



dedicated to finding a cure

Inquiry into International Research Collaboration

The Juvenile Diabetes Research Foundation

February 2010

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EXECUTIVE SUMMARY AND LIST OF RECOMMENDATIONS

The Juvenile Diabetes Research Foundation (JDRF) exists to find a cure for type 1 diabetes, a disease that affects 140,000 Australian children and adults.

Exciting basic research progress is being made in this field globally, with an increasing number of investigator and pharmaceutical company-driven concepts seeking the infrastructure and support to conduct preclinical and clinical trial research.

JDRF's role in supporting this research progress includes the facilitation and direct funding of significant amounts of international research collaboration, planning, and management. This "funder" or "patient group" perspective is one that is valuable to be added to complement the researcher perspective that will already have been provided to the Inquiry.

JDRF values and appreciates the intentions of the *Inquiry into International Research Collaboration*. This document intends to contribute towards the further exploration of the areas outlined in the announcement of the Inquiry.

JDRF's recommendations in response to the *Inquiry* are as follows:

RECOMMENDATIONS:

- 1 Include the guidance and management role of funding groups in planning for increasing and supporting international research collaboration**
- 2 Include a focus on the benefits of collaboration in research *funding* when considering benefits of international research collaboration**
- 3 Build funding for international collaboration more explicitly into research funding agreements**
- 4 Build greater levels of physical exchange of staff into research support models: across disciplines, geographies, and career stages.**

1 THE NATURE AND EXTENT OF EXISTING COLLABORATIONS

1.1 Patient organisations are an important element of many international collaborations

Patient organisations can be a significant driver of research planning, investment, management, and coordination. Patients are the ultimate beneficiaries of research progress, and the driver of patient group interest.

Patient groups are well placed to play a greater and more effective role in encouraging international collaboration, because

- They have a vested interest in the development and success of research, generally in specific disease areas.
- There are often existing international linkages between complementary patient groups (such as with the Juvenile Diabetes Research Foundation and type 1 diabetes internationally)
- In many instances they fund research directly, and can therefore positively influence the behaviours of researchers and institutions.
- The ‘patient perspective’ is an important complement and balance to the very differing motivations of academic researchers and pharmaceutical or biotech companies (see Figure 1 below)..

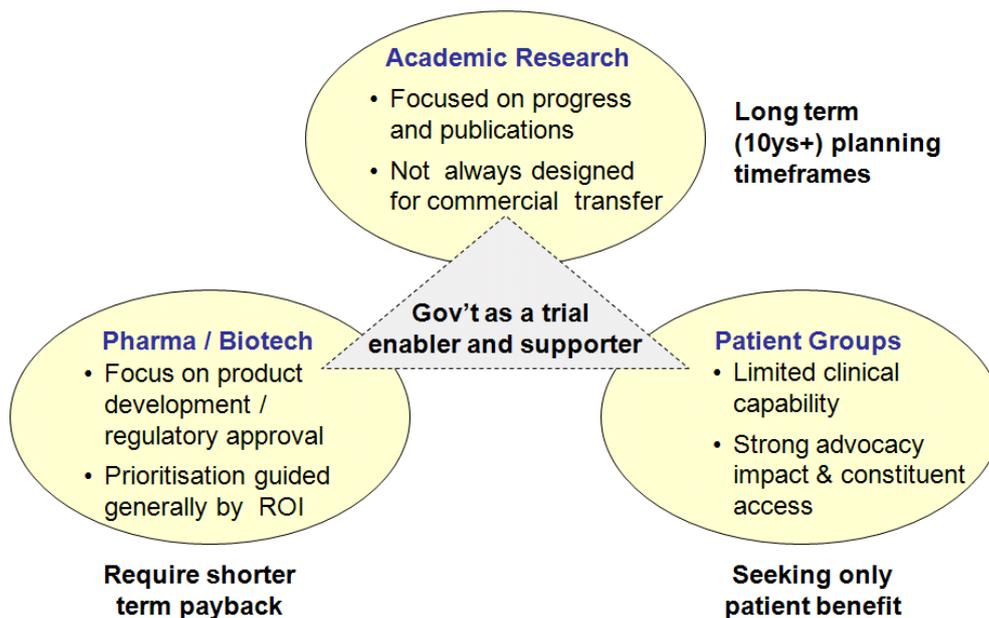


FIGURE 1: KEY CLINICAL TRIAL STAKEHOLDERS AND INTERESTS

As a result, the voice of patient groups is an important one to add in to discussions on how and why to support international research collaboration.

RECOMMENDATIONS:

- 1 Include the guidance and management role of funding groups in planning for increasing and supporting international research collaboration**

1.2 Examples of strong patient group / funder involvement in international research collaboration

There is a range of models of international collaboration that are more complex or different to direct researcher collaboration. These include models in which the collaboration is based around funding and governance, as well as execution. Examples include:

Government research support through partnership with patient group with the ability to drive international linkages (JDRF)

The Islet Transplantation Program (ITP)

Islet transplantation involves the transplant of insulin producing islet cells from a cadaveric donor to a patient with type 1 diabetes whose own insulin producing cells have been destroyed through the onset of the disease.

The Juvenile Diabetes Research Foundation has been directly funded \$30m over five years by the Department of Health and Ageing to manage and administer the program, separate to but coordinated with other projects funded through the NHMRC.

The ITP has established a clinical trial program to conduct islet transplantation procedures for people with severe cases of type 1 diabetes. It has also established a basic research program in support of improved clinical outcomes.

The researchers in this project are closely linked into comparable research projects overseas, through JDRF (who fund and coordinate many similar projects internationally)

Joint NHMRC / international patient group (JDRF International) partnership

The Diabetes Vaccine Development Centre

The Diabetes Vaccine Development Centre Ltd (DVDC) is a joint initiative of the Australian Government, through the National Health and Medical Research Council (NHMRC), and the Juvenile Diabetes Research Foundation International (based in New York and affiliated with JDRF in Australia). Both organisations initially contributed \$5m each to establish the DVDC, and have recently committed to a second round of funding.

The DVDC was established to accelerate the development of one or more vaccines that would prevent or delay the progress of early onset diabetes, aiming to have clinical proof of concept in 3-5 years, with studies conducted to a standard acceptable to regulatory agencies and to an eventual industrial partner

The DVDC currently manages a portfolio of preclinical and clinical research projects, and coordinates a network of eight sites across Australia involved in these projects as well as providing trial coordination, data management and other support services.

JDRF International both funds and is involved in the management / governance of the project, along with the NHMRC. This is a different type of research collaboration.

International trial networks

TrialNet

The Type 1 Diabetes TrialNet is an international network of researchers who are exploring immunologically-based ways to prevent, delay and reverse the progression of type 1 diabetes. It is jointly funded by the US Government, the Juvenile Diabetes Research Foundation in the US, and the American Diabetes Association.

TrialNet is conducting clinical trials with researchers from 18 Clinical Centers in the United States, Australia, Canada, Finland, United Kingdom, Italy, Germany and New Zealand. In addition, more than 150 medical centers and physician offices are participating in the TrialNet network.

To date, Australian participation in TrialNet has been limited. There is considerable potential to boost Australian participation in TrialNet trials in the future facilitated through the proposed type 1 diabetes clinical trials network. This is a funding and management type of international collaboration.

International trial networks

The Immune Tolerance Network

The Immune Tolerance Network (or ITN) is a non-profit consortium of researchers working together to establish new treatments for diseases of the immune system. The ITN conducts clinical trials in the following areas:

- the prevention of organ transplant rejection
- the treatment of autoimmune diseases such as type 1 diabetes
- the prevention and treatment of allergies and asthma

The ITN is funded predominantly by the US Government, with support from the National Institute of Diabetes and Digestive and Kidney Diseases and the Juvenile Diabetes Research Foundation in the US.

This program is active internationally, promoting and supporting collaboration and coordination of research.

RECOMMENDATIONS:

- 1 In considering of models of collaboration, include examples of collaboration in funding and governance as well as execution of research**

2 BENEFITS FOR AUSTRALIA

Increasing collaboration provides benefits beyond those related to research outcomes including:

- Access to sources of international funds (JDRF coordination of international research funding activities results in a net inflow of funds to Australia in the millions of dollars annually)
- Coordination of research planning and funding ensures that Australian research funding is targeted at the best research in global, not just local, terms
- International collaboration in funding decisions requires an international understanding of the priority research agenda for any given area, which dramatically

increases the efficiency with which research projects can be chosen in any given jurisdiction

RECOMMENDATIONS:

2 Include a focus on the benefits of collaboration in research funding when considering benefits of international research collaboration

3 KEY DRIVERS OF COLLABORATION

In addition to the most commonly considered drivers of research collaboration, an oft-forgotten driver is patient interest.

JDRF requires international collaboration between researchers (at the funding, execution, and communication levels) to ensure that there is the greatest likelihood that patient interest will be best served through the research conducted. This is a layer of review on top of scientific review – now seen as a leading model internationally.

RECOMMENDATIONS:

3 Build funding for international collaboration more explicitly into research funding agreements

4 IMPEDIMENTS TO COLLABORATION

From the perspective of a patient group funding researchers globally, the main impediments to collaboration include:

- A lack of a culture of collaboration in some areas of research
- Differences between different scientific disciplines
- Few funding model incentives to overcome this cultural challenge
- Differences in time zones and geographies

The most effective way to overcome this is to facilitate a greater level of physical exchange of researchers across these boundaries. **Such exchange builds personal relationships, which are the foundation of effective collaboration**

RECOMMENDATIONS:

4 Build greater levels of physical exchange of staff into research support models: across disciplines, geographies, and career stages.

5 STRATEGIES FOR SUPPORTING COLLABORATION

RECOMMENDATIONS:

5 As outlined above in 1 – 4

6 ABOUT THE JUVENILE DIABETES RESEARCH FOUNDATION

6.1 Mission and background

JDRF exists to find a cure for type 1 diabetes and its complications through the support of research. JDRF Australia funds and manages some of Australia's leading type 1 diabetes research projects and programs, and is a proven partner of the Government, the NHMRC, and the research community.

- JDRF is the world's leading non-profit, non-governmental contributor of funds to diabetes research, funding an estimated 35% of all type 1 diabetes related research globally.
- JDRF was established in 1970 by parents of children with juvenile (type 1) diabetes. Over the past 35 years, JDRF has directed more than \$1.5 billion to diabetes research. Internationally during FY09, JDRF and its affiliates committed a further \$150 million to diabetes research.
- All JDRF research selection is coordinated with JDRF internationally, to ensure that only the best research is funded globally regardless of location
- In Australia in 2008/09, JDRF invested over \$14m in 63 research projects across every state in the country.
- Globally in 2008/09 JDRF directly supported **44 clinical trials in type 1 diabetes**
- JDRF Australia was awarded the inaugural PricewaterhouseCoopers Transparency Award in 2008 for governance and reporting, and has previously been Ethical Investor Best Practice Charity of the year.
- JDRF works closely with the research community, corporates, and members of the type 1 diabetes community in pursuit of its mission. JDRF has 70,000 supporters on its database

6.2 A proven partner of Government and the NHMRC

JDRF has a long and effective working relationship with both the Federal Government and the National Health and Medical Research Council (NHMRC).

In conjunction with the Department of Health and Ageing, JDRF administer and manage:

- The Australian Islet Transplantation Program, through which ten people have now successfully received life-changing islet transplants
- The Type 1 Diabetes Insulin Pump Program, providing Australia's first government subsidies for insulin pumps, which are proven to reduce the risk of complications

In conjunction with the NHMRC, JDRF jointly funds:

- The Diabetes Vaccine Development Centre (DVDC), having invested or committed \$10m since 2004
- Joint NHMRC/JDRF Program Grants, having committed \$10m since 2005

6.3 International activity and reach

JDRF Australia is an independent and separately governed organisation in Australia with an Australian Board of Directors, and has affiliates in the United States, Canada, the UK,

Inquiry on International Research Collaboration – JDRF contribution



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Denmark, and Israel. In FY09 JDRF International funded more than 1,000 centers, grants, and fellowships in 22 countries, including nearly 40 human clinical trials.

7 FURTHER INFORMATION

For further information or more complete background information on any element of this discussion paper, please contact:

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