

An Australasian-wide Registry of Juvenile Diabetes Patients in the Cloud

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THE ADDN REGISTRY

The Australasian Diabetes Data Network (ADDN - <http://addn.org.au/>) is a cloud-based registry of diabetes-related phenotypical data captured from juvenile diabetes clinics across Australia and New Zealand. The ADDN portal provides authorised clinicians and researchers with a set of tools unique in this space to query this dataset; clinics can generate aggregate reports and statistics on their patients and interrogate their own data-capture methodology, and diabetes researchers can design nation-wide trials with a statistically significant population of patients that have already consented to future research.

Funded and administered jointly by the Australasian Paediatric Endocrine Group (APEG - <http://www.apeg.org.au/>) and the Juvenile Diabetes Research Foundation (JDRF - <http://jdrf.org/>), the registry captures sixty-plus data-points about the patient and ninety-plus for each visit spanning the patient's history from diagnosis to present. In phase one of the ADDN project this data is provided in quarterly batches from major hospitals in Australian capitals, with subsequent phases including centres in New Zealand and rural Australia

This data is secured using modern password-hashing techniques, and a custom authorisation module allows for user-specific access to patient records on a centre-by-centre basis; this allows clinics to control record sharing in accordance with local ethical considerations, which can vary widely by region. This security and authorisation gives the capacity for direct data-entry through the secure online portal, allowing centres with limited IT resources to contribute to this Australasian-wide initiative. Future work will include the ability to store bio-banking information, provide geo-spatial mapping of specific patient fields, and the inclusion of adult diabetes clinics and data.

This talk will provide an overview of the ADDN project, discussing the technical aspects of designing and implementing the registry and search tools as well as highlight the challenges involved in designing and populating a composite dataset from clinical records stored across disparate IT environments.

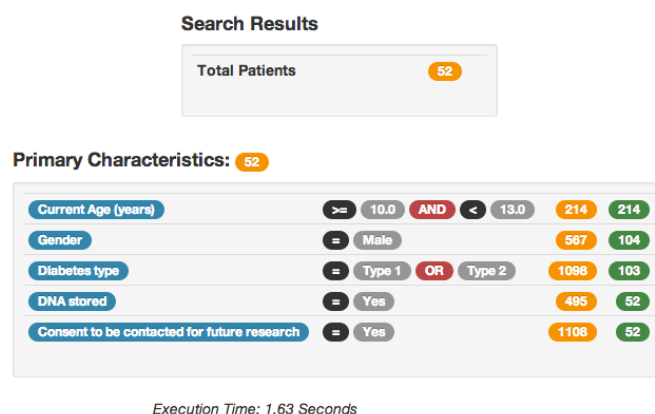


Figure 1: Example of Customisable Registry Search

ADDN Summary Report

| CHARACTERISTICS OF ACTIVE ADDN PARTICIPANTS AS OF 06/06/2014 | | | | |
|--|---------------|--------|--------|-------|
| | Diabetes Type | | | |
| | Total | Type 1 | Type 2 | Other |
| Number | 1136 | 1064 | 34 | 38 |
| Sex | | | | |
| Male | 50% | 50% | 47% | 39% |
| Female | 50% | 50% | 53% | 61% |
| Current Age (years) | | | | |
| < 5.0 | 3% | 3% | - | 11% |
| >= 5.0 and < 10.0 | 18% | 19% | 3% | 13% |
| >= 10.0 and < 15.0 | 36% | 37% | 26% | 24% |
| >= 15.0 and < 20.0 | 39% | 38% | 71% | 53% |
| >= 20.0 | 3% | 3% | - | - |
| State | | | | |
| NSW | 56% | 56% | 41% | 82% |
| QLD | - | - | - | - |
| SA | - | - | - | - |
| VIC | - | - | - | - |
| WA | 44% | 44% | 59% | 18% |
| Treatment | | | | |
| Insulin Pump | | 47% | 50% | 29% |
| Insulin Injections | | 52% | 24% | 26% |
| Comorbidities | | | | |
| Celiac | | 4% | | |
| Thyroid | | 2% | | |
| Median HbA1c (12m) | | | | |
| NGSP (%) | | 8.0 | 6.1 | |
| IFFC (mmol/mol) | | 64 | 43 | |

Figure 2: ADDN Summary Report

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ABOUT THE AUTHORS

Loren Bruns Jr. is a software developer in the Melbourne eResearch Group at the University of Melbourne, currently working on the Endocrine Virtual Laboratory and Australasian Diabetes Data Network.

Loren hails originally from Portland, Oregon, in the United States. He attended Reed College for his undergraduate studies in his hometown of Portland, completing a physics degree in 2005. He then entered industry, working as a software developer for Freightliner LLC, specializing in UI and database design. In 2008 Loren moved to Melbourne, Australia to continue his studies in physics. He began work on his doctorate in astrophysics at the University of Melbourne, while also free-lancing as a web developer for Babeltech computer services. In 2012, Loren joined the Melbourne eResearch Group as a full-time web and backend developer, and is continuing to write up his astrophysics dissertation in his spare time.

Richard O. Sinnott is the Director of eResearch & Chair of Applied Computing Science at the University of Melbourne He was formerly technical director of the National e-Science Centre, UK; director of e-Science at the University of Glasgow; Technical Director of the National Centre for e-Social Science and Deputy Director (Technical) of the Bioinformatics Research Centre at the University of Glasgow. He has published over 200 peer-reviewed papers in conferences/journals across a wide range of computing science areas with specific focus over the last ten years in supporting communities demanding finer-grained access control (security).