

Administrative Data Research Network (ADRN)

Mid-Term Review Report

November 8, 2016

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TABLE OF CONTENTS

TABLE OF CONTENTS	2
EXECUTIVE SUMMARY	3
INTRODUCTION	6
METHOD	9
SUMMATIVE EVALUATION OF PROGRESS AT THE MID-TERM POINT OF THE FIVE-YEAR GRANT	11
RECOMMENDATION 1: UTILISE A MULTI-PRONGED APPROACH TO THE ACQUISITION OF GOVERNMENT DATA	16
RECOMMENDATION 2: CREATE THE FLEXIBILITY TO ALLOW THE RETENTION AND RE-USE OF LINKED DATASETS	21
RECOMMENDATION 3: ESTABLISH A SINGLE NETWORK LEAD	24
RECOMMENDATION 4: LEVERAGE THE EXPERTISE AND RELATIONSHIPS OF LEADING RESEARCHERS– FLEXIBILITY OF PROCESS AND ROLE CLARITY BETWEEN ADRC RESEARCHERS AND THE ADS	27
RECOMMENDATION 5: CLARIFY ROLES AND ESTABLISH SEPARATION BETWEEN GOVERNING AUTHORITIES’ STRATEGIC ADVICE AND THE DELIVERY OF THE ADRN	30
FUTURE DIRECTIONS AND OVERALL CONCLUSIONS	33
SUMMARY OF FINDINGS AND RECOMMENDATIONS ORGANISED ACCORDING TO THE 10 AIMS OF THE MID-TERM REVIEW	34

EXECUTIVE SUMMARY

SUMMATIVE EVALUATION

The establishment of ADRN infrastructure is a significant accomplishment and an illustration of how the Network can achieve UK-wide objectives. Notwithstanding the ADRN's good overall progress to-date, the Network must make major advances accessing government data if it is to fulfil its mandate. The ADRN is at a critical juncture. At the end of the current grant, the Network's success will be depend on the number and nature of projects that use ADRN infrastructure to perform research based on linked government administrative data.

RECOMMENDATIONS

1. Utilise a Multi-Pronged Approach to the Acquisition of Government Data

There is near-unanimous agreement that lack of administrative data from government departments is the single biggest challenge that the Network faces. It is good that this is acknowledged widely. The ADRN should continue to prioritise activities aimed at increasing access to data, UK-wide (Whitehall) data in particular. With coordinated effort, and strong central leadership, it should be possible to make progress on near-term activities, e.g., by piloting more flexible data retention and re-use policies (see Recommendation 2). However, other remedies, such as building trusting relationships and contributing to culture change within government departments, will take more time and visible commitment from government. Appropriately, the August 2016 *ADRN Data Acquisition Plan* developed by the ADRN Directors focuses on short-term activities while laying the foundation for longer-term work. Making progress on access to data will require strategic and coordinated implementation of the *ADRN Data Acquisition Plan*. Given the complex roots of data access issues, flexibility, responsiveness, and reporting on progress vs. the plan in a way that allows redirection of resources (as necessary) will be essential.

2. Create the Flexibility to Allow the Retention and Re-use of Linked Datasets

The current ADRN policy of creating bespoke linked datasets that are destroyed after one use represents one of the most resource-intensive approaches to preparing linked administrative datasets. As outlined in the *ADRN Data Acquisition Plan*, the Network should explore changes to its data retention policy and consider promoting multiple uses of core linked datasets. UK and international examples demonstrate the potential for data retention and data use policies that address data custodian concerns. There are several options that would decrease the data preparation effort required per study while maintaining data privacy and security safeguards, and the Network should not limit itself to any single approach. Rather, the ADRN should plan to employ different approaches for different datasets and different data custodians to ensure that the Network has the flexibility to respond to the preferences and requirements of diverse data providers, while maintaining public confidence and trust.

3. Establish a Single Network Lead

Management of the Network by the Directors Group required a minimum of four individuals to participate in most decisions and created challenges for many ADRN stakeholders. Independent of the Mid-Term Review, the Network has been moving toward a more centralised leadership model since 2015. The Mid-Term Review findings support the ADRN's September 2016 decision

to establish the new role of ADRN Director who will serve as the overall Network lead. The ADRN Director is most likely to be successful if there are clear accountabilities, including contractual requirements for the four Administrative Data Research Centres (ADRCs) and the Administrative Data Service (ADS) to take direction from the ADRN Director. Strong visible support from the ADRN Board, ESRC and UK Statistics Authority for the individual in the role of ADRN Director will be essential.

4. Leverage the Expertise and Relationships of Leading Researchers– Flexibility of Process and Role Clarity Between ADRC Researchers and the ADS

Experienced individual researchers, and existing research and data centres, can play a greater role in achieving the step change of increased use of administrative data by the broader research community. International experience has shown that data custodians are most likely to provide data for studies performed by researchers with whom they have relationships, and in some cases will not release data for other studies before completing a study with a trusted internal or external researcher due to data quality and other concerns. For this reason, it may not be possible for the first pioneering use of a new administrative dataset to use the standard ADRN process. To increase the number of routes through which datasets can be brought into the Network, the ADRN process should include a clear path from an ADRN-funded researcher negotiating access and using a dataset for their own program of research, to integration of the dataset into the data service provided to researchers broadly. This would include obligations on the part of the researcher, e.g., mandatory creation of metadata and other documentation, to enable the use of the dataset by others. The transition between researcher-led pioneering use of a dataset to UK-wide data service should be defined so that there is a common understanding of the roles and contributions of ADRCs and the ADS.

5. Clarify Roles and Establish Separation between Governing Authorities’ Strategic Advice and the Delivery of the ADRN

Given the challenges with access to government data, and the highly relevant knowledge and expertise of ADRN Board members, the ESRC and UK Statistics Authority, the Network’s governing authorities have become deeply involved in mitigation strategies. As the ADRN is expected to require this kind of expertise for the foreseeable future, the Network would benefit from establishing a new Strategic Data Access Negotiator role filled by an experienced individual with strategic negotiation skills and experience working with senior government decision makers. The establishment of the ADRN Director and Strategic Data Access Negotiator positions would present a good opportunity to review the role of governing authorities in Network delivery and decision making, and to streamline and clarify roles. Once the Strategic Data Access Negotiator is in place, and reporting to the ADRN Board provides assurance that there is progress on data acquisition, the ADRN Board, ESRC and UK Statistics Authority should move to more traditional governance roles. Reduced involvement of the governing authorities in the delivery of the Network would better position the ADRN Board, ESRC and UK Statistics Authority to provide strategic advice and oversight.

CONCLUSIONS

The evidence at the mid-term point of the five-year ADRN grant indicates that:

- ADRN Infrastructure has been established including policies, procedures, core staff, training and secure access sites
- Researchers know about ADRN infrastructure and a significant number of researchers have been trained and are interested in using the Network
- The Network has a major issue in that it does not have the UK-wide data that is required for ADRN infrastructure to have its intended impact
- The leadership of the Network has recognised the issue and taken steps to address it through the *ADRN Data Acquisition Plan* and by establishing two new roles: ADRN Director and Strategic Data Access Negotiator

It was not an objective of the Mid-Term Review to validate activities that the ADRN has taken to address issues with accessing data. Rather, based on an independent assessment, the Mid-Term Review Team developed recommendations which, in some cases, align exactly with the Network's own plans. Overall, the Mid-Term Review findings and recommendations support the approach that the Network has taken to mitigation. The Mid-Term Review highlights the importance of coordination, role clarity and flexibility as the Network focuses its efforts on acquiring government administrative data.

The review identified room for improvement in Critical Success Factor and project progress reporting. Critical Success Factor reporting should be enhanced to provide more information about data access and the wider contributions of the ADRN (e.g., developing capability, methodology and public engagement). Project progress reporting is essential for the Network to (a) identify specific issues related to data access and (b) provide information about which mitigation strategies are working. There are a large number of projects at ADRCs that are not captured in Critical Success Factor or project progress reporting. These projects, both policy and linkage studies, should be assessed to determine if they warrant being included in the count of ADRN projects.

The value for money of the ADRN cannot be assessed until more data is available and more projects have been completed. The activities in the *ADRN Data Acquisition Plan* and the recommendations of the Mid-Term Review are much more than changes at the margin, but will take time to show effect. Collectively, they could have substantial impact on the number of ADRN projects that make use of government administrative data by the end of the current grant. Changes like establishing needed central leadership, bringing new senior negotiation expertise to the ADRN Director team and allowing re-use of linked datasets are major alterations that are expected to benefit the Network. However, ultimately the success of the Network will depend on government departments and agencies providing data. For the ADRN to fulfil its mandate, champions and activities within government departments and agencies will be as important as commitment and effort from the research sector.

INTRODUCTION

In December 2012, the Administrative Data Taskforce, a group of independent experts in academia, government and industry, prepared a report which identified opportunities and challenges around the use of administrative data for research purposes in the UK. The Taskforce report recommended:

- I. An Administrative Data Research Centre (ADRC) in each country of the UK*
- II. An independent Governing Board to provide strategic guidance and assurance*
- III. UK wide researcher training and accreditation process*
- IV. A strategy for engaging with the public*
- V. Generic legal gateways to access data*
- VI. Sufficient resources to provide for state-of-the art and safe facilities*

The Government responded to the Taskforce in June 2013, broadly supporting their recommendations. Capital funding was provided to the Economic and Social Research Council (ESRC) who launched a competitive call for proposals. In October 2013, the ESRC awarded five separate five-year grants to:

- ADRC-England: led by the University of Southampton
- ADRC-Northern Ireland: led by Queen's University Belfast
- ADRC-Scotland: led by the University of Edinburgh
- ADRC-Wales led by Swansea University
- The Administrative Data Service (ADS) led by the University of Essex

Significantly, the bids for the five centres were developed independently and the five grant agreements did not specifically require joint activities between the five grant recipients.

The four ADRCs combined with the ADS are generally understood by stakeholders to be the core of the Administrative Data Research Network (ADRN). Other materials define the Network broadly as *"a UK wide partnership between universities, government departments and agencies, funders and the wider research community"* comprising:

- I. Four ADRCs, one in each country, through which accredited and approved researchers will access de-identified linked administrative data*
- II. An ADS which coordinates the Network and is the first point of contact for researchers who require access to administrative data*
- III. Data custodians (government departments and agencies, and national statistical institutions)*
- IV. The Economic and Social Research Council (the funding body)*
- V. The UK Statistics Authority which is responsible for the governance of the Network through the ADRN Board*

In April 2014, Professor David Hand was appointed as Chair of the ADRN Board for a five year term by the UK Statistics Authority in consultation with the ESRC. Professor Peter Elias was the inaugural deputy Chair. Ms. Sharon Witherspoon was appointed deputy Chair to the ADRN Board by the ESRC in February 2016.

Additional background information about the ADRN, the ESRC, and the UK Statistics Authority are presented in the Excerpt from the the ADRN Mid-Term Review Invitation to Quote document (Appendix A).

Funding for the ADRCs and ADS began in October 2013. By November 2014, core establishment infrastructure was in place including an application process, Approvals Panel, safe and secure data access sites and an accreditation process and training for researchers.

Approximately one year later, there was general agreement among the strategic and operational leaders of the Network that studies based on administrative data were not progressing through the ADRN at the anticipated rate, primarily because government data were not being made available. Progress was particularly slow for UK-wide data from Whitehall departments, with better progress on data from Devolved Administrations in Scotland, Northern Ireland and Wales.

Publicly-available ADRN Board meeting materials note potential contributing factors to access to data issues such as: lack of legal clarity about the ability of government departments or agencies to provide data to the ADRN, cultural or political factors within government departments/agencies, lack of resources within government departments and/or agencies to prepare data for research purposes, and the general need to build relationships and better understand data custodians' concerns.

In response to the challenges with accessing data, and also to better address opportunities, the Network implemented a number of recent changes including:

- October 2015: Changed the Network management structure from a single large ADRN Management Committee with 16 representatives to establish the Directors Group consisting of:
 - I. The principal investigators or directors of each of the four ADRCs
 - II. The director of the ADS
 - III. The chair of the Operations Group (the group tasked with implementing the strategic direction decided by the Directors Group)
 - IV. The ADRN lead at the ESRC
 - V. The lead for the ADRN Board secretariat from the UK Statistics Authority
- June 2016: Development of the "Issue Mitigation Plan" – a 12 page document addressing access to data and other issues
- August 2016: Development of the *ADRN Data Acquisition Plan* – a 15 page document focused activities and potential Network policy changes aimed at increasing success with data acquisition
- September 2016: The creation of a new overall Network lead position - the ADRN Director, filled as of October 1, 2016 – as well an ADRN Secretariat that reports to and supports the ADRN Director
- September 2016: A plan to bring in an individual with strategic negotiation skills and experience working with senior government decision makers – the Strategic Data Access Negotiator – to lead work on data acquisition

It is not possible for the Mid-Term Review to evaluate the effectiveness of these changes. All of them had been in effect for less than one year when the Mid-Term Review commenced, and several of the changes occurred during the Mid-Term Review. However, the Mid-Term Review Report does present analyses and recommendations in the context of these new developments.

Noting that there was already widespread acknowledgment of issues related to accessing data and a mitigation plan in place when the Mid-Term Review commenced, at the July 2016 Board meeting the ADRN Board made recommendations regarding the focus of the Mid-Term Review:

- I. The review should provide recommendations about what the ADRN needs to do to achieve the objectives of the Network*
- II. The report should focus on how the Network can be improved in the future*
- III. The small number of completed research projects will make it a challenge to look beyond the data access issues*
- IV. It would be useful to investigate whether there are issues around governance that have impacted on the Network's ability to work in an agile way*
- V. The review should investigate the impact on demand if the Network moved to the model of retaining de-identified data*

As of June 2016, £25.3M (66%) of the £38.5M ADRN budget had been spent, and the Network was behind its intended schedule for linked data projects, and far behind schedule for projects that made use of linked UK-wide data.

As noted in Appendix A, the UK Statistics Authority will use the Mid-Term Review to seek assurance for the robust performance and governance of the Network. The Mid-Term Review will also inform the ESRC Council's decision, in February 2017, of whether and how the ESRC will re-commission the ADRN beyond the initial grant.

METHOD

The review team conducted a mixed method evaluation consisting of a summative evaluation to examine if intended goals and current contributions of the ADRN have been achieved, and an assessment of processes to address how the ADRN can best support stakeholders and provide value for money. The approach included a desktop document review, surveys and interviews as outlined in Table 1.

Table 1: Components and evidence sources of the mixed methods ADRN Mid-Term Review

Evaluation Component and Relevant Evidence Sources	Quantitative Methods	Qualitative Methods
Desktop Document Review <i>Review of available pre-existing relevant documents including: process map, performance reports, ADRN annual reports, governance and committee meeting materials, the ADRC and ADS submissions to the review team, and publicly available documents related to comparator organisations</i>	✓	✓
Online Surveys <i>Online survey designed to take 20 minutes or less to complete. Likert scale questions combined with open ended questions. Some common questions as well as separate sections for:</i> <ul style="list-style-type: none"> • <i>Design/delivery stakeholders</i> • <i>Individuals who work at government departments or agencies</i> • <i>Researchers, including researchers who have not used the ADRN</i> 	✓	✓
Interviews and Confidential Discussions <i>Interviews (30-60 minutes each) with key informants identified in consultation with the ESRC and UK Statistics Authority. Separate one-to-one confidential discussions with selected survey respondents all of whom indicated a willingness to be contacted.</i>		✓

The desktop document review focused on materials prepared for the ADRN Board, Terms of Reference documents for governance and management bodies and information submitted directly to the Mid-Term Review Team by the ADRCs and ADS. Select performance data were analysed for changes over time. Information about international comparator centres and networks was obtained primarily from public sources, supplemented by direct communications to the Mid-Term Review Team from the leads of comparator organisations.

An online survey questionnaire was used to gather input from stakeholders including: (i) design/delivery stakeholders*, (ii) people that work at UK government departments or agencies and (iii) researchers. The survey was tailored to address the challenge of individuals belonging to more than one stakeholder group and included a mix of open and closed (Likert scale) questions. The survey was confidential, and did not require respondents' names but did ask respondents to provide their email addresses if they were willing to be contacted. The survey was distributed widely by the ESRC and UK Statistics Authority and respondents were encouraged to share the

* Defined as individuals who work at an ADRC or the ADS or who are involved in governance and management bodies of the Network including the ESRC, UK Statistics Authority, ADRN Board, Directors Group, Operations Group and Approvals Panel.

survey link with others. The ESRC and UK Statistics Authority sent reminders about the online survey near its closing date.

Twenty-one key informants for interviews were identified by the Mid-Term Review Team considering advice from the ESRC and UK Statistics Authority (see Appendix B).

Interviews were conducted in-person or via telephone by the subject matter experts from the Mid-Term Review Team using a semi-structured interview format, and were audio-recorded. The interviews focused on governance and potential future-oriented activities of the ADRN, including potential changes to the Network aimed at improving data acquisition. An *Interview Guide* was developed a priori with open-ended questions to support interviewers in ensuring comprehensive coverage of topics (Appendix C). Interviews were conversational and guided by the direction of the interview participants until saturation of key topics was achieved. For areas requiring further investigation, and themes emerging from interviews later in the review process, six key informants were interviewed a second time.

In addition, the Mid-Term Review Team had confidential discussions about emerging themes with four individuals who indicated a willingness to be contacted in their online survey responses.

A descriptive analysis of quantitative data was performed and complemented with qualitative data to provide additional context including success factors, barriers, priorities and emerging issues. Open ended survey questions and interview notes were analysed using grounded theory. This included an iterative and constant comparison approach, triangulating findings with other data sources to identify the most salient themes. Recommendations for the most important themes were developed by the Mid-Term Review Team using an iterative process.

SUMMATIVE EVALUATION OF PROGRESS AT THE MID-TERM POINT OF THE FIVE-YEAR GRANT

SUMMATIVE EVALUATION: KEY FINDINGS

The ADRN Critical Success Factors (see Table 2), agreed by the ADRN Board in July 2015, highlight how the Network has been successful at establishing infrastructure to support research based on administrative data, but not successful at achieving a large number of completed projects.

Table 2: Progress on Critical Success Factors as of April 2016 as reported to the ADRN Board in July 2016[†]

Critical Success Factor	Measure	Progress
Accessible facilities in each country	Facility in each country of the UK	Each of the constituent countries of the United Kingdom has centres which are open for researchers.
	Facilities are accessible by researchers with Disabilities	All facilities are accessible to researchers with disabilities.
Everyone who uses the Network is trained to carry out safe research	Accreditation training programme in place	All researchers accessing the Network have undergone accreditation training.
Create infrastructure remaining acceptable to data owner, the public and funding stakeholders	Time between approval and data with the Third Trusted Party (TTP) set out by project	Of the eight (8) projects that have had data with the TTP, 6 had data with the TTP on or before the date that Approvals Panel approved the project (because the data had been secured previously), the other two had data with the TTP 20 weeks after approval and 25 weeks after approval. [†]
Approved projects are being executed	Total number of projects logged with Administrative Data Service (ADS) compared to those With approval from the Approvals Panel	As of June 2016, there are a total of 97 active ADRN projects, 44 of which are at the "Developing Application" stage. Of the 53 projects that have been submitted, 41 (77%) have been fully approved by the Approvals Panel. [†]
	Total number of accredited users named on projects approved by Approvals Panel	In total there are 64 accredited ADRN researchers (32 from academia, 24 from government and 8 from the third sector).
	Total number of completed projects	As of August 2016, there are 2 completed projects. [†]
Well developed public relations and public engagement direction	Percentage of research summaries available on the ADRN website to the public	As of August 2016, 100% of the projects that have been approved by the Approval Panel have research summaries for the public on the ADRN website. [†]

Other notable ADRN accomplishments identified by the desktop document review that are not captured in Critical Success Factor reporting include:

- A large number projects led by ADRC researchers, including methodology projects and research exemplar projects based on linked data, that are not included in project counts
- Public engagement activities including 10 public-engagement focused projects at the ADRC-Scotland
- Quantitative information about training, i.e., 150 researchers trained by the national accreditation training programme as of April 2016
- International contributions, e.g., providing advice to the US-based Actionable Intelligence for Social Policy initiative funded by the John D. and Catherine T. MacArthur Foundation

[†] Updated relative to April 2016 information provided by the ADRN for the July 2016 ADRN Board meeting

Most key informants and survey respondents considered the overall progress of the Network to be “good”, with some variation in perception across stakeholder groups (see Figure 1 and Table 3). The overall pattern of response was consistent across groups (see Table 3).

Figure 1: Online survey respondent views on ADRN progress

What is your overall view of the ADRN progress at the mid-way point of its first five years of funding?			Response Percent	Response Total
1	Very good progress		12.15%	13
2	Good progress		59.81%	64
3	Poor progress		25.23%	27
4	Very poor progress		2.80%	3
			answered	107

Table 3: Breakdown of online survey respondent views on progress by stakeholder group[‡]

	Very Poor Progress		Poor Progress		Good Progress		Very Good Progress		Total
Involved in design and/or delivery of the ADRN	1	(2%)	14	(23%)	40	(66%)	6	(10%)	61
Work at an ADRC or the ADS	1	(2%)	12	(26%)	29	(63%)	4	(9%)	46
Other, e.g., work at ESRC or UK Statistics Authority, member of ADRN Board, Approvals Panel or Directors Group	0	(0%)	3	(14%)	16	(72%)	3	(14%)	22
Researcher	1	(2%)	16	(26%)	32	(52%)	12	(20%)	61
UK Department or Agency	1	(4%)	5	(19%)	20	(74%)	1	(4%)	27
All Respondents	3	(3%)	27	(25%)	64	(60%)	13	(12%)	107

The Network, the physical and e-infrastructure, the single website, its policies and procedures and overarching strategies, and its advisory Board were all set up as planned and within a year...Progress is good, rather than very good, because the partnerships with key data owners have not established enough to translate to data access for many large projects.

When provided with the opportunity to identify the most significant accomplishments of the Network, design/delivery survey respondents identified accomplishments related to infrastructure two times more frequently than any other type of accomplishment. This was corroborated by qualitative interviews.

More than two thirds of researcher respondents to the online survey indicated that all steps of the ADRN process, with the exception of “ADRN negotiating access to data and linking data for you”, were “good” or “very good.”

There were 10 comments in the survey and interviews related to the Approvals Panel, including positive and negative comments, with several key informants noting that the Approvals process had

[‡] Numbers do not add to totals because some respondents belong to more than one stakeholder group. Geographically, more than half of the survey respondents were from England, see Appendix D for additional information on survey respondents and Appendices D, E, F and G for complete quantitative survey results.

been improved relative to how it functioned when the Network was first launched. Data on the key dates for projects provided by the ADS confirms that the time for Approvals has decreased over time:

- The first nine projects approved by the Approvals Panel took an average of 182 days to complete the Approvals process, and seven of the nine projects required multiple Approvals Panel meetings before they were approved.
- For the nine projects that received final approval in April and May 2016, approvals took an average of 83 days, and five projects were approved the first time that they were presented to the Approvals Panel.

Notwithstanding the positive statements stakeholders made related to infrastructure establishment, survey respondents emphasised that the overall “good” rating includes “poor” progress in important areas.

The desktop document review included gathering budget and output information for comparator centres (see Appendix H). Comparisons should be made with caution because each of these centres/networks has its own context, and because no multi-country comparator networks were identified. General findings from the review of comparator centres/networks were:

- There are centres/networks that required start-up funding at levels that are comparable to what the ADRN has expended for its start-up
- In several cases, a start-up grant that was equal to or larger than the centre/network annual operating budget was required
- Generally the models which involve core linked datasets or standing linkage keys appear to be able to support large numbers of projects at lower cost (see Recommendation 3 for additional discussion of the models)

My answer is somewhere between good and poor: overall, many of the initial network aims are being met and infrastructure and internally-led research is being delivered. However, there are fundamental problems that may not be resolvable.

Qualitative survey responses indicated that Brexit is seen to be the largest external contextual factor/emerging issue that will impact the ADRN (identified in 21 of 59 comments). Respondents also named legislation, within the UK and the EU (16 of 59 comments) and commercial access including care.data (8 of 59 comments) as important.

Considering the desktop document review, online survey responses and interviews together, the most important themes that the Mid-Term Review Team identified related to the summative evaluation are:

- The ADRN has made good progress on establishing infrastructure
- Progress on accessing government administrative data has not been good, though better for Devolved Administrations than Whitehall departments
- The Network requires government data in order to fulfil its mandate

SUMMATIVE EVALUATION: ANALYSIS AND DISCUSSION

The UK Statistics Authority website states *“the ADRN has been established to facilitate accredited researchers in accessing de-identified administrative data for the purposes social and economic research.”* With that as context, it is understandable why most stakeholders rate the overall performance of the ADRN as “good.” Based on the successful establishment of infrastructure in a short time frame, the Mid-Term Review findings confirm that the overall Network progress to date has been good, with the most progress in areas that were identified as being both important and within the control of the ADRCs and ADS, such as establishing policies, secure access sites and training.

Across all stakeholder groups, approximately one quarter of online survey respondents indicated that progress has been “poor” or “very poor”, with respondents from England more likely to view progress negatively. The examples of good progress in Devolved Administrations generally were attributable to (a) existing trust relationships between researchers and government or agency representatives and/or (b) strong central leadership within government departments or agencies. Even among those who saw overall progress as “good”, survey responses and interview remarks indicate that most the vast majority acknowledge that the Network needs more government administrative data for ADRN infrastructure to have its intended impact.

The Mid-Term Review Team believes that the current Critical Success Factors reported to the Board do not reflect the importance of access to data adequately. Critical Success Factor reporting could be strengthened by adding metrics related to data acquisition such as:

- The number of datasets that have been linked and accessed by researchers via the ADRN with breakdown including:
 - The number of datasets that had not previously been used by academic researchers
 - The number of academic researchers working with linked administrative data for the first time
 - The number of novel dataset linkages (i.e., reporting when two datasets that may have been used previously for research are linked for the first time)

It is the view of the Mid-Term Review Team that Critical Success Factor reporting could also be improved in other ways:

- The current metric of “Percentage of research summaries available on the ADRN website to the public” under “Well developed public relations and public engagement direction” is a simple output measure that doesn’t capture the breadth of what the Network has been doing, or could do in the future
- There would be benefit in expanding the Critical Success Factors metrics to capture other areas identified as important for the Mid-Term Review, e.g., the contribution of the ADRN to the development of capability and methods, locally and internationally
- Given the focus of the Network on secure access, one or more indicators related to privacy would add value (e.g., absence of major breaches, response time to address identified risks)
- Critical Success Factor reporting, and other reporting to the ADRN Board, could be focused more on reporting for projects that have been submitted, as opposed to including projects that may never be submitted.

Regarding Value for Money, the Mid-Term Review Team notes that the amount of investment required for any new investment in linked data infrastructure for research would depend mostly on what existed before the investment was made. This general view is supported by information from comparator centres and networks (Appendix H). For example, in the case of the Canadian Research Data Centre Network (CRDCN), because Statistics Canada has led and funded linkage work and provides data that is research-ready, a relatively modest investment in centres at universities across Canada facilitates broad researcher access to limited linked data. On the other hand, the Institute for Clinical Evaluative Sciences (ICES) in Ontario Canada was started with an initial investment of \$20 million CAD in 1992 (equivalent to \$30.6 million current CAD, £18 million current GBP), when tasked with creating and supporting the use of new health administrative data infrastructure for a single sub-national jurisdiction in an era when data access and privacy constraints were considerably simpler.

The Mid-Term Review Team believes that the Value for Money of the ADRN cannot be assessed until more projects have been completed, and even then will be hard to determine conclusively. As part of fiscal oversight, auditing (performed outside the Mid-Term Review) would determine whether spending on facilities, information technology, core staff and other expenses is in alignment with comparable investments in the UK. This would form part of the Value for Money assessment. Taking direct and indirect costs into account, studies based on administrative data are generally low cost compared to other types of research such as trials and biomedical research. A future assessment of the total cost per ADRN project[§] would contribute to the Value for Money assessment of by providing information about whether this is also the case for projects that use ADRN infrastructure.

However, the ultimate decision about the ADRN's Value for Money will depend on how much value funders place on the ability of the UK to use its own data for economic and social policy research. Investments in research administrative data infrastructure stand apart from other potential research investments in that no other jurisdiction will invest in preparing another country's administrative data infrastructure for research, and for policy-relevant research, there is no substitute for what a country can learn from its own data.

SUMMATIVE EVALUATION: CONCLUSIONS

The establishment of ADRN infrastructure is a significant accomplishment and an illustration of how the Network can achieve UK-wide objectives. Notwithstanding the ADRN's good overall progress to-date, the Network must make major advances accessing government data if it is to fulfil its mandate. The ADRN is at a critical juncture. At the end of the current grant in September 2018, the Network's success will be measured based on the number and nature of projects that use ADRN infrastructure to perform research based on linked government administrative data.

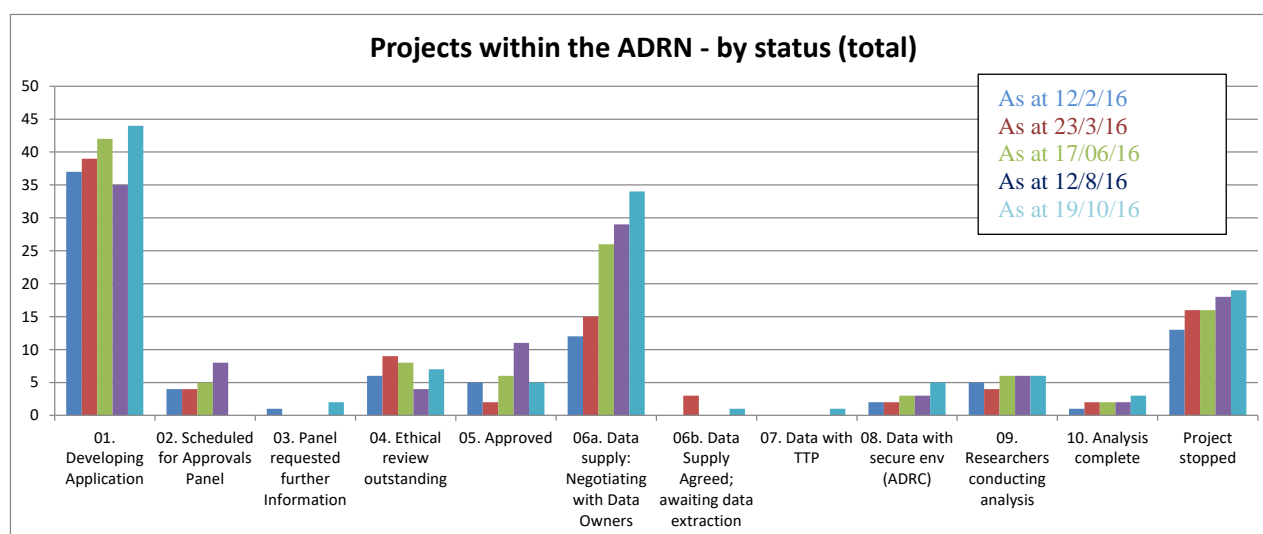
[§] The method for determining the total cost per project would need to be determined, and should exclude ADRN start-up costs and include the indirect costs covered by the ADRN

RECOMMENDATION 1: UTILISE A MULTI-PRONGED APPROACH TO THE ACQUISITION OF GOVERNMENT DATA

RECOMMENDATION 1: KEY FINDINGS

Every key informant interviewed, including representatives from Devolved Administrations, raised the issue of access to government data without being prompted. A report prepared for the July 2016 ADRN Board meeting indicates that many approved projects are not progressing past the “Negotiating with Data Owners” stage of the ADRN process (Figure 2).

Figure 2: Projects by stage of ADRN process as presented at the Nov. 2016 ADRN Board meeting



Publicly available materials from ADRN Board meetings note that the ADRN Board is working toward improving the Network’s *Highlight Report* so that the ADRN Board has better information about, and can provide advice related to, the time it takes for projects to progress through the ADRN process.

Design/delivery respondents’ comments and quantitative responses to the online survey identified that progress on UK-wide (Whitehall) data is a major issue, while access to Devolved Administration data is better:

- Forty (40) of 59 design/delivery respondents (68%) indicated “Poor” or “Very Poor” progress on Accessing data from Whitehall departments
- Forty-seven (47) of 59 design/delivery respondents (80%) indicated “Good” or “Very Good” progress on Accessing data from Devolved Administrations

Approximately half of the design/delivery survey respondents identified “Cultural barriers with government departments and agencies” as the single most important barrier to ADRN success.

In general, the departments holding the data seem reluctant to provide it to researchers and are highly risk averse. In defence of these departments, it is hard to see what the benefits are currently for the civil servants and bureaucrats who are data custodians.

It is about resource and about being realistic...data that is supposed to exist doesn't really exist in a way that it can be used as intended [for research studies]. Government departments need safe space to say these fields are not worth using...

Interviews with design/delivery stakeholders gave a more nuanced view, making it clear that the people involved in managing and governing the Network understand the barriers aren't just "cultural", and that data acquisition will depend on the interplay of a number of factors.

In the online survey, respondents from government department and agencies identified several factors contributing to slow progress access data including:

- A lack of resources within government departments and/or agencies to prepare data for research purposes - 21 of 25 respondents (84%) indicated this was an "Important" or "Very Important" contributor
- A lack of legal clarity about the ability of government departments or agencies to provide data to the ADRN - 17 of 25 respondents (67%) indicated this was an "Important" or "Very Important" contributor
- Other data-related activities within government departments/agencies are higher priority- 17 of 25 respondents (67%) indicated this was an "Important" or "Very Important" contributor
- Cultural or political factors within government departments/agencies 15 of 25 respondents (60%) indicated this was an "Important" or "Very Important" contributor

Key informants had mixed views on the effect of upcoming potential UK legislation on data supply. A small number spoke about specific positive impacts that the legislation would have (e.g., creating a legal gateway for HMRC to contribute data, potentially allowing data held by the Office for National Statistics to be used more broadly). Other key informants did not feel that legislation was a significant barrier for most departments, and expressed the view that legislation would take a long time to be passed and implemented, and that the legislation would not address the underlying cultural factors that make some departments hesitant to provide data to the ADRN.

Approximately half of the 25 researcher respondents who had experience with the process step of "ADRN negotiating access to data and linking data for you" indicated that the step was "poor" or "very poor". Less than half of the 61 researcher respondents who have submitted applications to the ADRN are certain that they will submit a project in the future. Eleven researcher respondents to the online survey indicated that poor access to data had or would influence their decision to submit an application to the ADRN.

In July and August 2016, the ADRC and ADS Directors worked together to create the *ADRN Data Acquisition Plan* (the Plan). The Plan articulates the issue of poor access to government administrative data and a number of activities to address it:

The core aim of the ADRN is to produce an effective step change in research access to linked administrative data. For this it is necessary for ADRN to deliver access to government data assets. However, despite the establishment of a state-of-the-art national infrastructure to enable sensitive administrative data to be analysed safely and the progress being made through the effort of a high quality data acquisition team, the ADRN has not secured the data resources at a rate that we and our funder would have hoped for...

...The Data Acquisition Plan involves (i) augmenting the resources available to the data acquisition process to include the directors and other senior academic staff as appropriate (ii) the involvement of strategic assets in external organisations (such as the ESRC's CEO and head of the UK Statistics Authority) where these can be brought to bear in an effective manner (iii) an approach based on

targeted supply facilitation rather than demand channeling and (iv) the implementation of SMART objectives through milestones.

*...The ADRN DG and Board have also agreed to move towards the implementation of two strategic changes which will support the development of ADRN as a key national infrastructure: **ADRN led data extraction** and enabling **government commissioned research**.*

Collectively, the interviews, ADRN Board materials, *ADRN Data Acquisition Plan* and online survey responses identified many factors that could contribute to the hesitancy of government departments and agencies to provide data to the network including:

- Lack of resources to prepare data within government departments
- The large amount of data preparation effort required per study under the current ADRN model
- The absence of a clear legal gateway or the lack of clarity as to whether an existing gateway applies
- ADRN communications that focus on technical steps and risks vs. inspiring participation
- Data owner concerns about data quality
- The incompatibility of government's practice of working with commercial researchers and firms on government-initiated studies with the ADRN's restrictions on who can use the Network
- Overall, insufficient benefit for government compared to the effort and risks involved with providing data

Considering the desktop document review, online survey responses and interviews together, the most important themes related to data acquisition are:

- Access to data is the most important issue for the ADRN
- There are a number of contributing factors
- The governing authorities and Directors of the Network are aware of the issue and the Directors have developed a multi-pronged plan to address it
- It is important that the Network has effective reporting to (a) identify specific issues related to data access and (b) provide information about which mitigation strategies are working

RECOMMENDATION 1: ANALYSIS AND DISCUSSION

It is good that the issue of access to data is widely acknowledged by ADRN leaders and stakeholders. The risk for the Network would be much higher if there was not consensus on this point. Only a handful of stakeholders present simple remedies to the issue. Most acknowledge that a multi-pronged approach will be required, including short-term technical, process and policy work and longer-term activities aimed at improving trust and relationships with government departments and agencies.

The *ADRN Data Acquisition Plan* was developed by the Directors Group independent of the Mid-Term Review, but includes many activities that the Mid Term Review Team would have recommended. In particular, the Mid-Term Review Team supports the Plan's emphasis on relationship building and the fact that the Plan identifies a single ADRN lead for communication with key government departments and agencies. In practical terms, each government department or agency likely has a limited amount of time that it is willing to invest in discussions and work with the ADRN, so it is critical that the time with government departments and agencies is used for

maximum effect. Identifying main points of contact is a good way to avoid duplication or potential confusion of message.

Given the large number of factors that could work against government departments and agencies providing data to the Network, and acknowledging that trust relationships take time to build, it is likely that some of the activities identified in the *ADRN Data Acquisition Plan* will not proceed exactly as planned. It is the view of the Mid-Term Review Team that this is to be expected, and should not be interpreted as a failing of the Plan. What will be important is that the Network is flexible and responsive as it implements the *ADRN Data Acquisition Plan*:

- Successful implementation of the Plan will likely depend on knowing when to stop a non-progressing activity, or put an activity on hold, even in the absence of a firm “no” from a government department or agency.
- The Plan should be dynamic and change alongside new developments. For example, when a dataset is provided for first use, the Network should develop and implement a clear plan to augment the impact by actively promoting the use of the dataset in other studies, even if that means redirecting resources to do so.
- New legislation, if passed, will present some new opportunities for the Network, the ADRN will need to adapt the Plan to make the most of them.
- The Plan begins to articulate the benefits or value proposition of participating in the Network from a government data owner’s perspective (e.g., the ADRN assists the government’s transparency agenda). As the Network learns more about what is most important to government departments and agencies, the list of benefits should be updated so that it can be used in meetings with government/agencies in a coordinated way.

In summary, the Mid-Term Review Team believes that flexibility and responsiveness will be the key to successful implementation of the *ADRN Data Acquisition Plan*.

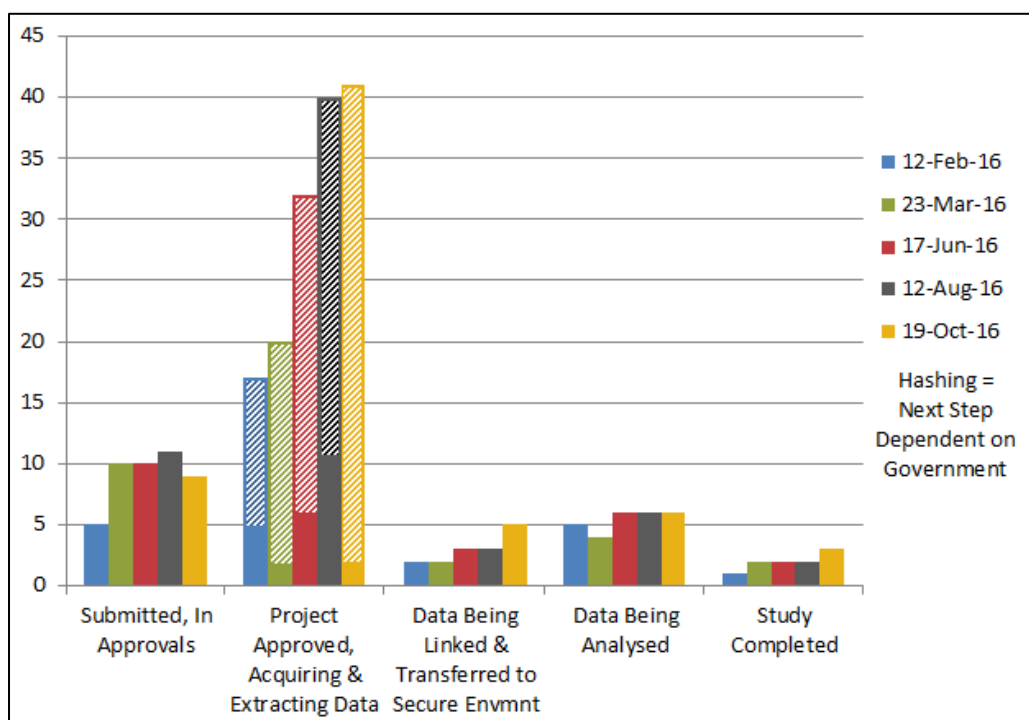
Fine tuning and redirecting activities directed at data acquisition will require effective monitoring and reporting. The Mid-Term Review Team appreciates that the *ADRN Data Acquisition Plan* makes specific reference to the importance of reporting and suggests that there is also an opportunity to improve reporting to the ADRN Board as the Plan is implemented. Specifically, project reporting to the ADRN Board could be more focused on the projects that are truly active in the Network, as opposed to including projects that have not been submitted or have been stopped.

Information provided to the Mid-Term Review Team by the ADS indicates that, as of October 2016, 44 of 127 ADRN projects are the “Developing Application” stage of the process and have not been submitted – this includes some projects that have not progressed past Step 1 of the ADRN process since 2015. In addition, 19 of the 127 projects have been stopped for various reasons. Once issues related to data access have been resolved, there may be value in investigating both “stopped” and “not-submitted” projects to see if ADRN process changes could be made to address them, but the most important projects for the Network at present are the ~60-70 projects that have been submitted and have not been stopped.

A simplified chart such as Figure 3, or variants of it, would highlight the dependence of the Network on government activity more clearly than previous project reporting to the ADRN Board (e.g., see

Figure 2). Further, Figure 3 could be adapted to present subcategories of projects that are dependent on specific government activities (e.g., separate shading for “requires legislation change”, “data owner assessing data quality” etc.). The five groupings of steps on horizontal axis of Figure 3 are sufficiently high-level that they would apply even if the ADRN expands its process to provide access to core linked datasets (see Recommendation 2).

Figure 3: Alternative presentation of ADRN project progress data (including new Oct. 2016 data)



However the Network chooses to address reporting, it is essential that the reports support effective communication between the Network Directors and between the Directors and ADRN governing authorities. From the *ADRN Data Acquisition Plan* it is clear that there will be many activities

happening in parallel. The *ADRN Data Acquisition Plan* is long and detailed. Effective leadership and coordination of the activities in the Plan will be paramount, particularly when it comes time to link datasets from different departments.

RECOMMENDATION 1: CONCLUSIONS

There is near-unanimous agreement that lack of administrative data from government departments is the single biggest challenge that the Network faces. It is good that this is acknowledged widely. The ADRN should continue to prioritise activities aimed at increasing access to data, UK-wide (Whitehall) data in particular. With coordinated effort, and strong central leadership, it should be possible to make progress on near-term activities, e.g., by piloting more flexible data retention and re-use policies (see Recommendation 2). However, other remedies, such as building trusting relationships and contributing to culture change within government departments, will take more time and visible commitment from government. Appropriately, the August 2016 *ADRN Data Acquisition Plan* developed by the ADRN Directors focuses on short-term activities while laying the foundation for longer-term work. Making progress on access to data will require strategic and coordinated implementation of the *ADRN Data Acquisition Plan*. Given the complex roots of data access issues, flexibility, responsiveness, and reporting on progress vs. the plan in a way that allows redirection of resources (as necessary) will be essential..

RECOMMENDATION 2: CREATE THE FLEXIBILITY TO ALLOW THE RETENTION AND RE-USE OF LINKED DATASETS

RECOMMENDATION 2: KEY FINDINGS

Based on the ADRN Board's recommendation, a question related to data retention was integrated into the *Interview Guide* (Appendix C) for the Mid-Term Review. However, most key informants raised the topic of dataset retention and re-use without being prompted. Many key informants noted the potential of this policy change to increase the number of studies being performed using government administrative data and decrease the time from a researcher requesting data to analysis. Key informants referenced the fact that this practice is already happening under other centres/networks in the UK and information gathered on comparator organisations found that well known centres/networks in other countries maintain repositories of linked datasets and/or standing linkage keys (Appendix H).

Once one researcher has accessed a dataset, can there not be an agreement for other researchers (subject to approval) to use this data and also updates of the dataset as new data is generated?

The *ADRN Data Acquisition Plan* includes a section on "ADRN led data extraction and retention" and identifies a lead for these activities. In multiple places, the Plan highlights the importance of understanding public attitudes and the legal/procedural issues related to data retention.

The topic of data retention also figured prominently in online survey results. For example, in response to the open ended questions "Are there key activities or deliverables that you believe the ADRN should start, stop, enhance or make a point of continuing in order to have its maximum impact?" 16 separate respondents indicated that changes should be made to the Network's data retention policy – this was more suggestions than were received on any other topic. Two thirds of the government and agency respondents to the online survey indicated that "The ADRN data retention model requires too much data preparation effort per project" as either a moderate or severe barrier from their perspective.

The Network should overtly switch from a 'request whatever you want' offer for researchers to a more managed offer of data...the ADRN could retain the offer of bespoke dataset creation but set lower expectations for that more speculative area of work.

In survey responses and interviews, there was generally support for a move to retain linked data sets and/or establish core linked datasets for multiple use, but it was not unanimous. A small number of stakeholders noted that the change in policy may not be aligned with data owner and public values and preferences.

Changing the data retention policy will severely impact on data supplier trust and will reduce data availability

Considering the desktop document review, online survey responses and interviews together, the most important themes related to data retention and multiple use of datasets are:

- The present ADRN approach of creating and destroying bespoke datasets is resource intensive
- There are alternative approaches
- The views of data owners and the public need to be considered if policy changes are to be made

RECOMMENDATION 2: ANALYSIS AND DISCUSSION

Almost all ADRN stakeholders support the proposal to allow retention and multiple uses of datasets, but those who do not raise valid concerns. While some government departments may be endorsing or even requiring the proposed policy change, it may raise red flags for others. As was noted for implementation of the *ADRN Data Acquisition Plan* in general, flexibility is essential. In cases where the provision of data by a government department is conditional on a linked dataset being destroyed after one use, the ADRN should agree to that condition. It is also possible that a data owner would agree to multiple uses of certain datasets, while wanting to retain project-by-project control of linkage for others. The ADRN should have the flexibility to agree to both.

There are a range of approaches that can be applied to decrease the data negotiation, preparation and transfer effort required per study. Options include:

- Establishing prepared minimum datasets within government departments that are linkage ready
- Standing, unlinked, datasets that reside in an ADRN repository with the ability for bespoke linkages for specific projects once approvals are in place
- Standing linkage keys that are deployed when project-specific approval is obtained
- Core linked datasets in a repository that are used to prepare cuts of data for specific projects

Every one of these approaches can allow for project by project approval of studies by the data custodian (if required) and would lower the cost per study and decrease the time from request to analysis relative to bespoke creation of linked datasets without advanced preparation of data.

The impact on demand would likely depend on what data is retained. Both survey respondents and key informants noted that a bespoke linked dataset that was prepared to answer a very specific research question would have limited use to other researchers. The Mid-Term Review Team is of the view that retaining individual bespoke datasets could still have an impact on the number of projects served by the ADRN (e.g., if the researcher who initially requested the dataset was able to perform additional studies on it or if other researchers used the dataset to test the sensitivity of the study to certain assumptions) but the overall effect on demand would be small. In contrast, demand could be increased significantly if the Network identifies and retains core datasets and makes them available for linkage and research. The Mid-Term Review Team recommends that the ADRN consider both retention/multiple uses of individual bespoke datasets and the promotion of multiple uses of core datasets.

If there is a shift of ADRN resources toward offering core linked datasets away from the bespoke dataset requests that have already entered the ADRN process, it will be important to communicate this change to researchers. With appropriate structured communication it is likely that the researchers who already have projects in the ADRN pipeline will understand why this change is happening, and how they might benefit in the long-term, but that should not be left to chance.

RECOMMENDATION 2: CONCLUSIONS

The current ADRN policy of creating bespoke linked datasets that are destroyed after one use represents one of the most resource-intensive approaches to preparing linked administrative datasets. As outlined in the *ADRN Data Acquisition Plan*, the Network should explore changes to its data retention policy and consider promoting multiple uses of core linked datasets. UK and international examples demonstrate the potential for data retention and data use policies that address data custodian concerns. There are several options that would decrease the data preparation effort required per study while maintaining data privacy and security safeguards, and the Network should not limit itself to any single approach. Rather, the ADRN should plan to employ different approaches for different datasets and different data custodians to ensure that the Network has the flexibility to respond to the preferences and requirements of diverse data providers, while maintaining public confidence and trust.

RECOMMENDATION 3: ESTABLISH A SINGLE NETWORK LEAD

RECOMMENDATION 3: KEY FINDINGS

Half of design/delivery stakeholders in the online survey viewed the distributed leadership model/design of the ADRN as a moderate or severe barrier to its success and there were multiple comments related to the distributed leadership model of the ADRN in responses to open ended questions of the online survey. The idea of establishing a single Network lead for the ADRN was raised, unprompted, in most of the interviews with governing authorities and by the Directors themselves. Generally, key informants contrasted the co-led management of the ADRN by the Directors Group with other management structures they had experienced, and commented on how the requirement to manage by consensus created issues. For example, key informants noted that the management structure led by the Directors Group has, in some circumstances, led to:

- Centres working independently rather than as a Network
- Decisions taking a long time
- Lack of clarity as to whether multiple parties are required for a decision, or if it is within the authority of a single Director
- Lack of clarity about who should represent the Network at key meetings
- Other effects, e.g., reporting to the ADRN Board that doesn't fully capture the breadth of activities within individual centres in the absence of overarching leadership on what should be reported

Governance for the development of coordinated approaches to problem solving appears to be quite weak, largely because of the collegiate structure

I do not feel the current structure with a centralised ADS and separate ADRCs works well currently... The ADRN does seem to be quite disparate with each centre doing its own thing

The desktop document review found that the ADRN has been taking itself toward a more central leadership model since 2015. Initially, the management of the Network was led by the ADRN Management Committee. The ESRC provided the secretariat to and chaired the Management Committee which had ~ 16 representatives including the Directors of the ADRCs and ADS and their project managers. In October 2015, a new structure was put in place, organised and chaired by the ADRN Directors. At that time, the Management Committee was replaced by two new groups – the Directors Group and the Operations Group. The Directors Group consists of:

- I. The principal investigators or directors of each of the four ADRCs
- II. The director of the ADS
- III. The chair of the Operations Group (the group tasked with implementing the strategic direction decided by the Directors Group)
- IV. The ADRN lead at the ESRC
- V. The lead for the ADRN Board secretariat from the UK Statistics Authority

Several key informants commented that the Directors Group approach was better than the large Management Committee, while noting that there was still room for improvement.

Considering the desktop document review, online survey responses and interviews together, the most important themes related to central Network leadership are:

- The Network would benefit from more central leadership
- Having a rotating chair of the Directors Group is not the same as having a single Network Lead

RECOMMENDATION 3: ANALYSIS AND DISCUSSION

Consistent with accepted governance best practices, the Mid-Term Review Team believes that it is better to have a single lead than co-leads for management. Having a single lead helps ensure that work is not duplicated or missed and provides a clear line of communication and accountability between the funded centre/network and its governing authorities. Most research programmes and networks identify a single lead, even in cases where there are multiple strong contributors.

The grants used to fund the ADRN follow this practice. For example, though the ADRC-England includes multiple sites, a single Lead was identifying while allowing for the contribution of Deputy Leads. However, at the Network-level, the ADRN has been functioning without a single lead since funding started in 2013. It is the view of the Mid-Term Review Team that the move from a large Management Committee with 16 representatives to management led by the Directors Group in October 2015 was a positive development, but one that did not go far enough.

The establishment of a rotating chair of the Directors Group did establish a temporary single point of contact, but didn't provide that role with authority. This is particularly problematic given that the five grants used to fund the ADRCs and ADS were established independently and do not specifically require cooperation between the ADRCs and the ADS. Further, a temporary Chair who will return to the position of co-lead at a defined point in time will never have as much authority as a (non-rotating) Lead. With the creation of the role of ADRN Director, the October 2016 ADRN governance structure more closely resembles best practice in that there is a single point of accountability. For these reasons noted above, the Mid-Term Review Team strongly endorses the move to having a single Network Lead.

From the perspective of the Mid-Term Review Team, important competencies and attributes for the ADRN Director would be:

- A solid track record of executive leadership and administrative leadership in a research/policy enterprise, including strategic planning, financial and human resources management; ideally this experience will include leading a distributed network of research/policy centres
- An appreciation for the complexity of, and a demonstrated capacity for, working with diverse stakeholders
- Experience working with a Board of Directors
- Experience working with government departments and agencies
- Strategic and conceptual thinker with the ability to see and anticipate the bigger issues on the horizon and to position the ADRN to take advantage of and respond to these changes
- An exemplary track record of research success - a PhD is preferred, combined with extensive and progressive management experience in research and/or policy
- Proven ability to recognise and articulate the relevance of research findings for policy and practice
- The stature and credibility to gain the confidence of key stakeholders, including the ADRC and ADS Directors, so they engage constructively in assisting the realisation of the ADRN vision
- Superior verbal, oral and written communication and facilitation skills augmented by effective media relations skills/experience

At the time of the Mid-Term Review, an individual had been appointed to the ADRN Director role for a one-year period beginning October 2016. A full recruitment process for the position is recommended; however, practically speaking, recruitment should not commence unless or until there is certainty that the ADRN will have funding for at least two years from the time that the successful candidate would start work in the role.

The ADRN Director role is expected to help ADRN management and governance, but will not be a “silver bullet” for the challenges that the Network faces accessing government data. The Mid-Term Review Team believes that the role will have its largest impact if there is written authority for the ADRN Director to represent and make decisions on behalf of the ADRN. Recognising that it may not be possible to renegotiate the agreements that would be required to provide this authority in the short-term, visible support from the ESRC, ADRN Board and UK Statistics Authority for the ADRN Director is essential.

RECOMMENDATION 3: CONCLUSIONS

Management of the Network by the Directors Group required a minimum of four individuals to participate in most decisions and created challenges for many ADRN stakeholders. Independent of the Mid-Term Review, the Network has been moving toward a more centralised leadership model since 2015. The Mid-Term Review findings support the ADRN’s September 2016 decision to establish the new role of ADRN Director who will serve as the overall Network lead. The ADRN Director is most likely to be successful if there are clear accountabilities, including contractual requirements for the four ADRCs and the ADS to take direction from the ADRN Director. Strong visible support from the ADRN Board, ESRC and UK Statistics Authority for the individual in the role of ADRN Director will be essential.

RECOMMENDATION 4: LEVERAGE THE EXPERTISE AND RELATIONSHIPS OF LEADING RESEARCHERS– FLEXIBILITY OF PROCESS AND ROLE CLARITY BETWEEN ADRC RESEARCHERS AND THE ADS

RECOMMENDATION 4: KEY FINDINGS

Materials submitted to the Mid-Term Review Team directly from ADRCs identified at least 12 research exemplar projects based on linked data that resemble the projects that ADRN is intended to support in many ways except that they have not been through the formal ADRN process. In some cases these projects were initiated before the ADRN process was established. In other cases they are studies based on data that was acquired, or is being acquired, based on existing long-term trust relationships between ADRC researchers and specific data owners.

The existing process does not reflect the complexity of using linked administrative data and is more appropriate to survey data or applications to a data archive for well documented and curated data.

Key points from interviews and responses to open ended questions in the online survey were:

- Administrative datasets that have not been used for research previously are different than survey data and other well-curated data:
 - Creating/defining a linked dataset for the pioneering first use of a new administrative dataset requires collaboration between an experienced researcher and the data owner (e.g., dialogue about what variables would be relevant to the research question alongside discussion about the data quality and availability of those variables)
 - The first analyses based on new administrative datasets are done under controlled conditions
 - It may not be possible for the first pioneering use of a new administrative dataset to use the standard ADRN process
- There can be a greater role for individual experienced researchers in negotiating first use of new administrative datasets for the research community broadly
- One of the objectives of the ADRN is to remedy the fact that only a small group of experienced researchers have been performing studies based on linked administrative data to date – the Network will not fulfil its mandate if, at the end of the grant, studies are only performed by the same small group of researchers that had access to data before the ADRN was created
- Generally, there is an opportunity for the ADRN to do more to integrate assets and expertise that existed before the ADRN was founded, this applies to:
 - The expertise and relationships of researchers that are currently part of the ADRCs
 - The data holdings of sites that are part of the ADRN Network, e.g., the Office for National Statistics
 - Secure data access sites that are not part of the ADRN
 - ESRC-funded researchers outside the ADRN, e.g., at the Institute for Fiscal Studies (IFS) and Institute for Social and Economic Research (ISER)

The network should better leverage what exists already

There is a need to be much clearer about the ADRCs being points of assistance as well as centres for research

We should build on the considerable headway the individual country ARDCs have made and then think of ways of making these linkages more widely available

Considering the online survey responses and interviews together, the most important themes related to involving researchers in data acquisition are:

- There are expertise and assets that existed before the ADRN was created that could be used for the benefit of the Network
- In particular, there is researcher expertise at the ADRCs that could help with negotiating access to new administrative datasets, that has not been brought into the formal ADRN process
- ADRC researchers are involved in a significant number of projects which are not included in project metrics reported to the ADRN Board
- There is not a common understanding about the roles that the ADRCs and ADS are and should be playing in the Network

RECOMMENDATION 4: ANALYSIS AND DISCUSSION

In the experience of the Mid-Term Review Team, the first studies based on new administrative datasets usually involve relationships between the data owner and a trusted senior researcher. There are many reasons why this is the case, including the fact that it is easier and less risky for a data partner to provide access to a new dataset to one researcher for one study than to provide broad access to the dataset from the start.

Even at the Institute for Clinical Evaluative Sciences (ICES), which has become known internationally for providing all researchers with research ethics committee approved studies with access to core linked datasets, certain datasets are only available to ICES Scientists, and the standard process for working with new data partners generally involves ICES scientists working directly with data owners to determine what data will be used and for what purposes. By creating a process that does not involve experienced researchers in data negotiation, the ADRN has inadvertently left out one of its most promising routes to acquiring data.

On the surface, the policy focussed studies that are being performed by ADRC researchers bear very close resemblance to the kind of studies the ADRN is intended to support. Further, ADRCs have provided information about a significant number of “linkage studies” that do not have policy-relevant research as their primary aim, but nevertheless appear to provide information about the relationship between variables in datasets which is likely to be relevant to policy makers. It is the view of the ADRN Mid-Term Review Team that all of these ADRC projects, both policy and linkage studies, should be assessed to determine if they warrant being included in the count of ADRN projects. The core question to be asked in such an assessment is “Do these projects make use of ADRN resources (data and/or staff) to help fulfil the ADRN mandate?” as opposed to automatically excluding a project because it followed a different process and/or used a secure access site outside of the ADRN. The ADRN Director could begin the assessment process by working with the ADRC Directors to identify ADRC researcher-led projects that could reasonably be considered ADRN projects. The criteria for the final decision should be determined *a priori* by the ADRN Board and Approvals Panel in consultation with ADRN Director. The criteria should be based on the extent to which the project addresses the objectives of the ADRN.

The ADRN Mid-Term Review Team agrees that the Network must provide broad access to administrative data in order to fulfil its mandate. It would be misuse of resources if most of the studies that the Network supports involve only the small number of experienced researchers who had access to data before the ADRN was created. What is needed is a process that outlines the steps between (i) a first-use study led by a researcher with a trust relationship and (ii) data being available to the research community broadly.

This could be accomplished by defining a new process and class of ADRN First-Use Projects with specific requirements, e.g.:

- From the outset, making it clear in data negotiation discussions that the intent is to provide broad researcher access once the suitability of the datasets for research has been demonstrated
- As a condition of ADRN funding, requiring that the researcher(s) who lead the First-Use studies create metadata and other documentation to enable use of the dataset by others

The ADRN First-Use Process could also include a modified Approvals Panel review and/or mechanisms for the First-Use researcher to provide training to others (e.g., via a webinar that is recorded).

It should be noted that this new proposed ADRN First-Use Process wouldn't preclude the possibility of the Network negotiating broad access to data. Rather, the recommendation is that the Network gives itself the flexibility to integrate additional ways of acquiring data. If the new ADRN First-Use Process is established, coordination and role clarity between the ADRC Researchers and the ADS would be essential to ensure that data owners receive clear messages and requests regardless of who is contacting them, and to ensure that they are not contacted by multiple parties about the same dataset.

RECOMMENDATION 4: CONCLUSIONS

Experienced individual researchers, and existing research and data centres, can play a greater role in achieving the step change of increased use of administrative data by the broader research community. International experience has shown that data custodians are most likely to provide data for studies performed by researchers with whom they have relationships, and in some cases will not release data for other studies before completing a study with a trusted internal or external researcher due to data quality and other concerns. For this reason, it may not be possible for the first pioneering use of a new administrative dataset to use the standard ADRN process. To increase the number of routes through which datasets can be brought into the Network, the ADRN process should include a clear path from an ADRN-funded researcher negotiating access and using a dataset for their own program of research, to integration of the dataset into the data service provided to researchers broadly. This would include obligations on the part of the researcher, e.g., mandatory creation of metadata and other documentation, to enable the use of the dataset by others. The transition between researcher-led pioneering use of a dataset to UK-wide data service should be defined so that there is a common understanding of the roles and contributions of ADRCs and the ADS.

RECOMMENDATION 5: CLARIFY ROLES AND ESTABLISH SEPARATION BETWEEN GOVERNING AUTHORITIES' STRATEGIC ADVICE AND THE DELIVERY OF THE ADRN

RECOMMENDATION 5: KEY FINDINGS

During the time that the Mid-Term Review was conducted, the governing authorities (i.e., the ESRC, UK Statistics Authority and the ADRN Board) were deeply involved in key activities related to data acquisition. For example, the *ADRN Data Acquisition Plan* makes 15 references to the ADRN Board and 11 references to the ESRC, and the leads for the ADRN from the ESRC and UK Statistics Authority regularly attend monthly Directors Group meetings.

The *ADRN Governance Overview* document provided to the ADRN Mid-Term Review Team defines separate roles for the ADRN Board, ESRC and the UK Statistics Authority and provides details about each role including the Directors Group:

The Directors Group is responsible for the development of ADRN policies and strategy. It is responsible for initiating/agreeing Network innovation and new developments, and for the Network's strategic forward look. It is responsible for deliberating policy queries from the Operations Group or from individual Centres, and agreeing amendments to policies and developing new ones where necessary.

... The Directors Group will have a chair chosen among the five Directors by their mutual agreement...

... The Directors Group meeting will be considered quorate if 4 of the 5 Directors are present, plus the OG Chair or his/her deputy. For the ESRC and the Board representative, their attendance is not mandatory for the meeting to be quorate, but it would be expected that they would deputise someone to attend in their stead should they be unable to attend. Directors will not deputise.

The topic of governing authority involvement in the delivery of the ADRN was discussed in detail during the interviews with Directors and representatives from the ADRN Board, the ESRC and the UK Statistics Authority. In total, there were approximately 4.5 hours of interview time focused on the topic. As part of these discussions, key informants made reference to the plan to augment with expertise of the Network by bringing in an individual with strategic negotiation skills and experience working with senior government decision makers.

Considering the desktop document review and interviews together, the most important themes related to governing authority involvement in the delivery of the Network are:

- The current level of involvement of the governing authorities in the delivery of the ADRN goes beyond what is described in the Terms of Reference documents for ADRN governance bodies
- This deep involvement has happened for a specific reason – the expertise of governing authorities, and the relationships that they have with government departments, are very helpful to mitigation strategies for access to data
- The senior strategic government negotiation expertise that the ADRN requires is seen being beyond what would reasonably be expected of the ADRC or ADS Directors
- The deep involvement of the governing authorities of the Network in delivery is not desirable in the long-term

RECOMMENDATION 5: ANALYSIS AND DISCUSSION

Beginning fall 2015 – one year after the ADRN became operational – it was generally acknowledged within the Network that the assumption that data from government would flow automatically once ADRN infrastructure was established was not accurate. In response, individuals from the ADRN Board, ESRC and UK Statistics Authority became very involved in mitigation. While it is not unusual for Board members and governing authorities to become involved when external issues threaten an initiative, the Mid-Term Review Team believes that the prolonged involvement of ADRN governing authorities in issue mitigation has the potential to cause significant problems including:

- Governing authorities becoming directly involved in operational decision making and losing the separation that they need to provide objective strategic advice
- Uncertainty about what decisions are within the scope of the Directors of the Network leading to a weakening of the authority and decision making power of the Directors

The Mid-Term Review Team believes that the risk of unclear authority of the Directors to lead and manage the Network is increased by the fact that the original Management Committee of the ADRN was chaired by an ESRC staff person, and by having the ADRN lead at the ESRC and the lead for the ADRN Board secretariat from the UK Statistics Authority be named members of the Directors Group. While the Directors Group Terms of Reference imply that the ESRC and UK Statistics Authority members of it are not involved in decision making (by noting they are not required for quorate), practically speaking, the presence of governing authority representatives will always affect discussions. It is the view of the Mid-Term Review Team that separate and distinct roles for the governing authorities and Directors were established with good reason, and that they have become blurred over the last year of the Network's operation.

To address the fact that the ADRN needs senior strategic government negotiation expertise – beyond what would be reasonably expected of the Directors of the Network – the Mid-Term Review Team supports the establishment of the new senior role for Strategic Data Access Negotiator. As with the new role of ADRN Director there is no “silver bullet”, but insofar as the Strategic Data Access Negotiator role clearly addresses the highest priority issue of the Network, it is expected to be helpful to the ADRN and decrease the reliance of the Directors on the governing authorities for that kind of expertise.

For that reason, good timing for the governing authorities to move away from ongoing deep involvement in the work of the Network would be ~ 6 months after the Strategic Data Access Negotiator position has been filled. Governing authorities and members of the Board would continue to be involved in the work of the ADRN after this point, but in more strategic ways. For example, in addition to providing strategic oversight, the governing authorities of the ADRN, including representatives from the Department for Business, Energy & Industrial Strategy (BEIS), have an important role as champions of the ADRN.

The Mid-Term Review Team believes that the role of the ADRN Director will be strongest if the Strategic Data Access Negotiator role reports directly to the ADRN Director. Further, there is a high likelihood that having the Strategic Data Access Negotiator report to any person or body other than the ADRN Director would increase risk by creating uncertainty about who is accountable for what, which could negate the benefits associated with the single point of accountability ADRN Director role (see Recommendation 3).

Whatever the decision about the reporting of the new Strategic Data Access Negotiator role, the Terms of Reference for the Directors Group will need to be updated. The Mid-Term Review Team suggests that the participation of representatives of the ESRC and UK Statistics Authority in Director level discussions be more tightly defined in the updated Terms of Reference. For example, the Directors Group Terms of Reference could state that the UK Statistics Authority and ESRC representatives attend Directors Group meetings only for specific agenda items related to reporting, strategic direction from the ADRN Board, and topics that the Directors ask them to provide advice about. Additionally, with the creation of the new ADRN Director role, it may be most productive for the UK Statistics Authority and ESRC representatives to meet with that person more regularly, attending Directors Group meetings ~quarterly (vs. attending monthly meetings). This would leave the majority of the Directors Group meeting time available for Directors to discuss and refine work products and plans before they are presented to higher levels of authority.

RECOMMENDATION 5: CONCLUSIONS

Given the challenges with access to government data, and the highly relevant knowledge and expertise of ADRN Board members, the ESRC and UK Statistics Authority, the Network's governing authorities have become deeply involved in mitigation strategies. As the ADRN is expected to require this kind of expertise for the foreseeable future, the Network would benefit from establishing a new Strategic Data Access Negotiator role filled by an experienced individual with strategic negotiation skills and experience working with senior government decision makers. The establishment of the ADRN Director and Strategic Data Access Negotiator positions would present a good opportunity to review the role of governing authorities in Network delivery and decision making, and to streamline and clarify roles. Once the Strategic Data Access Negotiator is in place, and reporting to the ADRN Board provides assurance that there is progress on data acquisition, the ADRN Board, ESRC and UK Statistics Authority should move to more traditional governance roles. Reduced involvement of the governing authorities in the delivery of the Network would better position the ADRN Board, ESRC and UK Statistics Authority to provide strategic advice and oversight.

FUTURE DIRECTIONS AND OVERALL CONCLUSIONS

The Mid-Term Review found that there continues to be widespread support for the opportunity described by the Administrative Data Taskforce:

“...the UK has the opportunity to be a world leader in research using de-identified administrative data routinely collected by government departments, agencies and statutory bodies. Such data, made accessible for research in ways that prevent the identification of individuals, will inform a wide research agenda relating to the health, wealth and security of the UK population, guiding the development, implementation and evaluation of related policy interventions.”

The ADRN has made significant progress in creating the infrastructure will be required to realise the Taskforce vision; however, significant challenges remain. ADRN infrastructure will only have its intended impact if the Network has improved access to government administrative data.

When stakeholder were asked about external factors that might affect the future of the ADRN, Brexit, the June 2016 decision by referendum for the UK to exit the European Union, figured prominently. Some stakeholders noted that once the UK leaves the EU, there could be increased government need for research based on UK data resulting in more data being made available to the ADRN, while others voiced concern that Brexit could result in less funding for research. Regardless of the long-term effect of Brexit, most stakeholders agreed that it would consume government resources and time in the short-term, making it more challenging for the ADRN to engage with senior government and agency leaders and staff.

Within that context, the overall recommendation of the Mid-Term Review is that the ADRN maintain persistent focus on activities that are most likely to increase access to government data, continuously monitoring and refining its approach. The Mid-Term Review did identify other issues and opportunities that the ADRN might consider in the future, such as process improvements to address projects that are never submitted or stopped; however, these are much lower priority than the imperative to acquire data for the Network.

Overall, the independent Mid-Term Review findings and recommendations support the approach that the Network has taken to mitigation. The Mid-Term Review highlights the importance of coordination, role clarity and flexibility as the Network focuses its efforts on acquiring government administrative data.

The value for money of the ADRN cannot be assessed until more government administrative data is available to it and more projects have been completed. The activities in the *ADRN Data Acquisition Plan* and the recommendations of the Mid-Term Review are much more than changes at the margin, but will take time to show effect. Collectively, they could have substantial impact on the number of ADRN projects that make use of government administrative data by the end of the current grant. Changes like establishing needed central leadership, bringing new senior negotiation expertise to the ADRN Director team and allowing re-use of linked datasets are major alterations that are expected to benefit the Network. However, ultimately the success of the Network will depend on government departments and agencies providing data. For the ADRN to fulfil its mandate, champions and activities within government departments and agencies will be as important as commitment and effort from the research sector.

SUMMARY OF FINDINGS AND RECOMMENDATIONS ORGANISED ACCORDING TO THE 10 AIMS OF THE MID-TERM REVIEW

I) THE CURRENT CONTRIBUTION OF THE ADRN IN FACILITATING AND SAFEGUARDING THE LINKAGE OF ADMINISTRATIVE DATA FOR RESEARCH PURPOSES IN THE UK THAT SERVE THE PUBLIC GOOD (E.G. THE ROLE OF THE ADRN IN THE WIDER DATA SHARING LANDSCAPE)

The ADRN has established infrastructure including policies, procedures, core staff, training and secure access sites. The ADRN will only be in a position to make its intended contribution to the data-sharing landscape, when it has more government data and more active projects.

II) THE CURRENT WIDER CONTRIBUTION OF THE ADRN BEYOND THE ACCESSING OF DATA, SUCH AS DEVELOPING CAPABILITY, METHODOLOGY AND PUBLIC ENGAGEMENT

The ADRN has done what it can on wider contributions in the absence of having the data that the Network requires to fulfil its mandate. Through its accreditation and training program the ADRN has enhanced the capability of 150 researchers to work with administrative data. ADRC researchers have performed tens of projects related to methodology and public engagement. These are positive outputs but not, in themselves, the reason that the ADRN was created.

III) WHETHER THE ADRN IS BEING DEVELOPED, MANAGED AND MAINTAINED IN A WAY THAT MAXIMISES ITS BENEFIT TO RESEARCHERS, AND POLICY MAKERS, AND PROVIDES VALUE FOR MONEY, TAKING ACCOUNT OF THE PROJECT SCOPE AND RESOURCES

The management and model of the ADRN that was in effect until June 2016 did not produce the desired results. Both the *ADRN Data Acquisition Plan* and this Mid-Term Review report recommend significant changes to management and model of the Network.

IV) HOW THE ADRN SHOULD PRIORITISE, ORGANISE AND MANAGE ITS FUTURE WORK TO ENSURE THAT ADRN RESEARCH IS HAVING MAXIMUM PUBLIC OR POLICY BENEFIT

The Network should focus on implementing the activities focused on increasing access to data as described in the *ADRN Data Acquisition Plan* and the recommendations of this Mid-Term Review report. There may be additional activities that the ADRN could undertake to increase its public or policy benefit in the future, but nothing is more important than increasing access to data at this time.

V) THE OPPORTUNITIES FOR SUSTAINABILITY AND FUTURE DEVELOPMENT OF THE NETWORK, INCLUDING EXTENSIONS TO SCOPE AND RESOURCES WITHIN AND BEYOND CURRENT FUNDING COMMITMENTS

The ADRN should extend its scope to allow retention and multiple uses of linked datasets, and expand the role of ADRCs researchers in acquiring data. Generally, no other scope extensions are recommended by the Mid-Term Review team at this time. Rather, the Network should focus its

efforts and resources on bringing in more government data and implementing suggested changes to leadership and management model.

VI) HOW THE GOVERNANCE ARRANGEMENTS CAN SUPPORT THE STRATEGIC AIMS OF THE NETWORK

The ADRN should establish a single Network lead and, once the Strategic Data Access Negotiator role has been filled, increase the separation between governing authorities and the Directors of the Network (see Recommendations 3 and 5).

VII) THE PROGRESS OF THE NETWORK AGAINST THE ORIGINAL STATED OBJECTIVES OF THE NETWORK AND THE CRITICAL SUCCESS FACTORS THAT HAVE PREVIOUSLY BEEN AGREED WITH THE BOARD

Critical Success Factor reporting indicates that the Network has met its objectives related to infrastructure establishment but has not met its objectives regarding the number of research projects that make use of government administrative data using ADRN infrastructure. Critical Success Factor reporting should be enhanced to provide more information about data access and the wider contributions of the ADRN (e.g., developing capability, methodology and public engagement). There are a large number of projects at ADRCs that are not captured in Critical Success Factor project reporting. These projects, both policy and linkage studies, should be assessed to determine if they warrant being included in the count of ADRN projects.

VIII) THE WIDER CONTEXTUAL FACTORS THAT HAVE INFLUENCED THE ADRN'S PROGRESS, SUCH AS THE LEGISLATIVE ENVIRONMENT IN WHICH THE ADRN IS OPERATING

The most important wider contextual factors that have influenced the ADRN progress are practical and cultural factors within government (see Recommendation 1).

IX) THE WIDER CONTRIBUTION OF THE ADRN TO THE INTERNATIONAL RESEARCH COMMUNITY

The ADRN has attracted international attention based on its model and the magnitude of the investment made, but is not having the international impact that it would have with more data and more projects.

X) THE IMPACTS OF EMERGING ISSUES ON THE ADRN.

Brexit is the most important emerging issue that is likely to negatively impact the ADRN, primarily because it will decrease the time and availability of government departments to engage with the ADRN. Legislative changes are expected to have some positive impact on the ADRN's access to government to data, though the magnitude of that impact is uncertain because there are many factors that are contributing to the hesitancy of government departments and agencies to provide data to the Network.