

Research Initiative of the World Transplant Games Federation

The purpose of this document is to provide a clear definition of the Research Initiative of World Transplant Games Federation (WTGF) including an outline of its strategic aims, structure and programme of activities. We hope that this document helps to provide some transparency about the Research Initiative as well as helping to ultimately guide future research in this important area. This document has been prepared by the current co-chairs of the Research Initiative in consultation with the WTGF Executive Manager, Kim Reynard, an international network of researchers, the WTGF Executive and the Board of Trustees. It is intended that this document be updated and published periodically for as long as the Research Initiative is needed.



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1. Background

The purpose of the WTGF is to visibly demonstrate the benefits of successful organ transplantation, work to increase public awareness of its success and thereby increase organ donation rates, as well as promote the full rehabilitation and wellbeing of our participants. The promotion of full rehabilitation and wellbeing is best captured in the mission of the *Fit for Life* initiative: to get “more transplant recipients, more active, more often.”

Seeking diverse ways to realise these aims, the WTGF has for many years engaged with research. Members of the WTGF Education and Medical Committees have regularly presented at The Transplantation Society’s Annual Conference and numerous studies have been conducted with World Transplant Games participants as facilitated by the federation. Yet, the WTGF recognises that research is an underexplored area of their remit and is motivated to build on its existing foundations. Not only can research help the WTGF realise its aims but research can also provide the evidence base needed to inform its initiatives and add credibility our assumptions about the benefits of sport and exercise for organ and tissue transplant recipients.

Concurrently, researchers from around the globe have been interested in sport, exercise and health for organ and tissue transplant recipients for many years. As far back as the 1990s, studies were being conducted to better understand the impact of sport and exercise on patients, including McGee and Horgan’s early investigation into how participating in the Cardiac Games impacts health-related quality of life in 1996. Since then, there has been a proliferation of research in the area from a broad range of disciplines.

Most people in the transplant community are rightly in awe of the medical research that has allowed clinical teams to do the amazing things that they do. However, with more recipients living longer and healthier lives than ever it is important to broaden the remit of research to include aims that look beyond survival. Fortunately, there is a growing number of researchers, recipients and clinicians interested in investigating how recipients can live healthy, fulfilling, and meaningful lives after surviving an organ transplant. A vast array of exciting research topics open up when we think about such aims. Life after transplantation is, of course, reliant on the physiological functioning of the body. Yet, if recipients are to live well after transplantation it would be wise to pay attention to the importance of psychological experiences, social support, life opportunities, healthcare systems and supportive policies and regulations. Across all these areas, there are gaps in knowledge and curious questions to be answered.

While good progress appears to have been made within the literature, we believe that research will benefit greatly from being better coordinated, supported and disseminated. Effective research requires collaboration, funding, access to participants and an audience to share findings with so that knowledge can be translated into practice. The Research Initiative of the World Transplant Games Federation aims to help realise these ambitions by acting as a conduit to leading research and ultimately helping to improve the lives of organ and tissue transplant recipients on an international scale.

2. Mission and Strategic aims

Taking the background context into account, the Research Initiative has one mission and five strategic aims.

The mission for the Research Initiative is:

to support the growth of research into sport, exercise and health for organ and tissue transplant recipients by harnessing the synergies between the WTGF, its partners and the global network of researchers working in this area.

We have set out five strategic aims that shape the direction of this mission.

-  **1. Connecting:**
Connecting researchers from across the globe
-  **2. Generating ideas:**
Generating novel research ideas, questions and agendas
-  **3. Funding:**
Creating and enhancing funding opportunities
-  **4. Facilitating:**
Enabling new empirical studies to be conducted
-  **5. Disseminating:**
Sharing knowledge with the transplant community

The first aim, **connecting researchers from across the globe**, is about building and engaging with a network of researchers interested in sport, exercise and health for organ and tissue transplant recipients. The WTGF is in a good position to bring together existing researchers with shared interests who would otherwise be disconnected. Collaborative research projects, especially with international collaborators, help maximise the available labour capacity and are highly valued by Universities.

The second aim **generating novel research ideas, questions and agendas** focuses on the important intellectual and creative elements of scholarship. The Research Initiative can contribute to the development of new directions related to sport, exercise and health for organ and tissue transplant recipients largely as a result of increasing interactions between experts of various kinds and thought leaders across diverse academic disciplines.

The third aim, **creating and enhancing funding opportunities**, focuses both on supporting researchers in their funding applications and to directly provide small grants for research related to sport, exercise and health for organ and tissue transplant recipients. A modest budget will be made available for small research projects with an associated application procedure that is steered towards key priority areas.

The fourth aim, **enabling new research to be conducted**, is included in light of the WTGF's potential to help recruit participants through social media platforms and their data base of organ and tissue transplant recipients who have registered to take part in events.

The final aim acknowledges the importance of **sharing knowledge with the transplant community**. We believe that the Research Initiative is capable of – and obliged to – help disseminate research findings amongst researchers as well as the wider community of people interested in sport, exercise and health for organ and tissue transplant recipients.

4. Programme of activities

In practice, the WTGF Research Initiative is expected to deliver a programme of activities in order to accomplish its aims as follows:

Research network discussion forum

The Research Initiative will host online meetings – held every other month – as a space for networking, exchanging of ideas and fostering collaborations. Co-chairs will facilitate discussions and often introduce a topic, but attendees will be invited to contribute and shape the conversation.

Targets for 2022:

- Host 6 online meetings
- Grow network of attendees to over 20
- Highlight two novel research ideas that have emerged from the meetings

Webinar series

The Research Initiative will host webinars – held every other month – as another effective way of connecting researchers and generating novel research ideas, questions and agendas. Speakers will usually be leading researchers and their remit will be to aim at other researchers, medical professionals and postgraduate students interested in sport, exercise and health after transplantation. Each webinar will be recorded and made available on the WTGF website.

Targets for 2022:

- Host 6 webinars
- Engage over 100 participants

Web content and digital presence

Having an online presence is crucial for promoting the initiative and housing relevant information for researchers wishing to engage. New webpages on the WTGF website will be created for the Research Initiative. Content will include: recordings of previous webinars, details of upcoming webinars and events, an accessible library of published studies categorised by discipline, information about funding opportunities, and contact information. A social media presence will help generate interest in the initiative and develop the network. Research-related content for social media will be posted through existing WTGF accounts.

Targets for 2022:

- Publish new webpages on the WTGF website
- Provide weekly research-related social media posts

Small research grants

Being able to offer small grants is a clear way of supporting research to get off the ground. Small grants are vital to enable pilot studies to be conducted, to pay for necessary equipment or services, to fund travel for collaborative meetings, to help researchers develop ideas leading to larger grants and even to co-fund PhD studentships. Funds for research may be generated in conjunction with ongoing WTGF initiatives (such as *Fit for Life*) or may be raised by working with the WTGF to raise funds from existing partners or new sources.

Our vision for offering small grants in future is to be able to raise around \$100,000 per year and to distribute this funding through a competitive application process that includes grants

intended for: conference attendance (\$1,000), development awards (£5,000), small investigations (\$10,000) and PhD studentships (\$50,000). This approach would involve invitations for applications once per year and will be organised around key priority areas that are important to the WTGF. It will be the responsibility of the Chair(s) and the panel members to provide information about small grants on the website, publicise their availability, handle incoming applications, make decisions about which projects to fund and work with the WTGF to arrange transfer of funds.

Targets for 2022:

- Raise \$10,000 for research activities
- Establish application handling and financial distribution process
- Fund five conference attendances and one development award

Letters of support

Applications for research funding often require supporting documents to demonstrate that external stakeholders are supportive of the research idea and/or to confirm that a consultation has taken place. The Chair(s) of the WTGF Research Initiative are happy to provide letters of support (providing that the projects fits within the remit and values of the WTGF) as well as engage with the research project more broadly as part of a stakeholder involvement process.

Targets for 2022:

- Create letter of support template
- Provide letters of support on request

Participant recruitment and patient involvement

Conducting primary research often relies on the participation of human subjects. Recruitment of participants can be a challenging part of research, especially so for international studies. With a large mailing list of transplant recipients, the WTGF is in a good position to facilitate the recruitment of participants. The Research Initiative can assist in this process by screening requests largely to ensure that studies have undergone necessary ethical approval processes so that the WTGF can be confident that they are supporting legitimate research.

Patients and other end-users are increasingly being included in the designing and planning of research. In many cases, involving patients and other end-users has become a necessary component of research funding applications. As with participant recruitment, the WTGF is in an excellent position to help find willing volunteers to be involved in such activities but it is appropriate to ensure that requests from researchers are screened before the WTGF can deal with such requests.

Targets for 2022:

- Support the recruitment of participants for research and patient involvement activities on request

Secondary data

The WTGF collects data on organ and tissue transplant recipients through the registration process for the World Transplant Games as well as ongoing initiatives such as the *Billion Steps Challenge* and *Fit for Life*. Information collected about recipients has the potential to be a valuable resource for researchers working in this area. Following proper ethical and legal regulations, the Research Initiative hopes to build a large and international data set that can help to answer important research questions in future. Once secondary data is available, it will be necessary to put a process in place in order to manage researchers' access. Researchers should contact the Chair(s) in the first instance to discuss access options.

Targets for 2022:

- Be in a position to offer secondary data to researchers by the end of 2022
- Work with WTGF management to clarify what data is available
- Clarify GDPR compliance, ethical and regulatory best practice

Research content for the WTGF Journal

The WTGF Journal, *Transplant World*, provides an excellent opportunity to disseminate summaries of research to a wide, non-academic and international audience.

Targets for 2022:

- Provide an executive summary of recently published research for each of the journal publications

Research Symposium held at the World Transplant Games

The existing symposium event held during the World Transplant Games presents an appropriate opportunity to showcase some of the research that the WTGF has supported as well as offering a potential meeting place for researchers who have engage in the programme of activities in the preceding two years.

Targets for 2022:

- Engage with the local organising committee of the Perth 2023 Games to support the planning of the symposium

4. Structure

The work of the Research Initiative is carried out by the Chair (or two Co-Chairs) appointed by the WTGF Executive and four panel members appointed by the Chair(s). The Research Initiative operates as a sub-committee of the WTGF Medical Committee although is not formally recognised as part of the WTGF organisation or constitution. It is expected that personnel be in place for two years, coinciding with the normal two-year cycle of World Transplant Games events. While it is anticipated that no staffing policy is required, it is recommended that the WTGF Executive exercise judgement in approaching Chair(s) in light of the need to balance continuity and the need for diversity.

The responsibilities of the Chair(s) include leading on the Programme of Activities, reporting back to the WTGF Medical Committee on successes or shortcomings and dealing with any matters arising.

The responsibilities of the 4 panel members include serving on one panel meeting to help decide on funding allocation and to support the Programme of Activities at the request of the Chair(s). The Chair(s) should actively seek to recruit a panel that offers diversity across protected characteristics, geography, and ensure that a transplant recipient is represented.

