support activities)

Patients

4 domains + sociodemographic characteristics :

1. Health status, symptoms (e.g., pain, physical activity)
2. Managing health (e.g., patient activation, digital and health literacy)
3. Experiences of primary health care services
4. Experiences of other health care services

PROMs - Patient Oriented Outcome Measures

Cover symptoms, functioning, self-reported health status, health-related quality of life, health-related physical activity, social health, mental health, pain, sleep disturbance, fatigue, depression, anxiety, physical function and satisfaction in social roles, and self-management capacity.

PREMs - Patient Oriented Experience Measures

include domains related to access, comprehensiveness of care, quality of care, person-centredness, continuity of care, support for self-management, safety, and trust.

Sampling

Setting primary care practices across Canada

Inclusion criteria for providers are:

Providers

- With a patient panel (e.g., family physicians, nurse practitioners)

Patients

- Aged 45 years or older
- At least one registered contact with a recruited provider during the six months preceding the selection procedure
- Lived in the community (in a private household)

Instrument

Based on the framework of the PaRIS-OECD survey and approved by the PaRIS working party.

Canadian recruitment strategies

Strategies	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.B.	N.S.	P.E.I.	N.L.
Practice based research and learning network (e.g.:Canadian Primary Care Sentinel Surveillance Network)	X	X		X	X	X	X	X		
Provincial chapter of College of Family Physicians of Canada	X	X	X		X					
Provincial medical association		X	X							X
SPOR support unit		X	X			X				
Individual primary care champions (e.g. physicians, Practice Based Research and Learning Networks)	X		X	X		X	X	X		
Collaboration with other provincial organizations		X	X			X				
Reaching out to individual primary care clinics or physicians offices by phone, email or fax	X		X	X		X	X	X		X
Connecting with representatives from the local health authority and department of health				X			X	X		
Participants										
Providers	5	8	10	7	13	15	9	Did not collect data		5
Patients	682	48	1274	71	967	1478	141			120

Total Practices: n=70 | Total patients recruited: n=4,754 | Total eligible patients who gave consent included in OECD-PaRIS: n=3,887

Strategies for Engagement

Challenges

Organisational

- Minimize burden for practices (maximum task handling by the research team)
- Full-time resource within the research team to support recruitment (student or research assistant)
- Shared decision making (on some level)
- Seeking to learn (having patient partners)

- Varied primary care practice structure for practices
- Asking primary care providers to recruit patients
- Using a QR code approach was resource intensive for some clinics and research staff
- Administrative duties layer of burden for primary care providers

Legal/Ethics

- Meet in-person or virtually with an ethics officer to avoid unecessary delays

- Important delays (multilevel, Law 25 in QC)
- Patients must provide an agreement before being contacted for some province (drop-in)
- Navigating approvals for Health Autorities affiliated sites

Engagement

- Attended events where primary care providers were (e.g. College of Family Physicians Annual Meeting)
- Understanding clinic needs and workflow
- Used an incentive to patients (money or draw)
- Used a monetary incentive to practices
- Identified champions in each practices
- Face-to-face engagement between practices and research team

- Challenges receiving consistent engagement
- Limited engagement of patients as members of the research team
- Low patient response rate (bad timing like holidays and vacations)
- Recruitment from areas with high Indigenous presence
- Length of survey (survey fatigue)

Relational

- Celebrating little successes
- Personal approach and strong partnerships established with practices (meetings)
- Strong engagement and leadership from the research team

- Technical and technological challenges (limited internet connectivity, limited access and use)
- Cold e-mails and calls

Technology

Increased access by :

- Sending electronic massive invitations using a marketing platform
- Providing a phone or paper option for completion of survey

- Unequal literacy (related to research and technology)
- Reaching the desired number of participants with mail and QR code approach

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