

A variations analysis of data linkage centres: Governance, infrastructure and funding

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The number of data linkage centres is small. Even so, the variation in their mandates, governance, the types of infrastructure in place, and their sources of sustaining funding is impressive. It is not likely – or even necessarily desirable – that there will be a move to create convergence for data linkage centres in these areas. But as health services research has shown time and again, there is much to be learned from understanding the variation itself. Though there are many different models in play, are there basic similarities even if the details are different? Are there key features or critical success factors? Are some combinations of factors more successful than others? Are other combinations fraught with unforeseen risk?

The purpose of the time allotted for discussion of this topic is to work through and modify a proposed framework for this analysis. What features are most relevant or important for a variations analysis? Are the questions posed below the most important? What should be added or taken away?

This kind of analysis can tell us (at least) two things. First, it allows a single data linkage centre to assess its practices in comparison to others, which may point to development opportunities, or areas of further work. Second, it can help create a blueprint that future data linkage centres could use as a starting point. At the very least, it provides a framework for the things that data linkage centres ought to consider in these areas.

Data linkage centres

This analysis is limited to data linkage centres that participated in an international collaborative workshop in London in December 2008. It includes centres from the UK, Scotland, Australia, New Zealand and Canada.

The analytic framework

1. Governance

<i>What is the mandate of the data linkage centre?</i>	Solely for linkage / embedded as part of a research organization / embedded as part of a provider organization
<i>Where is the data linkage centre located?</i>	University-based / blended (University plus other) / health system-based / government based
<i>What types of partners are involved in the data linkage centre?</i>	Single-institutional / multi-institutional
<i>Who or what is involved in oversight /</i>	Single source / advisory board

<i>authority?</i>	
<i>Is there a role for the public?</i>	Yes / no
<i>Who can use the data / who has access? Who are the data stewards?</i>	Open access / bona fide researchers / closed access
<i>What are allowable uses of the data? How is access vetted?</i>	Research only / administrative uses of data

2. Infrastructure

<i>What is the physical infrastructure?</i>	Independent / embedded
<i>What is the technical infrastructure?</i>	On-site storage / virtual storage Open source IT / commercial IT
<i>What is the human infrastructure?</i>	Dedicated, stable staff / project-based staff # of dedicated FTEs
<i>What is the data infrastructure?</i>	Holds all data / only holds data / only holds identifiers Administrative data / survey data / mixed data sources Single source (data provider) / multiple data providers Data come with link IDs / linkage on site

3. Funding

<i>What are the funding streams? What is the amount of funding?</i>	Single source / multi-source Stable grant funding / fluctuating Minimal / sufficient / substantial
<i>Is there a charge for users?</i>	User pay all costs / user pay fixed costs / user pay marginal costs / users do not pay
<i>Do data providers or others provide funding in exchange for analyses of data?</i>	Yes / no