

# Lessons learned in establishing a pan-Canadian surveillance system for people living with dementia and their caregivers



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## 1. Background

The relationship between people living with dementia (PLWD) and their caregivers is important for the health and well-being of both individuals



By linking health data, we can examine how the health journeys of caregivers and PLWD interact to better direct dementia care management.

**Objective:** To identify, link, and engage people living with dementia and their caregivers within a de-identified pan-Canadian primary care electronic medical record (EMR) repository.

## 2. Methods

**Study Design:** Prospective cohort study

**Dataset:** The Canadian Primary Care Sentinel Surveillance Network (CPCSSN), a network of practice-based research networks and repository of routinely extracted EMR data drawn from primary care providers (PCPs) across Canada. Eight CPCSSN networks from Nova Scotia, Newfoundland, Quebec, Ontario, Manitoba, Alberta and British Columbia are contributing data and supporting recruitment for this study

**Population:** Community-dwelling people living with dementia and their caregivers who both attend CPCSSN-affiliated primary care clinics.

**Outcome Measures:** The creation of a baseline cohort of 1000 linked people living with dementia-caregiver dyads within the CPCSSN database for routine health data extraction and surveillance.

## 3. Results

- Site ethics approvals for the creation of the linked cohort
- Recruitment of PCPs and participants was limited due to multiple barriers
- Changes to the protocol were implemented

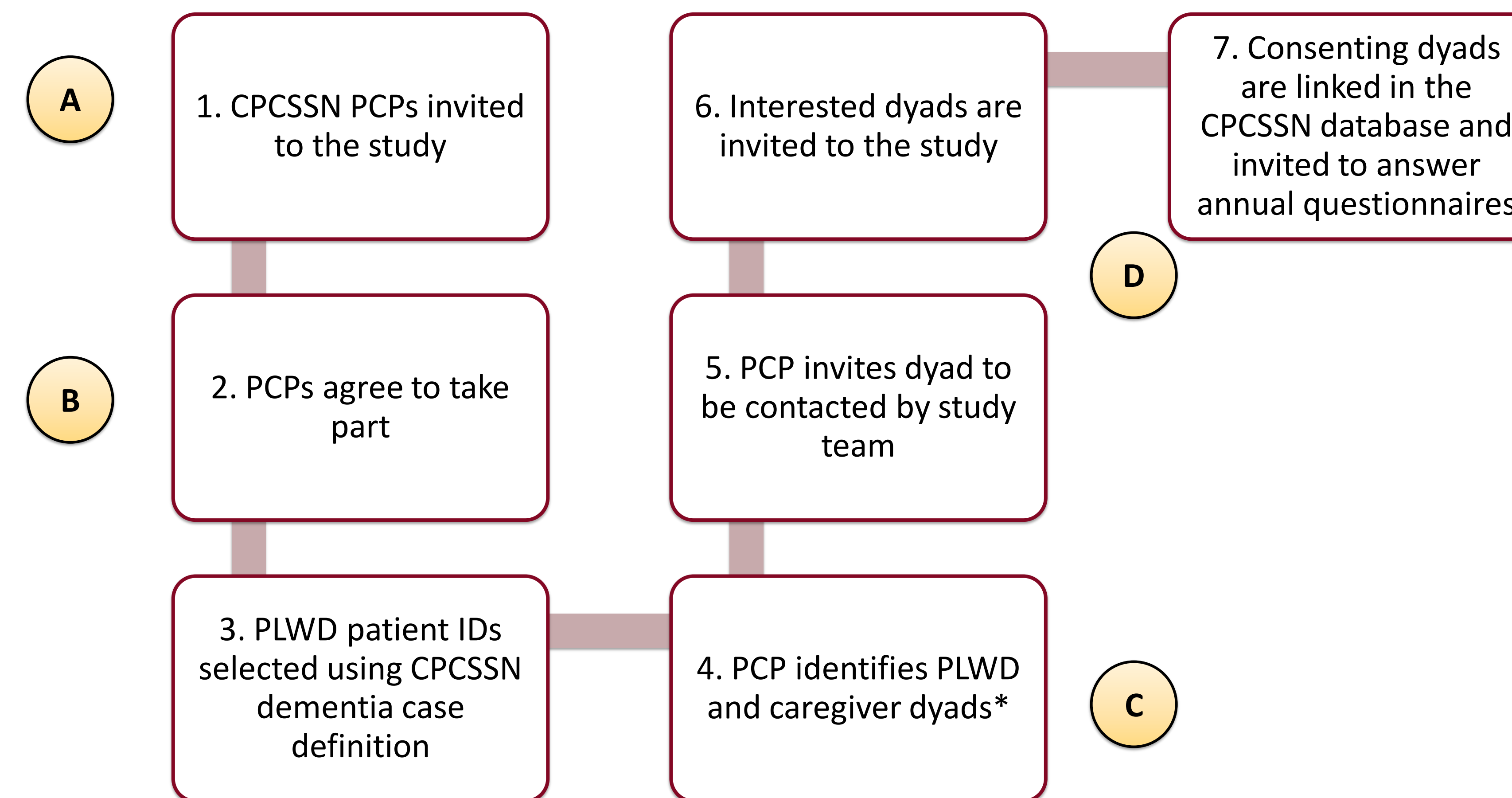


Figure 1: Original methodology flow diagram. \*Reidentification process not permitted in Manitoba.

### Barriers

- A** Variable ethics and privacy requirements by province or ethics board
- B** Reduced capacity for PCPs to support research due to Covid-19 and workforce burnout
- C** Resource-intensive dyad linkage process
- D** Limited response or interest from PLWD and care partners

### Facilitators

- Sharing resources i.e., documentation, letters of approval
- Direct dyad recruitment with posters for participant self-referral to study team
- Increased clinic compensation
- Development of recruitment videos with patient partner input; Waiver of consent

The most effective solution was the implementation of the waiver of consent to allow linkage of dyads in the CPCSSN database for routine health extraction and surveillance.

Dyad consent for linkage in CPCSSN was not required based on the following:

- Data are deidentified; only PCPs have access to patient information for the purpose of linkage
- Dyads could opt-out of the study or the CPCSSN database at anytime



Table 1: Network Recruitment and Dyad Identification Status October 2022

Network	Location	PCPs Recruited	Dyads Identified	Dyads Recruited	Site-specific challenges
BC-CPCSSN	British Columbia	3	4**	-	PCP capacity/interest
SAPCRen*	Calgary, Alberta	47	53	2	PCP capacity/interest
EON*	Eastern Ontario	30	93	-	PCP capacity/interest
MaPCRen*	Manitoba	2	7	2	Re-identification not permissible
RRSPUM	Montreal, Quebec	34	4**	-	Ethics timeline >1 year
APBRN*	Newfoundland	17	18	2	Small network, limited # of PCPs
MaRNet*	Nova Scotia	7	6	-	No data manager to identify PLWD
OPEN	Ottawa, Ontario	-	-	-	Pending ethics
<b>Total</b>	<b>Canada-wide</b>	<b>140</b>	<b>185/1000</b>	<b>6/1000</b>	

\* Obtained ethics approval for waiver of consent to allow dyad linkage; \*\* Pending confirmation.

## Conclusion

Identifying and linking people living with dementia with their caregivers is challenging and requires engagement of both primary care providers and participants by local research teams.

Facilitators to creating a pan-Canadian surveillance system with linked people living with dementia-caregiver dyads were developed and implemented to increase recruitment and linkage of dyads.

Overall, CPCSSN is positioned to facilitate the development of a national surveillance system which provides a significant opportunity to impact the health and health care provision for people living with dementia and their caregivers.



Figure 2: Participating CPCSSN Network provinces in blue

