ICHOM

International Consortium for
Health Outcomes Measurement

ICHOM Breast Cancer Learning Collaborative

ICHOM has convened a network of global breast cancer treatment experts who work together to improve clinical practice and patient outcomes. The collaborative serves to share best practices, and identify areas for learning including optimal clinical pathways, equity, and shared decision-making. Phase I is 2 years with 4-5 participants. The following participants have confirmed their agreements for Phase 1 with several others currently reviewing and completing the Memorandums of Understanding:"

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Erasmus MC (The Netherlands)
Dr. Linetta Koppert and Prof. Renske Los

The Royal Melbourne Hospital (Australia)
Dr. Christobel Saunders, Prof. Anita Skandarajah

Saint-Luc UCL (Belgium)
Mr.Jean Stoefs, Mr. Kiswendsida Sawadogo

Santa Rita Hospital and Hospital Nossa Senhora das Graças are supported by the Saude IAG Consultancy Group.

Sheba Medical Centre (Israel)
Dr. Yair Edden MD & Dr. Yuval Levy MD, MHA

Collaborative Objectives:

Assess and compare

patient outcomes over a two year period across multiple sites, determining optimal care pathways as a primary study objective

Learn from performance

variations to drive local improvement efforts, enabling sites to pursue secondary study objectives with peers, as desired, using a federated learning platform that protects all sites data

Resources & Benefits Provided

We aim to minimize your burden by providing the following resources free of charge (no cost to participate!):

1. ICHOM BrCa Digital Set to enable ease in data collection from your EHR/data warehouse
2. PROM data collection tool, if needed to assist with automated PROMs capture at point of care
3. Federated learning software installed at your site to eliminate data from leaving your firewall, for ease in data use/data sharing within the Collaborative, as implemented by Rhino Health (a Boston-based tech company)
4. ICHOM-provided Data Scientist, to develop primary study objective analytics, as well as work with sites on any desired secondary study objectives
5. Priority access for presenting research findings at the annual ICHOM 2025 Conference. Additionally, we hope to present the initial findings at the ICHOM 2024 Conference in Amsterdam.
6. Collaborative facilitation and program management services to oversee the project's successful execution, from initial planning to project closure

Find out more @ichom.org

Data Collection using the ICHOM Breast Cancer Primary Subset:

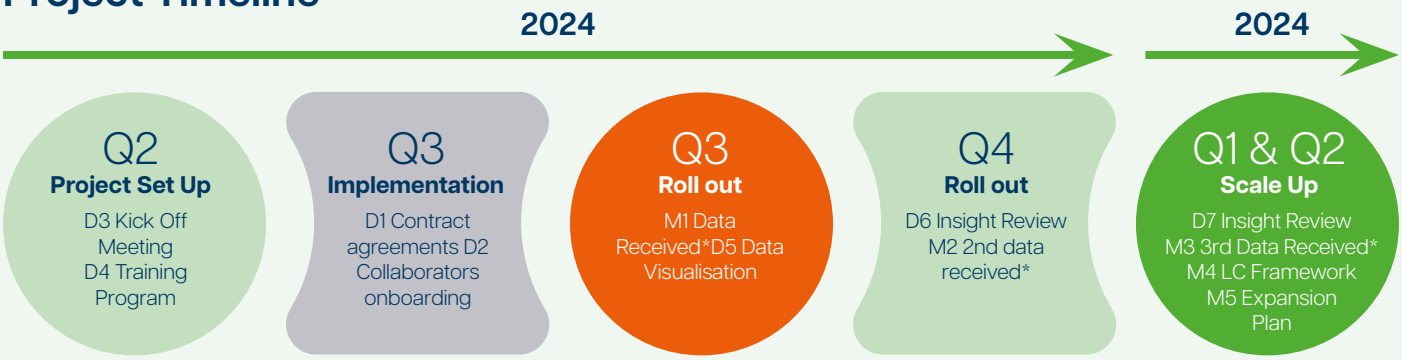
The data elements gathered are on Page 2 of this document. Participants will get an installation date for the Rhino federated learning software (www.rhinohealth.com), then be trained on how to get their data onto the platform. This securely enables data sharing with peers without data leaving your hospital (no sharing of PHI/PII). Your technical person (or IT/Informatics Department) will be responsible for 1-time data gathering, and your clinical researcher will work with peer researchers within the Collaboratives.

Data will be analyzed quarterly, with optimal care pathway analyses focused on as primary study objectives. Your technical leads will be responsible for ensuring accurate data is pulled from the EHR system into the Rhino Health Technology platform, also on a quarterly basis, with support from the ICHOM Data Scientist as needed.

ICHOM Learning Collaboratives enable:

- Assessment and comparison of patient outcomes across global sites
- Learning from performance variations to drive local improvement efforts
- Identification of predictors of better/worse patient outcomes
- Defining qualitative benchmarks of excellence, serving as a reference for providers worldwide
- Description of outcomes for specific patient sub-groups
- Generating real world evidence for researching new therapies, drugs, medical devices etc.

Project Timeline



The full ICHOM Breast Cancer set includes 129 outcome variables and is well published in the literature (e.g., Schouwenburg, et al., JAMA oncology, 3(5), 677-685.) The primary subset includes **29** of these outcome measures along with the **case-mix** and **treatment variables.** These will be used as a starting point for collecting the measures needed to begin participating in the learning collaborative. These will be shared in a JSON format (or CSV or FHIR if desired). The outcome domains included in the primary subset are shown below:

Outcomes domain	Measure	Patient Population	Reporting Source
Survival and Disease Control			
Vital Status	Vital status	All patients	Clinical
	Date of death		
	Death attributable to breast cancer		
Recurrence free survival	Recurrence	Patients with curative intent	Clinical
Degree of Health			
Overall wellbeing	EORTC-QLQ-C30 (Q29-30)	All patients	Patient-reported
Physical functioning	EORTC-QLQ-C30 (Q1-5)		
Ability to work	EORTC-QLQ-C30 (Q6-7)		
Emotional functioning	EORTC-QLQ-C30 (Q21-24)		
Endocrine therapy symptoms	EORTC-QLQ-BR45 (Q54-56, Q63-69)		
Satisfaction with breasts	EORTC-QLQ-BR45 (Q74-75)	Patients with surgery/radiotherapy	

Contact Information

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