Learning health systems supporting primary care

LESSONS LEARNED AND OPPORTUNITIES

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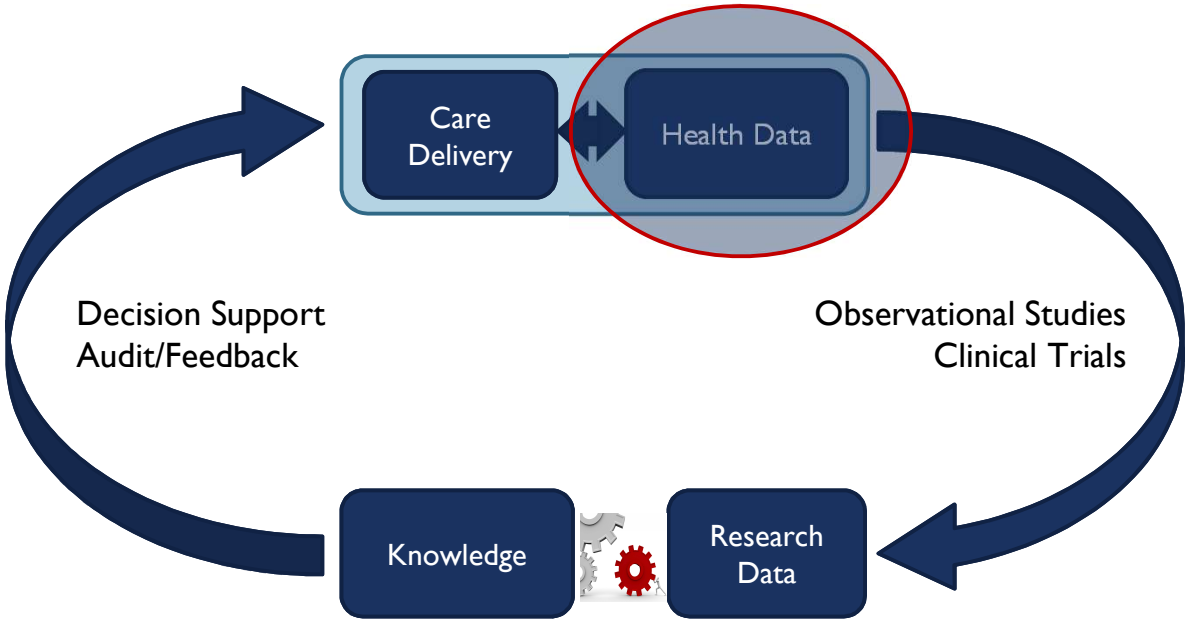
Overview

- LHS: vision and challenges
- LHS: requirements to support primary care
- A first proof of concept in Europe:
  - The TRANSFoRm project
- Deployment of a platform in Quebec
  - … and beyond

LHS: VISION AND CHALLENGES

LHS


Care Delivery
Health Data
Decision Support
Audit/Feedback
Observational Studies
Clinical Trials
Knowledge
Research Data

Health data challenge : Fragmentation

- **Clinical**
  - **Clinics**
  - Hospitals
  - Health Ministry
  - Health agency
- **Personal information (Quantified self)**
  - Fitbit
  - Smart phone
  - Home automation (e.g.: thermostat)
  - Twitter
- **Research**
  - Cohort
  - RCT
  - Biobank
  - Excel spreadsheets

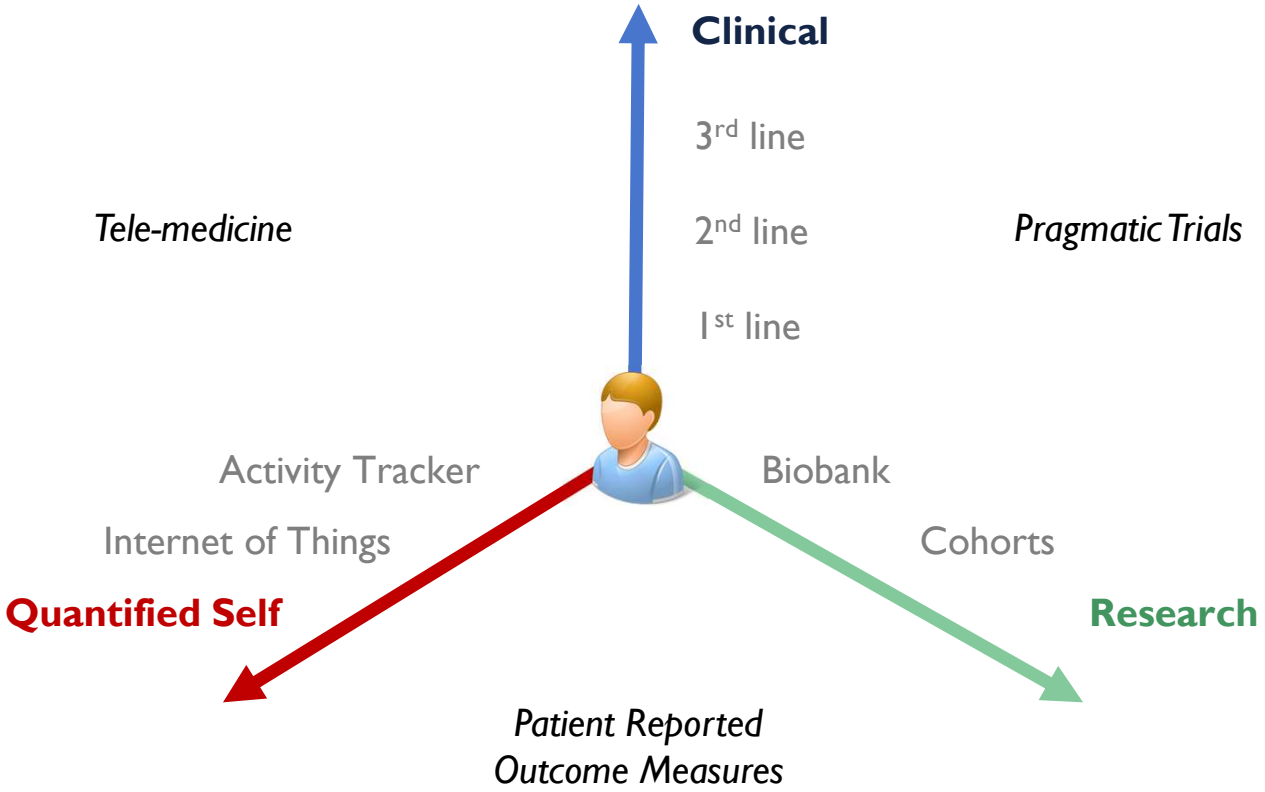
Quantified self: SCI FI?

- A physician and a bracelet: together for the win
  - September 2016


Interrogation of Patient Smartphone Activity Tracker to Assist Arrhythmia Management

Joshua Rudner, DO, Carol McDougall, MSN, APN-C, Vivek Sailam, MD, Monika Smith, DO, Alfred Sacchetti, MD

Individual centered view



Paradigm Shift

- **Present**: focus on data warehousing – organisation centered

- But…
  - Not all information will ever live in the same organisation
  - Nor in the same system

- **Future**: Distributed systems – **individual centered**
  - Better understanding of each individual
  - Collaboration (provincial, national… or even between two clinics)
  - Use data where it lives (and is kept updated)

Social contract for LHS:
3 important principles

- **Engagement**
  - patients, care givers, stakeholders, clinicians
- **Transparency**
  - Good communication about what is happening on the platform
  - Patient specific information on contribution
- **Responsibility**
  - Plan and demonstrate care improvement, ideally including PROM/PREM

Faden, R.R., et al., An Ethics Framework for a Learning Health Care System: A Departure from Traditional Research Ethics and Clinical Ethics. Hastings Center Report, 2013. 43(s1): p. S16-S27.

LHS IN PRIMARY CARE

A RICH AND COMPLEX ENVIRONMENT

Limitations to research and knowledge transfer in primary care

- **Research**
  - **RCT in primary care**
    - Few and apart
    - Not easily transferable to primary care
    - Prevalence, spectrum, demographics, comorbidities
  - Generating research hypotheses from primary care data with primary care patients
- **Knowledge transfer**
  - Conflicting guidelines
  - Audit/Feedback: gold standard?

Environment

- Multiple sites
- Different EMRs
- Small teams
- Limited resources

- Private organisations
- Different legal and administrative frameworks

- Often the first contact for new problems

- Multiple sub-populations
  - Women's health, pediatric…
  - Few disease specific clinics

Requirements in primary care
A platform must…

- **Minimise resources** needed:
  - For onboarding
  - To maintain participation
- Handle varying data **scope and granularity**
- Not be based on a predetermined set of questions
- Allow **recruitment** of patient **as they present** to the clinic with new problems
- Enable decision support with **live data**
- Be able to coordinate with other partners
  - E.g.: hospitals

TRANSFoRm

TRANSLATIONAL MEDICINE AND PATIENT SAFETY IN EUROPE

TRANSFoRm

- 2011-2016
- ~ 10 million euros from EU
- Primary care

- Observational
  - Clinico-genomic | Diabetes

- Decision support
  - Clinical | three common presenting complaints

- **RCT**
  - Clinical | Antiacid daily vs on demand
  - **4 countries**
  - **5 EMRs**
  - **3 languages**

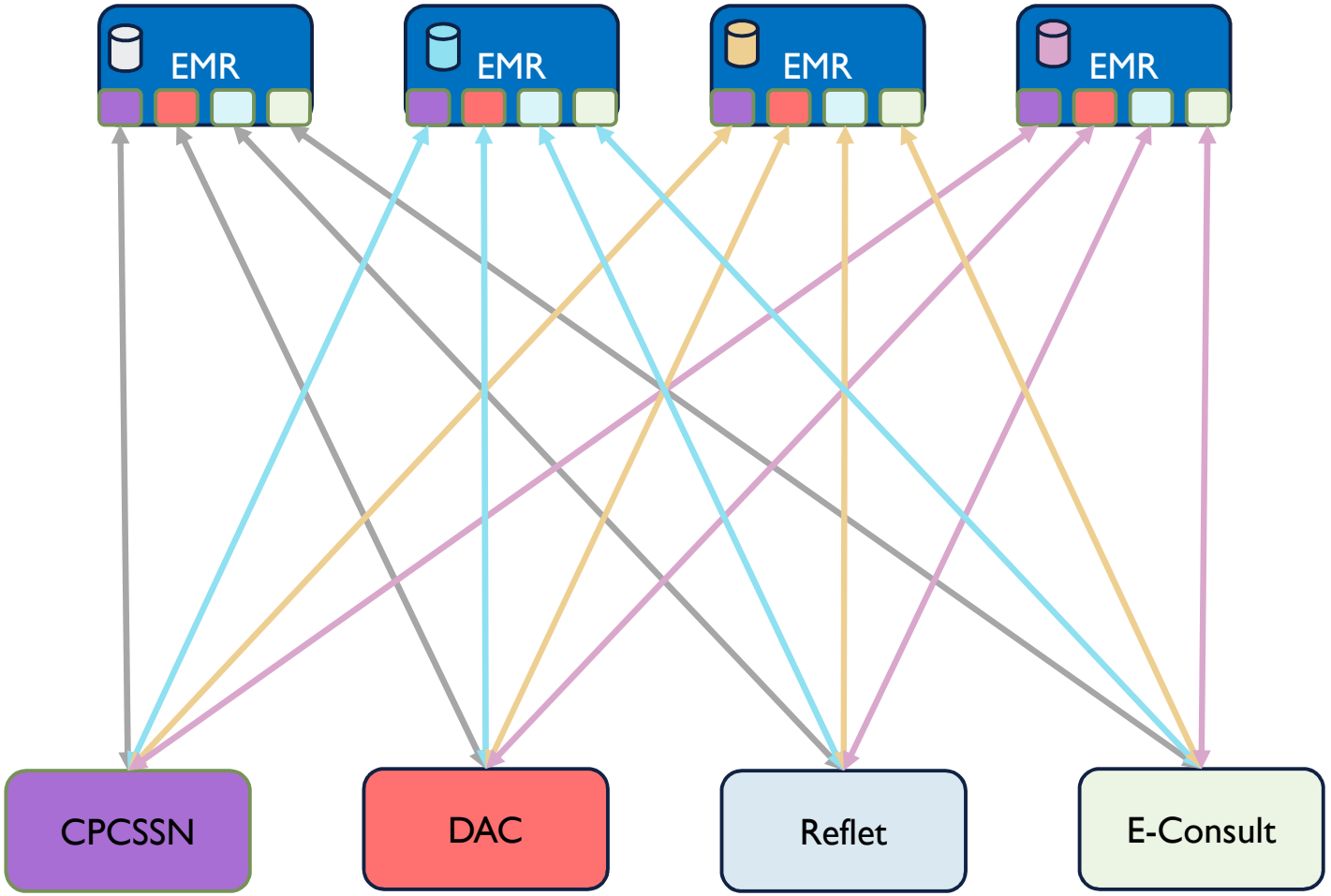
PARS^3

A LEARNING HEALTH AND SOCIAL SERVICES RESEARCH PLATFORM

Situation in Quebec
(and in many other jurisdictions I suspect)

- Many great ideas and pilot projects
  - **Rare scaling up**
- **Lack of infrastructure**
  to share the burden
- Technical problem having to be solved
  by clinicians or researchers in each project

- Main difficulty:
  - **Getting EMR to participate**
  - Associated **costs**
  - Understanding **each system**
    - Coding
    - Structure
    - Communications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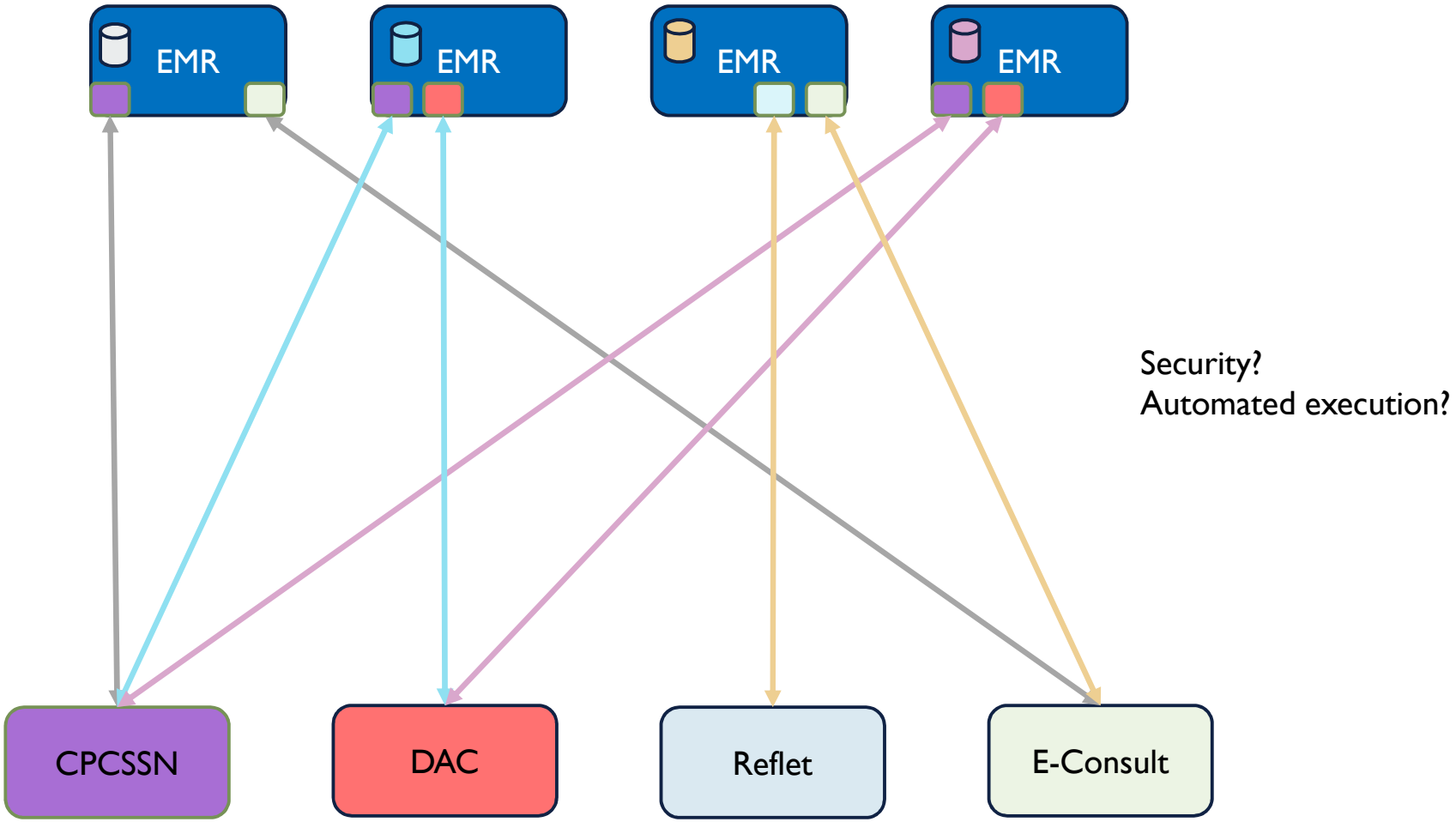
E-Consult



Security?
Automated execution?

PARS^3

- **LHS backbone** in Quebec to form a **strong, shared** and **flexible infrastructure**

- Project of the Quebec SPOR Support Unit

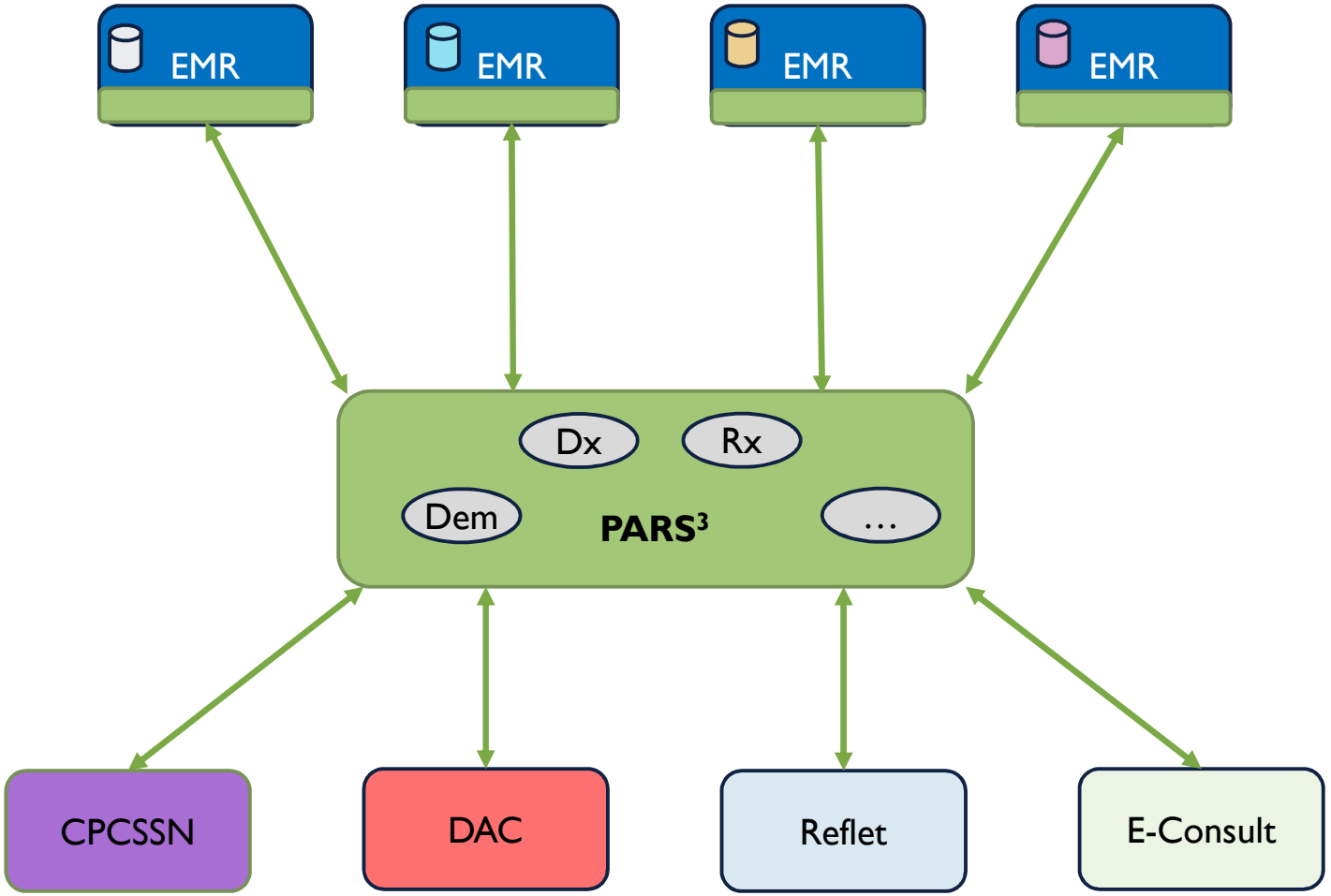
- Partnerships
  - Quebec **Health Ministry**
  - INESSS (health technology and processes assessments)
  - Réseau-1 Québec **(PBRNs)**
  - Diabetes Action Canada (**SPOR network**)
  - …

Vision
Build an **ecosystem** implementing:

- Strong **security** features
- **Automated** execution
- **Transparency**
  - Both for application code and activities
- **Engagement**
  - Patient portal (information and consent)
- Strong **collaboration** with other sectors or organisations
- Support of
  - **Care delivery**
    - E-consult
  - **Research**
    - RCT | Observational
    - Present forms to capture new data
  - **Knowledge transfer**
    - Audit/feedback
    - Decision support

Platform Principles

- Project based
  - **Nothing moves before** a project workflow is fully **signed by each party**
- **Minimal data extraction**
  - Patient identification without moving data
    - Feasibility
- Research standards compliant (CDISC)
- **Minimal knowledge of technical details** of source required
  - Exposed model about domain, not technology
  - Data returned in same format
- **Open entry**
  - Not centralised
  - No single point of control
  - Choice of components for each project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IN SUMMARY

Future

- **LHS in primary care**
  - Rich, complex, fragmented environment
  - Limited resources
  - **Essential to realise the full vision** of a LHS
- Current limitations
  - **Access to EMR**
- **PARS^3**
  - Deployment started in Quebec
  - Code is open source
  - Other aspects also addressed
    - Ethics, policy…
  - More than happy to **collaborate for deployments outside of Quebec**

Thank you very much

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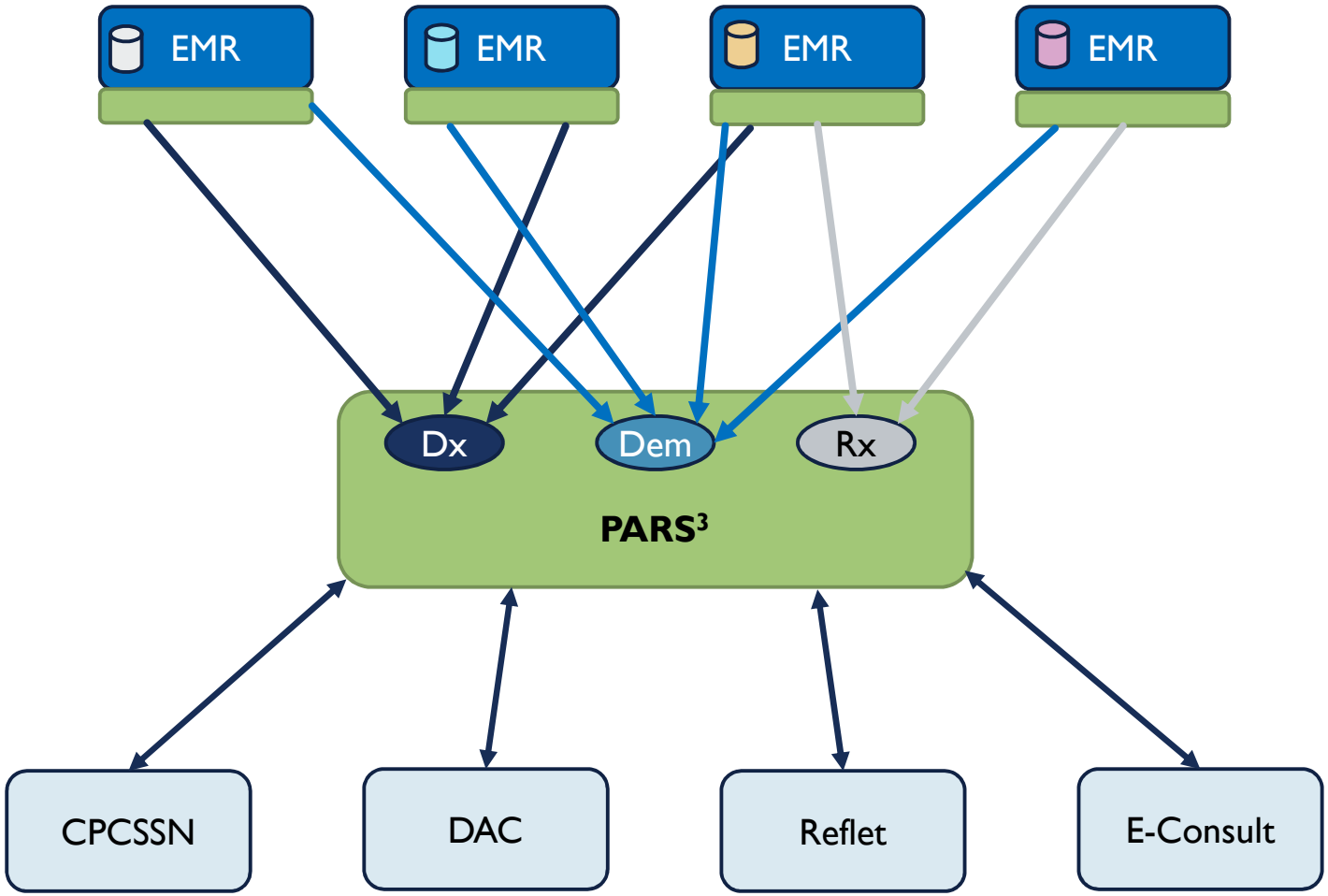
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