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Political and Policy Arguments for Integrated Data

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Introduction

There is little argument that integrated data can provide a valuable resource for improved health system management, planning, and accountability as well as discovery and commercial use, but policies to enable and support integrated data fall short of the potential represented by integrated data. To understand the current level of progress on policy for integrated data, we looked at two successful and two unsuccessful efforts to support the creation and use of integrated data in health systems.

Methods/Approach

We used document and literature analysis to develop descriptions of the Icelandic Health Sector Database Act, the creation of the Institute for Clinical Evaluative Sciences in Ontario (Canada), the care.data initiative in the United Kingdom, and the Health Datapalooza initiative in the US and used an Ideas, Institutions and Actors framework to compare the experience with integrated data policy and politics

Results and Discussion

Our analysis suggests that institutions around integrated data remain under-developed and largely focused on specific aspects of integrated data policy or use. There are at least two sets of dominant ideas around integrated data - data as a tool for economic development and health system performance and data as a threat to privacy and liberty - that are often diametrically opposed in different jurisdictions. To a great extent, powerful actors remain disengaged from integrated data discussions and leadership engaged in integrated data policy and politics remains

isolated from larger policy and political discussions. The medical profession along with civil society groups can mount effective opposition to integrated data initiatives, although potentially for different reasons (accountability and privacy concerns respectively).

Conclusions

Our analysis suggests several key issues around successful integrated data policy and politics that support the importance of strong leadership, an incremental approach to institution building that focuses on public benefits, strongly alignment to missions that are congruent with societal values, and stronger attention to effective and rapid implementation of policy. In addition to the cases studied here, the success of smaller sub-national (e.g. state or provincial) efforts suggests that smaller efforts tend to work better although their success may not receive the attention that could support larger efforts to integrate data on the national level. Further work should focus chiefly on the extension of these arguments to non-health sectors to realize the full value of integrated data.

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