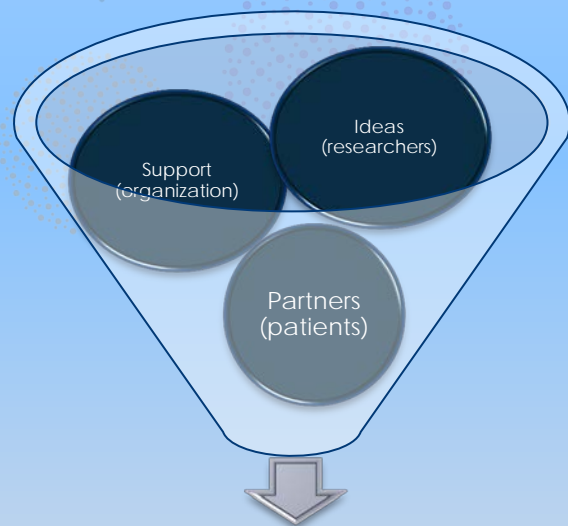


Permission to Contact Program

Rebecca Barnes
Project Manager
Research Engagement & Outreach



Business Case for Research



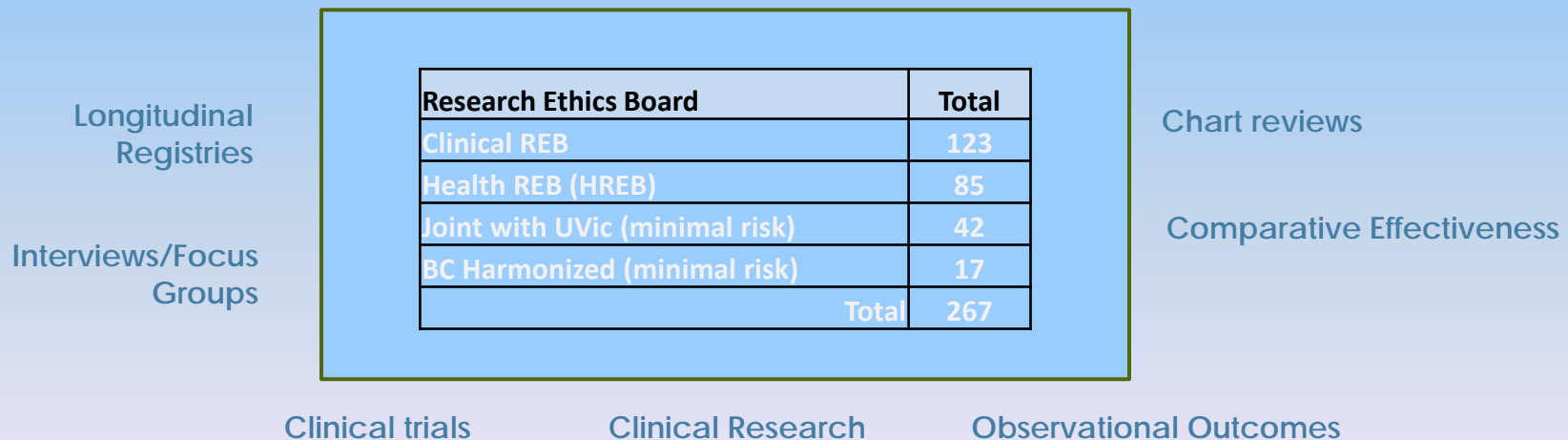
Progress

- Inform practice
- Improve quality
- Reduce health inequities
 - Contain costs
- Stimulate new research
- Enhance reputation of VI as a destination for health care professionals
- Maximize research and learning
- (Cerner/IHealth, new facilities)

Island Health research activity

- **Island Health's Purpose Statement:** To provide superior health care through innovation, teaching and research and a commitment to quality and safety – creating healthier, stronger communities and a better quality of life for those we touch.

Total Active Studies ~280



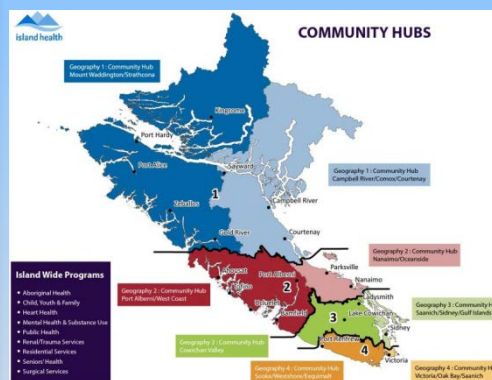
Strategic Research Focus

3 Key Populations

1. Seniors Health
2. Mental Health
Substance Use
3. Aboriginal
Health

and...
*creative
opportunism*

4 Geographic Regions

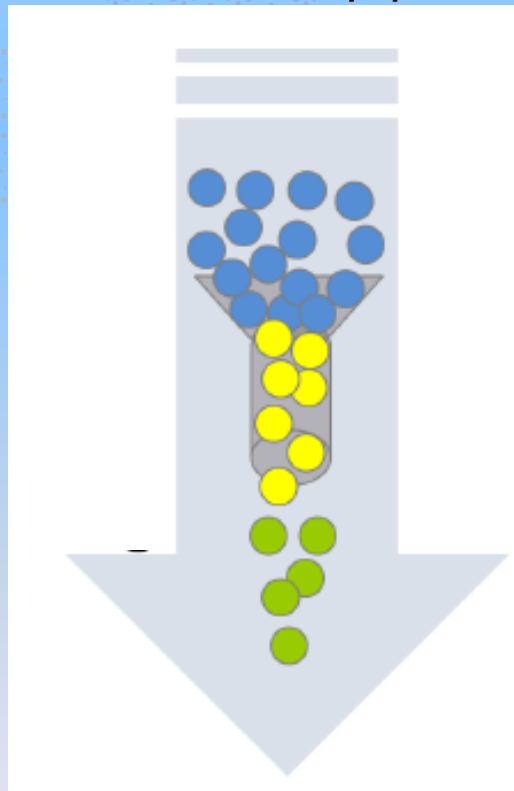


5 Activity Tracks

1. Collaboration
2. Capacity
3. Patient/Public
Engagement
4. Funding
5. Compliance

What is Permission to Contact?

Traditional Approach

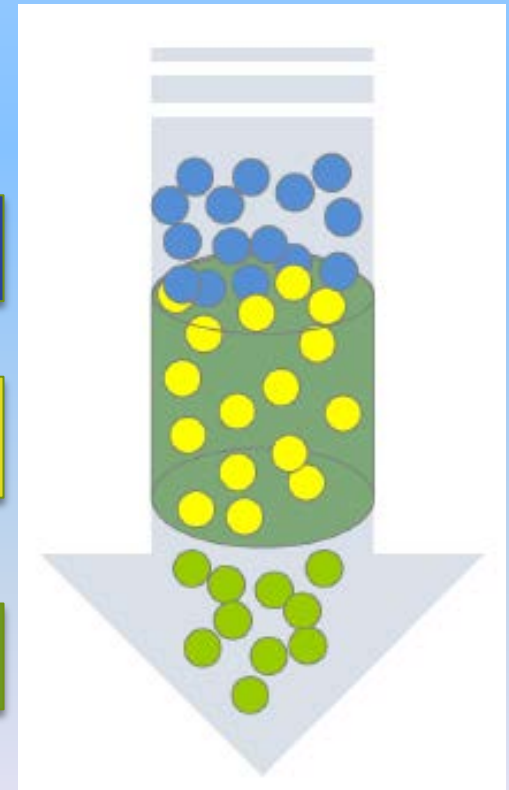


PATIENTS ELIGIBLE

REFERRED or OFFERED
PTC

PATIENTS ENROLLED

PTC



PTC – high level view



Initial encounter

Ongoing encounter

Diagnosis

Treatment

Follow-up

Permission to Contact

Patient Notification
= A specific research study is introduced and interest is confirmed

Informed Consent
= Informed consent process regarding the research study is implemented

Research Programs

Clinical studies

Biomedical research

Population health research

Health Services research

Why PTC at Island Health?

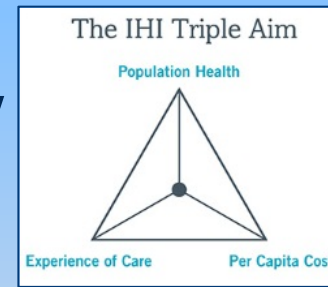
- Research-readiness



- Research Quality



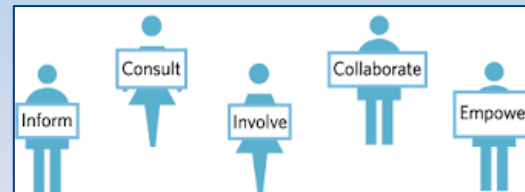
- Improved health care quality



- Staff engagement



- Patient Engagement



PTC and Patient Engagement



A majority of Canadians say they are interested in participating in health and medical research

But...

Only 33% are familiar with health & medical research conducted in their province and 24% are aware of opportunities to do so

Canada Speaks 2015 Poll. Research Canada. <http://www.rc-rc.ca/polling/2015-poll>

PTC and '*Meaningful*' Patient Engagement



Public

Patients

Participants

- **Increase** research awareness
- **Provide** study opportunities to patients as a part of their care
- **Create** opportunities to be actively involved in all stages of research

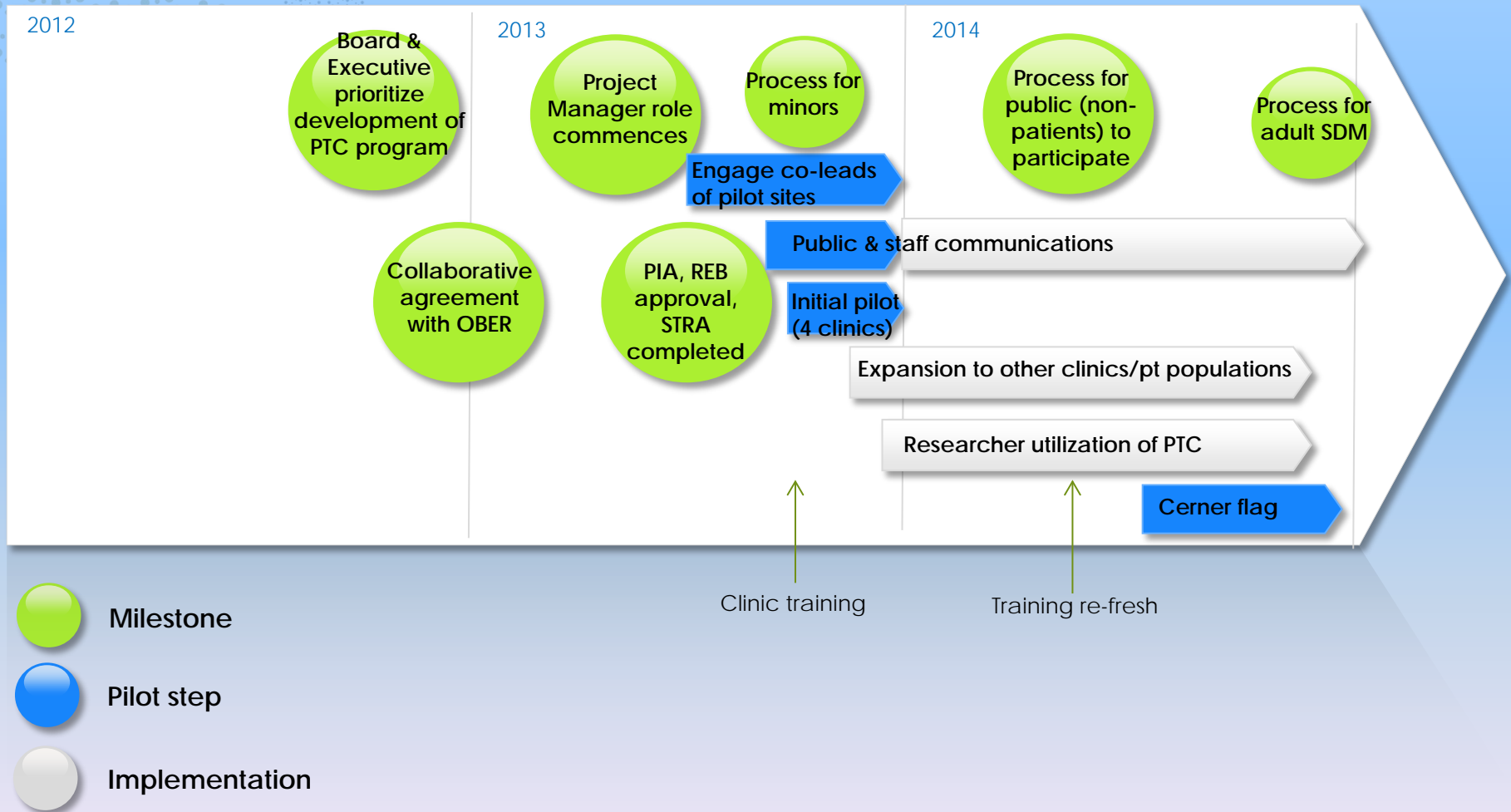
Question: What does PTC mean at Island Health?

Answer

A PTC participant is agreeing to:

- 1) allow authorized personnel to access their health record for the purpose of pre-screening
- 2) allow authorized personnel to contact them to provide information about research studies for which they may be eligible
- 3) to allow the PTC Program to collect a limited set of personal health information to facilitate pre-screening and contact

The approach



Phase 1 of 2 – PTC accrual

- **Step 1:** Eligibility assessed
 - Patient (or LAR if applicable) is able to speak and understand English
 - A reasonable assessment of the patient (or LAR if applicable) would find that they have the capacity to understand the purpose of the PTC Program and what participation involves
- **Step 2:** Trained staff member oversees documentation of PTC decision – recites script
- **Step 3:** PTC info form is labelled (PPID) if 'yes' and stored



Are you interested in learning about research study opportunities?

Part of VIHA's purpose is to carry out health research to improve health care for its patients and residents of the Vancouver Island region.

The **Permission to Contact for Research** program allows you to let us know if you would like to be notified of research study opportunities for which you may be eligible. By choosing to participate in the Permission to Contact for Research program you are not consenting to participate in a research study.

Participation is voluntary and you may choose not to do so without any impact on your continuing clinical care.


If you are interested in learning more about this program or to discuss any related concerns, please contact VIHA's Research and Capacity Building department:

(250) 370-8261 (collect calls will be accepted)
Email research@viha.ca

U259ap02015

Data process – PTC accrual

1



Patient ID label here

Are you interested in learning about research studies?

If you are, please sign this form to participate in Island Health's 'Permission to Contact for Research' program. If you sign this form, it does not mean that you are agreeing to participate in a research study.

If you sign the form, it means:

- You allow restricted research personnel to contact you to provide information about research opportunities.
- You allow restricted and authorized research personnel to check your Island Health medical records for specific information to see if you may be eligible for a research study, and
- You allow us to securely store some of your health information for this purpose (name, birth date, gender, major medical conditions, Personal Health Number, hospital identification number, phone number, mailing address, and location where this form is signed).

Signing this form is voluntary. If you do not sign this form, Island Health will provide you with the same level of medical care. If you sign this form, we may notify you of research studies conducted at Island Health or other BC locations. If you are not interested in one research study we may still notify you of other research studies. You may withdraw your participation at any time.

Please contact Island Health's Research department if you have any questions related to this form, to withdraw your participation, or if your contact information changes: (250) 370-3261 or email to research@vha.ca


Yes, I want to participate.

Signature _____ Printed name _____ Signed date _____

If you want to include email as a method for us to communicate with you, please enter your email address here* _____

Form: 107-01 Version: 3.0 Effective: 23APR2014
*Please note, email is not a secure method of communicating; therefore, we cannot guarantee the confidentiality of information sent to you in this way.

2



Permission to Contact

Actions: [Download PDF of Instrument\(s\)](#) [Share Instrument](#) [VIDEO: Basic data entry](#)

PTC Recruiting

Adding new PTC ID test

Event Name: Recruiting

PTC ID: test

PTC Disease code: [dropdown]

Contact Information

First Name: [text box]

Last Name: [text box]

MOB: [text box]

PHB: [text box]

DOB: [text box] Today 0:00:00

Gender: ☐ Female ☐ Male [reset](#)

Date recruited: [text box] Today 0:00:00

Out of VHA? ☐ Yes ☐ No [reset](#)

Street: [text box]

Postal Code: [text box]

Phone number: [text box] Include Area Code

E-mail: [text box]

General Comments

Comments: [text area] [Expand](#)

Form number: 107-01 107-02 1.0 [reset](#)

3

Perm. to Contact for Research:

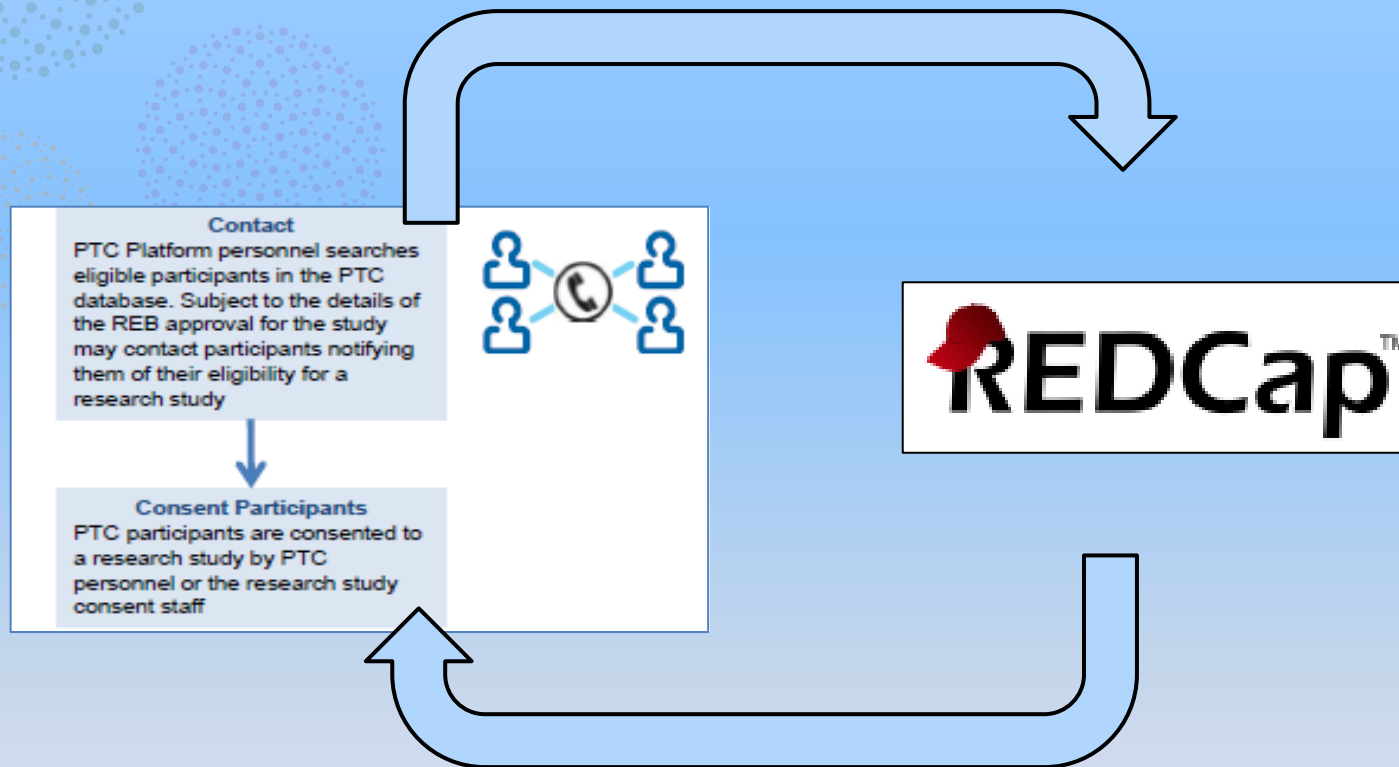
Begin Date Perm to Contact: 20-Mar-2014

Phase 2 of 2 – Research utilization

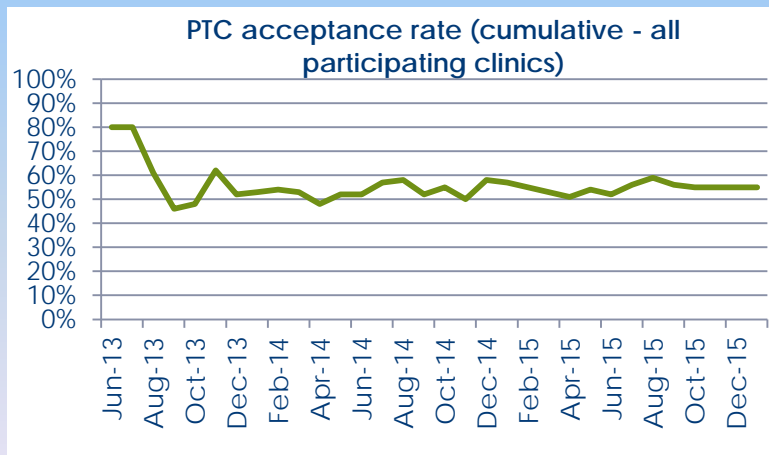
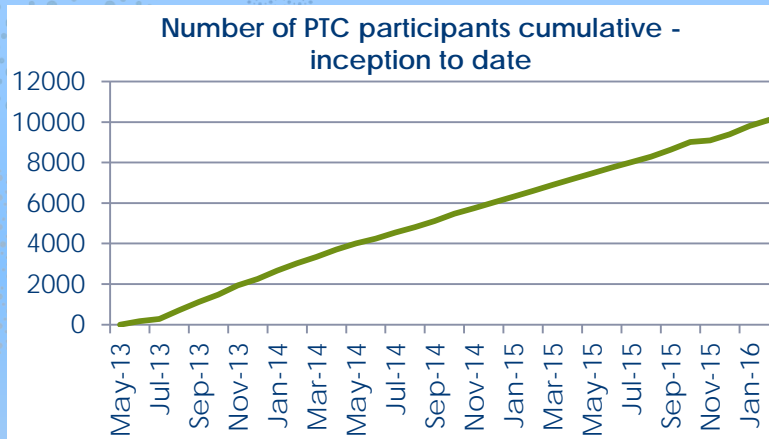
- **Step 1:** Research Program processes application and performs pre-screening
- **Step 2:** Study Notification is distributed
 - Email, mail, phone
 - % PTC with email address is ~70%
- **Step 3:** Interested people contact study contact person
- **Step 4:** Study personnel determine eligibility and informed consent process commences



Data process – Research utilization



Evaluation



Permission to Contact

Data Exports, Reports, and Stats

[VIDEO: How to use Data Exports, Reports, and Stats](#)

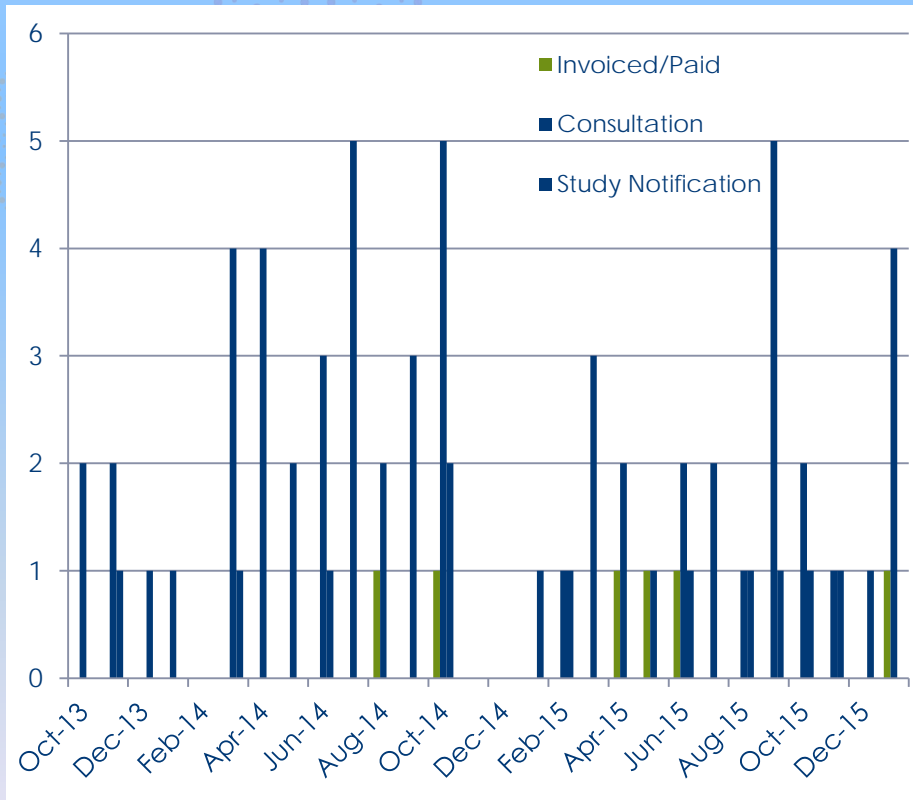
[+ Create New Report](#) [My Reports & Exports](#) [PDF & Other Export Options](#)

This module allows you to easily view reports of your data, inspect plots and descriptive statistics of your data, as well as export your data to Excel, SAS, Stata, R, or SPSS for analysis (if you have such privileges). If you wish to export your "entire" data set or view it in a plot, this is the best and quickest way. However, if you want to view or export data from only specific instruments (or events) on the fly, this is the best choice. You may also create your own custom reports below (if you have such privileges) in which you can filter the report to only the events you want using a vast array of filtering tools to make sure you get the exact data you want. Once you have created a report, you can export it out of REDCap in a specified format (Excel, SAS, Stata, SPSS, R), or view the plots and descriptive statistics for the data.

My Reports & Exports

	Report name	View/Export Options
A	All data (all records and fields)	View Report Export Data Stats & Charts
B	Selected instruments and/or events (all records)	Make custom selections
1	Active Subjects by Primary Disease	View Report Export Data Stats & Charts
2	Subjects recruited before 1/March/2013	View Report Export Data Stats & Charts
3	For flag	View Report Export Data Stats & Charts
4	Children 5 years expiration (have to update limit date)	View Report Export Data Stats & Charts
5	Adulthood of contacted Children	View Report Export Data Stats & Charts
6	To check off in Cerner	View Report Export Data Stats & Charts
7	emails list	View Report Export Data Stats & Charts
8	Subjects with PHN out of BC	View Report Export Data Stats & Charts
9	Percentage of PTC participants who give email address	View Report Export Data Stats & Charts
10	Participants turning 19 yrs old	View Report Export Data Stats & Charts
11	find 02sep2015	View Report Export Data Stats & Charts
12	find 2	View Report Export Data Stats & Charts
	+ Create New Report	

Sustainability



Patient populations (primary medical conditions)

- Alzheimer's
- Stroke
- TIA
- Multiple Sclerosis
- Diabetes (type I and II)
- Geriatrics
- Surgical (general, gynecological, urology, orthopedics, plastics, dental, other)
- Cancer
- Arrhythmia
- Coronary artery disease
- Myocardial infarction
- Hypertension
- Congestive heart failure
- Cardiovascular - other
- Pediatric neuropsychology
- Concussion/mild TBI
- Medical genetics – general
- Cardiogenetics
- Prenatal genetics
- Multiple sclerosis
- Cerebral palsy
- Muscular dystrophy
- Stroke
- Brain injury
- Spinal injury
- Arthritis
- Diabetes
- Autism spectrum disorder
- Fetal alcohol spectrum disorder

What's next

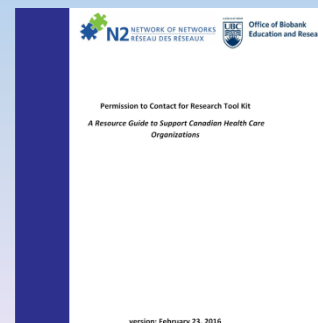
- PowerInsight



- Provincial PTC Platform



- National Harmonization



The Patient Perspective



Educate
Inspire
Summit Transforming Health Research on Vancouver Island

"Health research has the potential to really impact the patient journey. One of the biggest impacts of being involved in research is the satisfaction that you get knowing that you are participating in something that can help not only yourself but other people down the road. I think that is the biggest impact it has had for me."

Colleen McGavin, Patient Partner

Thank you



- rebecca.barnes@viha.ca



- www.viha.ca/rnd/



- @VIHealthRes



- 250-370-8261