

**AWARD NUMBER:** W81XWH-22-1-0535

**TITLE:** Development of a Biobank for Rare Pediatric Eye Cancers

**PRINCIPAL INVESTIGATOR:** Dr. Helen Dimaras

**CONTRACTING ORGANIZATION:** The Hospital for Sick Children

**REPORT DATE:** July 2023

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<b>14. ABSTRACT</b> Rare pediatric eye cancers (R-PEC) represent a significant threat to life if not diagnosed and treated in a timely fashion. Children that survive R-PEC may suffer from blindness or severe visual impairment, negatively impacting quality of life. It is notoriously challenging to study R-PECs, because it is difficult to accumulate the number of specimens, clinical data and images needed to yield reliable scientific results. The aims of this project are to (1) build a robust repository of R-PEC specimens, clinical data, images and derived resources from national and international Partner Sites; and (2) establish and evaluate an operational and governance structure that addresses patient lived experience and financial, operational and social sustainability. A total of 11 participants have been enrolled at SickKids with 10 specimens collected, processed and stored. Of the 8 Partner Sites listed on the original grant application, 2 have withdrawn from the project, 3 are nearing completion of the requisite material data access agreement (MDTA) and 3 are navigating unanticipated barriers before the MDTA can be executed. Processes have been established for material and data access requests, patient advocates have been engaged and a comprehensive business plan was created, inclusive of operational, governance and financial specifications.					
<b>15. SUBJECT TERMS</b> Eye cancer, pediatric cancer, biobank, human tissues, rare cancer, resource platform, patient-oriented research					
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## TABLE OF CONTENTS

	<u>Page</u>
1. Introduction	4
2. Keywords	4
3. Accomplishments	4
4. Impact	11
5. Changes/Problems	11
6. Products	11
7. Participants & Other Collaborating Organizations	12
8. Special Reporting Requirements	13
9. Appendices	14

## 1. INTRODUCTION

Rare pediatric eye cancers (R-PEC) represent a significant threat to life if not diagnosed and treated in a timely fashion. Children that survive R-PEC may suffer from blindness or severe visual impairment, negatively impacting quality of life. It is notoriously challenging to study the more than 30 types of R-PECs, because it is difficult to accumulate the numbers of specimens, images and data needed to yield reliable scientific results. The aims of this project are to (1) build - at The Hospital for Sick Children (SickKids, Toronto, Canada) - a robust repository of R-PEC specimens, clinical data, bioimages and derived resources from national and international Partner Sites; and (2) establish and evaluate an operational and governance structure that addresses patient lived experience and financial, operational and social sustainability.

## 2. KEYWORDS:

Eye cancer, pediatric cancer, biobank, human tissues, rare cancer, resource platform, patient-oriented research

## 3. ACCOMPLISHMENTS:

### What were the major goals of the project?

**Table 1.** R-PEC Biobank Accomplishments

<b>Major Task 1: Obtain Research Ethics Board approval</b>	Months	Site(s) <sup>1</sup>	% Completion
Subtask 1: prepare amendment application	1	1	100%
Subtask 2: obtain research ethics board approval	2	1	100%
Subtask 3: obtain USAMRDC Office of Human Research Oversight (OHRO) approval	2	1	100%
Subtask 4: execute material and data transfer agreements with Partner Sites	3	3,5-9	30%
<i>Milestone #1: Regulatory approvals obtained at all sites.</i>	3		85%
<b>Major Task 2: Recruit patients</b>	Months	Site(s)	% Completion
Subtask 1: introduce eligible patients to the biobank	3-36	1,3,5-9	5%
Subtask 2: obtain consent and release of medical information	3-36	1,3,5-9	5%
<i>Milestone #2a. 220 participants recruited.</i>	12		5%
<i>Milestone #2b. 440 participants recruited.</i>	24		Out of scope
<i>Milestone #2c: Projected total enrollment targets achieved.</i>	36		Out of scope
<b>Major Task 3: Collect specimens and data</b>	Months	Site(s)	% Completion
Subtask 1: collect specimen (as part of standard of care)	3-36	1,3,5-9	3%
Subtask 2: send specimens to Site 1	3-36	3,5-9	0%
Subtask 3: process and store specimens	3-36	1	100%
Subtask 4: document data associated with specimen collection and processing	3-36	1	100%
Subtask 5: collect clinical data (as part of standard of care)	3-36	1,3,5-9	50%
Subtask 6: send clinical data to Site 1	3-36	3,5-9	0%
Subtask 7: collect bioimages (as part of standard of care)	3-36	1,3,5-9	0%

<sup>1</sup> See Appendix for Site list.

Subtask 8: send images to Site 1	3-36	3,5-9	0%
Subtask 9: store and manage specimens and data	3-36	1	100%
<i>Milestone #3: Robust collection of specimens, data and images created.</i>	36		Out of scope
<b>Major Task 4: Review and approve data access requests</b>	Months	Site(s)	% Completion
Subtask 1: receive data access requests from Platform Users	6-36	1	10%
Subtask 2: review of data access requests by data access committee	6-36	1-9	0%
Subtask 3: respond to Platform Users data access requests	6-36	1	0%
Subtask 4: execute material and data transfer agreements with Platform Users	6-36	1	0%
Subtask 4: provide specimens and associated data to Platform Users	6-36	1	0%
Subtask 5: receive research findings from Platform Users	21-36	1	Out of scope
Subtask 6: add new research findings to the biobank	21-36	1	Out of scope
<i>Milestone #4: Biobank resources made available and utilized by Platform Users.</i>	36		Out of scope
<b>Major Task 5: Generate biobank resources</b>	Months	Site(s)	% Completion
Subtask 1: generate cancer genome data	6-30	1	0%
Subtask 2: generate tumor organoids	6-30	1	0%
<i>Milestone #5: Generation of data and models</i>	30		Out of scope
<b>Major Task 6: Disseminate biobank model</b>	Months	Site(s)	% Completion
Subtask 1: develop biobank website	1-6	1	50%
Subtask 2: identify and link relevant Platform Users to biobank	6-36	1-9	20%
Subtask 3: present at conferences	9, 21, 30	1-9	15%
Subtask 4: register biobank on relevant databases	12, 24, 36	1	0%
Subtask 5: publish and update key performance indicators (KPIs) and utilization metrics on website	12, 24, 3	1	33%
<i>Milestone #5: Platform Users are made aware of R-PEC biobank and the data, data, and downstream derivatives available.</i>	36		Out of scope
<b>Major Task 7: Establish governance structure</b>	Months	Site(s)	% Completion
Subtask 1: draft governance structure	1-2	1	100%
Subtask 2: establish data access committee	2	1	20%
Subtask 3: finalize governance structure	3	1	100%
Subtask 4: annual review of governance structure	12-36	1	33%
<i>Milestone #6: Manuscript published on biobank model (including governance structure)</i>	36		Out of scope
<b>Major Task 8: Develop and implement business plan</b>	Months	Site(s)	% Completion
Subtask 1: develop business plan advisory committee	2	1	100%
Subtask 2: develop business plan	2-8	1	100%
Subtask 3: implement business plan	8-36	1	33%
Subtask 4: prepare annual report	11-36	1	15%
Subtask 5: refine business plan	13-36	1	Out of scope

<i>Milestone #7: Business plan created and revised to reflect initial 3 years of platform existence.</i>	36		Out of scope
<b>Major Task 9: Develop and implement patient engagement in research plan</b>	Months	Site(s)	% Completion
Subtask 1: develop patient engagement plan	2-4	1	33%
Subtask 2: implement patient engagement plan	5	1	0%
Subtask 3: engage and mentor additional Patient Advocates	5-36	1	33%
<i>Milestone #7a. Two additional Patient Advocates integrated and engaged as part of the R-PEC biobank.</i>	20		Out of scope
<i>Milestone #7b: Two additional Patient Advocates are integrated and engaged as part of the R-PEC biobank.</i>	36		Out of scope
<b>Major Task 10: Conduct mixed methods analysis to determine impact of patient engagement</b>	Months	Site(s)	% Completion
Subtask 1: prepare research ethics board application	1-2	1	0%
Subtask 2: obtain research ethics board approval	4	1	0%
Subtask 3: administer Patient and Public Engagement Evaluation Tool	6, 9, 12, 15	1	0%
Subtask 4: conduct semi-structured interviews	15-18	1	Out of scope
Subtask 4: review adoption of patient engagement in research	15-18	1	Out of scope
Subtask 5: analyze results	18-21	1	Out of scope
Subtask 6: disseminate results	21-24	1	Out of scope
<i>Milestone #8: Manuscript published on patient engagement analysis</i>	24		Out of scope

### What was accomplished under these goals?

#### **Major Task 1: Obtain Research Ethics Board approval**

- Subtasks 1-3:
  - Protocol approved by the Hospital for Sick Children (SickKids) Research Ethics Board (REB) and USAMRDC OHRO.
- Subtask 4:
  - Status of Partner Site Material and Data Transfer Agreements (MDTA) are summarized in Table 2.
  - Sites 6, 7 and 9 are nearing MDTA execution.
  - Sites 3, 5 and 8 have had various delays including institutional barriers and resource constraints.
    - The R-PEC Principal Investigator (PI) and Co-Investigator are supporting Partner Sites with mitigating unforeseen barriers as they arise.
    - A Site meeting is being scheduled for October 2023. This meeting will include shared trouble shooting and showcasing success stories from leading Partner Sites.
  - In addition to the Sites named on the original grant application nine additional Sites have been approached for involvement in the R-PEC Biobank
    - Five of the additional sites are discussing the opportunity with the R-PEC PI
    - Three of the approached sites have declined collaboration due to institutional barriers or resource constraints

- One of the approached sites has agreed to participate as a Partner Site and has entered the MDTA review process as described in Table 3.

**Table 2. Partner Site Material and Data Transfer Agreements Status**

Site Number Per Grant Application	Site	MDTA Reviewed by Site	MDTA Revisions Requested by Site Approved by SickKids	MDTA Signed by Site	MDTA Signed by SickKids
1	SickKids	N/A	N/A	N/A	N/A
2	Boston Children's Hospital	N/A (withdrew)	N/A (withdrew)	N/A (withdrew)	N/A (withdrew)
3	BC Children's Hospital	In progress	Pending	Pending	Pending
4	The Stollery Children's Hospital	N/A (withdrew)	N/A (withdrew)	N/A (withdrew)	N/A (withdrew)
5	IWK Health Centre	In progress	Pending	Pending	Pending
6	Children's Hospital of Winnipeg	Yes	In progress	Pending	Pending
7	Children's Hospital of Eastern Ontario	Yes	Yes	Yes	In progress
8	Cleveland Clinic	In progress	Pending	Pending	Pending
9	University of Liverpool	Yes	Yes	In progress	Pending

**Table 3. Additional Partner Site Material and Data Transfer Agreements Status**

Site Number	Site	MDTA Reviewed by Site	MDTA Revisions Requested by Site Approved by SickKids	MDTA Signed by Site	MDTA Signed by SickKids
10	Centre hospitalier universitaire (CHU) Sainte-Justine	In progress	Pending	Pending	Pending

### Major Task 2: Recruit patients

- Due to the unforeseen delays in obtaining regulatory approvals as documented in the previous semi-annual progress report, accrual was delayed for the R-PEC Biobank.
- Accrual at SickKids (Site 1) commenced March 2023:
  - 11 participants enrolled:
    - 10 malignant neoplasms of the retina
    - 1 benign neoplasm of the retina
  - Staff at SickKids are requiring more support than initially anticipated to identify potential participants. So, additional personnel are being recruited to support accrual at SickKids:
    - A Research Assistant job search initiated spring 2023 was unsuccessful.
    - A new Research Assistant job search commenced June 2023, candidates are currently being screened.
- Accrual at Partner Sites is anticipated to commence August 2023 (Site 7).

### **Major Task 3: Collect specimens and data**

- 10 specimens were collected from enrolled (Site 1) participants.
  - Specimens include blood, aqueous humor, vitreous humor, tumor tissue and neoplastic tissue.
  - All specimens have been processed, stored and associated data documented.
- Preliminary clinical data for enrolled participants have been collected.
- A Standard Operating Procedure (SOP) for image collection and storage currently being developed and image collection is expected to commence October 2023.

### **Major Task 4: Review and approve data access requests**

- Efforts to engage with Platform Users were postponed due to the delays in regulatory approvals (Major Task 1).
- Significant progress has been made on the processes required to successfully facilitate data and material sharing:
  - Created Terms of Reference for the Data and Material Access Committee.
  - Developed a comprehensive pathway for material and data requests.
  - Finalized material and data access SOP.
  - Enhanced the Intake Form and Material and Data Request Form.

### **Major Task 5: Generate biobank resources**

- As documented in the previous semi-annual progress report, we determined that a Post-Doctoral Research Fellow role would be best suited to lead developed of the biobank resources under the direction of the Principal Investigator and that a Post-Doctoral Research Fellow would be most effective once Major Task 1 was complete.
- A Post-Doctoral Research Fellow job search initiated fall 2022 was unsuccessful.
- Targeted recruitment for the Post-Doctoral Research Fellow will commence October 2023.

### **Major Task 6: Disseminate biobank model**

- Created framework for biobank website, which is currently live.
- Identified potential Platform Users and initiated preliminary discussions.
- Submitted abstracts to the International Society of Pediatric Oncology annual congress.
- Created a list of relevant databases to register the biobank on.
- Created the KPI which will be shared as part of the broader business plan dissemination activities.

### **Major Task 7: Establish governance structure**

- The governance structure was finalized as part of the business plan (see appendix) and will be subject to an annual review.
- In implementing the business plan and corresponding governance structure, the following oversight committees and corresponding terms of reference were established:
  - Operations Committee – established and meets quarterly
  - Material and Data Access Committee – recruitment of members has commenced and initial meeting to occur September 2023
  - External Advisory Committee – recruitment of members has commenced and initial meeting to occur September 2023
  - Patient Advisory Committee – please see below, Major Task 9

### **Major Task 8: Develop and implement business plan**

- The R-PEC Biobank Business Plan is finalized and encompasses:

- Mission and vision
- Key elements and guiding principles
- Governance (see appendix)
- Management
- Operations
- Financial plan
- KPIs
- Accrual targets
- Marketing and communication
- Implementation plan; and
- Risks and mitigation strategies.
- Annual Report for year 1 will include:
  - Detailed accrual report – complete
  - KPI report – in progress

### **Major Task 9: Develop and implement patient engagement in research plan**

- The three Patient Advocates named on the grant (“Patient Advocate Committee”) have been developing plain language content for website and developing recruitment strategy for additional Patient Advocates.
- A framework for the patient engagement plan being developed by the Research Manager.
- The Patient Advocates will then co-develop the patient engagement plan alongside the Research Manager.
- The existing Patient Advocates are also developing a plan to recruit additional patient partners for the project.

### **Major Task 10: Conduct mixed methods analysis to determine impact of patient engagement**

- The purpose of this analysis was to determine the: (i) quality of patient engagement in biobank governance and operations; (ii) perceived impact of patient engagement on biobank operations and outputs by clinical, patient and research stakeholders; (iii) adoption of patient engagement in research by Platform Users, and (iv) satisfaction with the return of research results to participants.
- A Master’s student has been selected to lead this project and will commence September 2023.

### **What opportunities for training and professional development has the project provided?**

- International Society of Biological and Environmental Repositories (ISBER) meeting June 2023
  - ISBER aims to advance expertise and quality of biorepositories and biobanking science worldwide.
  - Attended by the Principal Investigator, Research Manager and Research Coordinator.
  - The R-PEC Study Team established connections with several important stakeholders in the field of pediatric biobanking.
  - Relevant sessions included:
    - Children’s Health, Research, and Biobanking – How Do We Juggle it All with Less?
    - Navigating the Needs of Our Researchers; Working Through Demanding Biospecimen Requests

- Universal Consent for Biobanking
- Building Bridges: Towards An International Framework for Specimen Sharing

### **How were the results disseminated to communities of interest?**

- The R-PEC Biobank was disseminated at a national retinoblastoma conference, January 2023, attended by patients, health professionals and researchers.

### **What do you plan to do during the next reporting period to accomplish the goals?**

#### **Major Task 1: Obtain Research Ethics Board approval**

- Host a Partner Site meeting in October 2023 to galvanize partnerships and support any Partner Sites with an incomplete MDTA and mitigate barriers.
- Enhance communication of the benefits for Partner Sites that participate in the R-PEC Biobank.
- Invest a concerted effort into executing the MDTA with highest yield Partner Sites.

#### **Major Task 2: Recruit patients**

- SickKids:
  - Hire a Research Assistant.
  - Recruit staff (i.e., Clinical Fellows, Research Coordinators) that work alongside health professionals treating patients with R-PECs to help identify potential participants.
- Partner Sites:
  - Recruit additional Partner Sites to ensure accrual targets are reached despite original partners withdrawing from the project.
  - Host Individualized onboarding sessions with Partner Sites. This will allow for minor customizations to operating procedures to ensure efficient recruitment workflow at each Partner Site.
  - Send newsletter to Partner Sites to foster a sense of togetherness and community.
  - Host quarterly virtual Partner Site meetings to share actual versus projected accrual numbers and strategies for improvement.

#### **Major Task 3: Collect specimens and data**

- Specimen and data collection will coincide with increased accrual (Major Task 2).
- A quarterly report will be sent to each Partner Site outlining real versus projected specimen collection and missing data.
- The image collection and storage SOP will be tested for enrolled participants at Site 1.
- Image collection and storage will commence October 2023.

#### **Major Task 4: Review and approve data access requests**

- The first Data and Material Access Committee Meeting will take place September 2023.

#### **Major Task 5: Generate biobank resource**

- Targeted recruitment for the Post-Doctoral Research Fellow will commence October 2023.
- A priority area for the Post-Doctoral Fellow will be to obtain institutional approval for the pilot studies governing the resource development and execute agreements with SickKids Cancer Screening Program.
- Sequencing 8 patient specimens by April 2024.

### **Major Task 6: Disseminate biobank model**

- Enhance the website with:
  - Content developed as part of the business plan (i.e., governance structure, cost recovery mode, implementation plan and KPI)
  - Annual Report for year 1
  - Information relevant to potential Platform Users (e.g., intake form, pathway for material and data requests, etc.)
- Enhance list of Potential Platform Users with External Advisory Committee members.
- Share website with Potential Platform Users.
- Present posters at SIOP Congress 2023.
- Register R-PEC Biobank with at least one database.

### **Major Task 7: Establish governance structure**

- Finalize recruitment of the following oversight committees and hold inaugural meetings September 2023
  - Data Material Access Committee
  - External Advisory Committee
  - Patient Advisory Committee

### **Major Task 8: Develop and implement business plan**

- Finalize Annual Report for year 1 and share on website.
- Follow established implementation plan and amend as required.

### **Major Task 9: Develop and implement patient engagement in research plan**

- Engage additional Patient Advocates.
- Host Patient Advisory Committee meeting.
- Draft patient engagement plan with Patient Advocates to include roles in; outreach and recruitment of R-PEC Biobank participants; dissemination of R-PEC Biobank outcomes; and recruitment and mentorship of new Patient Advocates.

### **Major Task 10: Conduct mixed methods analysis to determine impact of patient engagement**

- Onboard Master's student September 2023.
- Initiate development of protocol for mixed methods analysis.

#### **4. IMPACT**

Nothing to report.

#### **5. CHANGES/PROBLEMS:**

Nothing to report.

#### **6. PRODUCTS:**

Nothing to report.

## 7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS:

### What individuals have worked on the project?

Name: Helen Dimaras  
Project Role: Principal Investigator  
Researcher Identifier (e.g. ORCID ID): 0000-0003-1164-2001  
Nearest Person Month Worked: 2  
Contribution to Project: Provided scientific oversight and leadership to all R-PEC Biobank staff, engaged Partner Sites and Platform Users, directed all regulatory activities (including amendment submissions and MDTA development), directed development of key R-PEC Biobank assets (including the Business Plan, SOPs, and website), participated in recruitment efforts for new hires, participated quarterly Operations Committee meetings and weekly meetings with the Research Coordinator and Research Manager to discuss study progress.

Name: Kaitlyn Flegg  
Project Role: Research Manager  
Researcher Identifier (e.g. ORCID ID): 0000-0001-9606-6298  
Nearest Person Month Worked: 2  
Contribution to Project: Led Business Plan development, contributed to regulatory activities (e.g., MDTA development), provided mentorship and support to the Research Coordinator and Patient Advocate, participated in Partner Site onboarding, participated in developing website assets, developed project work plan, maintained project budget, co-led quarterly Operations Committee meetings, participated in weekly meetings with the PI and Research Manager to discuss study progress, and led recruitment efforts for new hires.

Name: Roxanne Noronha  
Project Role: Research Coordinator  
Researcher Identifier (e.g. ORCID ID): 0000-0002-4712-046X  
Nearest Person Month Worked: 12  
Contribution to Project: Recruited and consented participants at SickKids, collected specimens and clinical data from SickKids participants, coordinated procurement of materials and supplies, coordinated onboarding of all Partner Sites, coordinated development of SOPs,

coordinated amendments, coordinated the MDTA development, supported the Patient Advocates participating in developing website assets, organized Partner Site meetings, developed material to present at Partner Site meetings, co-led quarterly Operations Committee meetings, hosted weekly meetings with the PI and Research Manager to discuss study progress, maintained project work plan, and contributed to recruitment efforts for new hires and vetting activities.

Name:  
Project Role:  
Researcher Identifier (e.g. ORCID ID):  
Nearest Person Month Worked:  
Contribution to Project:

Ivana Ristevski  
Patient Advocate  
N/A  
1  
Attended quarterly Operations Committee meetings, coordinated the group of Patient Advocates by meeting with each individually to provide training, and maintained regular correspondence to support completion of tasks and to foster a sense of togetherness.

Name:  
Project Role:  
Researcher Identifier (e.g. ORCID ID):  
Nearest Person Month Worked:  
Contribution to Project:

Samuel Soroka  
Research Assistant  
N/A  
3  
Recruited and consented SickKids participants, assisted with collecting specimens and clinical data from SickKids participants, assisted with development of SOPs and assisted with ordering materials and supplies.

**Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?**

Nothing to Report

**What other organizations were involved as partners?**

Nothing to Report.

**8. SPECIAL REPORTING REQUIREMENTS**

Not Applicable.

## 9. APPENDICES:

**Table 4.** List of Partner Sites Named in Grant Application

<b>Site</b>	<b>Name</b>	<b>Address</b>	<b>PI Name</b>
1	The Hospital for Sick Children	555 University Ave, Toronto, ON, M5G 1X8	Dr. Helen Dimaras
2	Boston Children's Hospital	300 Longwood Ave, Boston, MA, 021155724	Dr. Efren Gonzalez
3	BC Children's Hospital	4500 Oak St, Vancouver, BC, V6H 3N1	Dr. Katherine Paton
4	The Stollery Children's Hospital	8440 112 St NW, Edmonton, AB, T6G 2B7	Dr. Carlos Solarte
5	IWK Health Centre	5850/5980, University Ave, PO Box 9700, Halifax, NS, B3K 6R8	Dr. Johane Robitaille
6	Children's Hospital of Winnipeg	CE216-820, Sherbrook St, Winnipeg, MB, R3A 1R9	Dr. Ian Clark
7	Children's Hospital of Eastern Ontario	401 Smyth Rd, Ottawa, ON K1H 8L1	Dr. Michael O'Connor
8	Cleveland Clinic	9500 Euclid Ave, #132, Cleveland, OH, 441950001	Dr. Arun Singh
9	University of Liverpool	200 London Road, Liverpool, L3 9TA	Dr. Sarah Coupland

**Figure 1. R-PEC Biobank Governance Structure**

