Research and Connect Care

Creating and Sharing Department Specific Permission to Contact Patient Lists
### The Connect Care Research Team

#### Research Triad

**Clinical Operations:**
- Carrie Farnell, CORe Lead
- Wendy Pratch, CIEL Research
- Cindy Schumlick, Clinical Informatics Lead
- Mehwish Rao, Senior Trainer, Research
- Nicole Tjepkema, Credentialed Trainer
- Tamara Murray, Credentialed Trainer
- Meaghan Creydt, Training Consultant

**IT:**
- Brian Preeper, Murray Taylor, Kathleen Wright and Gillian Stebner – IT Analysts
- Kris Phillips, Project Manager

**CMIO:**
- Dr. Stuart Rosser

#### AHS Research & Innovation
- Becky Wong, Director, Health System Access
- Trina Johnson, Provincial Lead, Research Ops
- Pedro Reis, Project Manager
- Leanne Blahut, Project Manager

#### Connect Care Research Triad Leadership
- **Clinical Operations:** Shelley Bannister
- **IT:** Marcus Norman
- **CMIO:** Leahann McElveen

#### AHS Research & Innovation Leadership
- Marc Leduc, Sr Provincial Director

#### Epic
- Sarah Richmond, Research Application Manager
- Ryan Nealon, Research Technical Support
Objectives

• Review of the most current provincial implementation timeline
• Readiness updates and resources
• Review functionality of those who are already trained and using Connect Care
  – How to use patient lists for research purposes
• Key takeaways
• Question and Answer Period
Research and Connect Care

Wave 1 Launched
November 3, 2019

Wave 2 Launched
October 24, 2 EDMONTON ZONE
Suburban acute and combined acute and long term care sites
PROVINCIAL PROGRAMS
Interim Dialysis and Renal Care (Walter C. Mackenzie Campus only)
PHARMACY & DI
Sites in: Suburban Edmonton
ALBERTA PRECISION LABS
Sites in: Suburban Edmonton

Wave 3 - APRIL 10, 2021

Wave 4 - NOVEMBER 7, 2021

EDMONTON ZONE
Walter C. Mackenzie Campus:
Aberdeen Centre, Clinical Sciences Building:
Kaye Edmonton Clinic; Mazankowski Alberta Heart Institute:
Stollery Children’s Hospital;
T&B Central Services; University of Alberta Hospital; Zedler Centre
East Edmonton Health Centre: Addiction & Mental Health Bed Management
CLINICIAN TRANSITION
Ambulatory clinics
PORTALS
Connect Care Patient Portal;
Connect Care Provider Portal
PHARMACY & DI
Sites in: Urban and Suburban Edmonton
ALBERTA PRECISION LABS
Sites in: Edmonton; All Edmonton Pathology;
A1 Dynalife in Alberta; Cross Cancer Institute;
Lab and Transfusion Medicine

CALGARY ZONE
Alberta Children’s Hospital; Peter Lougheed Centre;
Rural acute and combined acute and long term care sites;
Calgary T&B Clinic
URGENT CARE
Calgary Women’s Hospital;
Royal Alexandra Hospital;
Airdrie; Okotoks; Cochrane
EDMONTON ZONE
Glenrose Rehabilitation Hospital; Lethbridge Hospital;
Foothills Hospital; Airdrie;
Addiction Residency Programs
PHARMACY & DI
Sites in: Edmonton; Calgary including Central Production Pharmacy
ALBERTA PRECISION LABS
Alberta Children’s Hospital; Genetics Services South Lab;
Edmonton including Glenrose Rehabilitation Hospital;
Royal Alexandra Hospital; Grey Nuns Hospital;
MacEwan Community Hospital;

NORTH ZONE
Suburban acute and combined acute and long term care sites:
Edmonton East Community

We are here

Implementation sequence planning for Waves 3, 4, 5 and 8 is subject to change due to external factors, including COVID-19.
Implementation sequence planning is ongoing for sites in Waves 7, 8 and 9. As our knowledge improves future waves may be modified.
An updated implementation timeline will be published with further details.
Research and Connect Care

Communication Expectations in Relation to Connect Care Information

[Word cloud image: COMMUNICATION, PROCESS, UNDERSTANDING, PEOPLE, INFORMATION, NEWS, DEPARTMENTS, COOPERATIVES, TWO-WAY, IDEAS, EXCHANGE, BUSINESS, FUNCTION, BEHAVIOUR, MUTUAL, GIVES, KEY, MEANS, CONNECTING, RECEIVES, EMPLOYEES, SPEECH, WRITING, WORDS, ACT, VISUALS, SYMBOLS, SIGNALS, PERSON, MESSAGES, THOUGHTS, OPERATE, LEVELS, THOUGHTS, CONNECT, PLACE, ACTIVITY, ACT, CONNECT, CONNECTING, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, CONNECT, 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Remember: Research is care
Research and Connect Care

Getting Started with Connect Care for Research

How do I start my journey with Connect Care as a researcher?

All research ethics board (REB)-approved research studies are reviewed and, as it relates to Connect Care access, are approved by the AHS Health System Access (HSA) team according to the following steps:

1. After REB-approval, a notification is sent to the HSA team to follow up with the respective research team and start the work of preparing the study for Connect Care.
2. Research teams will be asked to fill out the HSA intake questionnaire (to assess their study needs) and IT access request form (to identify and assess the user(s) needs).
3. Even if a study is already ongoing and for whatever reason it was not set up as part of its respective Connect Care wave launch, or the study needs have changed and now requires to be set up in Connect Care, this can be requested using the appropriate HSA intake form.
4. For newly REB-approved studies, research teams can expect to be approached by an HSA advisor about Connect Care access and discussions about the in-system research functionalities.

If the requirements of the study change, including access requirements of team members, the research team should:

1. Update their ethics application; and
2. Contact the HSA Advisor that had previously reviewed the study and submit the requested changes in the HSA Change Request form.

Requests submitted using the HSA intake forms include:

- Requesting Connect Care access for your study.

Outlines key information for research teams that includes:

- Explanation on how to gain study approval and access
- What to do when study requirements change
- How to submit HSA intake forms
- Frequently asked questions.
Assumptions for Launch

The Connect Care Research - Assumptions for Launch document outlines four basic assumptions.

1. All patients enrolled in clinical research studies (that meet the in-scope study criteria) will be flagged with the details of the respective studies that may impact their health care and inform clinical decisions made by their clinical care teams.

2. The clinical care team and everyone working with the patient record will be aware of the patient's participation in a research study. The system users will also be to report on this information to enhance patient safety.

3. Individuals who previously did not have direct access to the patient chart, including university-employed research coordinators, will have access and responsibilities to keep the patient record (as it relates to research) up-to-date.

4. Training in all CIS research-related workflows will be role-specific. Users requiring access to inquiry tools and workflows will be assessed and assigned a user role, and there will be opportunities to identify others who require training that have not previously been identified through existing methods.

More information about Research in Connect Care is available on the Provincial Research Administration website: https://extranet.athabasca.ca/teams/AHSRA/SitePages/Home.aspx
Research and Connect Care

“A Day in the Life” – Benefits of Connect Care

Enhance Patient Safety
• Flag patient records by linking patients to research studies

Integrate Inquiry & Research into Operations
• Create processes and workflows to perform, track, and report on inquiry and research

Better Health, Powered by Information.

A Day in the Life of a Research Coordinator

Connect Care Benefits
• AHS and university-based research team members, including study coordinators, will have access to the Clinical Information System (CIS) according to their approved study role and access.
• Increased Patient Safety and study integrity by making patient enrollment visible to the care teams and the patient’s clinical encounters visible to research team members (in accordance with study role and approved access).
• Research team members, including research coordinators, will have access to clinical workflows including ordering medications and tests as well as scheduling, as appropriate.

How I work now
• I queue-up clinical workflows (orders, scheduling) using paper requisitions or through members of my team with access to an electronic system.
• I receive invoices for research services, including pharmacy, lab, and imaging. It can be difficult to determine which charge is associated with a particular participant or visit.
• When I need data for a study from an AHS data repository, the research team requests access.

How I will work with Connect Care
• Information I enter in the CIS will be visible to both research team members and the clinical care team, allowing for better information sharing.
• I will open a study record in the CIS and view or queue-up an order, appointments and enter relevant participant information.
• I will pull a report of all orders for each patient at each study-related visit.
• When I need data for a study from an AHS data repository, including the new CIS, the research team requests access and we may be able to use new self-service, in-system inquiry and reporting tools.

Eric is a Research Coordinator working at Stollery Children's Hospital

Research Coordinator Checklist

Currently under review in anticipation of wave 4 launch.
You asked. We listened.

- Request from research teams on how to translate existing department specific permission to contact lists into Connect Care
- Leverage the Patient Lists activity in Connect Care to create department specific patient lists
What is a Permission to Contact List?

- A streamlined approach that involves the identification of eligible patients who may be referred or offered contact with research teams that express interest to participate in clinical research.

- Permission is provided by a patient to be directly contacted by study teams about research opportunities in that department.

Reference taken from: Permission to Contact Program (islandhealth.ca)
Setting up PTC Lists

• Presentation will showcase how to translate existing PTC registries into Connect Care to capture information for research purposes

• If you do not currently have a specific department permission to contact list, discuss this option with the relevant AHS program/department manager and ensure the manager is aware how the PTC lists will used for that department and no other lists exist.

• For additional support regarding these conversations, or if you unsure if you have the right approvals in place such as REB waiver of consent please contact research.administration@ahs.ca
Resources

‘Department Specific Permission to Contact Lists’ guidance tip sheet

• Located on the ‘Research Coordinator Learning Home’ dashboard

• Document will be found under general resources
## Connect Care

### Resources

Our Resource Library provides access to Connect Care support documents such as templates, infographics, timelines and more.

- **Connect Care**
- **Epic Resources**
- **Implementation**

### Course Name

Filter: permission

<table>
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<tr>
<th>Course Name</th>
<th>Document Name</th>
<th>Application</th>
<th>Training Phase</th>
<th>Location</th>
<th>Training Content</th>
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<td>Research - Permission to Contact Lists</td>
<td>Research</td>
<td>Learning Home Dashboard (LHD)</td>
<td>Tip Sheet</td>
<td>Wed Apr 07 2021</td>
<td></td>
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Showing 1 to 1 of 1 entries (filtered from 3,221 total entries)
Best Practice Recommendations

Setting up Department Specific PTC List

• Identify two individuals who will be responsible to maintain and manage the list
  – Will add users
  – Will assign access level [recommend add/remove patients]

• Follow the tip sheet located on the Research Coordinator Learning Home Dashboard for further instructions.
Incorporating PTC into CC

1. Patients should not be added to any department list until they have provided written permission to be contacted.
2. If a Connect Care patient list is used to capture this information, the permission to be contacted document must be scanned into the patient chart.
   • If retroactively adding patients who have agreed to be on the PTC → you should upload the permission to contact document into Connect Care
   • Any user who adds a patient to the list → should upload permission to contact document into Connect Care

Refer to appendix A of tip sheet to learn more about what should be included in a PTC document
Workflow – Adding Patients to PTC Lists

1. Patient gives written permission to be directly contacted by study teams for research opportunities in this department.
2. Permission to contact document is scanned into Connect Care.
3. Patient is added to the department specific permission to contact list in Connect Care.
4. Study staff use report to find eligible participants.
Patient lists are utilized in both ambulatory and inpatient settings

- **Inpatient**: administrator created lists of admitted patients in the hospital
- **Ambulatory**: clinical staff may create their own list to follow a subset of patients requiring follow up (e.g. for lab work)
How to Create a Patient List?
Naming Convention for Permission to Contact Lists:

- Department Name + Research Permission to Contact + Specialty (if applicable for departments with more than one list)
- For example in Connect Care:
  - Stollery Children's Hospital Pediatric Hematology Program is listed as EDM STO WMC PED HEMATOLOGY CL
  - List name: EDM STO WMC PED HEMATOLOGY CL Research Permission to Contact
<table>
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<th>Age/Gender</th>
<th>PCP</th>
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<td>56 y.o. / M</td>
<td>FAMILY MEDICINE, PHYSICIAN</td>
</tr>
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<td>Research, Brian</td>
<td>91 y.o. / M</td>
<td>VAN DER WESTHUIZEN, MARINUS</td>
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Use Department Permission to Contact Report to Filter Patients
Key Points – Using the Report

• You can only run this report for patient lists that you have created or that have been shared with you.

• This report uses two databases in Connect Care to pull information
  – One for the users and patients connected to the patient list [updated at midnight]
    • You cannot use the report for a patient list the same day you were granted access to the list
    • Patients added to the list “today” will only appear on the report run tomorrow
  – One for patient information [uses live information] → Patient data will always be up to date
Key Takeaways

• If you are already collecting patient names who have provided PTC outside of Connect Care, this is an opportunity to integrate as part of your daily research practice!

• For groups who do not do this yet please use this resource as a way to follow best practice recommendations.
Question and Answer Period

Question #1: Where will this presentation be stored?
• The Power Point presentation is posted under ‘Presentations and Videos’ as per the following link: Provincial Health System Access - Home (ahsnet.ca)

Question #2: For the permission to contact report, if research staff add criteria, could we save as different report?
• Yes, individuals can save the report as their own personal copy.

Question #3: Are study teams able to use verbal consent for individuals that express interest to be contacted for research purposes?
• AHS does not accept verbal consent to contact. The gold standard is written consent that is documented and uploaded into the patient’s chart within Connect Care. If you have any questions specific to your study, please reach out to the Health System Access (HSA) advisor assigned to your study or email HSA at research.administration@ahs.ca.
Question and Answer Period

Question #4: What is the most number of people that can have the highest level of access to a department specific permission to contact list?

• The best practice recommendation is to identify a minimum of two people who will be responsible for managing and maintaining the list (i.e. – add users and assign access level). However, there is no limit of the number of individuals who can have access to the list to perform this task; that is based upon the decision of study teams.

Question #5: Where is the Department Specific Permission to Contact Lists guidance tip sheet located?

• The tip sheet is located on the ‘Research Coordinator Learning Home Dashboard’ and on the Insite on the Connect Care Training Course Materials page (please refer to slides #14 and 15 for instructions).
We are here to answer your questions!

Contact Connect Care: CC.Research@ahs.ca