

## Governance Challenges to Promoting Data Readiness and Data Linkage for Not-for-Profit Organizational Service Data

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### Introduction

Data collected by myriad not-for-profit (NFPs) agencies while providing social services represent a significant untapped source of intelligence. While much research has been conducted on the governance and capacity to share administrative and research data, little work has been done in the area of NFP data sources.

### Objectives and Approach

Six NFP agencies in Calgary participated in a data sharing project to measure various aspects of poverty. This collaboration required understanding the legal, ethical, policy and data challenges to working with data collected in the NFP sector. This case study will expose (a) the legal analysis on legal and governance issues for, and obligations of, NFPs when aiming to share and re-use information beyond service delivery in Alberta, Canada; and (b) the practical and policy challenges faced by the NFPs and repository. The legal analysis involved a systematic search of academic and grey literature; relevant legislation and case-law (especially privacy law).

### Results

The legal analysis demonstrated three key things. First, in many circumstances an NFP is not held to any information-handling legal obligations. This does not absolve NFPs from social privacy expectations, especially involving vulnerable populations. Second, privacy best practices are available to NFPs from other more-regulated sectors and from NFP sector standards. The trifecta of purpose, reasonableness and minimal extent are critical. Third, adhering to privacy best practices would not be overly costly, more efficient, and less risky of negative publicity and lost public trust from privacy complaints. These findings informed the NFP data sharing project. The six participant NFPs varied greatly in their approach to consent, governance and information-handling, which affected their data-readiness for cross-organizational data linkage and analysis.

### Conclusion/Implications

Unlike government, most NFPs have limited experience with data linkage. This paper informs ethical approaches to include NFP data in broad cross-sector data linkage. Appropriate data governance is imperative for data sharing amongst NFPs, researchers and public organizations, which promotes community service delivery, evaluation and improvements to benefit vulnerable families.

