

RESEARCH PRIORITIES IN LUNG TRANSPLANTATION



Developed in partnership with:



The Canadian **Donation and
Transplantation** Research Program
Programme de recherche en
don et transplantation du Canada



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alberta lung
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BACKGROUND

- Lung transplant patients and caregivers face **complex, lifelong challenges**.
- Research sometimes **overlooks what matters most** to those directly affected.
- Resources and funding for lung transplant research are **limited**.
- **Priorities** for future research about lung transplantation have not been established.
- This project aimed to identify the **most urgent and relevant** research priorities defined by patients, families, caregivers, and clinicians.

FINDING BETTER WAYS TO SUPPORT PATIENTS

This project used a **structured and open process** to **understand and set** the research priorities of all partners involved in lung transplantation.

Future research will be **strengthened** by helping researchers understand the **priorities that matter to patients, families, and caregivers**.

NEXT STEPS AND FUTURE DIRECTIONS

We aim to **empower patients, families, and caregivers to get involved** in research projects, to **partner with clinicians and researchers** to solve problems related to these research priorities.

Their perspectives can **make a difference** in all stages of research – from prioritization, to study design and conduct, to dissemination of results.

This project is now sharing the results of this project and results are being disseminated with researchers, funders, national, and international partners.

METHODOLOGY

This research project used the **James Lind Alliance** to determine the top 10 research priorities. **Through this method, we prioritized partnerships with patients and caregivers, who served on the steering committee to help shape research priorities.** Our process involved conducting surveys, analyzing data, and facilitating a consensus virtual workshop to co-develop the top 10 priorities. Patient and caregiver perspectives were embedded in all stages of the project.

HOW DOES IT WORK?

SURVEYS DISTRIBUTED

Pre- and post-transplant patients and their family members through clinics at all **4 lung transplant surgical centres, and a satellite non-surgical centre in Canada.**

Surveys asked respondents what the most important questions are for future lung transplantation research.



RESPONSES REVIEWED

and **grouped into related themes.** With patient, family, and caregiver partners, **we reviewed themes and wrote specific researchable questions.**



INTERIM SURVEY

We short-listed the top 30 priority questions and sent another survey to patients, families, caregivers, and clinicians.



SYSTEMATIC EVIDENCE SEARCH

We reviewed existing literature to the shortlisted questions to determine which were already sufficiently answered and which remained unanswered.



THE REMAINING 25 QUESTIONS WERE PRIORITIZED IN A VIRTUAL WORKSHOP WITH 11 PATIENTS, 6 CLINICIANS AND A CAREGIVER.

RESEARCH PRIORITIES

Below are some more research priorities that the participants identified.



REJECTION AND LUNG TRANSPLANT DYSFUNCTION

- How can we best reduce the risk of acute lung transplant rejection?
- How can chronic lung allograft dysfunction be prevented and treated?
- How can we prevent and treat baseline lung allograft dysfunction?
- What are the factors that drive the worsening of chronic lung allograft dysfunction over time?
- How can we improve methods to diagnose acute lung rejection earlier?



EDUCATION

- How can patient education and communication between lung transplant recipients and healthcare providers be optimized?

RESEARCH PRIORITIES

Below are some more research priorities that the participants identified.



INCREASING DONOR LUNG AVAILABILITY



What methods or techniques can be used to increase the proportion of available donor lungs that are suitable for transplant?



IMPROVING MEDICATIONS



How can we best monitor net immunosuppression' to tailor immunosuppressive medications to

- Maximize graft function
- Prevent acute and chronic rejection
- Minimize the risks of infection and cancer in lung transplant patients?



How can immunosuppressive medications be improved to minimize the degree of immunosuppression or pill burden in lung transplant recipients?



How can we best reduce the risk of kidney toxicity from Calcineurin inhibitors (i.e. Tacrolimus, cyclosporine) in lung transplant patients?

WHAT ARE THE IMPLICATIONS OF THIS PROJECT?

PARTICIPANT FEEDBACK

“The members of both groups I was involved with were well informed. Members helped explain the medical terms and processes that were being discussed and my individual prep allowed me to confidently make informed decisions.”

“I am satisfied with the top 10, only wishing that caregiver support and education could have come onto that list but I believe it's close. I was very impressed by the thoughtful and educational discussions during our times together & I felt that the medical professionals added so much without taking over. The facilitators were excellent.”

“I enjoyed the process. It opened my eyes to concerns that I had not really thought about until I heard other people's thoughts.”

“I agree with the top 10 we came to. As a pre- transplant patient my personal top 10 differed in some ways from the health care professionals and post transplant patients. Having their input helped me understand other topics and my perspective was changed on several topics.”

REFERENCES

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