



Patient Advocate Committee Information Guide

Part 1: The Kids Eye Biobank

The **mission** of the Kids Eye Biobank is to **collect and store high-quality data** on childhood eye conditions and **share** these resources with a **large global network of researchers**.

WHAT?

What is a biobank? A biobank is like a **library**, but instead of books, it **stores samples of human tissue** (like tumors or blood), as well as **health information** and **medical images**. This library of resources is used by scientists to study diseases and find cures.

What are rare pediatric eye cancers (R-PECs)? R-PECs include over 30 types of lesions or growths that can affect all parts of the eye, such as the retina or the eyelid.

WHY?

Why is the Kids Eye Biobank important?

- It serves as a **centralized resource** for research and learning and **connects researchers, clinicians, and affected individuals** around the globe, making it easier to study childhood eye conditions.
- It is the first biobank to have a segment solely dedicated to collecting data on rare eye cancers that affect children.
- It **enables** and **facilitates** research aimed at **reducing negative vision outcomes** and **promoting child health!**

WHERE?

Where is data stored? **Biological samples** (blood, tissue, fluids, etc) are stored at SickKids hospital in **liquid nitrogen freezers**. **Images and personal health data** are kept on a **secure server**.

HOW?

How are Kids Eye Biobank resources shared? Researchers and health professionals can put in a **request** to **access data** stored in the Kids Eye Biobank. These requests are **reviewed** by the **Material and Data Access Committee** (a team of patients, researchers and clinicians), who decide what information to share.

How are patients involved in research? Patients are involved in the governance and operations of the Kids Eye Biobank. **Check out Page 3** of this guide for **specific examples!**

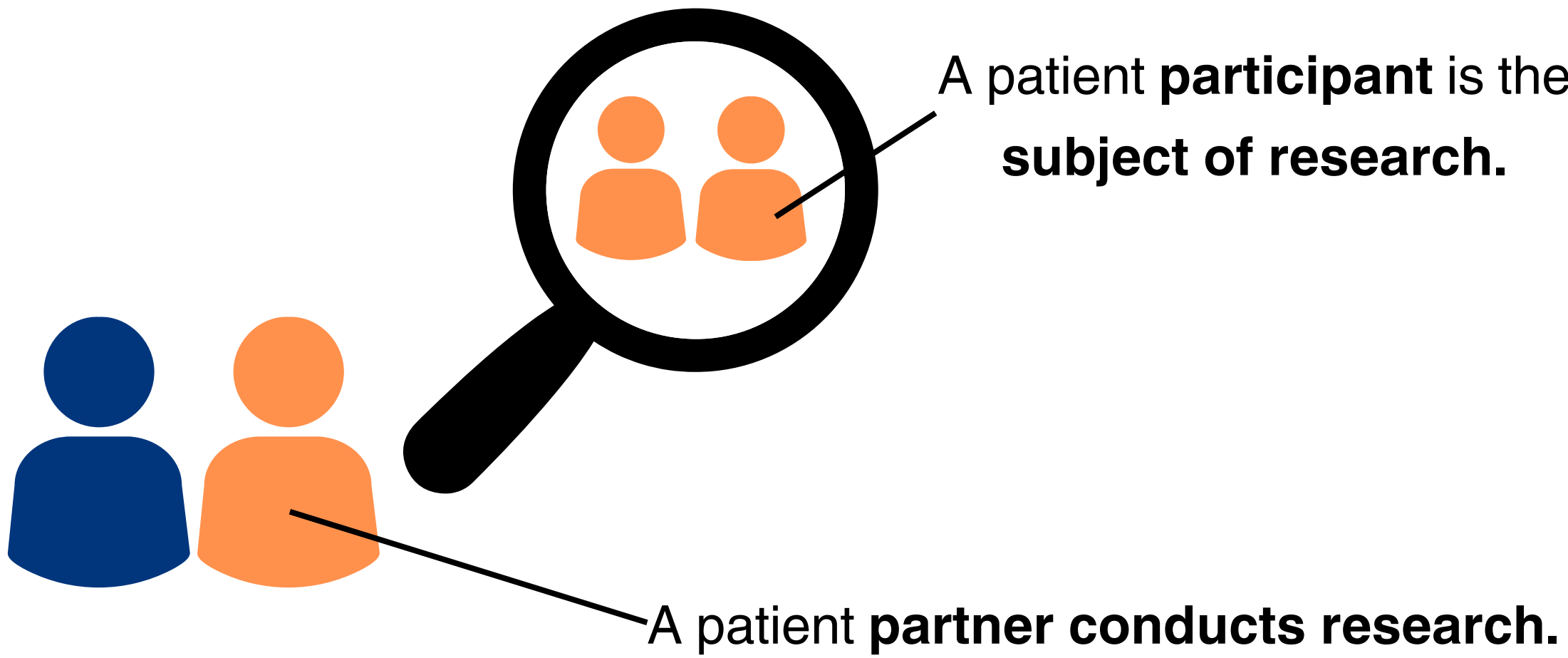
WHO?

Who are the key stakeholders:

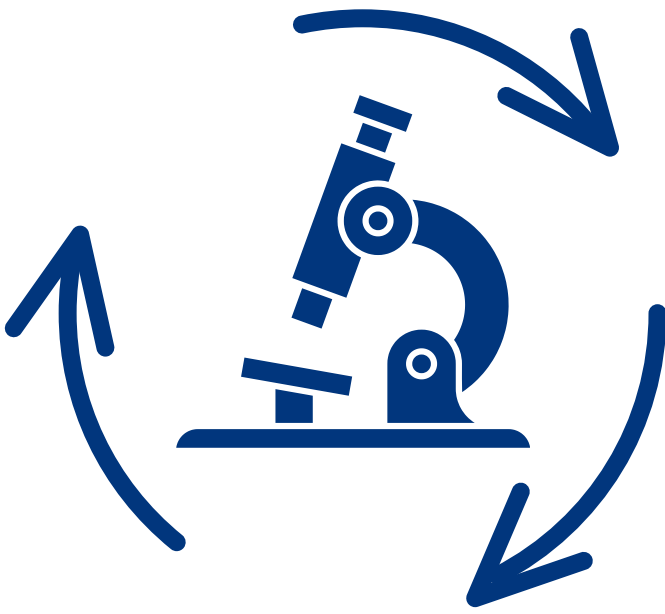
- **Patient participants:** Individuals who donate their health information to the Kids Eye Biobank. Participants are essential to the Kids Eye Biobank's operations!
- **Clinicians, researchers, patient partners** all collaborate and contribute to the Kids Eye Biobank's research, operations and decision-making processes.

The Kids Eye Biobank strives to **promote patient engagement in research through meaningful partnership and active collaboration.**

The term **'patient'** refers to a **person with a lived experience of disease.** This includes informal care givers, family and friends.

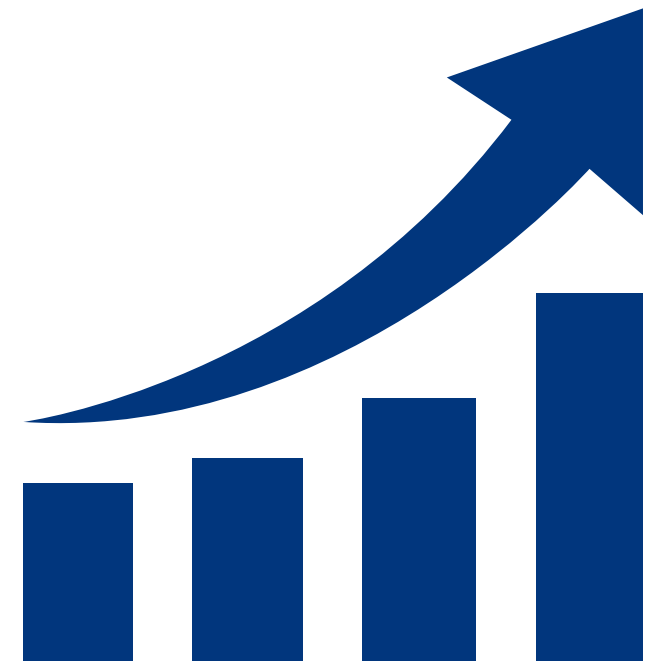


Why is Patient Engagement in the Kids Eye Biobank important?



SUSTAINABILITY

To foster the **long-term viability** of the **Kids Eye Biobank** it is important to engage patient partners who can provide input on its operations. **Your perspectives can help shape the Kids Eye Biobank's procedures and practices.**



RESEARCH IMPACT

Patients are the ultimate beneficiaries of research conducted using the Biobank's resources. Your involvement helps **ensure** that **researcher and clinician priorities align with patient needs.** Further, patient engagement can increase research impact, which may result in better patient health outcomes from research findings!



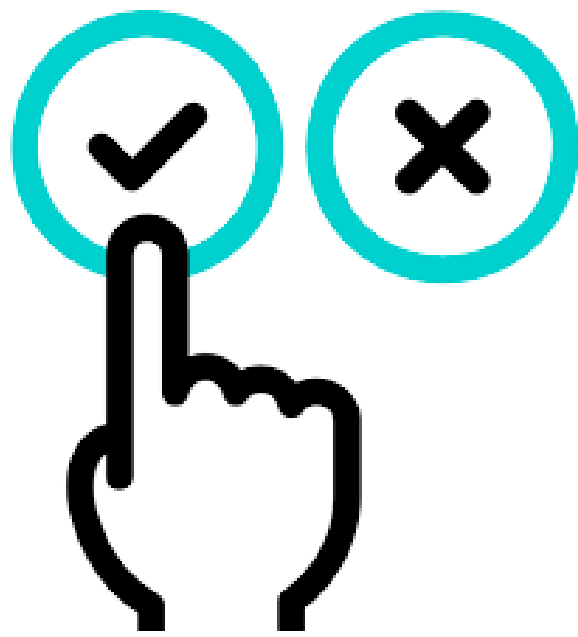
TRANSPARENCY

The Kids Eye Biobank relies on voluntary participation. This requires trust and communication between patient donors, the community, and the research team. Involving patient partners in decision-making processes promotes **transparency in how the Kids Eye Biobank operates, how data is used, and how research projects are conducted.**

Part 3: How are Patient Partners Involved in the Kids Eye Biobank?

Patient partners on the Kids Eye Biobank team work to facilitate the **inclusion** of the **lived experience** into **all levels of the Kids Eye Biobank's design and operations**. A few specific ways patients are partnered in the Kids Eye Biobank are listed below, however, **all skills and help are welcome and appreciated!**

DECISION MAKING



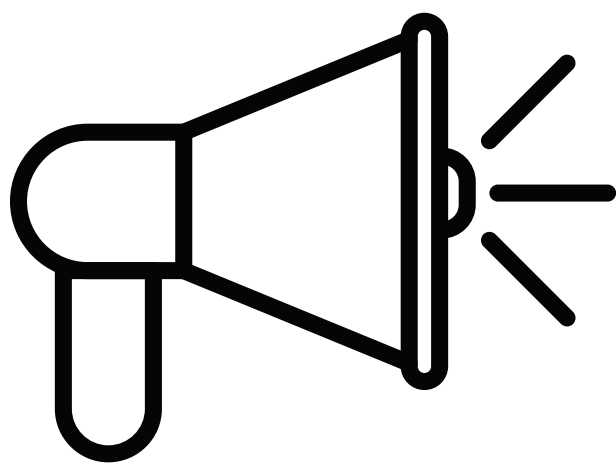
- Help **establish** the Kids Eye Biobank's **core governance structure**.
- Collaborate with researchers to **pick meaningful research directions**.
- Provide valuable insights to inform discussions of ethics, research relevance and quality.

RECRUITMENT



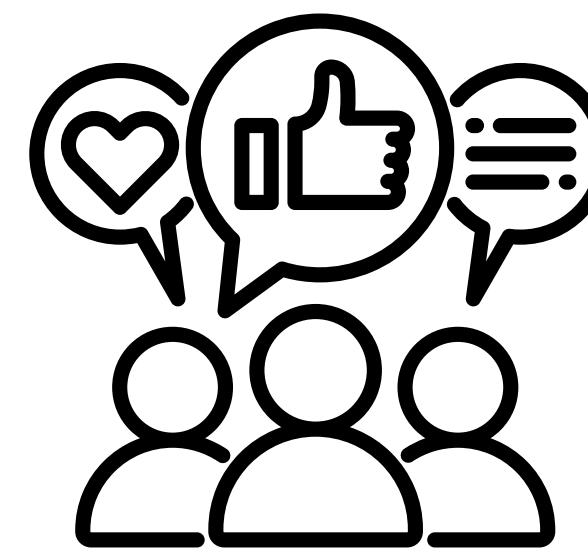
- Review and **improve consent documents**.
- **Identify barriers** to participation in the Kids Eye Biobank.
- Create materials to **enhance** patient participant **understanding, awareness, and support of the Kids Eye Biobank**.

AWARENESS



- **Engage in outreach efforts** to raise awareness of the Kids Eye Biobank and its importance.
- **Attend conferences and events**.
- **Create summaries of Kids Eye Biobank research**, to be shared with researcher and patient communities.

ENGAGEMENT



- Identify and **recruit** additional patient partners to increase diversity in experiences and diagnoses represented.
- Train and **mentor new patient partners** on the PAC, helping them develop research skills.

Have questions or ready to join? Reach out to us at advocates.kidseyebiobank@sickkids.ca

1. My R-PEC story began:

2. The reason I would like to get involved in research is:

3. I want to learn more about:

4. I am going to start by:
