

# Canadian Heart Function Alliance

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[www.chfalliance.ca](http://www.chfalliance.ca)



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# Conflicts of Interest

- ▶ DMC: Novartis, Bayer, AstraZeneca, BMS.



# CHF Alliance funding partners



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# CHF Alliance in kind funding & Collaborators



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# One network, one joint mission



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# Infrastructure of the Alliance

9

Provinces

1

Territory

30

Hospital  
centers

**>190** Participants  
**>30** Early career investigators  
**>40** Patient/caregiver partners  
**>20** Indigenous partners  
**5** Platforms  
**>35** Partners



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# A patient-driven initiative

Spanning the lifecycle of patients from children to elderly, from rural to urban, across geographic and socio-economic barriers.

## Patient Priorities

- Receipt of rapid & accurate diagnosis
- Improving access to & equity of care
- Self-management & empowerment
- Improving access to reliable information
- Lifestyle issues, mental health, sex & exercise
- Virtual care & innovative interventions



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**The CHF Alliance is *patient-driven*, spanning the lifecycle of patients from children to elderly, from rural to urban, & across geographic and socio-economic barriers.**

**The Patient Engagement & Empowerment Platform was founded on patient-driven priorities & developed in partnership with those with lived experience of HF**

## Survey of Patient Priorities:

- ✓ Receipt of rapid & accurate diagnosis
- ✓ Improving access to & equity of care
- ✓ Self-management & empowerment
- ✓ Improving access to reliable information
- ✓ Lifestyle issues, mental health, sex & exercise
- ✓ Virtual care & innovative interventions

*Adapting to a new normal was difficult at my age. We had to change our lifestyle completely and we didn't know anyone with heart failure. Who else could we talk to?*



*My sister, 18 years old, had significant HF symptoms. She consulted a general practitioner and was told she probably had a virus or needed to rest.... She died of sudden death, with HF 3 weeks later!*



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# Patient Engagement & Empowerment Platform



## Overarching goal:

- ▶ Advance patient engagement in research and the empowerment of patients in HF care.

## Objectives:

- ▶ Cultivate and expand HF research co-production through the meaningful engagement of patients across all network activities;
- ▶ Advance Patient Oriented Research methods and study the impact of patient engagement and empowerment in HF research and care;
- ▶ Promote and support patient-driven research; and
- ▶ Promote Indigenous patient engagement and empowerment.



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# CHFA Building Together



## Meaningful engagement from inception of grant application

Collaborative and co-designed network, patient engagement platform, and planning

Patient partners engaged across Alliance activities and governance

Working to expand engagement and learning from other networks

Identified patient and caregivers priorities



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# Year One Priorities

## Governance

- ▶ Structure and terms of reference
- ▶ Operationalization of committees
- ▶ Building patient partner database

## Partnership supports

- ▶ Patient partnership toolkit
- ▶ Patient partnership compensation policy
- ▶ Researcher support and training
- ▶ Research and engagement coordinator

## Platform communication

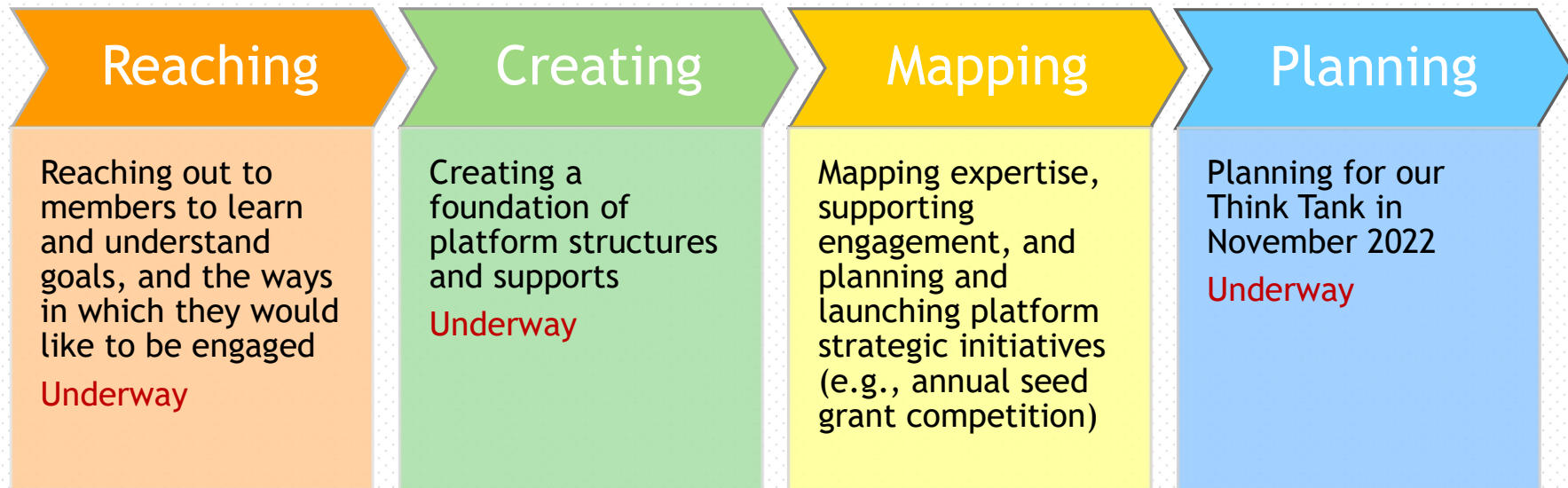
- ▶ Launch meetings and videos
- ▶ Newsletter – E-Power
- ▶ HeartLife Hub
- ▶ Foster linkages across the Alliance

## Strategic initiatives

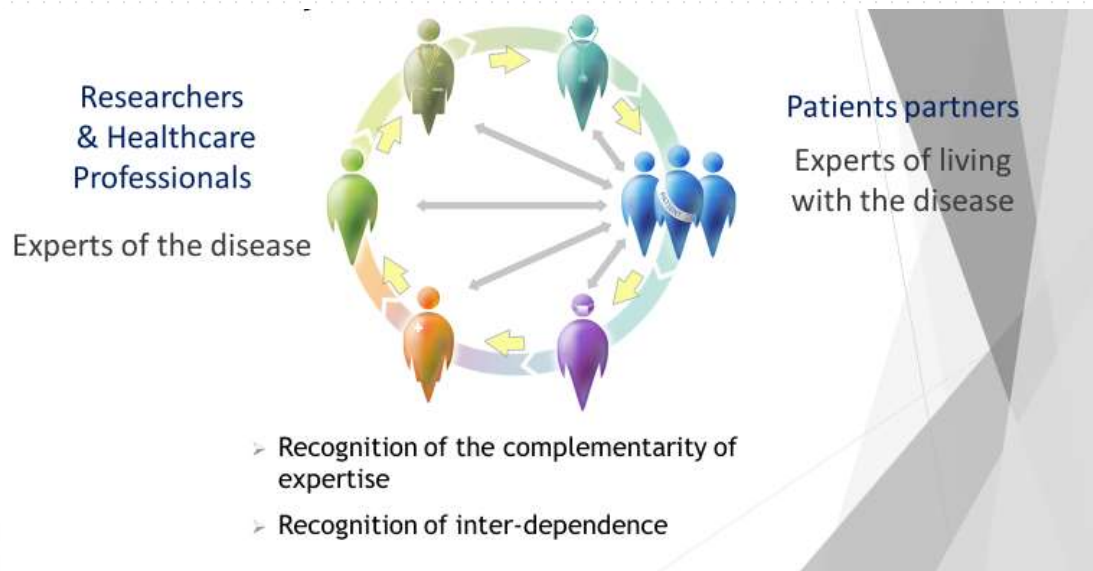
- ▶ Seed grant – Patient-driven & Patient-led research
- ▶ Evaluation of partnership inception



# Next Steps



# Getting Connected (Patients and HCPs)

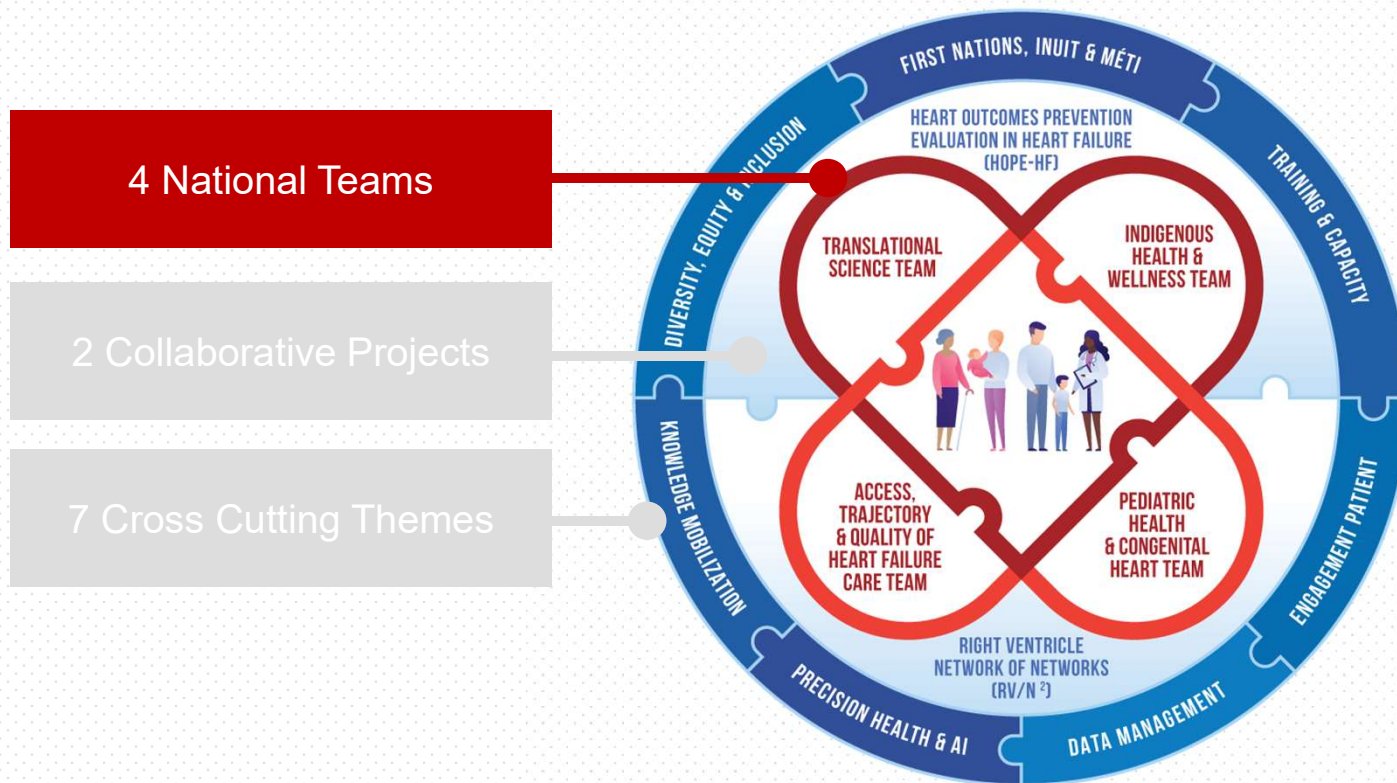


## Types of Opportunities

- ▶ Participation in governance and advisory committees
- ▶ Partnership within research programs and themes
- ▶ Partnership at individual project level
- ▶ Less structured activities (e.g., ad hoc committees, knowledge translation, or consultation activities)



# Overview of the Alliance



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# Indigenous Health & Wellness Team

Lead by Dr. Alexandra and Malcolm  
King from University of Saskatchewan

## 2 main goals :

- ▶ **Aim 1:** Develop an Indigenous People Engagement and Research Council (IPERC) for HF research
- ▶ **Aim 2:** Improve the prevention, early diagnosis, and treatment of HF in Indigenous people living in Indigenous communities (CAHBM)



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# Overview of Indigenous People Engagement

## Objective

Reconceptualize HF so it reflects Indigenous ways of knowing and being, and will work with Indigenous people to learn how to best incorporate Indigenous ways of doing in the prevention of and care for HF.

## Inclusion

Elders, Knowledge Holders and Indigenous people with lived experience, physicians, nurses, allied health professionals, researchers, and decision makers.





# Platform: HF-IPERC



## HF-IPERC: Heart Failure – Indigenous People Engagement and Research Council

- ▶ IPERC is a partnership between the Pewaseskwan Indigenous Wellness Research Group at the University of Saskatchewan (Usask), The Key First Nation, the Yorkton Tribal Council, the Cardiac Arrhythmia Network of Canada (CANet) and the CHF Alliance.
- ▶ To honour the research partnership, Pewaseskwan's co-leads were joined by members of The Key First Nation band council and members of Yorkton Tribal Council for a ceremony near St. Philips, during which they signed a letter of intent.



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# HF-IPERC

## Key Area's of Focus

- Overcoming anti-oppression and anti-racism in health care
- Cultural safety, ethical engagement and allyship
- Historical and contemporary forces resulting in Indigenous health inequities
- Indigenous land and culture based experiential learning opportunities
- Curriculum for Indigenous peoples with lived experience of HF



## Meaningful Engagement

- Guiding circle for the Network
- Overseeing the provision of an Indigenous curriculum for Network members
- Collaboration in Proposal Development
- Overseeing the development of Indigenous data sovereignty guidelines



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# The Projects

## Project 1

**Objective:** Conduct a qualitative study of the « heart failure journey » among Indigenous Communities.

## Project 2

**Objective:** Improve access to care for patients diagnosed with HF/LV dysfunction by adapting of the CANet VIRTUES and HOPE-HF trial program to a culturally safe and responsive model for Indigenous populations.



# Pediatric & Congenital Health Team

Co-lead by Dr. Seema Mital  
and Dr. Aamir Jeewa from SickKids

## 3 main goals :

- ▶ **Aim 1:** Develop and validate an AI-based model to diagnose Diastolic HF in childhood
- ▶ **Aim 2:** Implement Remote Physical Monitoring to assess feasibility & utility in childhood CMP
- ▶ **Aim 3:** iPeer2Peer Program to improve self-management in adolescent and transitioning patient



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# An AI approach for Diastolic HF

Lead: Dr. Seema Mital

**Population:** Expansion of the Ontario-wide Heart Centre Biobank registry for CMP families (over 10,000 participants with DNA, blood and myocardial cohort) to include pediatric and young adult patients with hypertrophic, restrictive, dilated, left ventricular non-compaction, and arrhythmogenic CMP, from across Canada.

**Methodology:** Apply AI approaches to clinical, biological, physiological and lifestyle data in order to diagnose and predict diastolic HF and clinical outcomes in CMP and assess response to therapy.

**Status:** Ongoing



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# Remote physiological monitoring in HF

Lead: Dr. Jennifer Conway

**Population:** 100 eligible CMP patients younger than 18 years.

**Methodology:** Multi-center pilot clinical trial to assess the feasibility of implementing wearable technology for remote physiological monitoring.

Validation of a Bluetooth-enabled smart textile that can collect and trend physiological parameters in children.

**Partners:** Myant (smart textile) and mmHg Inc. (data visualization platform).

**Status:** Protocol under development.



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# IPeer2Peer Program

Lead: Dr. Samantha Anthony

**Population:** Adolescents and transitioning patients

**Methodology:** Multisite study that matched trained peer mentors with mentees.

Mentors and mentees will connect virtually to provide peer support and promote self-management skills.

**Status:** REB approved at SickKids.



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# Translational Science Team

Leads: Dr. Philip Joseph and Eileen  
O'Meara from ICM

## 3 main areas :

- ▶ **Area 1:** HF phenotypes
- ▶ **Area 2:** Inflammation in HF
- ▶ **Area 3:** Ageing, comorbidity, and HF



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# Objectives for Translational Science and AI/Digital Health Theme

- ▶ Improving our understanding of HF
  - Underlying causes
  - Social determinants
  - Pathophysiology
  - Prevention
  - Detection
- ▶ Through a National Network, including participants at all levels, patients, technical and scientific experts to create new knowledge and make its implementation possible
- ▶ Create new models of care in HF



# Support for innovative RCTs

- ▶ **MAPLE-CHF**: a study to improve early HF diagnosis,
- ▶ **iPeer2Peer program** to improve self management in adolescent and transitioning patients,
- ▶ **Implementation of remote physiological monitoring** using smart textile in children with cardiomyopathy,
- ▶ **COLT-HF** trial evaluating the effects of colchicine and thiamine in HF,
- ▶ **COLpEF** trial evaluating the impact of colchicine on microcirculation and biomarkers in HFpEF
- ▶ **BRAVE** study to evaluate the impact of bariatric surgery in obese patients on CV risk and outcomes,
- ▶ **CAPITAL DOREMI2** trial to evaluate inotropes in cardiogenic shock,
- ▶ **STICH 3** Trial to compare PCI to CABG in patients with LVEF $\leq$ 40%,
- ▶ **CRAVE RCT** Canadian RV failure adaptive randomized control trials group
- ▶ **PHARM-HF** Pharmacist-led uptitration to GDMT



# Translational Science and AI

## **CLSA, *Canadian Longitudinal Study on Aging***

Collaboration with Dr. P. Raina - PHRI

50000 participants, 45-85 y.o.

- More than 30000 in person F/U q 3 years
- Complete characterisation, including environment, socioeconomic, biomarkers, imaging, GWAS, metabolomics (in process), proteomics (to begin), complete exome sequencing (in planning stage), etc...

CHFA's help:

To add echocardiograms to contribute to the dx of HF by training non-echocardiographers to obtain imaging and echo reports through AI.



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# Translational Science and AI

## CAHMM, *Canadian Alliance for Healthy Hearts and Minds*

Collaboration with Dr. S. Anand - PHRI

10,000 participants, including 1,300 Indigenous participants

- Complete characterisation, including head and chest MRI (8,500) GWAS (being completed), multiplex biomarker panel (partial), ?complete exome sequencing, re-imaging

CHFA's help:

General: To complete the GWAS (complete exome sequencing) and biomarker panel, and repeat MRI in selected patient groups and possibly early diagnosis of HF.

Indigenous: Support the co-development of Indigenous co-identified priority projects, including identification of high-risk individuals for HF, improving the health of pregnant Indigenous women, improved access to care, and the patient journey of an Indigenous person living with HF in a remote community.



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# Canadian Cardiomyopathy Collaborative

## Collaboration with Dr. A Krahn (UBC), (HeartShare)

Ontario province-wide Heart Centre biobank of >10,000 families including ~500 families with cardiomyopathy who have provided data and biological samples

Precision Medicine in Cardiomyopathy (PRIMaCY) international registry of 20 centres (4 Canadian, 15 US, and 1 Australian) which includes >2,000 childhood patients with HCM.

Hearts in Rhythm Organization (HiRO) registry and biobank which includes over 5,700 participants with unexplained cardiac arrest, arrhythmogenic cardiomyopathy, and cardiac channelopathies and over 2,500 biobank samples collected from 21 HiRO participating centers coast-to-coast across Canada.(partial)

### CHFA's help:

To provide the infrastructure to create data linkages across complementary datasets (clinical, biological, environmental, physiological) in cardiomyopathy patients across Canada available through CHFA, PRIMaCY, HiRO, others, and eventually, HeartShare.



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# Characterisation of HF and AI recognition of specific types of HF

Dr. **Seema Mital and coll.** SickKids and UHN:  
Creation of a cardiomyopathy and congenital  
heart disease databases, **from children to  
elderly characterisation**

**Current discussion to include several centers  
in Canada**

Drs. **Marie-A. Chaix and Duncan Stewart:** The  
RV in Congenital and non-congenital heart  
disease

Collaboration with **HeartShare** – Deep  
phenotyping of HFpEF – **Dr. Sanjiv Shah and  
NHLBI**



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# Improving Access & Quality of the HF journey Team

Lead by Dr. Sean Virani from  
Providence Health Care, Cardiac  
Services, BC

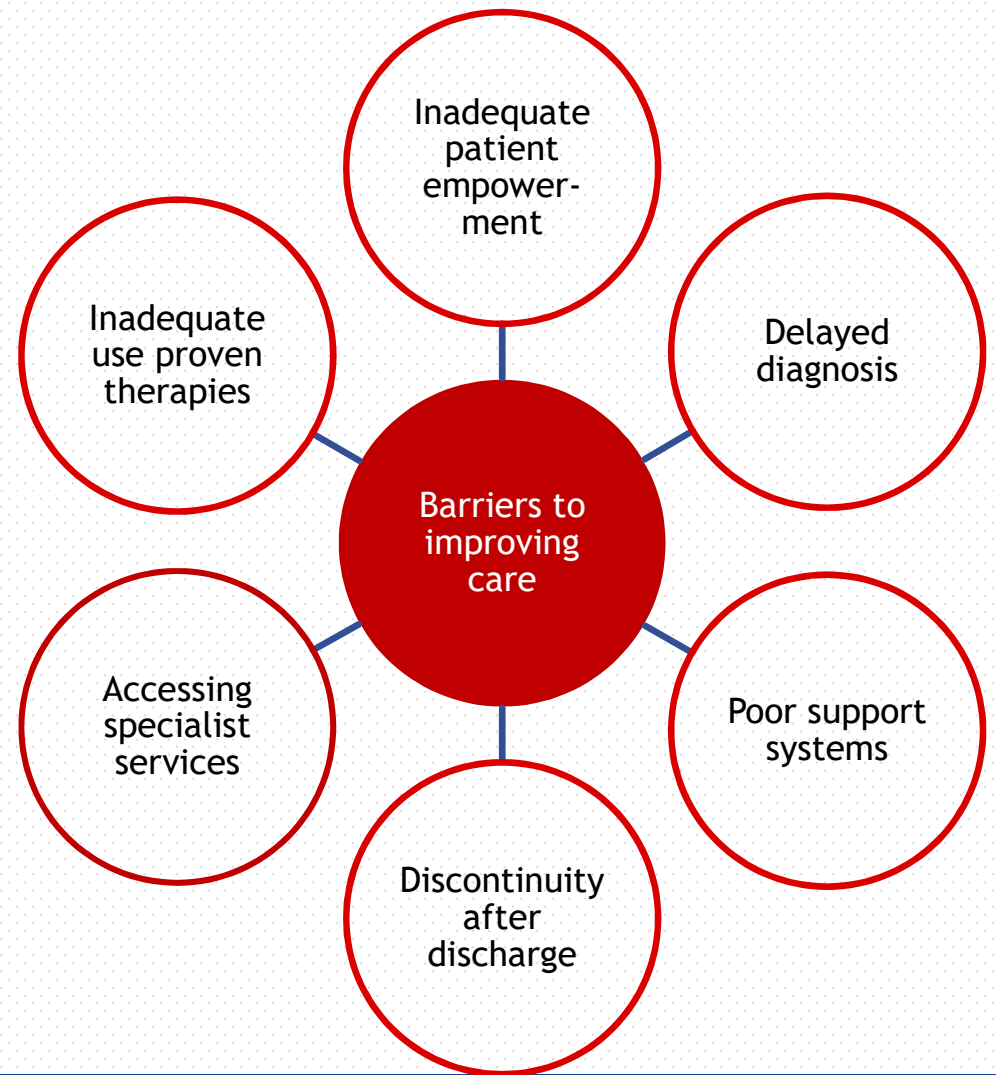
## 3 main goals :

- ▶ **Aim 1:** Patient Empowerment to improve care in HF
- ▶ **Aim 2:** Improving early diagnosis and prevention of HF in primary care
- ▶ **Aim 3:** Improving access to data to better inform and integrate patients, caregivers (primary care and HF teams) and decision makers: VIRTUES-HF/WeITel



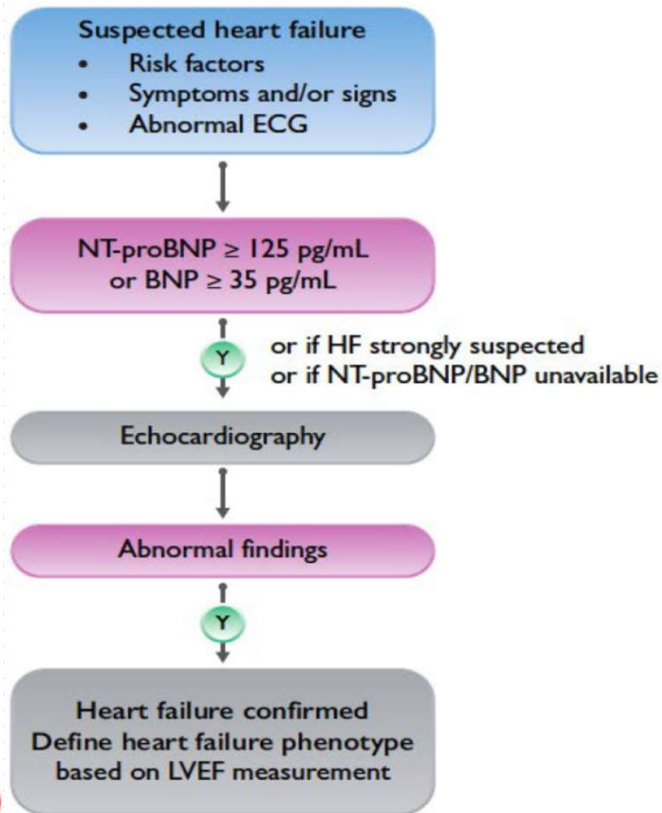
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# Barriers to Improving Care





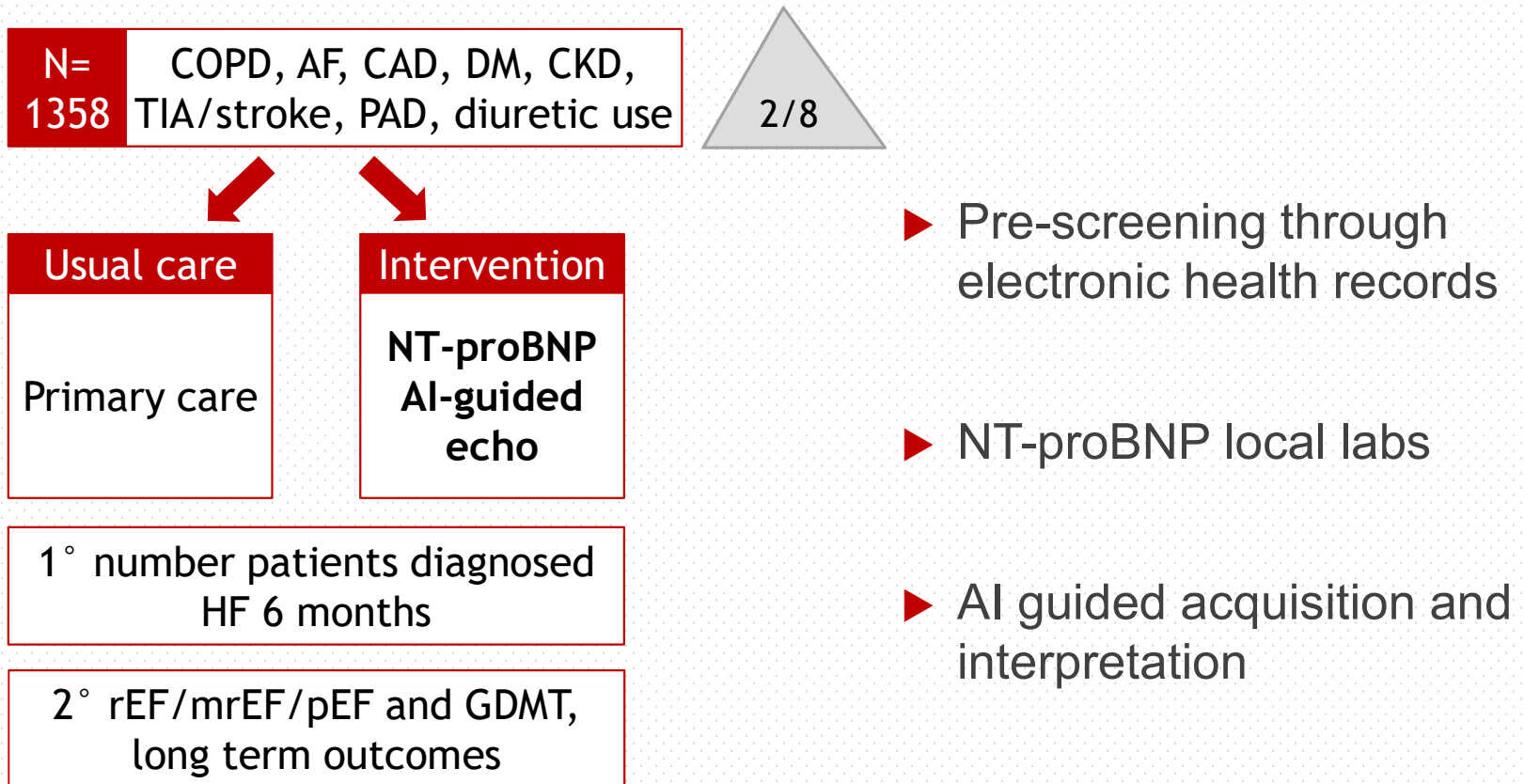
# Improving early diagnosis and prevention of HF in Primary care



- ▶ MAPLE-CHF Canadian arm in SYMPHONY global program
- ▶ 5 countries: Canada, Denmark, Scotland, Sweden, US
- ▶ Each country screening strategy aligned with ESC diagnostic algorithm



# Multidisciplinary Approach for high-risk Patients Leading to Early diagnosis in Canadians with Heart Failure (MAPLE-CHF)



# Pharmacists' role in HF management: Evidence & Canadian perspective

- ▶ Multiple high-quality RCTs: Having a pharmacist on the team caring for patients with HF improves outcomes (including ↓ death/hospitalization)
  - ▶ Pharmacists delivering now-standard care as part of universal scope of practice
- ▶ Pharmacists are core members of specialized ambulatory HF clinics
  - ▶ Yet most Canadian HF clinics don't have a pharmacist at all
- ▶ **Could pharmacists do more if they prescribed?**
  - ▶ In HF, evidence limited to single-center observational studies
  - ▶ RCTs in several other disease states (CKD, diabetes, dyslipidemia, HTN, smoking cessation) – primarily with AB Additional Prescribing Authorization model – show improved outcomes



CJC 2017;33:1342-433 CJC Open 2020;2:151-60 Arch Intern Med 2008;168:687-94 J Card Fail 2013;19(5):354-69 JAHA 2014;3:e000718  
JACCP 2021;4:862-70 RxACTION. Circulation 2015;132:93-100 Rx EACH. JACC 2016;67:2846-54 RxACT. Can Pharm J 2016;149:283-92

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## Next step: PHARM Optimal-HF pilot trial

**n=60** HFrEF, current NYHA 1-3, not on target-dose ARNI-based GDMT, initial HFC visit

### Usual care


Multidisciplinary HFC care, standard of care clinical pharmacy services (intake appointment only)

### Intervention

Usual care +  
Referral to PHARM-HF clinic for medication optimization

**1° Feasibility** (recruitment, intervention adherence, PROM completion, retention)

**2° Modified “OMT” score, PROMs** (QoL, adherence, treatment burden & satisfaction)

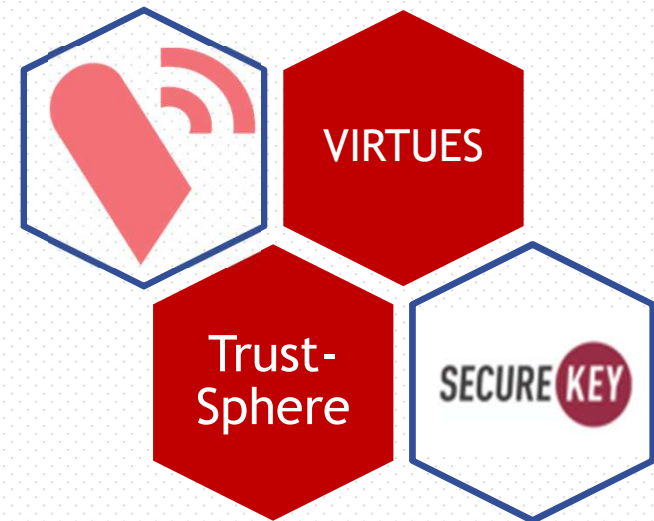
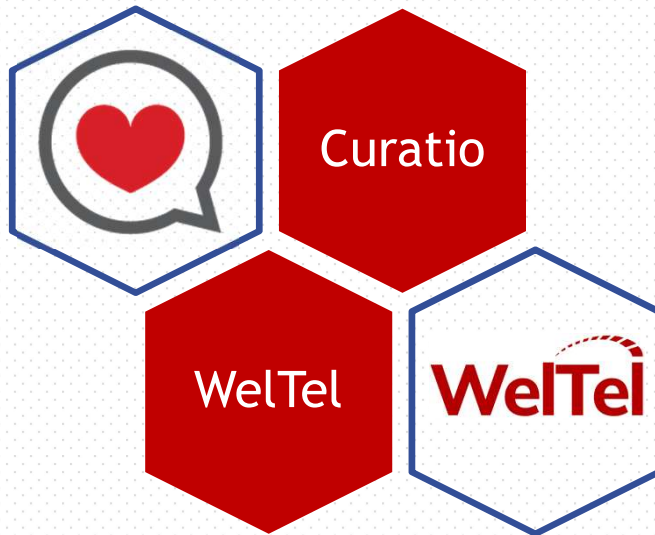
- ▶ Consented in clinic or virtually
- ▶ Follow-up
  - ▶ At months 3, 6, 12
  - ▶ Entirely remote (phone/electronic PROM questionnaires + routinely-collected data from EMR)
- ▶ Pilot funded by  Canadian Foundation for Pharmacy
- ▶ 6 participants recruited (2/week)

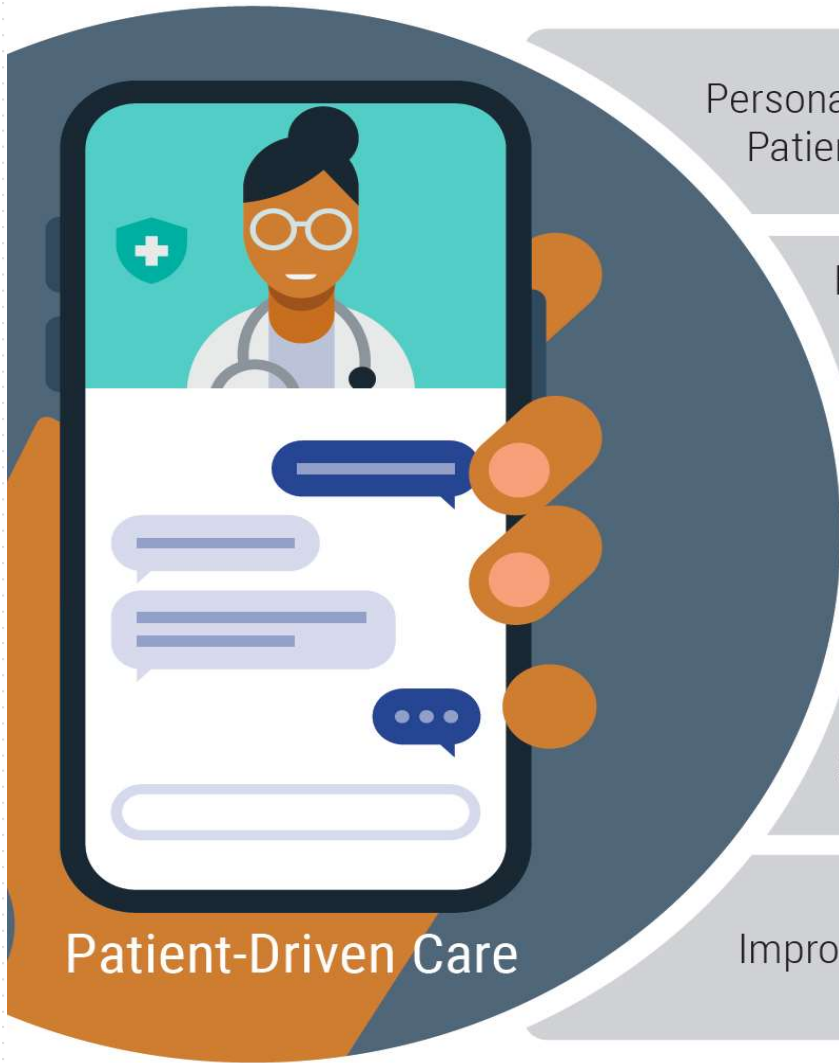
<https://clinicaltrials.gov/ct2/show/NCT05623358>

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# Improving access to data to better inform patients, caregivers and decision makers





Personalized  
Patient Education



Personalized  
Management  
Recommendation



Reduced Cost to Patient  
and Health System



Improve Access to  
Specialist-Directed Care



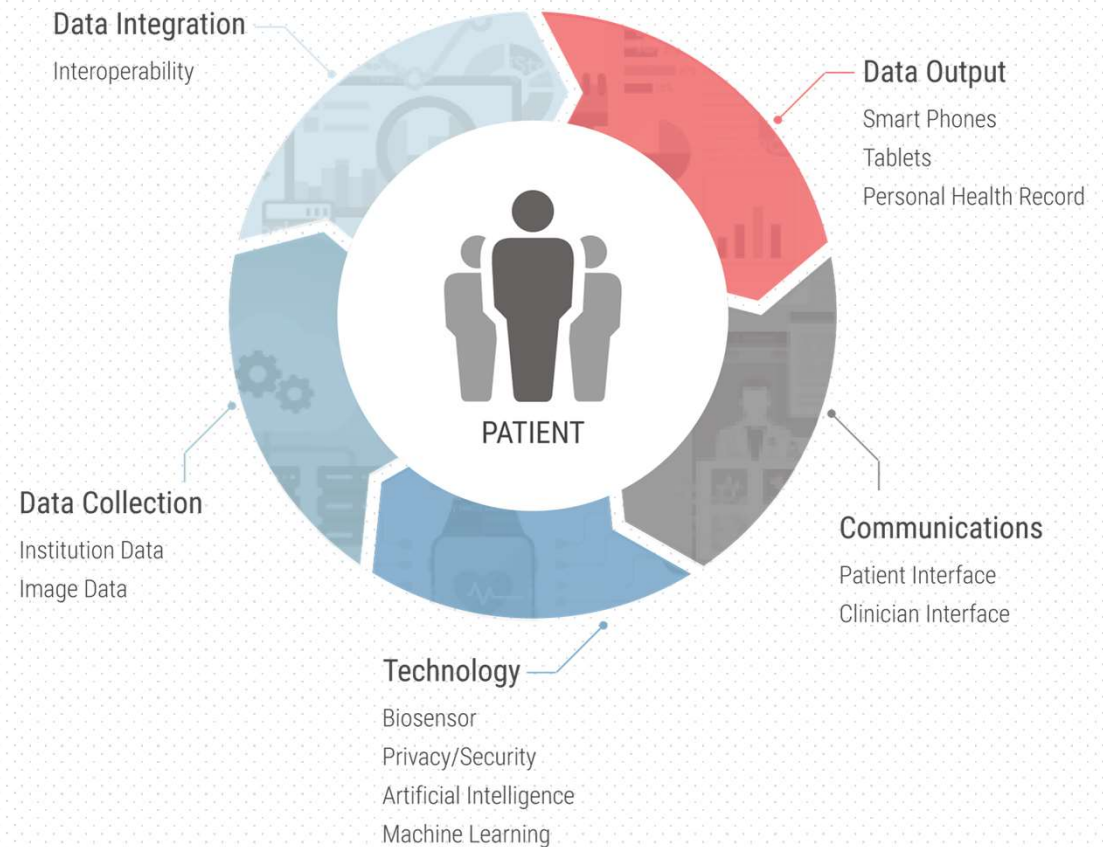
Improve Efficiency of Care



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# VIRTUES (Virtual Integrated Reliable Transformative User-Driven E-health System)

- ▶ Cloud-based virtual healthcare data and disease management platform
- ▶ Assembles, integrates and interprets personal health data for patients and caregivers to give guideline driven expert recommendations



# Clinical care management module development pathway

- ▶ Assemble and integration of Practice Guidelines – CCS/AHA/ACC/ESC
- ▶ Develop decision tree logic map based on practice guidelines
- ▶ Review the decision tree logic map with clinical experts
- ▶ Coding and app development according to the logic map
- ▶ Assemble clinical case scenarios relevant for the care module
- ▶ Compare the decision outcome from the algorithm vs. a panel of expert decision
- ▶ Employ the module to a group patients
- ▶ Usability and patient experience are being collected through surveys, focus group interviews, as well as via direct monitoring of patient use





# Patient education materials development

- ▶ Determining Number of Items to be Generate
- ▶ Background Research on Items and Creating Learning Point
- ▶ Expert Review (Clinicians and Patients)
- ▶ Content Creation
- ▶ Review of Final Content by Experts and Patient
- ▶ Integration into VIRTUES



# VIRTUES-MI To VIRTUES-HF

**My Profile**

KYEY Study ID 002-020  
DOB: October, 1958

My Record >

Medical contact information >

Feedback

Notification settings

Change password

App features

Sign out

Resources My Targets Reminders My Profile

**My Targets Settings**

- Ejection Fraction ?
- Beta Blocker ?
- Ras Blocker ?
- Smoking Cessation ?
- Resuscitation Education Attend... ?
- Cardiologist Visit ?
- Cardiac Rehabilitation ?
- Defibrillator Referral ?

Save changes

**My Targets**

- Ejection Fraction**  
26% • 03/09/18  
35 days until next EF assessment due
- Beta Blocker**  
Bisoprolol (Zebeta Monacor) 1.25 mg once a day
- Ras Blocker**  
Ramipril (Altace) 5 mg twice a day
- Cardiologist Visit**  
Pending • 12/14/18

Resources My Targets Reminders My Profile

**REDUCED** Ejection Fraction

Percent of blood pumped out

- ≤ 40%
- ≈ 41-49%
- ≈ 50-70%

**Ejection Fraction Measurement and Heart Failure**

Published by: American Heart Association

Short YouTube video from American Heart Association:  
<https://youtu.be/qS4jHMppRms>

Mark as read

Was this information helpful?

👍 👎



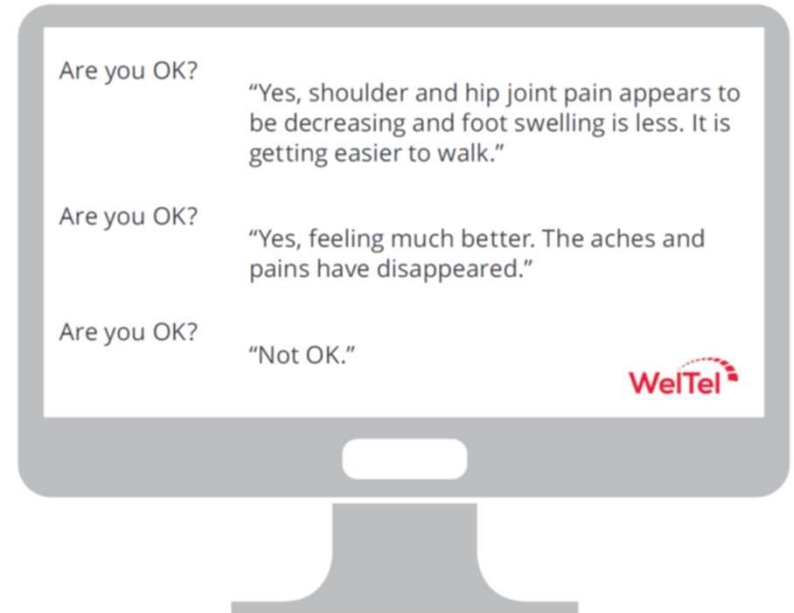
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# WelTel

- ▶ interactive two-way short message service (SMS), content sharing, voice and video outreach
- ▶ scheduled and automated, open, natural language messages
- ▶ Used and integrated in BC Children's Hospital
- ▶ Remote services in Haida Gwaii

## BI-DIRECTIONAL COMMUNICATION

Patients choose how they respond to weekly SMS



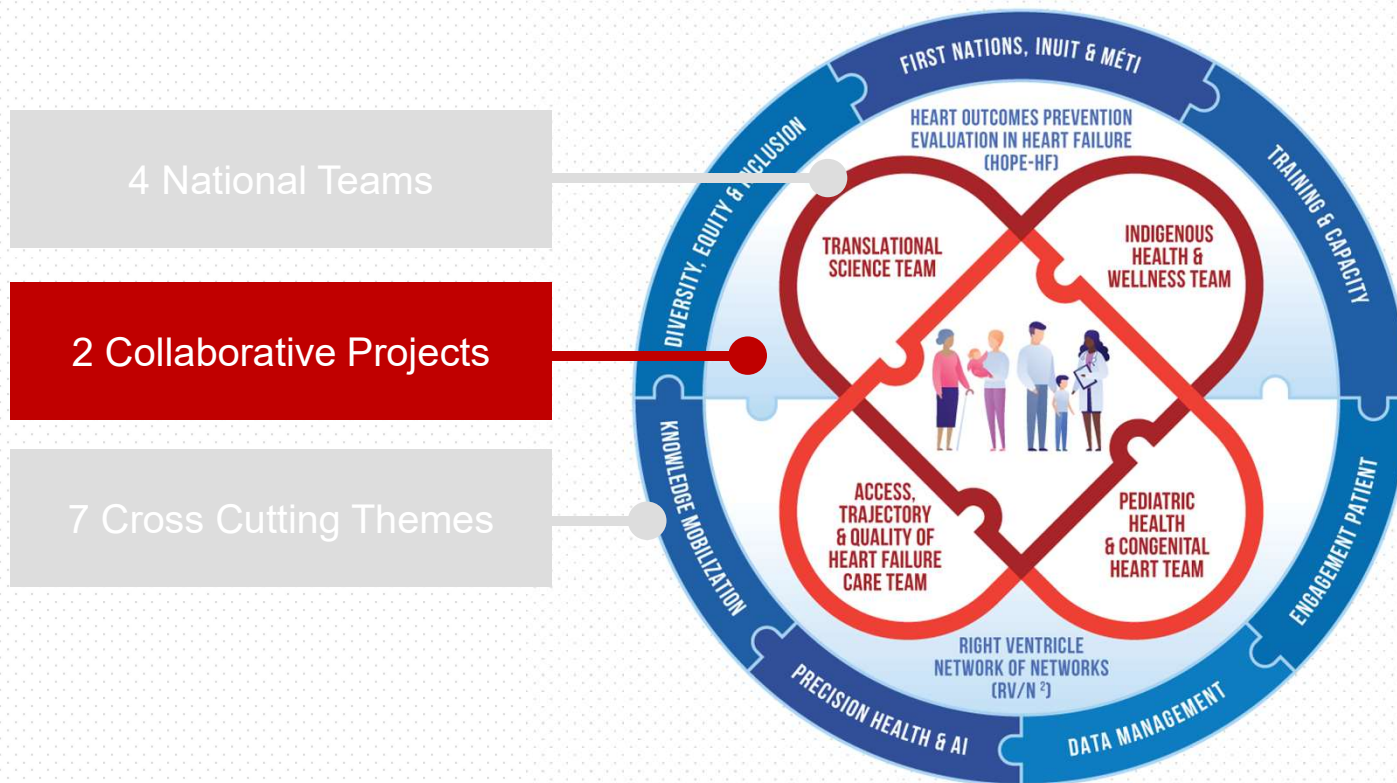
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# WelTel pilot

- ▶ Population
  - ▶ HF any LVEF
  - ▶ remote and local patients
  - ▶ attending HF clinic network
  - ▶ possibly recent HF hospitalization
- ▶ Randomization
  - ▶ individual patient
- ▶ Intervention SMS
  - ▶ feedback and education
  - ▶ dynamic frequency
- ▶ Endpoints
  - ▶ self-care
  - ▶ quality of life
  - ▶ patient empowerment
  - ▶ adherence
  - ▶ utility/economic

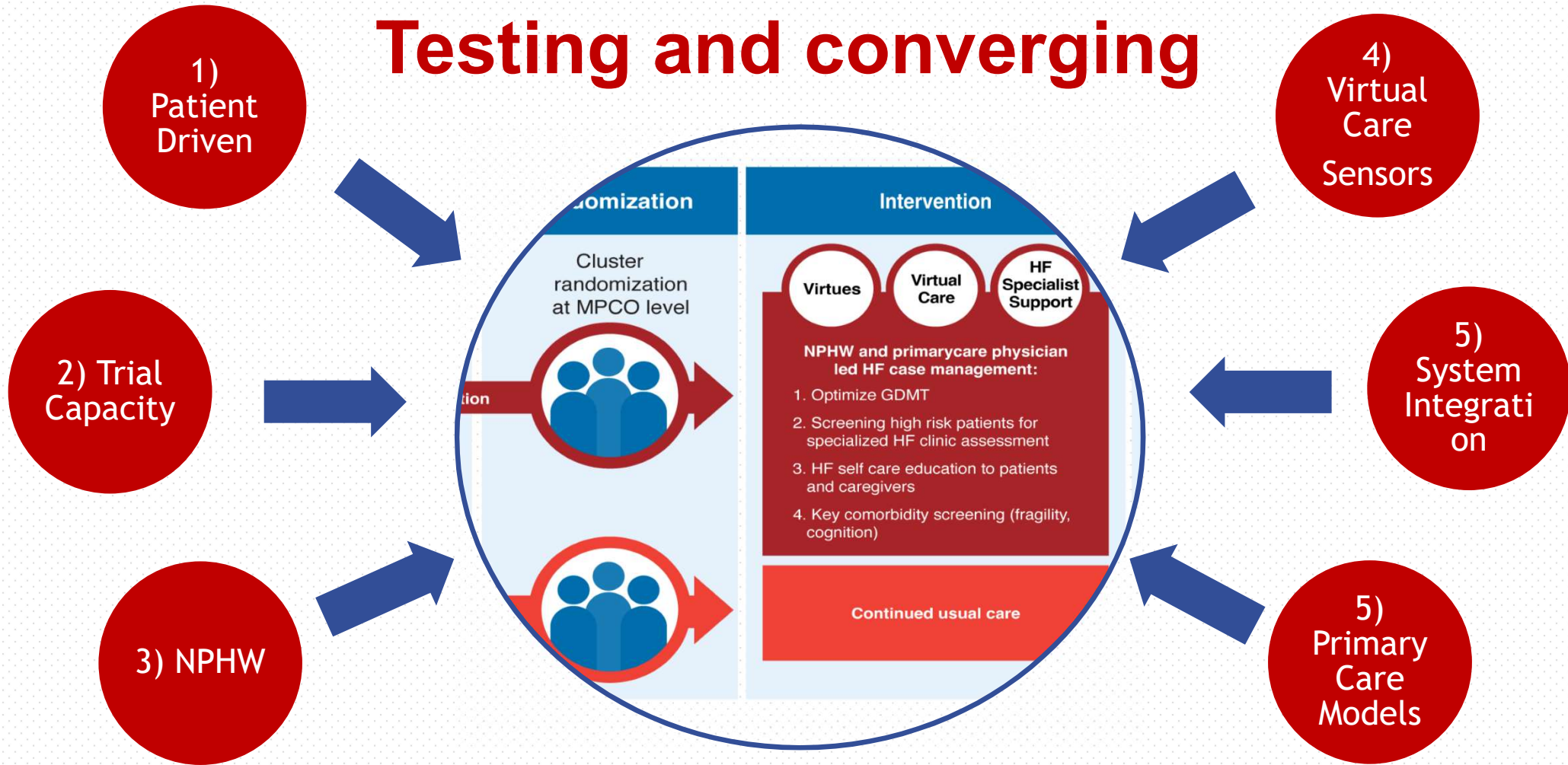


# Overview of the Alliance

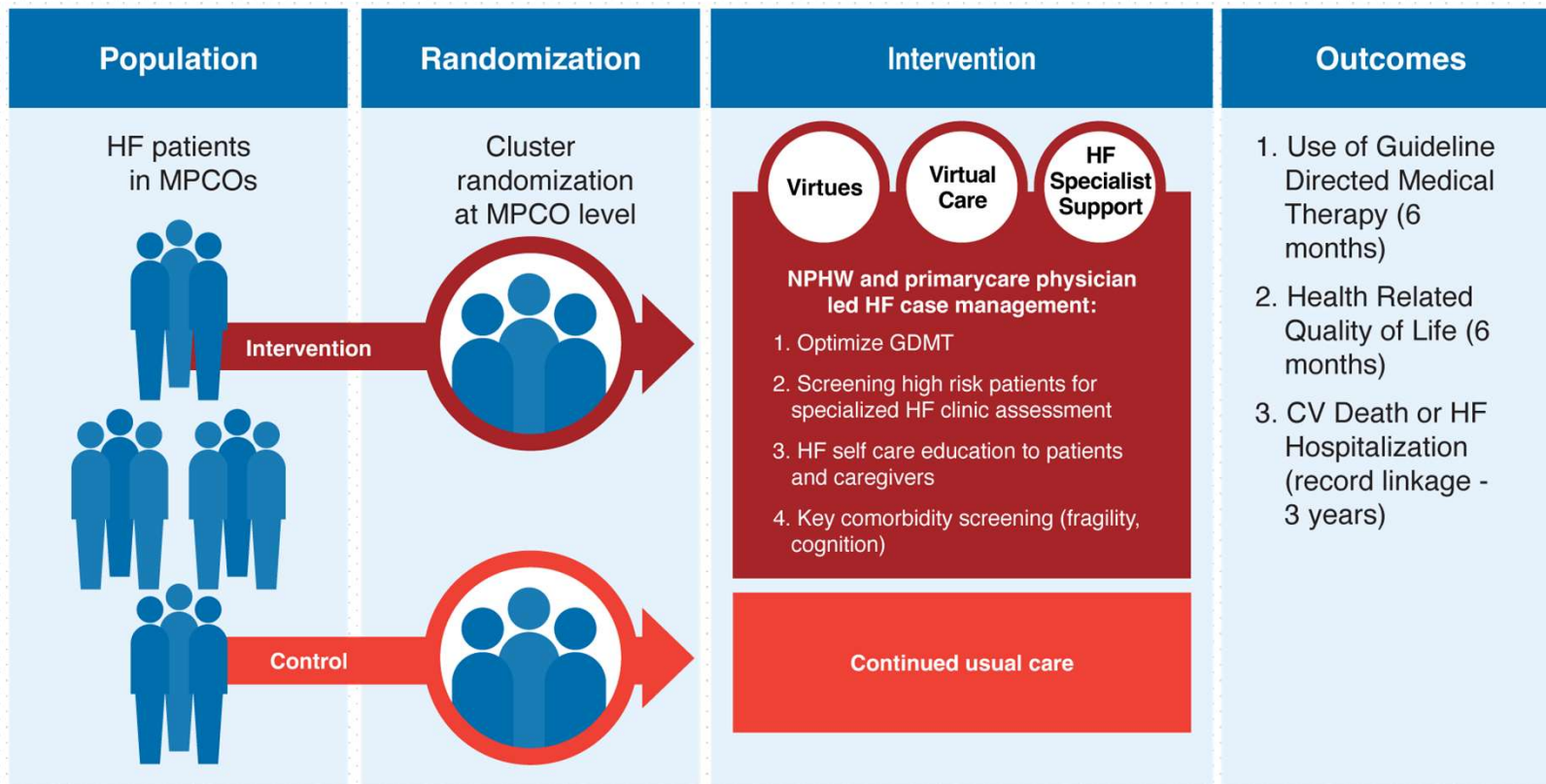


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# Testing and converging



# HOPE-HF



MPCO: Multidisciplinary Primary Care Organization; NPHW: Non-Physician Health Workers



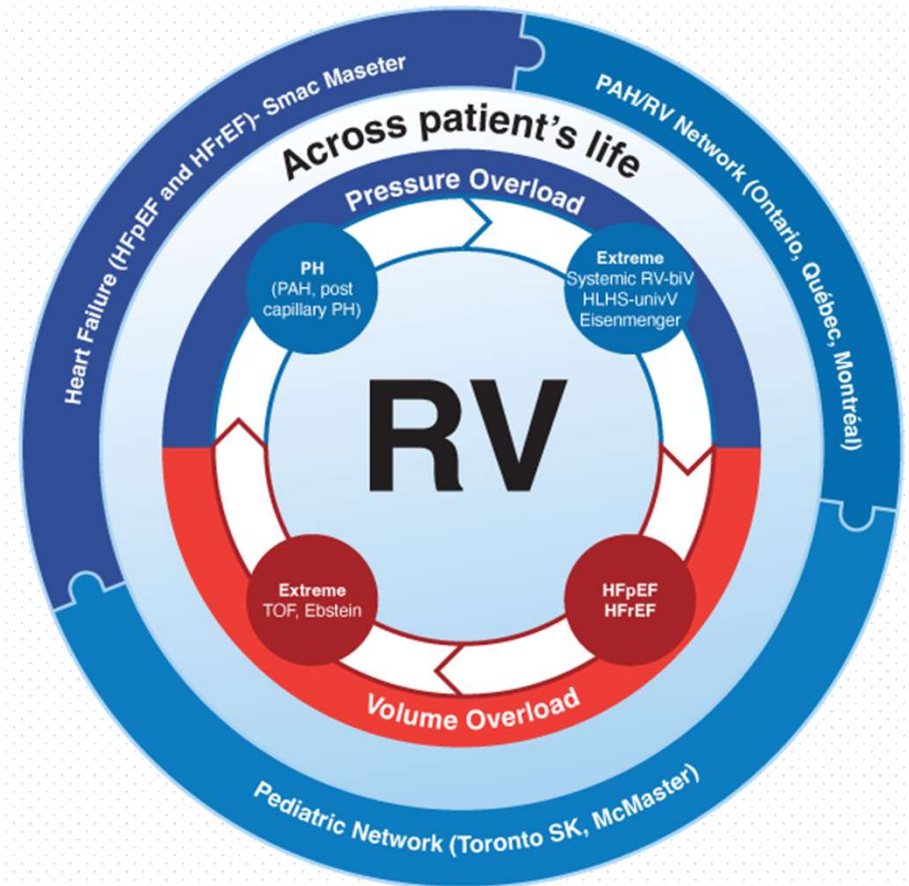
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# RV/N2

Therapies proven to work in LVHF have not worked on RVHF

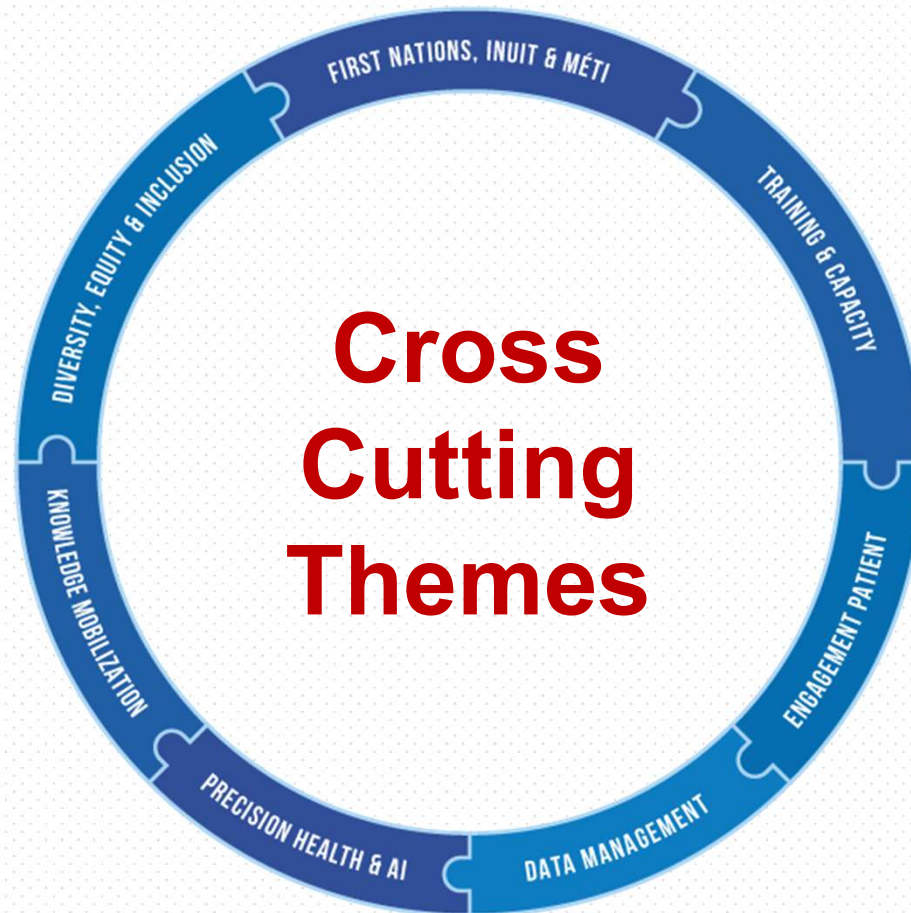
## Focus on “metabolomics” of RV function

- Exploring the use of DCA for PAH treatment through activation of glucose oxidation
- CRAVE – Canadian RV Failure Adaptive trials group
- Interventional studies testing novel therapeutic candidates enhancing RV adaptation in response to pressure and volume overload



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# Cross Cutting Themes

## **Patient Engagement:**

Promote patient engagement and empowerment across all network activities, from research to care.

## **Data Management:**

Centralize the Network's data for a better management and accessibility.

## **Training & Capacity:**

Develop training and mentoring in the Network. Offer financial support to CHF Alliance trainees and members through awards competition.

## **Diversity, Equity & inclusion:**

Ensure diversity, equity and inclusion within the Network.



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# Cross Cutting Themes

## **First Nations, Inuit & Métis:**

With IPERC's guidance, interweave Indigenous ways of knowing, being and doing with Western science, and work with Indigenous peoples to improve prevention, early diagnosis and treatment of HF.

## **Knowledge Mobilization:**

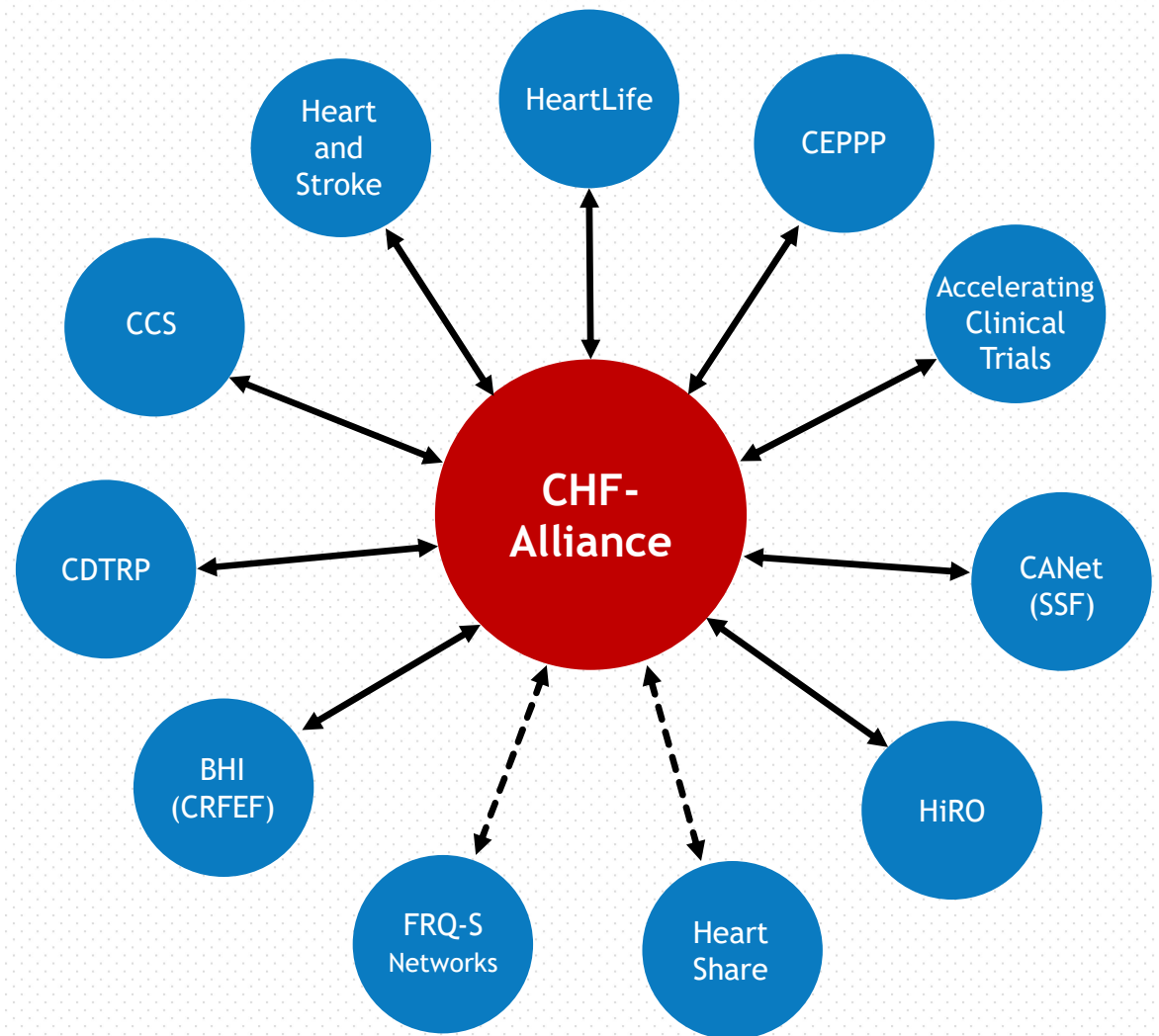
Develop and create content, and develop customized approaches in consultation with targeted population.

## **Precision health and AI:**

Utilize next generation "omics" coupled with social, behavioural, lifestyle factors to inform precision health strategies, and implement AI and digital solutions in the diagnosis and management of HF.



# Networking with Networks/ Organizations



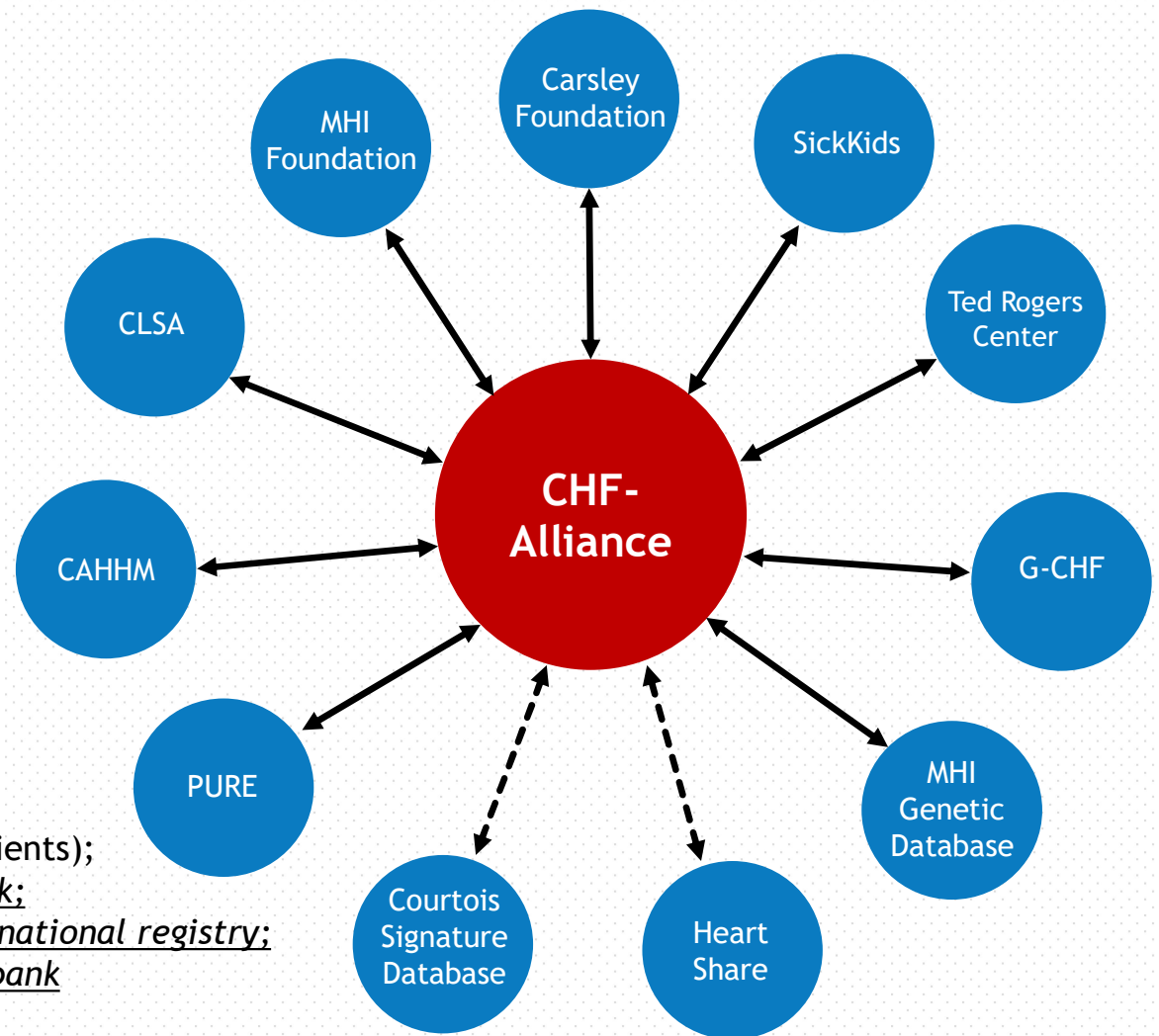
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# Networking with Networks/ Organization



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# Networking with Foundations and cohorts

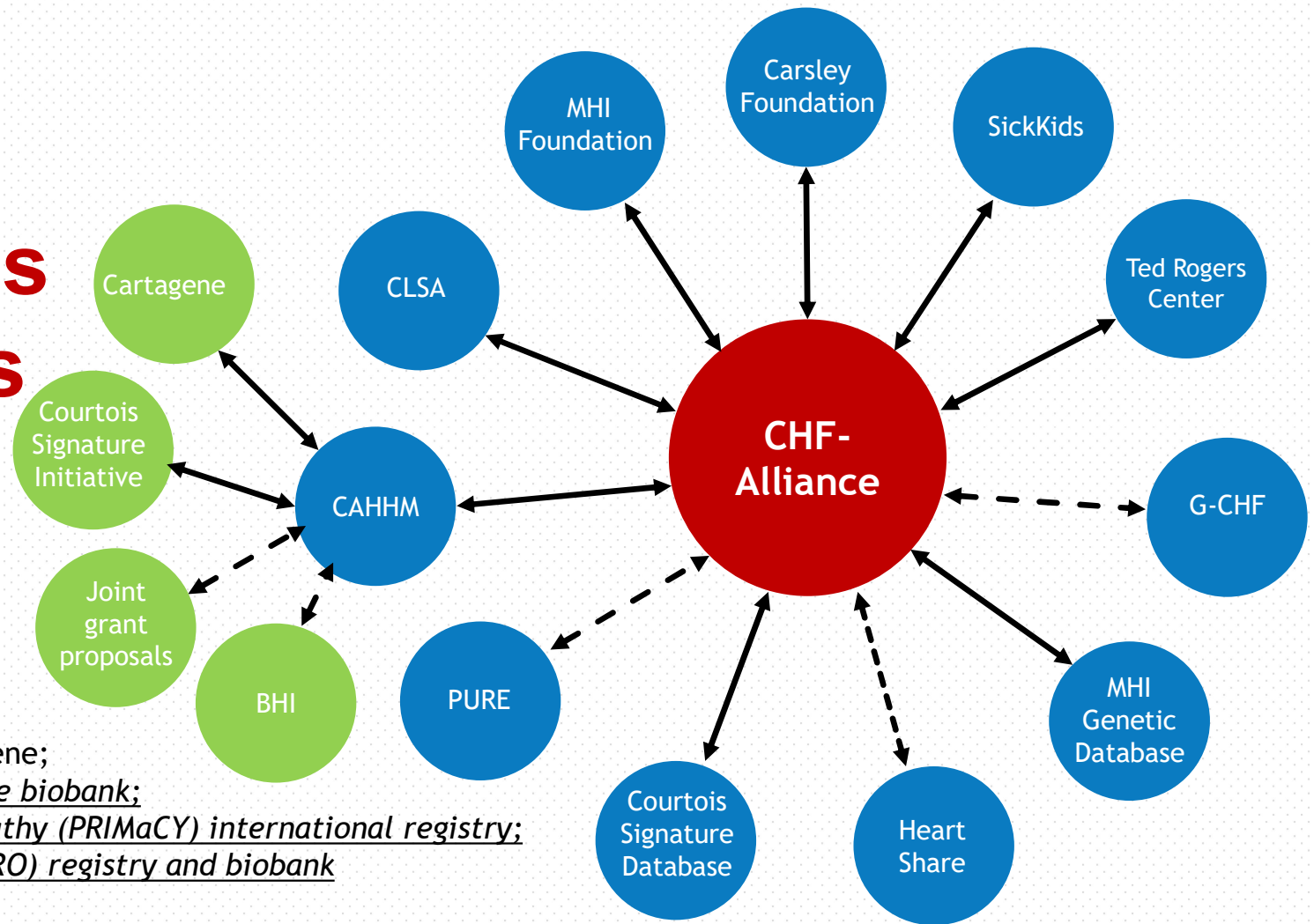


Also: PURE (200,000 individuals), G-CHF (23,000 HF Patients);  
Cartagene; Ontario province-wide Heart Centre biobank;  
Precision Medicine in Cardiomyopathy (PRIMaCY) international registry;  
Hearts in Rhythm Organization (HiRO) registry and biobank



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# Networking with Foundations and cohorts

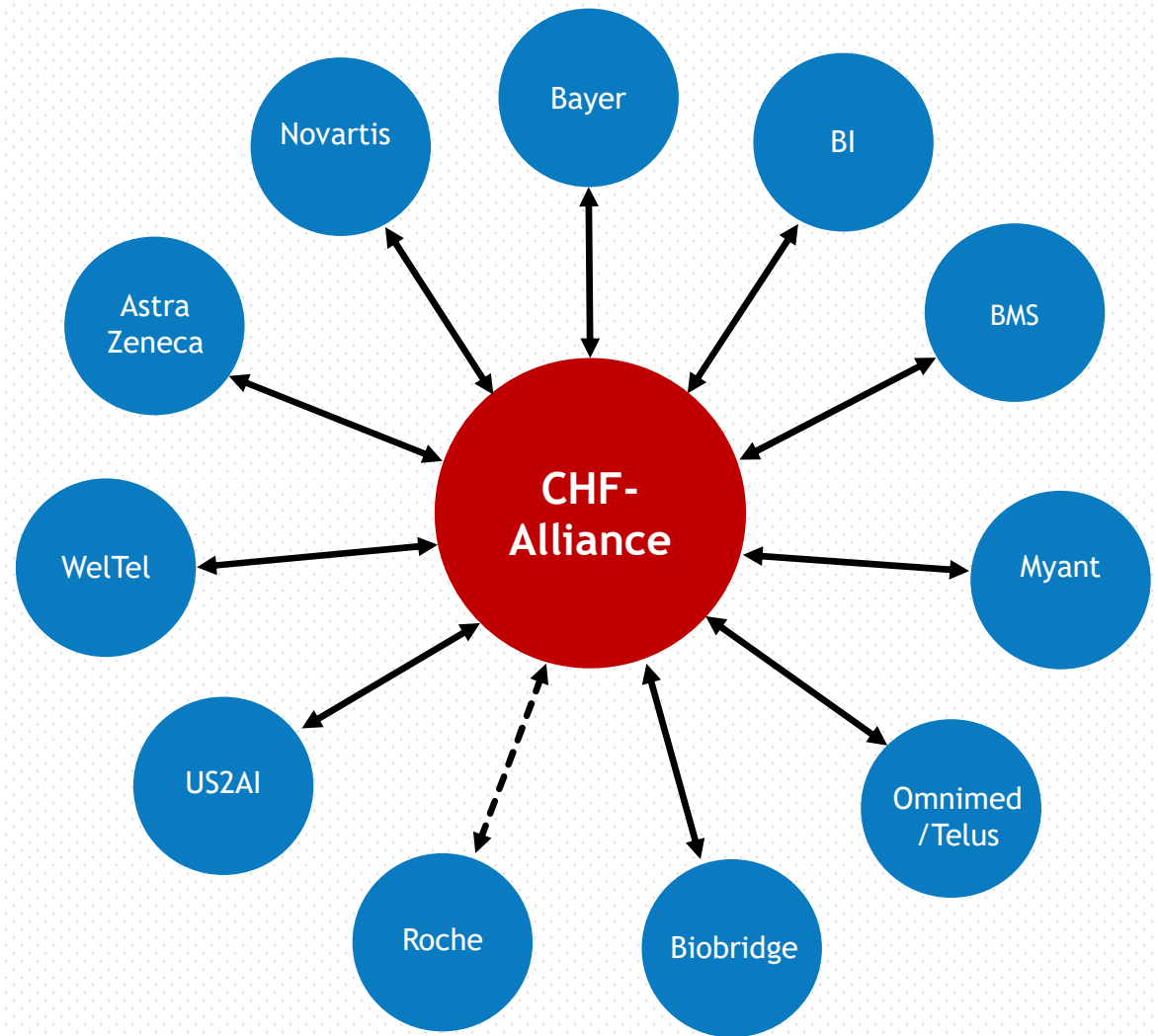


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# Networking with Industry



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# CHF Alliance Activities

- ▶ CHF Alliance webinars
- ▶ CHF Alliance weekly and monthly Newsletters: The Quick BEAT and the BEAT
- ▶ Trainee Awards Competition, application deadline was April 28, 2023
- ▶ Early Career Investigator Grant Competition, deadline is June 1, 2023
- ▶ CHF Alliance in-person meeting: May 11, 2023

Follow us on Twitter @chfalliance and LinkedIn

Website : [www.chfalliance.ca](http://www.chfalliance.ca)



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**Let's Unite to  
Create for the  
Future of  
Patients with HF!**

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*[www.chfalliance.ca](http://www.chfalliance.ca)*



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