

ADDN Newsletter No 1 - April 2014

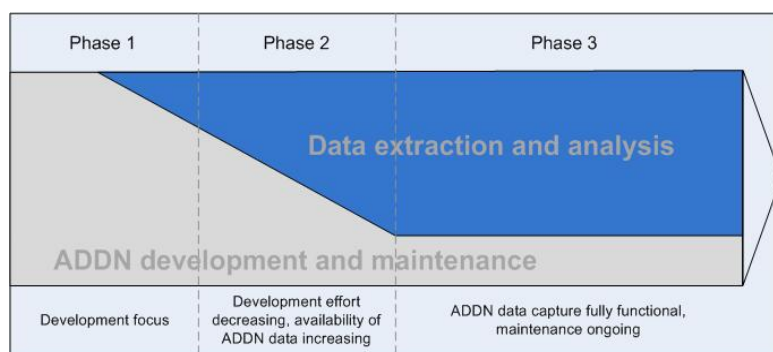
Australasian Diabetes Data Network (ADDN)

By now you have probably heard about ADDN and your centre may already be recruiting patients. Just to recap, ADDN is a central database and data collection system that is currently being developed by the University of Melbourne for the Australasian Paediatric Endocrine Group (APEG). ADDN will enable the collection and sharing of data that are routinely collected at diagnosis of paediatric diabetes and at follow-up clinic visits across Australia and New Zealand. The data collected in ADDN will not include patient names to protect the identity of participants. The project to develop ADDN is a collaboration between APEG and the Juvenile Diabetes Research Foundation Clinical Research Network (JDRF CRN).

ADDN involves the majority of paediatric diabetes centres throughout Australia and New Zealand. All children and adolescents attending these centres with all types of diabetes are eligible to participate in ADDN. Participants do not need to do anything apart from consenting to be included.

ADDN Project Overview

The ADDN project has been divided in to three phases. Phase 1 is due to finish by April 2015.



By the end of Phase 1, we aim to have....

1. *Recruited* 6000 patients to ADDN
2. *Loaded* the records for 4000 patients in to the ADDN database
3. *Implemented* regular batch uploads of data to ADDN from five major centres around Australia:
 - Children's Hospital at Westmead, NSW (CHW)
 - Princess Margaret Hospital for Children, WA (PMH)
 - Royal Children's Hospital, Vic (RCH Vic)
 - Women's and Children's Hospital, SA (WCH)
 - Mater/Royal Children's Hospital, Qld (RCH/Mater Qld)
4. *Developed* a fully functional, web-based ADDN system that can be used for direct entry of data at centres that do not have access to batch loading of data. The system will also include a series of reports that may be used by individual centres to report on their own data.

In Phase 2 we will continue implementing batch uploads of data from additional centres around Australia and New Zealand. Priority will be given to larger centres and to those using the DPMS database for their local data collection and management. DPMS (Diabetes Patient Management System) has been developed at Princess Margaret Hospital in WA and can be made available to any other centres on request. Please contact Helen Clapin (details below) for further information.

As data from more centres is loaded, the ADDN database will become a valuable resource that enables:

- Australia and NZ-wide recruitment of children and adolescents to research studies
- Long-term monitoring of diabetes interventions and outcomes
- Auditing and benchmarking of diabetes centres
- Provision of epidemiological and clinical evidence in support of advocacy on behalf of children and adolescents with diabetes.

ADDN Project Update

Recruitment

More than **4000 patients** have been recruited to ADDN so far. This has required a concerted effort from many people – **THANK YOU** and well done!!

Data in the ADDN Database

Data for **790 patients and more than 10,000 visits** has been loaded to ADDN to date. This data comes from CHW in NSW.

Phase 1 Centres

Batch uploading of data from CHW has been implemented and we are close to completing the upload of data from PMH in WA. Work is also progressing on the upload of data from the merged data sets belonging to RCH/Mater in Queensland. RCH in Vic and WCH in SA are both planning to use DPMS to manage their data locally. RCH Vic is currently working with their IT department to ensure that this option can be supported. WCH has the necessary approvals in place and is aiming to implement and begin using DPMS very soon.

ADDN System Development

The ADDN system is still in a prototype version as we work through the specific requirements for direct data entry, data maintenance and search/reporting functionality.

DPMS

The DPMS system in use at PMH has been upgraded to align it more closely to ADDN and to make it flexible enough to use at other centres. The system has been successfully installed at Starship in Auckland but it is not yet in use there. Several other centres around Australia are currently progressing towards implementing DPMS or investigating the possibility of doing so.

By the time that DPMS is in use at other centres, the extraction and upload of data to ADDN from this system will have been finalised at PMH. Other centres using DPMS can be provided with the automated extraction and upload module, making it simple for them to link to ADDN and begin contributing data to the central database.

Please contact Helen Clapin (details below) if you would like more information about DPMS.

Any questions?

Please feel free to contact us if you have any questions about ADDN.

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