Diabetic Complications Consortium

Application Title: LANDMark BioBanks –a 5-year longitudinal, NIDDK-affiliated bioresource

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1. Project Accomplishments:

The project accomplishments include:

- Achievement of links between data records and biosamples of all available data from the sites to date.
- To publicize the LANDMark biosamples, records have been published in QUT's Research Data Finder and Research Data Australia
- Creating a majority of the documentation required for the 'linkage' to the NIDDK repository.
- Creating a simple web interface to assist with international discovery of the bioresource
- Explored and determined the nature of the affiliation with NIDDK Central Repository.

2. Specific Aims:

Specific Aim 1: To extend the existing LANDMark study database to link records of biosamples collected longitudinally to corresponding longitudinal clinical phenotypic data of three microvascular complications of diabetes (neuropathy, nephropathy and retinopathy) from two sites.

Results:

The existing LANDMark study database has been extended to link records of biosamples collected longitudinally to corresponding longitudinal clinical data via the customized, web-based tool, Slidepath Distiller. The database includes over 31 000 samples linked to longitudinal clinical data. Tables 1 and 2 represent the number of visits and serum, plasma, buffy coat and skin samples available at both the Manchester and Brisbane sites. Due to ongoing data collection at the University of Manchester site we estimate approximately 20% of the Manchester biosamples are not linked with their corresponding data; however, this linkage will continue as the data is provided by the Manchester site.

Table 1. Number of visits of clinical data.

	Baseline	Year 1	Year 2	Year 3	Year 4
T1DM	290	250	230	215	180
T2DM	121	110	78	75	93
Controls	157	121	112	96	58
Total	447	371	342	311	238

Table 2. Number of biosamples

	Baseline	Year 1	Year 2	Year 3	Year 4
T1DM	3525	3692	3334	2930	2225
T2DM	-	-	-	-	-
Controls	1545	1537	1392	1173	1181
Total	10718	6433	5764	4961	3760

We have recently been awarded an NIH grant to extend the 4-year longitudinal dataset by the addition of a 7-year visit, hence further enriching the dataset associated with these biosamples.

Specific Aim 2: To develop a user-friendly data retrieval and management tool using a web-based interface.

Results:

A LANDMark BioBanks website has been created, hosted by Institute of Health & Biomedical Innovation (IHBI) at QUT. The website can be found at the following URL:

https://www.qut.edu.au/research/research-projects/landmark-biobanks.

The website includes information about the LANDMark study, the sites collaborators and publications arising from the project. From the website researchers can see at a glance the number of samples held in the BioBanks, and in future we will provide information of research currently underway.

Discoverability of the bioresource has been enhanced by creating records in QUT's Research Data Finder, found at https://researchdatafinder.qut.edu.au/display/n5687 (Figure 1), which in turn feeds Research Data Australia.

The data mining functionality to assemble specific research cohorts via the website was not pursued. The cost associated with this data mining capability feature we believed was not going to be able to substantially expand the utility of the current simple clinical dataset representing the biosample collection.

Specific Aim 3: To explore the feasibility of creating an NIDDK-affiliated repository.

Results:

Development of an NIDDK-affiliated repository is a novel undertaking. We perceived the benefits of affiliation to include high visibility and discoverability of our bioresource, as well as potentially enhancing the opportunities for collaboration, and hence advancement of knowledge in diabetes. The types of affiliation considered were adding the LANDMark biobanks sample count to the NIDDK Central Repository register while maintaining the samples in Australia and UK, submitting samples and clinical data to the Central Repository, and linking our registry from the NIDDK website.

The LANDMark BioBanks hold a variety of tissues for researchers of diabetic complications and other research communities. The biosamples were collected longitudinally and are associated with corresponding longitudinal clinical phenotypic data of three microvascular complications of diabetes (neuropathy, nephropathy and retinopathy) from two sites. The database of specimens, from a JDRF-funded project, is available for use by researchers with approved projects.

It was proposed that NIDDK Central Repository would promote and/or provide information regarding the LANDMark BioBanks as an affiliated repository. It was desirable to provide researchers access to rich metadata describing the project, dataset and samples. Subsequent requests for samples could then be a collaborative initiative between the LANDMark BioBanks and the NIDDK and/or JDRF.

This type of affiliation was deemed to be cost-prohibitive. A cost-benefit assessment of sample submission to the NIDDK repository was deemed too high a cost relative to the benefit of having the samples in a centralised, well-known and established bioresource. The cost of shipping samples to be held at an NIDDK site was high (approx. AU $10 000), which was not in the scope of the award. Further

costs were expected to be associated with preparation for transport of samples and mapping of the databases. It was determined the most efficient use of resources was to promote the LANDMark BioBanks resource using simple, low-tech and low-maintenance tools rather than the web-based searching tool originally proposed. The reasons for this were twofold – the NIDDK has the greatest attention and connections with the research community and offers linkage to other repositories on the NIDDK Central Repositories webpage under "Other Resources". Approval to link to our webpage from this site has been established.

An adaptation of the original idea has been made to accommodate the low practicality and high cost of the originally proposed affiliation. To date, our rich bioresource has been underutilised; however, we anticipate this will change once the link to the NIDDK Other Resources is established. Several queries for samples have recently been received.

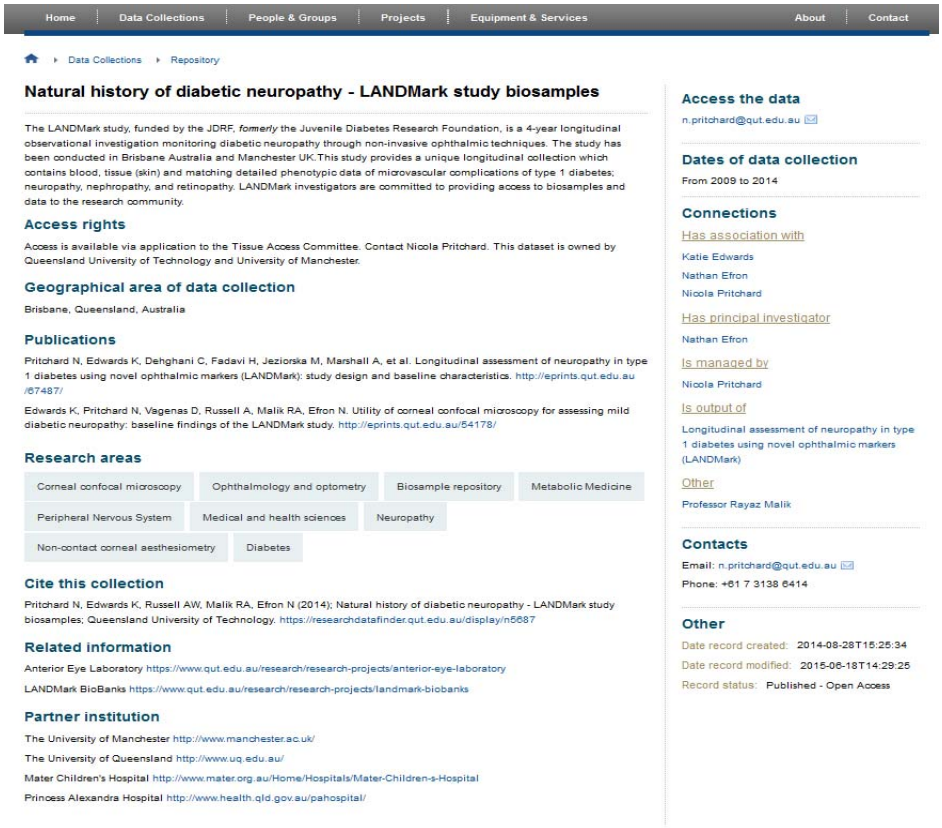

Figure 1. LANDMark biobanks record in Research Data finder.

3. Publications:

Due to the nature of the project, no peer-reviewed publications have resulted from the project. There is however, several opportunities for discoverability and advertising of the bioresources. The most significant of these will be this link which will soon appear on the NIDDK Central Repository page in "Other Resources". In the past year we have two active, and two pending projects using our samples which will invariably result in publications. All publications associated with the original LANDMark study and biorepository will be linked to from the QUT LANDMark BioBanks webpage.