



**Final Report to ARACY/ARC NHMRC Research Network  
Round 5 Seed Funded Collaboration**

**This final report is due 4 weeks after the official end date of your funding agreement and must be submitted together with the financial report.**

Project title	Early Childhood Development Data Linkage Demonstration Project		
Convenor of collaboration	Professor John Lynch		
Email address	<a href="mailto:John.Lynch@unisa.edu.au">John.Lynch@unisa.edu.au</a>		
Administering organisation	University of South Australia, School of Health Sciences		
Contact for reporting purposes	Professor John Lynch		
Address	University of South Australia CEA-01 GPO Box 2471 Adelaide SA 5001 Australia		
Business telephone	08 8302 2640	Mobile	
email	<a href="mailto:John.Lynch@unisa.edu.au">John.Lynch@unisa.edu.au</a>	Total grant amount	\$16,500.00 (GST inclusive)

Major activities undertaken (expand section as necessary)

Activity	Date	Description
Project Officer employed	10/08/09	3 days/week
Preparatory work	14/08/09 – 30/04/2010  18/01/10 and 22/01/10	<p>A quality review of the administrative datasets in scope of the Early Childhood Development (ECD) Data Linkage Demonstration Project began in August 2009. A group of researchers engaged with the South Australian Government health and education sector including the Department of Education and Community Services, Department of Health, Department of Families and Communities and Children, Youth and Women's Health Service. Representatives of each data custodian were met to establish lines of communication and enquires about the availability of metadata were made. Seeking this documentation required an ongoing series of meetings and phone calls to different people in the custodian agency. The existence and availability of metadata varied between custodians. In some cases it was established that suitable metadata did not exist and would therefore need to be created. The goal of this work was to create templates for dataset research utility statements with reference to the Australian Bureau of Statistics Data Quality Framework. The template includes both qualitative and quantitative information that can be used by researchers of the ECD Data Linkage Project collaboration to understand the data available for linkage purposes.</p> <p>The draft dataset research utility statements were sent out for comment to the ECD research collaboration and the SA NT DataLink Steering Committee. The statements were considered informative as they not only provided information about data linkage but information such as the representativeness of the data. The statements were also thought to be useful not only for the research community but for the data custodian as it provided an overview of the data they collect. Data custodians whose dataset did not have a data dictionary commented on the benefit of having a statement that consolidated information from many disparate sources. The</p>

<p>Ethics Proposal</p> <p>Data Management</p>	<p>01/02/10 –</p> <p>02/10</p> <p>Feb-April 2010</p>	<p>metadata work will now be continued by the Metadata Advisory Group of SA NT DataLink. It is envisioned that this resource would be posted on the SA NT DataLink website therefore available not only for the ECD Data Linkage Demonstration Project but for researchers, Government and the broader community.</p> <p>Development of the ECD Data Linkage Demonstration Project ethics application (NEAF).</p> <p>Information Request aimed at informing the ECD Data Linkage Demonstration Project was submitted to the Children, Youth and Women’s Health Service (SA Health) on 25/02/10. The request asked for approval to look further into de-identified variables within the administrative dataset (Child Health Record) to provide information such as number of missing values and consistency of coding. The Information Request was approved in March 2010, the data was extracted in late April 2010 and arrangements for the project officer to analyze the data have been organized (to begin 09/06/10).</p> <p>Discussions with eResearch SA regarding data hosting and management of the linked Project dataset. These discussions have determined eResearch SA’s capability to securely host the dataset, giving researchers of the ECD Data Linkage Demonstration Project remote access to undertake analysis.</p>
<p>Workshops and Meetings</p>	<p>27/08/09 -</p> <p>27/08/09</p> <p>21/10/09</p> <p>08/12/09</p> <p>19/01/10</p>	<p>Weekly meetings with collaborators from the Department of Education and Community Services and the Australian Bureau of Statistics were held to exchange information about the progress of the ECD Data Linkage Demonstration Project.</p> <p>Initial meeting to bring collaborators from UniSA, Adelaide and Flinders Universities and representatives of government agencies together to discuss research themes and projects of direct relevance to early childhood development policy and practice. Key outcomes included information sharing, agreement on an overarching theme and six potential research projects for the ECD Data Linkage Demonstration Project. The six research project areas proposed:</p> <ol style="list-style-type: none"> <li>1. Child protection and development</li> <li>2. Adverse perinatal risk factors and development</li> <li>3. Head injury and development</li> <li>4. COAG policy response</li> <li>5. Pathways for developmental competencies of children through the linkage of existing SA birth cohorts</li> <li>6. Oral health as a biomarker of risk</li> </ol> <p>The purpose of this half day research planning workshop in Adelaide was to bring together collaborators to present their research projects and to promote collaboration and idea sharing about formalizing these projects. An overview of the research utility of the administrative datasets available for data linkage and a presentation on each proposed research project was given. The workshop provided the opportunity to share information, provide feedback, advice and guidance to assist with the refinement of the research projects, describe and discuss the datasets and data items required to answer the research question, discuss any issues of capacity to undertake the work and offer practical support and thinking that may be needed relating to what was feasible to do.</p> <p>Collaborators from South Australia (SA), Northern Territory (NT) and Western Australia met in Adelaide to discuss child health research and data linkage research possibilities.</p> <p>An ECD Data Linkage Demonstration Project Information Session was held in Adelaide with 45 people attending from across Government and the research community. The information session was held to provide an update on the progress of the ECD project, provide details regarding the individual research questions, the process for further stakeholder involvement and the proposed process for ongoing</p>

	18/03/10	management and next steps of the project.  An ECD Data Linkage Demonstration Working Group meeting was held on 18/03/10. An update on the six research projects was given, discussions about the ethics application process and SA NT DataLink statistical linkage application form was discussed. It was agreed that John Lynch together with the project officer from the University of South Australia would develop a joint ethics application (NEAF) for the ECD Data Linkage Demonstration Project.
	12/04/10	Meeting with the data provider of the SA Hospital Inpatient Separations Activity and Emergency Department data sets (datasets in scope of the ECD Data Linkage Demonstration Project) to discuss diagnostic codes and clinical data items.
	18/06/10	A workshop in the NT has been organized to update collaborators of the ECD Data Linkage Demonstration Project and importantly progress the data linkage research collaborations. It is anticipated that common datasets and common variables across SA and NT will be identified to enable merging and joint analysis of the linked de-identified data (subject to HREC approval).
Workshops Summaries	10/11/09	All stakeholders of the ECD Data Linkage Demonstration Working Group were updated on the research workshop held on 21/10/09.
	18/03/10	All stakeholders of the ECD Data Linkage Demonstration Working Group were updated on the Information Session held on 19/01/10.
Project Governance	01/09/2009	The establishment of a Steering Committee to guide the ECD Data Linkage Demonstration Project was discussed.
	02/2010	Mr Jim Birch of Ernst and Young was formally invited to Chair the ECD Data Linkage Demonstration Project Steering Committee.
	30/03/10	Mr Jim Birch agreed to Chair the ECD Data Linkage Demonstration Project Steering Committee.
	30/04/10	The first ECD Data Linkage Demonstration Project Steering Committee meeting was held on 30/04/10. The Terms of Reference outlining the role and responsibilities of the Steering Committee were endorsed by all members. The Committee will oversee the management of the Project and facilitate communication with all stakeholders and coordinate work tasks relevant to the Project. It was agreed that membership would include nominees from the contributing government agencies, representatives of collaborating universities, a nominee from the ABS and from the Dept of Education, Employment and Workplace Relations.
<b>Benefits arising from the project and how these align to ARACY goals</b>		
<p>The benefits arising from this project have been significant. An ARACY goal is bringing together researchers, policy/practice and service providers. The ARACY ARC/NHMRC seed funding has importantly brought together Government and researchers across disciplines around a common theme which has highlighted the value of a collaborative approach to data linkage research. Another key ARACY goal is the production of knowledge, namely, resources that can be used for the ARACY community. The seed funding has allowed for important preparatory work such as gathering available metadata and producing metadata where none was available for the datasets to be linked in the ECD Data Linkage Demonstration Project. This has provided key information to improve not only researcher but data custodian understanding of the administrative datasets available for data linkage. The work describing the research utility of administrative datasets has been a time intensive process but it has established a template that can be used by the Metadata Advisory Group of SA NT DataLink to build a metadata reference resource. It is envisioned that this resource would be posted on the SA NT DataLink website therefore available not only for the ECD Data Linkage Demonstration Project but for researchers, Government and the broader community.</p> <p>The collaboration has also successfully established six research projects for investigating factors related to early childhood development. Much work has been done to navigate through the research question process and the workshops have provided an important conduit to shape and refine the research questions.</p> <p>Another important activity arising from the seed funding is that it provided the opportunity to present the progress of the ECD Data Linkage Demonstration Project to a broader audience (information session 19/01/10). This has enabled people not directly involved in the project, but interested in the topic areas to provide their details to stay abreast with the project.</p>		



The obstacles have been few but the time intensive nature of the work has meant that we have not progressed as far as we would have liked to. Another challenge has been finding suitable and sufficient time to meet with our Northern Territory collaborators.

In the next month the ethics application for the ECD Data Linkage Demonstration Project will be submitted (June 2010). We aim to continue and build the South Australian collaboration and foster data linkage research collaborations with academic and government partners in the Northern Territory.

**Name: Professor John Lynch**

**(Convenor) Date: 28/05/2010**

**Please return electronically to:**

Rachael Wilken at [rachael.wilken@aracy.org.au](mailto:rachael.wilken@aracy.org.au)



**Australian Research Alliance for Children & Youth**  
 Working together to enhance the wellbeing and life chances of children and young people.

## Financial Report to ARACY/ARC NHMRC Research Network Round 5 Seed Funded Collaboration

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Project title	Early Childhood Development Data Linkage Demonstration Project		
Convenor of collaboration	Professor John Lynch		
Administering organisation	University of South Australia, School of Health Sciences		
Contact for reporting purposes	Rachael Penning-Bourne		
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### Expenditure of the ARC Research Network Grant Funds:

Category	Item	Description / Details	\$ cost (ex GST)
Project worker salary	Project Coordinator	Research Associate: Angela Gialamas	\$11,460
Workshops and other meetings:			
Travel			
Accommodation	Workshops	Adelaide meeting with SA, NT & WA collaborators	\$3,400
Catering		NT work workshop scheduled in June 2010	
Printing	Business cards – Project Officer (used for meetings with data custodians and other collaborative work)		\$140
Other activities or products (describe date, location, title and itemize costs)			
			\$
			\$
		<b>Subtotal</b>	<b>\$15,000</b>
			\$
		<b>GST</b>	<b>\$1,500</b>
		<b>Total inc GST</b>	<b>\$16,500</b>

**Name: Professor John Lynch**

**(Convenor) Date: 28/05/2010**

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