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1. BACKGROUND

Context:

The health and experiences of people living with dementia and their caregivers are often intertwined. However, few studies have explored the nature of this relationship while considering the well-being of both parties simultaneously.^{1,2}

Objectives:

- Examine how caregiver health and experiences interact with those of people living with dementia
- AND
- Investigate the feasibility of establishing routine pan-Canadian public health surveillance for people living with dementia and their caregivers

2. METHODS

Study Design/Population:

A prospective cohort study of community-dwelling people living with dementia and their caregiver dyads. The eligible population constitutes 1,064,367 patients and 924 providers.

Data Sources:

- Clinical Records from Electronic Medical Records (EMRs):**
 - Canadian Primary Care Sentinel Surveillance Network (CPCSSN) routinely extracts, de-identifies and standardizes patient health data from electronic medical record (EMR) systems of participating primary care providers across Canada
 - 8 out of 13 CPCSSN networks are contributing data for this study (figure 1)
- Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs):**
 - Collected via surveys (figure 2)
 - Instruments used include
 - Zarit Caregiver Burden Scale (12)³
 - DeJong Gierveld Loneliness Scale (6)⁴
 - Disability Assessment for Dementia (40)⁵

Data Collection:

Linked CPCSSN dyad and PROMs and PREMs data will be assembled and analyzed after each bi-annual CPCSSN extraction cycle (figure 2)

3. METHODS CONT.

Data Analysis:

- Longitudinal analyses (e.g., latent growth curve model) to examine trajectories
- Time-varying and time-invariant analyses for predictors (e.g., age, gender, education) of trajectories

Outcome Measures:

- Trajectories of dyad quality of life, healthcare use and comorbidities
- Potential predictors of these trajectories such as demographics, caregiver burden, social support and dyad relationships



Figure 1:

The eight CPCSSN networks that are contributing data to this project from left to right are BC-CPCSSN, SAPCReN, MaPCReN, EON, OPEN, RRSPUM, MaRNet & APBRN

4. EXPECTED RESULTS

- 1000 dyads recruited by study end date (September 2023)
- Increased knowledge about the challenges faced and lived experiences of dyads
- Increased effectiveness of services offered to dyads
- Investigation into the feasibility of establishing routine pan-Canadian public health surveillance for people living with dementia and their caregivers

5. RESULTS (as of 2022-11-08)

- 185 dyads identified
- 140 providers
- 20 participating clinics
- 46 dyads linked

6. ACKNOWLEDGEMENT

We would like to acknowledge all the community primary care clinics and members of the patient and provider advisory committee for their valuable time and contribution.

Dyad Characteristics (N=89)	Caregiver (n=43)*	Care-recipient (n=46)
○ Age in years (mean (SD))	69.9 (12.9)	80.3 (9.5)
○ Sex (n, %)		
• Female	27 (62.8)	25 (54.3)
• Male	16 (37.2)	21 (45.7)
○ No. of CPCSSN conditions (median (IQR))	4 (3.00)	3 (2.75)
○ Top 3 most common CPCSSN conditions (<i>in decreasing order</i>)	Dyslipidemia Hypertension Osteoarthritis	Dyslipidemia Hypertension Depression

* 3 caregivers identified by sites were missing in the most recent 2022-Q2 CPCSSN data extraction

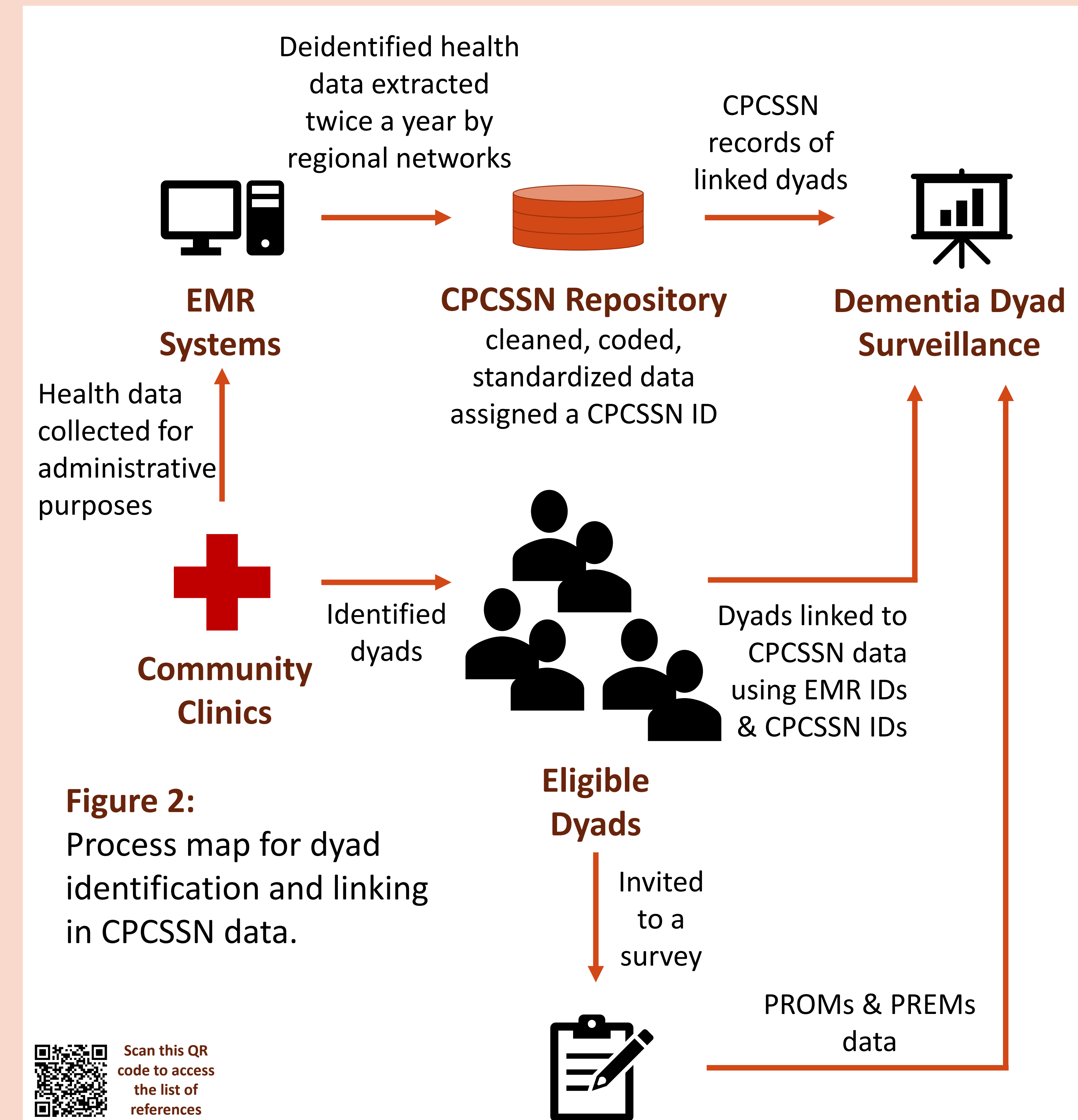


Figure 2:

Process map for dyad identification and linking in CPCSSN data.



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