Advancing cross-centre research networks: learning from experience, looking to the future

Jones, K\(^1\), Heys, S\(^2\), and Daniels, H\(^1\)

\(^1\)Swansea University
\(^2\)Bowden Jones

Introduction

Many jurisdictions have programmes for the large-scale reuse of health and administrative data that would benefit from greater cross-centre working. The Advancing Cross centre Research Networks (ACoRN) project considered barriers and drivers for joint working and information sharing using the UK Farr Institute as a case study, and applicable widely.

Objectives and Approach

ACoRN collected information from researchers, analysts, academics and the public to gauge the acceptability of sharing data across institutions and jurisdictions. It considered international researcher experiences and evidence from a variety of cross centre projects to reveal barriers and potential solutions to joint working. It reviewed the legal and regulatory provisions that surround data sharing and cross-centre working, including issues of information governance to provide the context and backdrop. The emerging issues were grouped into five themes and used to propose a set of recommendations.

Results

The five themes identified were: organisational structures and legal entities; people and culture; information governance; technology and infrastructure; and finance and strategic planning. Recommendations within these included: standardised terms and conditions including agreements and contractual templates; performance indicators for frequency of dataset sharing; communities of practice and virtual teams to develop cooperation; standardised policies and procedures to underpin data sharing; an accredited quality seal for organisations sharing data; a dashboard for data availability and sharing; and adequate resource to move towards greater uniformity and to drive data sharing initiatives.

Conclusion/Implications

The challenges posed by cross-centre information sharing are considerable but the public benefits associated with the greater use of health and administrative data are inestimable, particularly as novel and emerging data become increasingly available. The proposed recommendations will assist in achieving the benefits of cross-centre working.