



**UK Statistics
Authority**



**Eighth Meeting of the
Administrative Data Research Network Board**

Agenda and Papers

Monday 1 February 2016

11:00 – 14:30

Board Room, UK Statistics Authority
Drummond Gate, London

UK STATISTICS AUTHORITY
ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

Minute

Monday, 1 February 2016
Boardroom, Drummond Gate, London

Present

Board Members

Professor David Hand (Chair)
Ms Sharon Witherspoon (Deputy Chair)
Dr Fiona Armstrong
Mr Jonathan Athow
Dr Andrew Garrettt
Mr Guy Goodwin
Mr Roger Halliday
Professor Denise Lievesley
Mr Steven Marshall for Mr Glyn Jones
Dr Tracy Power
Mr Luke Sibieta
Mr Nicky Tarry for Mr David Frazer
Ms Melanie Wright
Ms Yee-Wan Yau for Mr Darren Warren
Ms Penny Young

UK Statistics Authority

Dr Simon Whitworth
Mr Robert Bumpstead

Economic and Social Research Council (ESRC)

Dr Paul Meller

Administrative Data Research Centre – England

Professor Peter Smith

Apologies: Mr Colin Godbold, Mr Roger Halliday

1. Minutes and matters arising from previous meeting

- 1.1 The meeting reviewed progress with actions from the previous meeting held on 3 November 2015. All actions are either complete or are in progress.

2. Chair's Report

- 2.1 The Chair welcomed Ms Sharon Witherspoon who has replaced Professor Peter Elias as the Deputy Chair of the Board.
- 2.2 The Chair reported that the non-executive Board members met prior to this meeting. It was reported that the non-executives spoke about a request that the Chair had received from the Directors of the Administrative Data Research Centres (ADRCs) for the Directors to become Board members. The Chair stated that one of the Board's roles was to provide independent assurance to the UK Statistics Authority about the progress of the Network and that therefore the non executives felt that it was important

to maintain the current balance between non executives and executives on the Board. At the same time, the non-executives also recognised the value of Director's contributions. Therefore, it was agreed that in future the Chair of the Administrative Data Research Network (ADRN) Directors Group, currently Professor Peter Smith, would replace Ms Melanie Wright as the Board Member who represents the Network on the Board. It was further agreed that Professor Smith would be joined by a different Director at each meeting who would present the Board with an update on progress from their ADRC or from the Administrative Data Service (ADS).

2.3 The Chair informed the Board that on the 8 December he had made a presentation on the ADRN with Ms Wright to the Government Departmental Directors of Analysis (DDANs) meeting. The Board heard that the DDANs had considered the value of the ADRN for Government researchers who could potentially access linked administrative data via alternative mechanisms. Feedback from DDANs suggested that the ADRN was not necessarily perceived as the quickest way of accessing data for Government departments, as they had various bilateral arrangements.

2.4 The Chair reported that he attended an informal meeting with HMRC to hear about HMRC's analytical work programme and had taken part in a roundtable discussion on the role of data science as part of the Sir Charles Bean's review of economic statistics. At both of these meetings the work of the ADRN had been discussed and highlighted.

3. Highlight Report [ADRN(16)01]

3.1 Ms Wright introduced the highlight report for the period between the beginning of October and the end of December 2015.

3.2 Ms Wright informed the Board that her main concern was around negotiating access to data. Ms Wright informed the Board that the ADRN Operations Group had now raised the risk that 'key data providers do not provide required data' to an issue.

3.3 It was reported that the ADRN were facing a number of different hurdles when trying to negotiate access to data from the Health and Social Care Information Centre and that consequently this was progressing very slowly.

3.4 In order that the Board could fully play its role in helping the Network to access data, the Board require much better management information about the progress of projects. For example:

- i. Future Highlight Reports should include information about the proportion of projects that had been at each stage of development and about the length of time they had been at that development stage.
- ii. It should be made clear how many projects have stopped for funding reasons and how many projects have been stopped because data was not available for other reasons.
- iii. Since Board members would need to pursue access issues between Board meetings, it was suggested that some sort of monthly update about specific delays would be helpful, and the ADS agreed to consider how this might best be taken forward.

3.5 The Board requested that the ADS ensure that concrete plans for these reports were put forward at the next Board meeting.

3.6 It was suggested that the ADRN are working in a competitive environment as there are other infrastructures available to the researchers who wish to access administrative data. The ADRN needs to clearly communicate to the research community the value it

can add relative to these other data sharing infrastructures. It was noted that this depended on setting up successful access arrangements.

- 3.7 The Board requested that the Secretariat work with the Network to produce a presentation that clearly communicates to the research community and policymakers the value the ADRN can add relative to other data sharing infrastructures. This should be focused on the research potential of the ADRN rather than the ADRN process and policies.

4. Report from the Approvals Panel [ADRN(16)02]

- 4.1 Dr Garrett presented an update from the Approvals Panel. At their meeting in January the Panel considered a report, containing proposed changes to the Terms of Reference and Operating Procedures. This had been commissioned by the ADRN Directors in response to the feedback gathered during the Panel's self-assessment process. The self-assessment process had included collecting feedback from wider stakeholders including researchers who had applied to the ADRN and had projects considered by the Panel. Dr Garrett reported that the Approvals Panel felt that they needed time to review the feedback from the self assessment and therefore the Approvals Panel's Terms of Reference would remain the same for the time being.
- 4.2 Dr Garrett informed the Board that it was sometimes difficult for the Panel to understand the aims and methods of the research from the methodological information that they were provided with. It was suggested that the application form should be reviewed to make sure that it ensured applicants provided the Panel with enough detail to know the implications of what the researcher is proposing in a way which is easy for the Panel to understand (especially since the Panel included lay members). The form should aim to reduce the numbers of requests for further information, and thus reduce delays.
- 4.3 The way in which the Approvals Panel communicated with researchers was discussed. It was suggested the role of the user support officer was important in communicating the decisions of the Approvals Panel to the researcher and in particular in communicating where the Approvals Panel wanted more information. It was agreed that it was important that requests for further information were not seen by researchers to be outright rejections.
- 4.4 The Board heard that the issue of the ADRN's communications with researchers was wider than just communicating issues from the Approvals Panel. It was reported that some in the research community do not want to submit research applications to the ADRN because they are unsure whether they will be able to access data through the ADRN in a timely fashion. It was suggested that the ADS needed to provide the research community with clearer information about what data they can access through the ADRN and how long it is likely to take.

5. Data Owner Engagement Update [ADRN(16)03]

- 5.1 Ms Wright presented the data owner engagement update. Ms Wright reported that the Universities and Colleges Admissions Service (UCAS) will only release data to the ADRN where consent to do so has been provided by the UCAS applicant. It was reported that UCAS will undertake work to produce weights to account for those who do not give consent. Board members expressed some concern about this, as it is likely to mean that some important analyses could not be carried out with a representative sample.
- 5.2 It was felt that access to data was now becoming a real risk to the success of the ADRN. It was clear that the Network would be judged on whether it could generate a

significant number of research projects that produced research with real public and policy benefits. The Board felt that it needed to be proactive in trying to unblock some of the blockages to data that are being experienced by the ADRN. To help do this there was agreement that the Board needed to receive precise information on the specific issues that were causing these blockages in a timely manner. Once this information is forthcoming the secretariat should work with the Board and the ADS to decide how the Board's expertise would be utilised to follow up with different departments and work to reduce blockages.

6. ADRN mid-term review [ADRN(16)04]

- 6.1 Dr Whitworth introduced the proposed Terms of Reference for the ADRN mid-term review. It was reported that these had been presented to the UK Statistics Authority Board who were content.
- 6.2 It was suggested that the Terms of Reference for the review might also explicitly include consideration of the value for money of the ADRN. It was also suggested that the Terms of Reference should give the reviewer the scope to consider the impacts of emerging issues on the ADRN.
- 6.3 It was agreed that the Secretariat would consider the comments of the Board in producing the final draft of the Terms of Reference.

7. A view from the ADRC-England

- 7.1 Professor Smith, Principal Investigator at the ADRC-England, presented on progress at the ADRC-England. This included establishing secure research laboratories in a number of sites, recruiting staff and PhD students, delivering training on the use of administrative data and progressing with a programme of research. The Board were provided with an overview of some of this research.
- 7.2 Professor Smith reported that there was currently only one ADRN research project that was active in an ADRC-England secure laboratory and that this project did not yet have access to all of the requested data. The Board expressed concern at the small number of active projects currently being progressed at the ADRC-England. Data access arrangements in particular were proving easier to negotiate in Scotland, Wales and Northern Ireland than in England.
- 7.3 The Board heard that the ADS was responsible for negotiating access to data from the central Government departments. Most ADRC-England projects would require this data. Consequently, a number of potential future ADRC-England projects were currently with the ADS user support team. Professor Smith reported that he was concerned that some of these projects would not be taken forward because of difficulties in getting access to the required data.
- 7.4 Professor Smith reported that he had concerns that some of the data scientists that had been recruited by the ADRC-England would look for alternative opportunities if the ADRC-England continues to host very few projects.
- 7.5 The Board were reminded that in contrast to the ADRCs in Scotland and Wales, the ADRC-England was not developed within a pre-existing data linkage infrastructure.

8. Information Security [ADRN(16)05]

- 8.1 Ms Wright informed the Board that the Network has been considering possible changes to the data retention and destruction policy. These changes would include the Network being able to retain data for longer and use retained data for multiple projects. The meeting heard that the current policy states that de-identified data that is supplied

to researchers can only be held for the life course of a particular project and archived for a maximum of five years. The current policy does allow for de-identified research data to be retained if the Accredited Researcher makes a valid application for an extension and this is approved by the data owner or where the data owner specifies that it can be kept for longer than five years. All data that is created to produce the de-identified research data, such as the creation of the indices by the trusted third party and the data linking carried out by the ADRCs using the indices, is currently securely destroyed once the linkage process is complete and the de-identified research data has been created. This creates difficulties if there are requests to validate analyses or interrogate results using alternative methods, and is therefore not perhaps in line with best scientific principles.

- 8.2 It was considered whether data could be retained as linked de-identified data in the ADRCs or a series of single source identifiable data sets which could be stored by the Trusted Third Party indexers and the ADRCs. The Network could then reuse data that has already been collected for one research project for other research projects, or to allow examination of the reliability of results, without having to go back to Departments to collect the data again. The Board noted further however that many analyses could not use out-of-date data, so some time-limited arrangements would be suitable in some instances.
- 8.3 It was reported that this would mean negotiations with data owners for linkage would only occur once for particular time-periods, resulting in a potential reduction on the burden on data owners and the ADRN. The Board were also informed that this would potentially increase the speed of the research lifecycle which would lead to more ADRN research projects and would make it easier to promote the use of the Network with researchers. It was also suggested that retaining data could help to make the research process more transparent as it would enable researchers to challenge the findings of earlier research by interrogating the data upon which earlier findings were based.
- 8.4 The meeting recognised that the proposed changes would make it easier for the Network to report the data that could be accessed via the ADRN to the research community as they could reuse data that they had already negotiated access to.
- 8.5 It was reported that the ADRC-Northern Ireland produce a prospectus of the data that has been made available for use by the research community whilst still fully abiding by the current data retention and destruction policy. In Northern Ireland the Chief Statistician chairs a meeting of data owners and encourages them to make data available to the ADRN. Once agreement with the data owners has been reached on what data will be provided, the ADRC-Northern Ireland publishes the prospectus. It was reported that this was working well. The Board suggested that the other ADRCs should explore the possibility of doing this. It was noted that this would prove particularly challenging in England.
- 8.6 The Board heard that five years after the ADRN had received the data was a suitable period of time to retain most de-identified research data as after five years most research data would be out of date and researchers would want refreshed data. It was also noted that the current policy allowed for the de-identified research data to be archived for longer than five years with the permission of the data owners. Therefore, it was suggested that changing the policy so that the Network could reuse data that has already been collected for one research project for other research projects without having to go back to Departments to collect the data again should be seen as a bigger priority. It was recognised that this may involve some changes to the data retention and destruction policy to enable the Network to retain some of the data that is created

to produce the de-identified research data. It was suggested that if this part of the policy was to change it would be important for the data owners to have a role in agreeing the further research that their data was used for, and this would require some sort of procedure.

- 8.7 The Board felt that the views of the public and data owners need to be fully understood before any change to the data retention and destruction policy can be progressed. The resource implications for the Network of any change in policy also need to be fully considered.
- 8.8 Ms Wright and Professor Smith agreed to prepare a paper that detailed the proposed changes in more detail and summarised some of the feedback that they had received in this meeting. The Board also requested that this paper included some case studies of international best practice in this area.
- 8.9 The Secretariat was asked to organise a sub group which would include representatives from the Board, the UK Statistics Authority, the Economic and Social Research Council and a representative from the ADRN Directors Group to look into the implications of the proposed changes in more detail.

9. Definition of an ADRN project [ADRN(16)07]

- 9.1 Ms Wright presented some suggested proposed changes to the policy which defined an ADRN policy. The proposed change would allow all projects that have an economic or social science focus and therefore, would come under the remit of the Economic and Social Research Council (ESRC) to use the ADRN. It was reported that this does not imply that projects need to be funded by the ESRC.
- 9.2 It was agreed that this policy change was sensible and felt that the use of examples in the policy made the policy clear and transparent.

10. Legislative Issues [ADRN(16)08]

- 10.1 Ms Witherspoon presented on UK data sharing issues. The Board heard that proposals for de-identified data for research and statistics purposes remain largely unchanged from those proposed through the Open Policy Making process last spring. The proposals provide for a permissive power inclusive of all public authorities (with the exceptions of health and social care) to share/link de-identified data for the purposes of research and statistics in the public interest using a trusted third-party sharing system, where data will be linked in a secure access facility and made available to accredited researchers under controlled conditions. Oversight of these arrangements will be provided by the UK Statistics Authority who will be acting as the accreditation body for indexers and providers of accredited secure access facilities.
- 10.2 It was stressed to the Board that the de-identified proposals were permissive. The Board heard that it was therefore important that the proposed clauses were supported with a statement which made it clear that the Government is convinced of the public benefits of sharing de-identified data for the purposes of research and statistics. It was reported that this would increase the chances that the enabling possibilities of the proposals will be realised, rather than merely creating a set of new stumbling blocks.
- 10.3 The Board were informed that the Cabinet Office has indicated a preference to initiate a formal consultation process on the entire policy (including the non research and statistics strands) in February 2016. It was suggested the Board might supply a response to the consultation.

- 10.4 The Secretariat was asked to circulate information about the consultation to the Board when the consultation is published and work with the Board to produce a consultation response from the ADRN Board.

11. Any other business

- 11.1 There was no other business.

**UK STATISTICS AUTHORITY
ADMINISTRATIVE DATA RESEARCH NETWORK BOARD**

Agenda

***Monday, 1 February 2016
Board Room, One Drummond Gate, London
11:00am – 2:30pm (coffee from 10:30am)***

**Chair: Professor David Hand
Apologies: Mr Colin Godbold
10:30 to 11:00 – Non-executive session**

Part A (11:00am to 12:15pm)

1 11:00am	Minutes and matters arising from previous meeting	Professor David Hand
2 11:10am	Chair's report	Oral Report Professor David Hand
3 11:20am	Highlight report	ADRN(16)01 Ms Melanie Wright
4 11:35am	Report from the Approvals Panel	ADRN(16)02 Dr Andrew Garrett
5 11:50am	Data owner engagement update	ADRN(16)03 Ms Melanie Wright
6 12:05pm	ADRN mid-term review	ADRN(16)04 Dr Simon Whitworth

Lunch (12:15pm to 12:45pm)

Part B (12:45pm to 2:30pm)

7 12:45pm	A view from ADRC-England	Oral Report Professor Peter Smith
8 1.15pm	Information security update	ADRN(16)05 Ms Melanie Wright
9 1.45pm	Definition of an ADRN project	ADRN(16)07 Ms Melanie Wright
10 2:00pm	Legislative issues	ADRN(16)08 Ms Sharon Witherspoon Dr Simon Whitworth
11 2:20pm	Any other business	

Next Meeting: Monday 11 April 2016, Drummond Gate, London

UK STATISTICS AUTHORITY
ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

Minute

Tuesday, 3 November 2015
Boardroom, Drummond Gate, London

Present

Board Members

Professor David Hand (Chair)
 Professor Peter Elias
 Dr Fiona Armstrong
 Dr Andrew Garrett
 Dr Tracy Power
 Mr Colin Godbold
 Mr Roger Halliday
 Mr Glyn Jones
 Professor Denise Lievesley
 Ms Penny Young for items 1 to 7
 Ms Melanie Wright
 Mr Nicky Tarry for Mr David Frazer
 Mr Darren Warren for items 8 to 9
 Mr Luke Sibieta

UK Statistics Authority

Dr Simon Whitworth
 Dr Richard Reed
 Mr Adil Deedat

Economic and Social Research Council (ESRC)

Dr Paul Meller

Administrative Data Research Centre – Scotland

Professor Chris Dibben

ESRC Phase 2 Big Data Investment

Professor Paul Longley for items 8 to 9

Apologies: Mr Jonathan Athow, Mr Guy Goodwin, Mr David Frazer

1. Minutes and matters arising from previous meeting

- 1.1 The minute from the previous meeting held on 3 November 2015 was agreed by correspondence and is published on the [UK Statistics Authority Website](#).

Chair's Report
Professor David Hand

UK STATISTICS AUTHORITY**ADMINISTRATIVE DATA RESEARCH NETWORK BOARD**

ADRN(16)01

Highlight Report**Purpose**

1. This paper presents an Administrative Data Research Network (ADRN) highlight report for the period between the start of October 2015 and the end of December 2015.

Recommendations

2. Members of the ADRN Board are invited to note and discuss the content of the highlight report at **Annex A**.

Background

3. The highlight report is structured around work streams that reflect the specific responsibilities of the ADRN Board (paragraphs 8i to 8iv of the terms of reference).

Simon Whitworth, ADRN Board Secretariat, and Jo Webb, Administrative Data Service, 20 January 2016

List of Annexes

Annex A ADRN Highlight Report, Jo Webb, Administrative Data Service

Annex A ADRN Highlight Report

			Reporting period: Start date: 01 October 2015 End date: 31 December 2015
Overview of progress since the last report:			
<p>The Administrative Data Service (ADS) organised an extremely successful joint event for the ADRN with the Royal Statistical Society on 8 October. Over 120 people attended to hear presentations from Vanessa Cuthill (Economic and Social Research Council (ESRC)), Prof. David Hand (Chair of the ADRN Board), Hetan Shah (Royal Statistical Society (RSS)) and Paul Maltby (Cabinet Office) on the possibilities for the Network. This was followed by presentations from the directors from the four Administrative Data Research Centres and ADS. For more information please see our infographic: http://www.adrn.ac.uk/news-events/latest-news/adrn-rss-8oct</p> <p>The annual report on the Network was launched at the RSS event https://adrn.ac.uk/media/309648/adrn-annual-review-2014-2015_web.pdf. This is a review of the challenges and successes for 2014-15. In addition, the newsletter for stakeholders was also launched called <i>Network</i>. The first edition can be accessed on our website at https://adrn.ac.uk/media/309651/newsletter-final_web.pdf</p> <p>The Management Committee in October agreed the new management structure for the Network. The Board were given an overview in November. The Directors' Group have had their first meeting under the new structure, followed by the first meeting of the new Operations Group. The Operations Group drafted their terms of reference and a proposed structure for task groups and standard sub-committees to deliver their work plan. These will be considered by the Director's Group at their January meeting.</p> <p>The ADRN project Approvals Panel has held three virtual meetings. The Panel will meet face to face in Belfast on 7 January 2016. The Panel has undertaken a self-assessment exercise, looking at their efficiency and areas to strengthen. This included an initial workshop discussion by the Panel, a follow up survey of panel members, and a survey to gather stakeholders' views. At the January meeting the outcomes of this exercise and ways forward will be considered.</p> <p>Felix Ritchie of ADS spent six days in November as a guest of the Australian Bureau of Statistics, working with them on their new data strategy. This revisits many of the default assumptions that are often made in data access, and is based upon the 'Five Safes' framework used at the UK Data Archive and the ADRN. The Australian government has an ambitious public sector data management strategy, and the Australian Bureau of Statistics is taking the lead along with the Department of Social Security and the Australian Data Archive.</p>			

List of current projects

‘Live’ Project Titles and current status: 82 in total with a mixture of academic and government lead projects. Details are below.

NB: a project is ‘live’ as soon as it is logged with the Administrative Data Service

There are currently no third sector projects. Please see table below for projects and stages. An overview of the projects and progress is in the summary below the table.

Project Number	Title	Project Development Led by	New Status
PROJ-001	Combining Survey Data, Paradata and Administrative Data for Non response Investigation	ADRC-England (ADRC-E)	Researchers conducting analysis
PROJ-002	Peace Walls in Northern Ireland: developing baseline indicators	ADRC-Northern Ireland (ADRC-NI)	Data supply, linkage and preparation underway
PROJ-003	Developing an Analytical Approach for Assessing the Effectiveness of the Flying Start Programme: Analysis of the Health and Education Impacts of Flying Start.	ADRC-Wales (ADRC-W)	Data supply, linkage and preparation underway
PROJ-004	Assessing the Health Impacts of Adults’ Participation in Sports in Wales: Investigating the mediating role of accessibility to sports facilities.	ADRC-W	Data supply, linkage and preparation underway
PROJ-005	The Feasibility of Creating an Individual Deprivation Score using Linked Data	ADRC-W	Developing Application
PROJ-006	Factors associated with decreased representation in higher education	ADRC-NI	Researchers conducting analysis
PROJ-007	Sociodemographic characteristics, educational attainment and self-reported health status of	ADRC-NI	Data supply, linkage and preparation underway

	farmers in Northern Ireland			
PROJ-008	Using Data Linkage to obtain accurate population estimates of migrants in Northern Ireland and their needs for and use of mental health and social care.	ADRC-NI	Data supply, linkage and preparation underway	
PROJ-009	Patterns of error in survey based estimates of consumption and their implications for energy consumption.	ADS	Data supply, linkage and preparation underway	
PROJ-010	An Exploratory Analysis of Parental and Child Limiting Long-term Illnesses in Northern Ireland	ADRC-NI	Developing Application	
PROJ-011	An Exploratory Analysis of the Socio-demographic Characteristics of Married versus Unmarried Mothers	ADRC-NI	Developing Application	
PROJ-012	Medication use in pregnancy and its risks/consequences in terms of birth outcome and later child development outcomes	ADRC-NI	Developing Application	
PROJ-013	Naming in Contemporary NI	ADRC-NI	Developing Application	
PROJ-014	The completeness and accuracy of the Electoral Register in NI	ADRC-NI	Developing Application	
PROJ-015	Evaluating linkage between children's health, education and social care data - pre-term birth sub-study.	ADRC-E	Researchers conducting analysis	
PROJ-016	An Investigation into the Impact of Disability on Employment in Wales	ADRC-W	Researchers conducting analysis	
PROJ-017	The Residential Mobility of Mental Health Service Users (MHSUs).	ADS	Data supply, linkage and preparation underway	

PROJ-018	Social Defeat in Northern Ireland: Assessing the Impact of Social Risk Factors on Serious Psychiatric Disorders Using Data Linkage	ADRC-NI	Developing Application	
PROJ-019	Link between congenital heart diseases early in life and educational outcome in NI.	ADRC-NI	Developing Application	
PROJ-020	Addressing in NI.	ADRC-NI	Scheduled for Approvals Panel	
PROJ-021	Understanding participation in post-compulsory education and training in Wales	ADRC-W	Data supply, linkage and preparation underway	
PROJ-022	Examining contributory factors in road traffic collision data involving older people in Wales	ADRC-W	Data with secure environment	
PROJ-023	Improving the experience of dementia and enhancing active life: living well with dementia - the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study– data linkage extension	ADS	Data supply, linkage and preparation underway	
PROJ-024	Refugees, Dispersal and Deprivation	ADS	Project stopped	
PROJ-025	Socioeconomic, Educational and Demographic (SEED) Better Decisions: Uncovering how patients' socioeconomic, educational and demographic factors impact clinical decision-making.	ADRC-W	Developing Application	
PROJ-026	Understanding the determinants of educational achievement and the association with health and well-being by age 14 in Wales	ADRC-W	Data supply, linkage and preparation underway	
PROJ-027	Informal care in the last days of life: a data linkage study.	ADRC-Scotland (ADRC-S)	Data supply, linkage and preparation underway	
PROJ-028	Past and Current Same Sex Couples in Northern	ADRC-NI	Developing Application	

PROJ-029	Ireland: An Exploratory Analysis. Understanding outcomes for children from Scottish Children's Reporter Association (in conjunction with the British Association for Adoption and Fostering)	ADRC-S	Developing Application	
PROJ-030	Investigating the impact of a sick sibling on family health and educational outcomes	ADRC-S	Developing Application	
PROJ-031	An investigation of maternal mental health and filial educational attainment in Scotland	ADRC-S	Data supply, linkage and preparation underway	
PROJ-032	Placement stability of children in out of home care in Scotland: A sequence analysis	ADRC-S	Data supply, linkage and preparation underway	
PROJ-033	Does priority need for homeless prison leavers reduce recidivism? A case study from Wales	ADRC-S	Developing Application	
PROJ-034	Extending the opportunities for prevention of suicide: linking dispensing and employment data to the Suicide Information Database- Wales (SID-Cymru).	ADRC-W	Ethical review outstanding	
PROJ-035	Examining the link between family health events and pupil performance indicators in Wales.	ADRC-W	Data supply, linkage and preparation underway	
PROJ-036	An exploration of maternal and infant health and educational outcomes following metformin exposure in pregnancy - using linked administrative data	ADS	Developing Application	
PROJ-037	Feasibility study exploring the use of data linkage in the evaluation of the Supporting People Programme	ADRC-W	Researchers conducting analysis	
PROJ-038	Evaluating the use of contextual data in undergraduate admissions	ADS	Developing Application	

PROJ-039	Economic change and internal population dynamics: an innovative study of new residential mobilities in Scotland	ADRC-S	Scheduled for Approvals Panel	
PROJ-040	Methodological innovation in the spatial analysis of educational micro-data: understanding social and spatial inequalities	ADS	Developing Application	
PROJ-041	A pilot ADRC-NI project linking Social Security Benefits and Census data to identify those least likely to claim disability related benefits.	ADRC-NI	Developing Application	
PROJ-042	Improving Migration Statistics by Combining Survey Data	ADS	Developing Application	
PROJ-043	Prevalence and variation in antidepressant prescribing across Northern Ireland: a longitudinal administrative data linkage study for targeted support.	ADRC-NI	Developing Application	
PROJ-044	Higher Education: Access, Earnings and Employment	ADS	Developing Application	
PROJ-045	The kinds of poverty in schools and their impact on student progress	ADS	Developing Application	
PROJ-046	Assessing the relationship between concessionary bus use and health for older people in Wales	ADRC-W	Developing Application	
PROJ-047	Leading for Growth: Top Teams and Small and Medium sized Enterprises (SME) Performance.	ADS	Developing Application	
PROJ-048	Use of out-of-home care for children born with drug withdrawal syndrome: longitudinal study of mothers and children using linked administrative data.	ADS	Developing Application	
PROJ-049	Assessing the impact of measures to raise attainment and take-up of Science, Technology, Engineering and Mathematics (STEM) subjects	ADS	Developing Application	

PROJ-050	Energy efficiency and household health co-benefits: building the evidence	ADRC-S	Developing Application	
PROJ-051	Residential mobility and diabetes.	ADS	Approvals Panel requested further information	
PROJ-052	The wider impacts of benefit sanctions: educational attendance, behaviour and attainment	ADRC-S	Data supply, linkage and preparation underway	
PROJ-053	Technical change, employment and inequality. A spatial analysis of households and plant data.	ADS	Developing Application	
PROJ-054	Examining the effect of relative housing wealth on individuals' Health and Well-Being (H&WB).	ADS	Developing Application	
PROJ-055	Examining risk factors for Domestic Abuse and Child Sexual Exploitation to inform future policing in the Swansea area	ADRC-W	Project stopped	
PROJ-056	Job quality, well-being and health.	ADRC-W	Project stopped	
PROJ-057	Understanding Educational Disadvantage among Primary School Children in England	ADS	Developing Application	
PROJ-058	Investigating the role of buses in access to hospitals	ADRC-W	Developing Application	
PROJ-059	Pipeline and Return to Science and Mathematics	ADS	Developing Application	
PROJ-060	A Longitudinal Examination of Educational Attainment throughout the School Lifecourse in Aberdeen: Inequality at the Starting Gate and Beyond	ADRC-S	Data supply, linkage and preparation underway	
PROJ-061	Evaluating the effects of Community Treatment Orders (CTO) in England	ADS	Panel requested further information	
PROJ-062	Evaluating the impacts of Welsh Government funded schemes designed to improve the energy efficiency of the homes of low income households on health outcomes through the use of existing data	ADRC-W	Panel requested further information	

PROJ-063	The effect of unexpectedly high patient demand in midwife units on educational outcomes.	ADRC-S	Developing Application	
PROJ-064	The Economic Burden Associated with Mental Ill Health Among Informal Caregivers in Northern Ireland: an investigation of economic transitions and economic costs.	ADRC-NI	Developing Application	
PROJ-065	Pilot of the Healthy Ageing In Scotland (HAGIS) study	ADRC-S	Scheduled for Approvals Panel	
PROJ-066	Case for support on linking Energy Demand Research Project (EDRP) data and Census data (tentative title)	ADS	Developing Application	
PROJ-068	Effects of 2011 Local Housing Allowance Reform on the Private Rental Market	ADS	Developing Application	
PROJ-069	Linking National Pupil Database (NPD) and School Workforce Census (SWC) (tentative title)	ADS	Developing Application	
PROJ-070	Liquidity Constraints and the Duration of Unemployment in the UK	ADS	Developing Application	
PROJ-071	Non education follow ups of education endowment foundation Randomised Control Trials (RCTS)	ADS	Developing Application	
PROJ-072	Fluctuations in Community Mental Health and Social Care Services for people diagnosed with a mental illness in England	ADS	Developing Application	
PROJ-073	Social factors influencing glaucoma treatment persistence in the Northern Ireland population	ADRC-NI	Panel requested further information	
PROJ-074	Self-rated health or medication record? Which best predicts suicide in Northern Ireland	ADRC-NI	Developing Application	
PROJ-075	Social factors influencing uptake of free eye examinations in Northern Ireland	ADRC-NI	Scheduled for Approvals Panel	

PROJ-076	Seeing the Whole Picture: A Holistic Analysis of the Profile of Pupils with Special Educational Needs (SEN) in Northern Ireland.	ADRC-NI	Developing Application	
PROJ-077	Social participation and higher education: exploring variation by elite and other university education	ADRC-W	Developing Application	
PROJ-078	Schooling and Higher Education: Exploring national variation between England and Wales	ADRC-W	Developing Application	
PROJ-079	Confusion and In-Work Benefits: Evidence from UK Welfare Reform	ADS	Developing Application	
PROJ-080	The relationship between benefit sanctions, poverty and deprivation	ADRC-W	Developing Application	
PROJ-081	Educational Attainment in Northern Ireland: Key Predictors and Outcomes at the Individual, School and Regional Level	ADRC-NI	Developing Application	
PROJ-082	Understanding the link between urban segregation and inequality	ADRC-S	Developing Application	
PROJ-083	Exploration of influencing factors that inhibit a return to work	ADRC-S	Developing Application	

	01.Developi ng Application	02.Schedul ed for Approvals Panel	03.Panel requested further informati on	04.Ethical review outstandi ng	05.Approv ed	06.Data supply, linkage and preparati on underway	07.Dat a with TTP	08.Dat a with secure env (ADRC)	09.Research ers conducting analysis	10.Analy sis complete	11.Proje ct complet e	Gran d Total
Stage												
Numb er	48	4	4	1	0	16	0	1	5	0	0	79

3 projects have been stopped for various reasons (funding or data not available).

NI researchers had two projects funded under the ESRC's Secondary Data Initiative (wave 3):

- a. Prevalence and variation in antidepressant prescribing across Northern Ireland: a longitudinal administrative data linkage study for targeted support
- b. An ADRC-NI project linking Social Security Benefits and Census data to understand the health and social needs of disability benefits claimants

Key metrics:

82 live projects (i.e. logged with ADS, since 21 May 2014)

27 projects approved by the Panel as at 31 December 2015

Website: website use has risen with the new academic year to around 6500-7000 page views a month from over 1600 visitors.

Social media: 737 Twitter followers; 1662 Tweets (in total). NI twitter followers have increased since December from 130 to over 200.

Please comment on any data security issues and how the Service is managing these issues:

None

Please comment on any issues in relation to obtaining data from data owners:

An item and update on the data owner engagement strategy is being prepared separately for the Board.

Planned activities for next reporting period, including dates:

Upon agreement of the proposed structure, task groups and standing committees will be formally tasked by their governing group to ensure a seamless transition. Working groups have continued to progress their areas of work, including the research conference group. The 2016 research conference is provisionally booked for 2 and 3 June in London.

A third animation/ infographic is in development to explain the user journey to take researchers through the user journey from initial contact through to publication of a summary of their findings. This is due to launch in January 2016.

Risks (at amber/red):

Risks:

A Network-wide risk register (**Annex A1**) has been prepared by the Project Managers Working Group. This was revised at the first Operations Group meeting of the Network to update risk owners to reflect the new management structure. This was reviewed by the Director's Group at their meeting on 11 January.

ADRCs have prepared their own risk registers and keep them under review.

Workstream Progress Reports and Outlook:

Workstream:	Infrastructure and Network coherence¹
Main achievements	
Management structure	
<p>The changes to the management structure are being implemented, with the Directors Group having met in November and January. The Operations Group met in early December and drafted their terms of reference and a proposed structure for task groups and standard sub-committees to deliver their work plan. These were considered by the Directors' Group at their January meeting. In the meantime, current working groups have been asked to continue to progress their work areas.</p>	
Infrastructure	
<p>ADRC-E: The Bloomsbury (Farr) and University of Southampton (UoS) secure rooms are both functional and ready for use by researchers once live project data is received. A total of 19 seats are available (12 in Bloomsbury and 7 at UoS). Annual re-accreditation of Bloomsbury and UoS secure rooms is underway with support from the Department of Business Innovation and Science as sponsoring department. The ONS/Virtual Microdata Laboratory now</p>	

¹ Board responsibility (from ToR): i) Guide the strategic direction of the Network and provide oversight of its development to provide assurance that the infrastructure is established and maintained in ways that serve the public good, and, that the Network functions as a coherent whole.

has provision to run overnight on an ad-hoc basis to support ADRC-E projects should it be required;

ADRC-W: Developments in terms of both the Cardiff site and the Swansea site are developing and progressing towards Pan Government Accreditation. The ADRC also operates within an ISO27001² compliant environment.

The online version of the ADRN application forms launched successfully. ADS User Services organised hands on training for staff across the network on how to use them and support the researcher in completing them.

The associated funded projects between ESRC, ADRC-W and Welsh Government (fuel poverty and social policy) are also proceeding well and there is also a fuel poverty project PhD student starting in September. This PhD will be based in Cardiff and will work closely with the fuel poverty analyst. The ADRC was very pleased to have been awarded two ESRC PhD studentships and awaits information on a third. This will bring the active cohort of ADRC PhDs to five.

ADRC-S Won 3x 1+3 ESRC Doctoral Training Centre (DTC) studentships for an Autumn 2016 start. These were to study the following topics: [1] *Linking housing, poverty and the labour market*; [2] *Modelling Survey Non-Response Using Linked Administrative Data in Healthy Ageing in Scotland (HAGIS)* and the *UK Household Longitudinal Study (UKHLS)*; [3] *Investigating relationship between diagnoses and social care provision in a national cohort: implications for social and health care integration*.

Safepods

ADRC-S hosted an ESRC visit to a SafePod prototype at St Andrews. A secure connection has been established using Joint Information Systems Committee (JISC) SafeShare router kit between the SafePod at the University of St Andrews and the University of Southampton data centre. The ADRC-S met with IGEL Technology to review configuration of SafePod thin clients to develop ability to map image to each ADRC as needed when a researcher makes a booking. A SafePod security assessment was booked for the 12th January 2016 aiming to identify any issues around SafePod current physical security. A working group involving CLAS consultants and JISC is under consideration to look at issues concerning the secure connection of the SafePods and if a third party (such as JISC) can be used.

Training courses

² **ISO 27001** (formally known as ISO/IEC 27001:2005) is a specification for an information security management system (ISMS). An ISMS is a framework of policies and procedures that includes all legal, physical and technical controls involved in an organisation's information risk management processes.

ADRC-E organised the following two short courses: Introduction to Hospital Episode Statistics, 15-16 Oct, London; and Handling Missing Data in Administrative Studies: Multiple Imputation and Inverse Probability Weighting, 19-20 Nov, Southampton. Both courses were very popular and fully subscribed with 19 and 9 people on the waiting list respectively.

A one day workshop 'Introduction to Bayesian Statistics" led by Dr Robin Samuel was held at ADRC-S on the 6 November 2015.

Events

11 participants including representatives from other ADRCs and non-ADRN participants, including from overseas (Dr R.Zijderman, Utrecht), came together on the 9 October 2015 for a Stata Codefest at the ADRC-S.

Professor Chris Dibben presented at a Predictive Analytics Event with the Scottish Government on 9 November 2015. Attendees requested a follow up meeting in the first half of 2016 to be hosted by ADRC-S.

Outlook for next reporting period

Management structure

Upon agreement of the proposed structure, task groups and Standing Committees will be formally tasked by their managing group to ensure a seamless transition. Working groups have continued to progress their areas of work, including the research conference group. The 2016 research conference is provisionally booked for 2 and 3 June in London. ADRC England is leading on the local organisation.

Infrastructure

ADRC –NI is working in conjunction with Ulster University and Queens University Belfast in a submission to the ESRC for a Doctoral Training Programme shared between the two universities and two universities in the North East of England.

Training courses

ADRC-NI: Department for Social Development – Social Security Benefits Data – 10 March - 27 attendees registered (capacity reached)
Northern Ireland Neighbourhood Information Service (NINIS) – 3 February 2016 – 10 attendees registered (capacity reached)

ADRC-E: are producing podcasts and slideshows to complement their 2016 training courses. These will be available on the ADRN website from Feb 2016 and will act as a short introduction to each course, encourage course attendance and website views. This will include filming videos of some of the courses to increase our online presence and training offerings to those who can't attend in person. The ADRC-E is scheduled to run the following short courses:

- ADRN Accreditation Training, 23 Feb 2016, London;
- Developing Synthetic Data for Admin Data Sources, 21-22 Mar 2016, Southampton.

ADRC-W: The ADRC-W will be hosting a Geographical Information System (GIS) workshop on the 1 March 2016.

ADRC-S: A public engagement training course is scheduled to take place at the ADRC-Scotland with participants from outside ADRC-S and from other ADRCs.

Events

ADRC-NI: The Administrative Data Forum is scheduled to take place in April 2016.

Workstream:	ADRN principles and policies³
Main achievements <p>ADS developed a Document Management policy to ensure that versioning and publication of documents are standard across the Network.</p> <p>The ADRN project Approvals Panel has met three times virtually. The Panel will meet face to face in Belfast on 7 January 2016. The Panel has undertaken a self-assessment exercise, looking at their efficiency and areas to strengthen. This included an initial workshop discussion by the Panel, a follow up survey of panel members, and a survey to gather stakeholder's views. At the January meeting the outcomes of this exercise and ways forward will be considered. The Board have received a separate report with the latest information from the Approvals Panel.</p>	

³ Board responsibility (from ToR): ii) Agree the principles and policies for access to the Network, identifying and resolving any high-level issues which inhibit access to the Network.

Outlook for next reporting period

The Approvals Panel will continue to meet once a month to assess project proposals.

Workstream:	Public Engagement and Communications⁴
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Main achievements:

ADS is collaborating with a consortium of ESRC investments: UK Data Service, Census and Administrative data Longitudinal Studies-Hub, ESRC Big Data Network Phase 2, Cohort and Longitudinal Studies Enhancement Resources, Understanding Society, and National Centre for Research Methods. The aim of this collaboration is to raise the profile of these ESRC resources amongst students, supervisors and lecturers. A cross-training webinar took place in September with a student webinar on 28th Oct; and an event aimed at supervisors is planned in the New Year.

The ADRC-E/Bloomsbury Data Linkage Working Group developed a data linkage standards document and held a very successful Academia-Government interface workshop on 17 Dec, attended by various academics working in data linkage and representatives from government departments such as BIS, Ministry of Justice, HMRC, Department for Work and Pensions, Health and Social Care Information Centre (HSCIC). Excellent feedback was received on this event.

In Wales, the regular workshop series is extremely well attended and the centre communications team have visited all universities in Wales to promote the work of ADRC-W. Other public engagement and communications activities undertaken by ADRC-W include: the delivery of a seminar, the development of bi-lingual website materials and the development of video testimonials.

ADRC-S is also completing filming introductory videos for web-dissemination on a range of topics with their researchers.

Laurie and Stevens from the ADCR-S delivered the opening presentations to the European Association of Health Law Conference in Prague at the beginning of October www.eahl2015prague.eu/detailed-programme.htm. Stevens also presented at "Data Safety in Scottish Health and Social Care Partnerships" in October.

ADRC-S established the ADRC-Scotland Public Panel and held the first meeting on 28 November 2015. The Panel consists of 16 members who range in age from 21-84 and who are from across Scotland.

⁴ Board responsibility (from ToR) iv) Provide oversight of the Network's public engagement and communications strategy.

ADS staff attended a meeting of Swansea's Consumer Panel for Data Linkage research. This was done to research best practise to inform a Network Citizens Panel. The objective for the Citizens Panel will be to provide a public viewpoint on policies and proposed policy changes.

ADRC-S team members took part in the ESRC Festival of Social Science in November 2015. In addition, ADRC-S staff presented at the Joint United Nations European Commission for Europe (UNECE)/Eurostat Work Session on Statistical Data Confidentiality in Helsinki in October. The following presentations were given:

- "Utility of synthetic microdata generated using parametric and tree-based methods" and Software demonstration" synthpop: An R package for generating synthetic versions of sensitive microdata for statistical disclosure limitation" (Nowok); and
- "Micro, remote, safe settings (safePODS) – extending a safe setting network across a country" (Dibben) – see unece.org/fileadmin/DAM/stats/documents/ece/ces/ge.46/2015/Report_SDC_Helsinki_15-10-2015_Amended.pdf

In addition, the ADRC-Scotland gave a presentation on "Using administrative data" at a at one day Quantitative Research for Social Work conference in Manchester in December 2015 www.eventbrite.co.uk/e/quantitative-research-for-social-work-tickets-19167519567.

Professor Peter Smith was invited to the European Commission Joint Research Centre in Italy on 9-10 Nov to talk about the ADRC-E's work. Professor Smith was also invited to talk about ADRC-E's work at a seminar organised by the London School of Economics on 4 Dec 2015.

Staff from the ADS presented to prospective researchers. Jo Webb presented at the UK Data Service Crime surveys user conference in December. Kasia Chatsiou presented at the Business and Local Government (BLG) Catalyst workshop on 8th December to a mix of commissioners and data officers from Essex County Council, Suffolk County Council, the National Health Service and the Police. They are particularly interested in the procedures that ADS follows when asked to merge data from different agencies and the extent to which these can be extended to local government. Chris Coates spoke about the benefits of using administrative data for research at Colchester's Café Scientifique on Wednesday 11 November.

Outlook for next reporting period:

A third animation/ infographic is in development to explain the user journey to take researchers through the user journey from initial contact through to publication of a summary of their findings. This is due to launch in January 2016.

ADRC-NI have plans to present on the ADRC at a Northern Ireland Council Voluntary Action event on 24 February 2016. The ADRC-NI also plan to host an event as part of the Imagine Belfast festival, which is a Civic Conversation called 'Big Data, Big Potential' in March 2016 and hold a launch event for the Access Research Knowledge data module for Northern Ireland Life Times when the data goes live on the website in June.

A Synthpop workshop is planned for March 2016 at ADRC-S. ADRC-S will also be hosting a meeting of the Government Council of Economic Advisers on the 2 February 2016 www.gov.scot/Topics/Economy/Council-Economic-Advisers.

Other comments:

Please use this section for any activities (achieved or planned) that are not covered within the workstreams above.

The Director of ADRC-NI, Dr Dermot O'Reilly has advised and recently reviewed the proposed structures and processes for the increased access to and linkage of health and other administrative data in the Republic of Ireland.

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)02

Report from the Administrative Data Research Network (ADRN) Approvals Panel

Purpose

1. This paper provides an update for the ADRN Board about the work of the ADRN Approvals Panel.

Recommendations

2. Members of the Board are invited to:
 - note the contents of this report; and
 - seek clarification on any issues raised by the report.

Background

3. The ADRN Approvals Panel ensures that the process for granting access to sensitive, linked administrative data is fair, equitable and transparent. The Approvals Panel assess each project against the following criteria;
 - i. the project must be purely non commercial research;
 - ii. the project must be feasible, ethical and have clear potential public benefit;
 - iii. a case must be made for using administrative data to carry out the research;
 - iv. a case must be made to show that data can only be accessed through the Network, rather than alternatives;
 - v. the research must not be research that a government department or agency would carry out as part of its normal operations; and
 - vi. the results of the research must be made public through the ADRN website.
4. Projects must be approved before data custodians make the final decision on whether to share their data.
5. The Approval Panel consists of the following members;
 - i. Professor Sir Ian Diamond (Chair);
 - ii. Jane Naylor (Office for National Statistics);
 - iii. Yee-Wan Yau (HM Revenue and Customs)
 - iv. Professor Richard Harris (University of Durham);
 - v. Dr John Power (Northern Ireland Assembly);
 - vi. Professor Robert T Woods (University of Bangor);
 - vii. Lynn Wyeth (Leicester City Council);
 - viii. Dr Andrew Garrett (ADRN Board member);
 - ix. Stephen Parker (lay member); and
 - x. Jen Persson (lay member).

Discussion

6. Since the last report to the Board, the Approvals Panel has met three times, with meetings on the 16 November 2015, 7 December 2015 and 7 January 2016.

7. The meeting in January was a face-to-face meeting in Belfast and incorporated consideration of a report, which had been commissioned by the ADRN Directors containing proposed changes to the Terms of Reference and Operating Procedures for the Approvals Panel. This had been commissioned in response to the feedback gathered during the Panel's 'self-assessment' process, which had included collecting feedback from wider stakeholders (including researchers who have applied to the ADRN and had projects considered by the Panel).
8. At the January meeting, the Panel also received a briefing from Health and Social Care Information Centre (HSCIC) on the enactment status of the 'opt-out from research' that is available to patients whose data is handled by HSCIC. Following this update, the Panel agreed that final approval could be confirmed for a number projects, where a final decision had been pending.

Update of any changes to Panel membership

9. Work is ongoing to recruit one member to fill the remaining vacant position on the Approvals Panel (to bring a data owner/government data analyst perspective).

Update on any changes to operating procedures

10. Since the last Board meeting, the Approvals Panel has not made any substantive changes to its operating procedures.
11. The Approvals Panel still intends to provide guidance to applicants around expected project application content (specifically in relation to description of project methodology). This is to reduce the number of occasions when the Approvals Panel needs to ask researchers to 'provide further information'.
12. Limited feedback has been received from the Research Ethics Committees, who were asked to comment on the usefulness and usability of the Ethics guidance note that was produced in July 2015. The feedback mainly highlighted the need to include more illustrative examples within the document.

Calendar of future Panel meeting dates

13. Approval Panel meeting dates for 2016 are:
 - i. 9 February;
 - ii. 7 March;
 - iii. 26 April (face-to-face in Southampton);
 - iv. 16 May;
 - v. 20 June;
 - vi. 18 July;
 - vii. 25 August (face-to-face in Edinburgh);
 - viii. 19 September;
 - ix. 11 October;
 - x. to be confirmed November; and
 - xi. 12 December.
14. Titles of projects approved since previous Board meeting:
 - i. Sociodemographic characteristics, educational attainment and self-reported health status of farmers in Northern Ireland
 - ii. Informal care in the last days of life: a data linkage study
 - iii. The kinds of poverty in schools and their impact on student progress

15. The following projects had previously been considered by the Panel and were awaiting a final decision, pending a briefing from HSCIC on the enactment of 'opt-outs'. Having received this briefing at the face-to-face meeting in January, the Panel agreed that the projects should be considered approved with effect from 1st February (subject to the completion of ethical review if still outstanding).

- Residential mobility and diabetes
- Evaluating the effects of Community Treatment Orders (CTO) in England

16. The panel requested further information for four of the approved projects before making a final decision to approve the projects.

17. The Panel has also viewed a number of projects where additional information has been requested from the applicants, or a further clarification is required, before a final decision can be made. This includes some projects where the only outstanding element of Panel approval is confirmation that a favourable outcome has been achieved through an ethical review process.

18. The Administrative Data Service (ADS) is continuing to work with the Administrative Data Research Centres (ADRCs) to provide 'public benefit summaries' for each of the projects approved by the Panel. For projects where this has been achieved, the summaries can be viewed here: <http://www.adrn.ac.uk/research-projects/approved-projects>.

Number of projects rejected since previous Board meeting (and the type of reason for rejection), number of appeals (and the outcomes):

19. The Approvals Panel has rejected two projects (one of these did not demonstrate sufficient potential public benefit and the other did not demonstrate sufficient potential public benefit or sufficient scientific merit) since the previous Board meeting, but welcomed new applications from the applicants with proposals, which addressed the reasons for rejection.

20. There have been no appeals of Approval Panel decisions.

John Sanderson, Administrative Data Service, 20 January 2016.

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)03

Data owner engagement update

Purpose

1. This paper provides an update for the Board on the Administrative Data Research Network's (ADRN) data owner. Blockages to accessing data and areas where the Board's assistance is requested will be covered in an oral update accompanying this report.

Recommendations

2. Members of the Board are invited to:
 - i. note the range of data owner engagement activities that have been undertaken (**Annex A**); and
 - ii. discuss how the Board may assist the Network when engaging with data owners.

Background

3. The Administrative Data Service (ADS) lead on data owner engagement. In the case of Devolved Administrations, the ADS and the Administrative Data Research Centres (ADRCs) work together to engage with data owners and stakeholders in a coordinated and effective way.

Simon Whitworth, UK Statistics Authority, 13 January 2016

List of Annexes

Annex A ADRN Data Owner Engagement Activity, Jo Webb, Administrative Data Service.

Annex A – Administrative Data Research Network (ADRN) Data Owner Engagement Activity

Administrative Data Service (ADS)

1. Communications Electronic Security Group (CESG): An update meeting is being arranged between ADS and CESG.
2. Clinical Practice Research Datalink: No response for request for dialogue.
3. Cabinet Office: Melanie Wright and two members of ADS attended a meeting at the Cabinet Office to present on the ADRN.
4. Department for Communities and Local Government: No update since previous report.
5. Department of Energy and Climate Change (DECC): Dialogue is ongoing with the most recent meeting in January 2016.
6. Driver and Vehicle Licensing Agency: No negotiations open at the moment. This was highlighted to the Board in a report at its November meeting.
7. Department for Work and Pensions (DWP): Regular meetings (every 2 weeks until Christmas and then monthly) are taking place between External Data Sharing Advice Centre (EDSAC) and the ADS User Support Team, along with representatives of the DWP Analytics section, with the aim of establishing effective relationships and data sharing procedures. DWP are currently using a recently approved ADRN project as a way to explore the details of how the process should work.
8. Higher Education Statistics Authority (HESA): No update since last report.
9. HM Revenue and Customs (HMRC): A meeting is planned between the ADS and HMRC in January.
10. Health and Social Care Information Centre (HSCIC): The ADS User Services met with HSCIC staff in Leeds in November to discuss the process to access data. At present, ADS is confirming which secure environment carries the appropriate information security certification.
11. Ministry of Justice (MoJ): ADS assisted MoJ to develop metadata for some of their key surveys. Together with their statistical team, ADS have developed a User Guide for probation data, which is currently under revision with a completion date of January 2016. MoJ will support ADRN queries and the ADS aim to increase the interest in the data source, by publishing better metadata.
12. Office for National Statistics (ONS): The departure of key members of staff at ONS has slowed the data sharing process. However, these members of staff have now been recruited. The ADS and the ADRC England met with ONS to make contact and discuss ways of working.
13. Universities and Colleges Admissions Service (UCAS): UCAS have requested certain conditions be met before allowing data access. The ADRN Directors Group have responded to this request and asked for the opportunity to discuss the issues further.
14. Valuation Office Agency (VOA): The ADS Co-Director will be meeting with the Director of Information and Analysis on 10 November to discuss ADRN access to VOA data. The

VOA suggested that it would be easiest to transfer the data to the HMRC Lab. ADS is currently scoping this solution.

ADRC England (ADRC-E) activity

15. ADRC-E has been involved in conversations with HSCIS alongside ADS. ADRC-E in particular is looking at work needed to complete the HSCIC Information Governance Toolkit and provide details of Official (Sensitive) accreditation.
16. ADRC-E has also been involved in discussions with ADS and ONS about data access. After ADRC-E completes their annual accreditation process, it is anticipated that the ONS will agree, in principle, for the University of Southampton to hold all ONS datasets, except the census. While datasets will need to be considered on a case-by-case basis, this should streamline data access discussions with ONS.
17. ADRC-E had two meetings with NatCen (in November 2015 and January 2016) to discuss collaborative working opportunities and access to their data. NatCen seek explicit consent for linkage, so many of their datasets would not be available for ADRN use in the short-term. However, they may be available in the medium- to long-term as they update their consent requests in later survey waves.

ADRC Northern Ireland (ADRC-NI) activity

18. Since the last report, agreement in principle has been secured with Department of Social Development, Business Services Organisation and Department of Education, which should increase access to social security benefits and a number of important health and education-related datasets. In accordance with the relevant secondary legislation, the necessary overarching data sharing agreements that will permit the sharing of data with the ADRC-NI are in the process of being developed. There are ongoing discussions with other departments and presentations have been delivered to senior management in Department of Justice, Police Service of Northern Ireland, Department of Education and the Northern Ireland Cancer Registry.

Table 1: Summary table on data acquisition

Agreement in principle – Data prospectus updated		
Department of Finance and Personnel (DFP)	of	1991-2011 Census (100%)
	and	Land and Property Services (house value and attributes)
		Vital statistics
		Central Survey Unit
Department for Employment and Learning (DEL)		Northern Ireland HESA data
Department of Agriculture and Rural Development (DARD)		Farm Census
Northern Ireland Office (NIO)		Electoral Register (Northern Ireland)
Agreement in principle – Data Sharing Agreements to be put in place		
Business Services Organisation		Registration data, Dispensed prescriptions etc
Department of Education		School Census and School Leavers Survey
Department for Social Development		Benefits data
Ongoing discussions		
Department of Justice		To Be Confirmed
Police Service of Northern Ireland		To Be Confirmed
Department of Health, Social Services and Public Safety (DHSSPS)		Secondary health and social care data
Department of Employment and Learning		Further Education and Training/Apprenticeships
Department of Education		To Be Confirmed
Cancer Registry		To Be Confirmed

19. Negotiations are continuing with Department for Social Development, Business Services Organisation and Department of Education on developing the high level data sharing agreements and on finalising resources. However, applications for research using these datasets can proceed whilst these issues are being actively pursued.

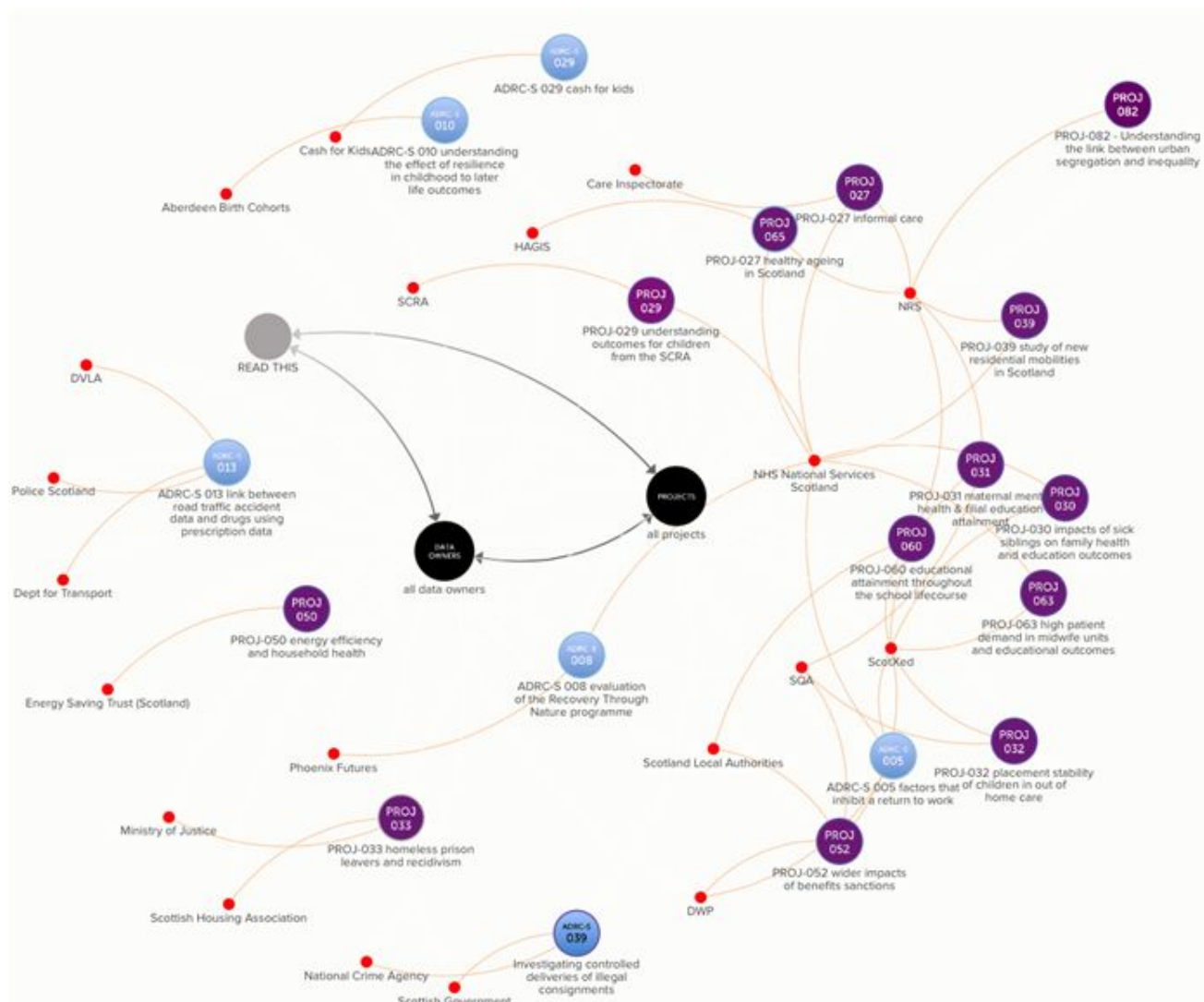
ADRC Scotland (ADRC-S)

20. ADRC-S has been in conversation with data owners in over 15 organisations, both specific to Scotland and UK wide, including:

- I. Aberdeen Birth Cohorts;
- II. Care Inspectorate;
- III. Cash for Kids;
- IV. Energy Saving Trust (Scotland);

- V. Department for Transport;
- VI. DVLA;
- VII. DWP;
- VIII. Healthy Ageing in Scotland;
- IX. Ministry of Justice;
- X. National Records Scotland;
- XI. National Health Service (NHS) National Services Scotland;
- XII. National Records Scotland;
- XIII. Phoenix Futures;
- XIV. Police Scotland;
- XV. Scottish Childrens Reporter Association;
- XVI. Scotland Local Authorities; and
- XVII. Scottish Qualifications Authority.

21. The figure below presents the ADRC-S internal interactive visual. This network diagram displays how discussions with data owners' organisations relate to datasets that can contribute to more than one ADRC-Scotland linkage project. The projects referenced include projects in development; submitted to the Approvals Panel and approved by the Approvals Panel.





ADRC- Wales (ADRC-W)

22. The ADRC-W data owner engagement strategy is built on existing and newly developed relationships, with key strategic bodies that have responsibility for the collection and management of data most relevant to ADRC-W based projects.

Welsh Government

23. Welsh Government is a key strategic partner in the activities of the ADRC-W and is also the main data owner in Wales for administrative data. Welsh Government is highly supportive of the ADRC-W and is very proactive in the development and support of its projects.

24. There is a monthly meeting between the Chief Statistical Officer for Wales and ADRC-W staff. This meeting looks at all Welsh Government data requirements for projects and subsequent routes to access. It also reviews all current ADRC projects to identify any added value and to look at any potential crossover with other data analysis centres within Wales (e.g. Secure Anonymised Information Linkage (SAIL) Databank) where this data may already be held.

25. Welsh Government also provides a route to other data owners, such as Local Authorities and has facilitated data access discussions.

Third sector

26. For third sector data, the ADRC-W has links with the Welsh Council for Voluntary Action, the umbrella body for third and voluntary sector organisations in Wales.

Utilisation of research networks

27. The ADRC-W also utilises its allied research groups and networks to assist in the identification of data and data owners for projects. These contacts are facilitated through the Co-Applicant network of the ADRC-W, on which representatives from a range of research groups and networks, such as the below, are represented:

- I. SAIL is a Wales-wide research resource focused on improving health, well-being and services. Its databank of anonymised data about the population of Wales is world recognised. SAIL receives core funding from the Welsh Government's National Institute of Social Care and Health Research (NISCHR). A range of anonymised, person-based datasets are held in SAIL and, subject to safeguards and approvals, these can be anonymously linked together to address important research questions.
- II. Wales Institute of Social & Economic Research, Data & Methods;
- III. Swansea's Research Centre for Criminal Justice and Criminology;
- IV. the Centre for Improvement in Population Health through E-records Research;
- V. the Universities' Police Science Institute;
- VI. Cardiff Centre for Crime, Law and Justice;
- VII. the Centre for the Development and Evaluation of Complex Interventions for Public Health Improvement;

- VIII. the Older People and Ageing Research and Development Network in Wales; and
- IX. Swansea Research Institute for Applied Social Sciences.

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)04

ADRN Mid-term Review

6

Purpose

1. This paper presents the proposed Terms of Reference for the Administrative Data Research Network (ADRN) mid-term review.

Recommendations

2. The group are invited to consider and agree the proposed Terms of Reference that are put forward at **Annex A**.

Background

3. The ADRN Board approved the high level plans for the mid-term review at the ADRN Board meeting on 3 November 2015.
4. The UK Statistics Authority and the Economic and Social Research Council (ESRC) will work together on a joint independent mid-term review. This will avoid duplication, reduce time and resource demands on the ADRN, and produce outcomes for the UK Statistics Authority and the ESRC Council that are in synch with each other.
5. The UK Statistics Authority will use the mid-term review to seek assurance for the robust performance and governance of the Network. This will help the Authority to fulfil its role as the reporting body to the UK Parliament for the ADRN.
6. The independent mid-term review will also inform the ESRC Council's decision, in February 2017, of whether and how the ESRC will seek to re-commission the ADRN beyond the initial grant.
7. The review will consider the entire Network. This will include:
 - i. the four Administrative Data Research Centres;
 - ii. the Administrative Data Service;
 - iii. data custodians (government departments and agencies, and national statistical authorities);
 - iv. the ESRC; and
 - v. the UK Statistics Authority.
8. The ADRN Board and the ESRC will jointly appoint an independent reviewer to conduct the mid-term review. The reviewer(s) will have no current involvement with any of the parties involved in the ADRN and will have experience of accessing administrative data for research and statistical purposes.
9. The independent reviewer is yet to be appointed. The UK Statistics Authority has received input from the ADRN Board and the ESRC to identify suitable candidates to fulfil the role.
10. The planned high level timetable for the review is as follows:
 - i. the Terms of Reference for the review will be discussed at the ADRN Board meeting in February 2016;

- ii. the independent reviewer will be appointed in Spring 2016;
- iii. the review will take place during the Summer of 2016; and
- iv. the findings of the review will be shared with the ESRC and the UK Statistics Authority in the Winter of 2016.

Simon Whitworth, UK Statistics Authority, and Paul Meller, Economic and Social Research Council, 18 January 2016.

Annex A ADRN Mid-term Review Terms of Reference, Simon Whitworth, UK Statistics Authority and Paul Meller, Economic and Social Research Council.

Annex A – Terms of Reference for the independent mid-term review of the Administrative Data Research Network (ADRN)

INDEPENDENT MID-TERM REVIEW OF THE ADMINISTRATIVE DATA RESEARCH NETWORK (ADRN)

TERMS OF REFERENCE

To review the progress of the ADRN in the first two and a half years of the Economic and Social Research Council (ESRC) five year ADRN grant. The main aims of the review are to consider:

- 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);
- ii. the current wider contribution of the ADRN beyond the accessing of data, such as developing capability, methodology and public engagement;
- iii. whether the ADRN is being developed, managed and maintained in a way that maximises its benefit to researchers and policy makers, taking account of the project scope and resources;
- iv. how the ADRN should prioritise, organise and manage its future work to ensure that ADRN research is having maximum public or policy benefit;
- v. the opportunities for sustainability and future development of the Network, including extensions to scope and resources within and beyond current funding commitments;
- vi. how the governance arrangements can support the strategic aims of the Network;
- 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;
- viii. the wider contextual factors that have influenced the ADRN's progress, such as the legislative environment in which the ADRN is operating; and
- ix. the wider contribution of the ADRN to the international research community.

The review will be led by [To be confirmed]. [To be confirmed] will assist the review.

The review will report to the ADRN Board and the ESRC council. The ADRN Board will use the mid-term review to seek assurance for the robust performance and governance of the Network. This will help the Authority to fulfil its role as the reporting body to the UK Parliament for the ADRN. The ESRC council will use the review to inform the ESRC Council's decision in February 2017, of whether and how the ESRC will seek to re-commission the ADRN beyond the initial grant (2014 to 2018).

The review will deliver a final report for publication with recommendations by November 2016.

Professor Peter Smith

A view from the Administrative Data Research Centre England

Oral report

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)05

Information Security update

Purpose

1. This item provides an opportunity for the Board to discuss the data retention and destruction policy. This policy can be found at **Annex A**. Melanie Wright will provide an oral update on the Network's current thinking about potential changes to the data retention and destruction policy.

Recommendations

2. Members of the Board are invited to note and discuss the data retention and destruction policy at **Annex A** and the Network's current thinking about potential changes to the policy.

Background

3. At the Administrative Data Research Network (ADRN) Board meeting on 21 July 2015, the Board had a detailed discussion about the five year data retention policy and whether this was a long enough time period to make sure researchers were able to fully exploit the value of the data, which could be made available through the ADRN. The following points were made in the discussion:
 - i. it was suggested that it was important to strike a balance between the aim to take full advantage of the research potential of the data, whilst making sure that the length of time data is retained is publicly acceptable;
 - ii. it was reported that scientific journals are increasingly insisting that data created through the research process should be maintained;
 - iii. it was suggested that a more nuanced data retention policy could be developed over time, with different retention periods for more sensitive and less sensitive data; and
 - iv. the Board requested that the Administrative Data Service produce a paper that presents international best practice with regards to data retention and destruction.

Simon Whitworth, UK Statistics Authority, 18 January 2016

List of Annexes

Annex A Data retention and destruction policy, Tanvi Desai, Administrative Data Service

Annex A - Data Retention and Destruction Policy



An ESRC Data
Investment

8.1

Data Retention and Destruction Policy

PUBLIC

01 JULY 2015

Version: 01.00

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www.adrn.uk

Scope

To support ADRN's commitment to protect the privacy and confidentiality of data subjects a suite of Information Assurance policy documents have been developed to provide a framework for ADRN operations and to guide practice across all ADRCs and the ADS. This document outlines the ADRN policy in relation to data retention and destruction. All ADRCs will in addition have local procedural documents that outline how these policies are operationalised.

Other associated documents include:

ADRN030 Information Security Principles

ADRN031 Trusted Third Party Policy

ADRN032 Secure Environments Policy

ADRN033 Data Movement Policy

Contents

1. Policy 2

For definitions of terms please see the ADRN glossary at <http://www.adrn.ac.uk/using-the-network/documentation>

1. Data Retention and Destruction Policy

Data of varying types are created and processed during the research process; Personal Identifiable data (e.g. names, addresses, dates of birth) are used within the Trusted Third Parties for the purpose of matching individuals across datasets and facilitating the creation of de-identified research datasets. The research datasets accessed by Accredited Researchers will not contain person identifiable information. Initially all linked research data will be destroyed at the end of a research project. However, the ADRN recognise that there are potential research benefits and efficiency savings that could accrue from the retention of de-identified research datasets. Therefore this policy will undergo regular review taking into account the views of the public and data controllers, and research needs.

This policy outlines data retention and disposal requirements at different stages of the data journey. The policy also covers data generated by Data Controllers; however this should be seen as advisory only.

A. ADRN

These first are overarching policies that apply to all data and information held by ADRN and partners.

1. When deleting or destroying any data or information ADRN, TTPs, researchers and other partners must ensure that it is done securely and effectively, and in line with CESG or data controller requirements.
2. Local ADRCs, TTPs and ADS must have clear policies that ensure that data are deleted properly and that physical media are destroyed securely (whenever necessary).

B. Trusted Third Party (TTP)

Information held by TTPs and covered by this policy includes, but is not restricted to: the direct identifiers received from data owners; syntax or program configurations used to create matches and project specific index numbers; metadata related to matching rates (to be sent to ADRC); sets of index numbers transferred to the ADRC, and any data returned to the data controllers.

1. TTPs must securely destroy all data on completion of the linkage process.
2. For the lifetime of the ADRN, TTPs will retain metadata on the linkage method, quality and where applicable matching statistics. This will also be supplied to the ADRC, and the ADS who will retain this information.

C. Staging environment for the creation of linked research data

All data linking using the indices created by TTPs takes place in a secure staging environment within an ADRC. The staging area is separate from the safe setting within which the researcher accesses the final research dataset.

Information created within a secure staging area that are covered by this policy includes, but is not restricted to: a copy of the attribute data created by the data controllers; the project specific matched index numbers supplied by the TTP; derived variables created by the ADRC; metadata.

1. Metadata will be retained by the ADRC for the lifetime of the ADRN.
2. Researchers will only receive access to data they need as specified in the application. Any data that has been created as part of the linking process that is not specified in the project application will be destroyed before the data are transferred to the safe setting for research access.
3. Once the research dataset has been created and deemed ready for access all the data within the staging environment will be securely destroyed.

D. Research data

Research data covered by this policy include but are not restricted to: the de-identified research dataset accessed by the Accredited Researcher; any additional copies of research data created by the researcher; processed versions of the data; analyses or statistics that have been created but not approved for release; and syntax (analytic code that has been created in statistical packages such as SPSS, SAS, R, STATA).

1. The research data will be archived by the ADRC for a maximum of 5 years unless the end date stated in the project application is before that or unless the Accredited Researcher makes a valid application for an extension (that is approved by the data controllers), or the Data Controller specifies otherwise.
2. Following the active analysis phase of the project data will be archived for the remainder of the five year period and only made available on receipt of a valid application (via the approvals panel) from the researcher (for example, to enable them to make revisions to a paper to have it accepted for publication).
3. Data controllers will be informed that after the archiving phase the data may still be retained on copies of IT backups. The length of time that IT back-ups will be retained will be described in local ADRC procedure documents.
4. The syntax generated by the research team will be retained by the ADRC for audit purposes for as long as the data are archived (see above). Syntax may also be retained by the Administrative Data Service for future use.

E. Approved statistical results and analytic outputs.

This policy covers all research outputs that have undergone statistical disclosure control and been approved for release into the public domain.

1. Statistical results and analytic outputs will be archived for as long as the ADRN (or similar) is in existence.

F. IT back-ups

This policy covers: all information on the TTP network, staging environment and the ADRC safe environment.

1. The maximum time a backup may be retained in a TTP, an ADRC staging environment must be 48 hours.
2. All other areas data back-ups will be determined by local procedures.

G. Data extracts created by the data controller

This recommendation includes, but is not restricted to: syntax used to create the dataset, data containing the personal identifiers sent to the TTP, and attribute data sent to the ADRC/Secure Environment. Retention decisions for these data are the responsibility of the data controller, however:

1. The ADRN encourages data controllers to retain any code/syntax used to extract data for ADRN projects, ideally for the life time of ADRN.
2. The ADRN encourages data controllers to retain copies of the direct identifiers and the attribute data until the completion of the analysis phase of the project.
3. Where possible, the ADRN encourages data controllers to retain copies of the extracts that could be used to replicate the specific research dataset in the future or re-use the data for a different project.

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)07

Definition of an Administrative Data Research Network (ADRN) Project

Purpose

1. This paper presents suggested changes to the definition of an ADRN project that has previously been agreed by the ADRN Board and which can be found in **Annex A**. The suggested changes to the definition of an ADRN project are presented in **Annex B**.

Recommendations

2. Members of the ADRN Board are invited to note and discuss the suggested changes detailed in **Annex B**.

Background

3. In the ADRN Board meeting on 3 June 2014 the ADRN Board approved the policy detailed in **Annex A**, which sets out the criteria that defines a project that is suitable for the ADRN.
4. The suggested changes to the definition of an ADRN project that are presented in **Annex B** have been agreed by the ADRN Directors Group.

Simon Whitworth, UK Statistics Authority, 20 January 2016

List of Annexes

Annex A Definition of an ADRN Project, Tanvi Desai, Administrative Data Service

Annex B Proposed Changes to the Definition of an ADRN Project, Professor Chris Dibben, Administrative Data Research Centre-Scotland

Annex A – Definition of an ADRN Project

Definition of an ADRN Project

EXTERNAL

8th May 2014
Version: 03.00

Tanvi Desai

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Purpose

This paper is a revision of that presented at the ADRN Board meeting on the 14th April 2014. The aim of the paper is to establish a set of criteria that defines a project suitable for acceptance by the ADRN. The paper is submitted for the Board's approval as a formal ADRN policy applicable for the first active phase of the ADRN (May 2014-March 2016) at the end of which time all ADRN operations will be reviewed.

9.1

1. Background

A paper outlining a proposed definition of an ADRN project was presented to the ADRN Leadership Group on 26th February 2014. This paper takes into account input from the Leadership Team (26th February and 27th March), the ADRN User Services Working Group, the Policies and Procedures meeting (25th March 2014) and the ADRN Board meeting on 14th April. This paper is accompanied by a paper outlining the proposed ADRN Independent Approvals Panel.

2. An ADRN Project - Definition

- The project is for non-commercial research purposes
- The project has evident potential public benefit
- There is a demonstrable value from using unit level administrative data to answer the research question.
- The project would not be more appropriately served by other existing services (e.g. FARR, UKDS Secure Lab, Longitudinal Studies, HMRC Data Lab, etc.)
- The project does not constitute normal operational functions undertaken by government departments or their agencies.

3. An ADRN Project - Eligible people

- The researcher must be a 'fit and proper person' i.e.
 - They must be capable of carrying out the research either independently or under the direction of an appropriate supervisor or lead investigator;
 - They must have completed the ADRN Accreditation Training.
- The researcher must be from academia, the public sector or a research organisation on the Research Councils UK list of eligible independent research organisations (<http://www.rcuk.ac.uk/funding/eligibilityforrcs/>).

4. An ADRN Project - Conditions

- All projects must be approved by the ADRN Independent Approvals Panel (assessed for ethics, privacy impact, feasibility, scientific merit, and potential public benefit).
- The results of the project including all research outputs must be made available in the public domain. Where no formal publication mechanism is available the research results must be published as an ADRN working paper.
- The ADRN will be informed of all publications, presentations and other forms of dissemination that are produced in relation to ADRN research projects.
- The researcher will provide a maximum 2-page summary of research findings in accessible language for the data provider and the Network. These will be made publicly available on the ADRN website.
- The researcher must make copies of relevant code, syntax and documentation developed for the project available for reuse following the project end date. These materials must be appropriately structured and annotated to facilitate reuse.

Annex B – Proposed Changes to the Definition of an Administrative Data Research Network (ADRN) Project

1. The medical research councils and charities have invested capital into research infrastructures to support linked administrative data based research but, on the whole, not into the person time required to negotiate, link and manage administrative datasets. Their expectation is that this cost will be recovered from research grants. This presents a potential problem, given the relatively large community of medical researchers and the charges they will have for using the various service. The ADRN may be at risk of being used for medical research projects, unless it can differentiate between medical vs. social science research.
2. This is one reason why the existing definition of an ADRN project (**Annex A**) states that applicants must “ensure [their] project would not be more appropriately served by other existing data services (such as FARR, UKDS Secure Lab, Longitudinal Studies, HMRC Data Lab, etc.)”.
3. However, there have been problems assessing this ‘exclusion’ requirement and it is therefore proposed to change it to an ‘inclusion’ requirement, where the applicants have to “ensure their project has an economic or social science focused in nature and, therefore, would come under the remit of the Economic and Social Research Council (ESRC). This does not imply that projects need to be funded by the ESRC”.
4. To assess whether a project meet this criterion a two track approach is suggested;
 - Track 1 is the standard route for projects defined as strongly economic or social science focused in nature. These will be eligible (as constrained by resources) for ADRN support.
 - Track 2 is a discretionary route for projects that are not defined as strongly focused on social science.
5. A project that was identified as appropriate for the standard route would go to the ADRN Approvals Panel and through the normal assessment process. Projects put into the discretionary route would only be taken forward if there is capacity after track 1 projects have been accounted for at the Administrative Data Research Centre (ADRC) director’s (or someone deputised by her or him) discretion.
6. A research proposal might be defined as economic or social science in focus if it can be demonstrated that the core part of the study focuses on economic or social science questions (i.e. studying cultural, psychological, social, economic or religious phenomena etc.). The “core part” is defined as the hypothesis or research question being directly related to the social or economic issue in the proposal and that any paper or report emanating from the research would discuss at some length the social or economic issue in its findings.
7. The test of this might be the following:

If:

[1] There is no evidence of any social or economic¹ science in the proposal, the project would not be supported.

[2] Otherwise:

¹ Social and economic would include: cultural, sociological, psychological, religious dimensions, economic etc.

[2a] if the main outcome of interest is economic or social in nature, then the project would be supported via Track 1.

[2b] if a significant factor² that is being examined as causally important is economic or social in character, then the project would be supported via Track 1.

[2c] if the use of social and economic variables is simply used for characterisation, to produce matched samples, then the project would be supported via Track 2.

8. Examples of how this would work for some potential research projects are provided below:
 - i. the impact of asthma on a child's school attendance and achievement - would be track 1 (test 2a);
 - ii. the measurement of unmet health need in a health economics study - would be track 1 (test 2b);
 - iii. a non-randomised follow-up on survival after different types of surgeries, where a measure of poverty was used to match groups - would be track 2 (test 2c);
 - iv. a study of the different compliance to drug therapies between different social groups, where the research question really focused on difference in health outcomes between different social groups (i.e. the socially produced differences in compliance was the focus of the study) – would be track 1 (test 2b);
 - v. a study of transport related pollution and its impact on the risk of developing heart disease – would be track 1 (test 2b); and
 - vi. a study of the long term impact of drug X on survival follow up of Randomised Controlled Trials (RCT), where the follow up is entirely in terms of an individual's health – would not be supported (test 1).

² By significant factor we mean that there would be hypothesis or research question directly related to the social or economic issue in the proposal. That any paper, report emanating from the research would discuss at some length the social or economic issue in its findings.

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)08

Legislative Issues

Purpose

1. This paper presents updates on:
 - i. UK data sharing legislation;
 - ii. EU data protection regulation; and
 - iii. other relevant activity.

Recommendations

2. Members of the Administrative Data Research Network (ADRN) Board are invited to:
 - note and discuss the content of the paper; and
 - consider the potential implications of the activities discussed for the ADRN in order to inform the UK Statistics Authority and the ESRC in its discussions with partners.

Background

3. At the November 2015 meeting the ADRN Board discussed a paper on data sharing legislative issues. This included updates on proposals for UK data sharing legislation, developments in EU data protection regulation discussions, and other relevant activity.

UK Data Sharing Legislation Proposals

4. Members will recall that between March 2014 and March 2015 the Cabinet Office ran an Open Policy-Making (OPM) process to discuss how government could be made more efficient and effective through its use of data. The core focus was to:
 - i. enhance the availability of high quality research and statistics from administrative data held within government and the wider public sector;
 - ii. prevent fraud and help citizens manage any debts they might have with government; and
 - iii. provide tailored public services offered to the right person at the right time.

The OPM process involved collective discussions between the Cabinet Office, civil society organisations, privacy groups, other government departments, academics, and representatives of the wider public sector. Further information about the OPM process is available at www.datasharing.org.uk.

5. Since the ADRN Board's last update, Statistics Authority and ESRC officials have continued to engage with the Cabinet Office data sharing policy team to further refine the procedural and legal details of the research and statistics strand of the policy, to identify indirect and direct costs and benefits and to address feedback emerging from two pre-consultation plenary sessions (see paragraph 8 and following).
6. The proposals for de-identified data for research and statistics purposes remain largely unchanged from those proposed through the OPM process last spring. The proposals provide for a permissive power inclusive of all public authorities (with the exceptions of health and social care) to share/link de-identified data for the purposes of research and statistics in the public interest using a trusted third-party sharing system, where data will be linked in a secure access facility and made available to accredited researchers under

controlled conditions. Oversight of these arrangements will be provided by the UK Statistics Authority who will be acting as the accreditation body for indexers and providers of accredited secure access facilities.

7. The proposals for identified data have been further developed. As currently articulated within the policy framework the proposals includes legal provisions to:
 - i. give the National Statistician a right of access to data held by public and private sector bodies for the sole purpose of statistics and statistical research;
 - ii. enable the National Statistician to securely share information with the Devolved Administrations for their statistical purposes;
 - iii. re-affirm rigorous penalties for the misuse of identifiable data to maintain public trust; and
 - iv. include an obligation to consult the National Statistician before changes are made to the way administrative data are collected, stored or retrieved.
8. Cabinet Office has indicated a preference to initiate a formal consultation process on the entire policy (including the non research and statistics strands) in early 2016. In advance of this, this January Cabinet Office invited those who were involved in the original OPM process to two plenary sessions. These meetings were held to review the latest data sharing proposals against the recommendations of the OPM process to check:
 - i. they still fit the spirit of the agreements emerging from the OPM;
 - ii. scope for improvements; and
 - iii. any aspects of the policies as developed that crossed red lines.
9. The Minister for Cabinet Office introduced the first of these meetings by reaffirming his strong commitment to the policy proposals. The Minister emphasised the importance of legislation in enabling data users to better exploit existing and emergent data sources, but also of striking a balance between harnessing the opportunities of data and protecting citizens.
10. The conversations were supportive of the research and statistics strand of the policy developments. There were however some requests for procedural clarification and collective agreement on the importance of ensuring clarity and consistency of message and key definitions across the various streams of the proposals.
11. The ESRC is engaged with the Cabinet Office and other funders of research in order to assist the Cabinet Office in developing their draft clauses and to prepare the consultation documentation.
12. There is no further update at this time on the anticipated legislative vehicle for the data sharing provisions. Discussions are ongoing.

EU Data Protection Regulation

13. On 15 December 2015, it was announced that agreement has finally been reached in trilogue discussions on the text for the new Data Protection Regulation. This Regulation will come into effect in the next two years in all EU member states. Individual Member States may set higher data protection standards than those enshrined in the Regulation if they so wish, and there were a number of derogations that would impact on research to be decided by Member States.
14. The Regulation covers a range of data protection concerns and in the agreed text uses the terminology 'scientific research' throughout. It defines genetic data and the scope of health data, but pseudonymized data is not defined but is implied as being where the

code is held by the same data controller, that this is still to be considered personal data and safeguards should be used (Article 4 (3b)).

15. Below are a number of important areas covered by the draft text that will be of interest to ADRN Board members.

Consent

16. In the final discussion of trilogue there was agreement that consent that should be given by a clear affirmative action establishing a freely given, specific, informed and unambiguous indication of the data subject's agreement to personal data relating to him or her being processed, such as by a written, including electronic, or oral statement.
17. However there is recognition in the text (25aa) that for scientific research: 'it is often not possible to fully identify the purpose of data processing for scientific research purposes at the time of data collection. Therefore data subjects should be allowed to give their consent to certain areas of scientific research when in keeping with recognised ethical standards for scientific research. Data subjects should have the opportunity to give their consent only to certain areas of research or parts of research projects to the extent allowed by the intended purpose.'
18. In Article 5(1)(b) the text states that further processing for 'scientific research' purposes is to be considered compatible lawful basis; and in Article 9(2)(a) it states that it is lawful and legitimate to process 'sensitive data' for scientific research, either based on consent which includes a broad consent, or without consent if the Member State has introduced a derogation, and if 'appropriate' safeguards are in place. It is included in the text that technical measures such as pseudonymization should be used where possible as safeguards in research.
19. These points on consent are important to note and fully understand, and it will be essential that the UK introduces a derogation for scientific research. Working with the European Data in Health Research Alliance, led by the Wellcome Trust, the ESRC and other funders have been seeking an exemption for scientific research from the consent provision and it appears that the letters, petitions and meetings have led to European officials being receptive to the concerns expressed by the research community, as reflected in this final compromise text agreed during trilogue between the European Parliament, the European Commission and the Council of Ministers.

Data Processes

20. There are a number of articles imposing obligations on data processors, including: Article 28 which obliges processors to maintain certain records of all processing activities; Article 30 which requires a processor to take appropriate security measures to protect personal data: "to ensure a level of security appropriate to the risk"; Article 77 states that where there is a breach, individuals may be able to seek compensation directly from processors and that the processor will only be responsible if it has not complied with a direct obligation imposed by the regulation, and may escape liability where it can prove it is not in any way responsible for the breach.

Other Safeguards

21. There is a requirement for data protection safeguards to be built into firms' products and services from the earliest stage of development (data protection by design), and that privacy-friendly techniques such as pseudonymization will be encouraged, to reap the benefits of big data innovation while protecting privacy.
22. Citizens will gain more rights to control their data, such as a right for their data to be destroyed, and being asked to give unambiguous consent for their data to continue to be

used or shared. There is a right to be forgotten (and other data subject rights) but importantly a derogation for research can be applied by Member States.

Next Steps

23. The text has been sent for legal-linguistic checks, ahead of formal votes in the Parliament's plenary session and the Council of Ministers in the first half of 2016. The final text will be confirmed after this formal vote, which will lead to a two-year implementation period for Member States.
24. It will be important during the coming months and the two years of implementation period that the members of the European Data in Health Research Alliance and research community work with the European Commission and Member State governments to ensure it produces a clear framework for scientific research. Therefore, although trilogue is now completed, it is important not to lose sight of how this is progressing.

Richard Reed, UK Statistics Authority, and Vanessa Cuthill, Economic and Social Research Council, 20 January 2016

Any other business