



# Ninth Meeting of the Administrative Data Research Network Board

**Agenda and Papers** 

Monday 11 April 2016

11:00 - 15:00

Board Room, UK Statistics Authority Drummond Gate, London

## **UK STATISTICS AUTHORITY**

## ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

### Minute

## Monday, 11 April 2016 Boardroom, Drummond Gate, London

### Present

Board Members Professor David Hand (Chair) Ms Sharon Witherspoon (for items 7 to 11) Dr Fiona Armstrong Dr Andrew Garrett Mr Colin Godbold Mr Guy Goodwin Mr Roger Halliday Mr Glyn Jones Dr Tracy Power Professor Peter Smith Mr Luke Sibieta Mr Nicky Tarry

#### **UK Statistics Authority**

Dr Simon Whitworth Mr Robert Bumpstead

Economic and Social Research Council (ESRC) Dr Paul Meller

### Administrative Data Research Centre (ADRC) – Wales

Professor David Ford

**Apologies:** Mr Jonathan Athow, Professor Denise Lievesley, Mr Darren Warren, and Ms Penny Young.

#### 1. Minutes and matters arising from previous meeting

1.1 The meeting reviewed progress with actions from the previous meeting held on 1 February 2016.

### 2. Chair's Report

- 2.1 The Chair reported that the non-executive Board members met prior to this meeting. It was reported that the non-executives considered, amongst other issues, the ADRN issue mitigation action plan and data retention.
- 2.2 The Chair informed the Board that he and Ms Witherspoon had attended a roundtable discussion with many of the leaders of the English health and care system, to discuss how English health and care statistics could be enhanced to better serve the public good and how the statistics might be improved, in order to support better decision making.

### 3. Highlight Report [ADRN(16)09]

- 3.1 Professor Smith introduced the highlight report for the period between the beginning of January and the end of March 2016.
- 3.2 The meeting heard that a large amount of training had been provided by the different parts of the Network to the research community and a number of new research projects had been proposed throughout the reporting period.
- 3.3 It was suggested that for future meetings the Highlight Report should be restructured so that the quantitative information about the number of projects and the time it was taking for projects to progress through the system was presented in the main paper with the qualitative information about engagement activities presented as an annex.
- 3.4 There was some discussion about how to measure the time it was taking for projects to progress through the system. It was agreed that the Board wanted to know how long the process was taking from the first point of contact with the Administrative Data Service. This would be used to enable the Board to understand the researchers' experience of the whole ADRN process.
- 3.5 The Secretariat was asked to liaise with the Administrative Data Service who should ensure that this guidance was followed in future Highlight reports.
- 3.6 News that the ONS and the Department for Business Innovation and Skills have approved the security arrangements at the ADRC-England/University of Southampton Secure Environment was welcomed by the Board. It was suggested that it would be useful if each department could share with the ADRCs the criteria which secure environments were expected to meet to be able to hold deidentified data from a particular department. Mr Goodwin offered to put the ADRCs in contact with appropriate staff in ONS to share ONS' criteria.

### 4. Report from the Approvals Panel [ADRN(16)10]

- 4.1 Dr Garrett presented an update from the Approvals Panel. He reported that the Panel had further considered the feedback gathered in the self-assessment process to date. The Board were informed that the self-assessment was ongoing as the Panel had requested that clearer information be produced to describe the timescales of Panel decisions, and the timescales that apply to wider Network operations.
- 4.2 Dr Garrett informed the Board that the Approvals Panel were contributing to guidance for researchers on the methodology description that they provide for their project application. Dr Garrett suggested that this guidance should reduce the amount of documentation received by the Approvals Panel and that there was scope to reduce this further.
- 4.3 It was noted that there was still one vacancy on the Approvals Panel. It was suggested that the Approvals Panel may wish to appoint a representative from a Departmental data custodian to involve them in the ADRN and build up some trust and connections.

### 5. National Statistician's Data Ethics Advisory Committee [ADRN(16)11]

5.1 Mr Bumpstead, the Deputy Chair of the National Statistician's Data Ethics Advisory Committee (NSDEC), presented an overview of NSDEC. Mr Bumpstead reported that NSDEC had been established to advise the National Statistician that the access, use and sharing of public data, for research and statistical purposes, was ethical and for the public good. The Board heard that NSDEC contained independent members and was guided by a set of ethical principles.

- 5.2 Mr Bumpstead reported that NSDEC had met three times and had deliberated on a number of projects.
- 5.3 The Board were informed that NSDEC is scheduled to meet four times a year and that the NSDEC Secretariat was working with colleagues across the Government Statistical Service and the Devolved Administrations to raise awareness of the Committee, and outline how it could benefit relevant parties.
- 5.4 The Board heard that NSDEC had agreed to include ADRN projects from government and third sector researchers within its remit and that NSDEC's advice on ADRN project proposals would be directed to the ADRN Approvals Panel. The Board agreed with the proposal that appeals against NSDEC's advice on prospective ADRN projects would be directed to the ADRN Appeals Panel. It was agreed that appeals would only be considered by the ADRN Appeals Panel if an applicant had reason to believe that due process had not been followed.

#### 6. A view from the ADRC-Wales

- 6.1 Professor Ford, Principal Investigator at the ADRC-Wales, presented on progress at the ADRC-Wales. The Board were informed that many of the research projects being undertaken at the ADRC-Wales had a high degree of support from officials in the Welsh Government. Professor Ford also reported on the challenges facing the Network. He expressed the opinion that the biggest single risk to the ADRN was the lack of progress in getting access to UK wide administrative data and that the ADRN had received no firm commitment from Government departments about supplying data to the Network.
- 6.2 The Board heard that experience in Wales and Northern Ireland suggested that Government Officials respond better to requests for data from colleagues they had preexisting relationships with and who were familiar with the work. One factor in the ADRC-Northern Ireland's relative success in acquiring access to data was the fact that senior civil servants from the Northern Ireland Statistics and Research Agency (NISRA) were responsible for negotiating access to data. The relatively close working relationship between different Government departments in Northern Ireland helped to make this work. The degree to which this could be replicated in the UK was discussed. It was suggested that this would be more difficult in the UK as UK Government departments tended to be less focused on cross departmental activities than was the case in the Devolved Administrations.

### 7. Data Owner Engagement Update [ADRN(16)12]

- 7.1 Professor Smith reported a wide range of on-going data owner engagement. The Board thanked the Administrative Data Service, for responding to comments on previous Data Owner Engagement papers.
- 7.2 It was reported that there was a further update on the information provided in the Department for Work and Pensions (DWP) section of the paper. Mr Tarry was asked to work with the Secretariat to update the paper with the appropriate information.
- 7.3 The Board heard that recent meetings with senior executives from the DWP and the Department for Education placed into question the extent to which there was high level support for sharing data collected for operational purposes with the ADRN. The Board were informed that action is being taken to clarify the level of commitment.
- 7.4 It was reported that in Northern Ireland, the functions of DWP are carried out by the Department for Social Development and it has ownership of any information recorded. DSD has agreed to share data with the ADRC-Northern Ireland. The ADRC-Northern

Ireland plan to link benefits data to Census data. This may lead researchers to ask why this cannot be done elsewhere in the UK.

#### 8. ADRN issue mitigation action plan [ADRN(16)13]

- 8.1 Ms Witherspoon presented the ADRN issue mitigation action plan which sets out the mitigation planned and already in place to address the core issues of access to data and demand.
- 8.2 It was recognised that the actions focused on data owners needed to be taken forward with pace. It was agreed that the Chair would approach the Cabinet Office to discuss the issues the Network was facing in getting access to UK wide data. It was also agreed that the Secretariat would organise for the ADRN to be discussed at a future Data Leaders Network meeting. It was suggested that this would be an opportunity to reinforce the potential benefits of sharing data with the ADRN and discuss the issues the Network was experiencing in trying to access UK wide data. Potential routes of escalation for the future were also considered.
- 8.3 It was reported that there was a danger that the research community would become disillusioned with the Network because of the relative lack of data in the ADRN. Therefore, the actions focused on researcher demand were designed to maintain interest in the ADRN within the research community.
- 8.4 It was suggested that the actions to explore the potential of private sector access to the ADRN should be more nuanced and include specific actions to enable the private sector to access the ADRN to carry out work for the public sector.
- 8.5 The Board approved the mitigation action plan subject to the suggested amendments being made and asked the Directors Group to further develop details of the plan and implement.

## 9. Data Retention [ADRN(16)14]

- 9.1 Professor Smith presented a paper on data retention issues.
- 9.2 The Board had a detailed discussion about data retention and the following points were made in the discussion:
  - i. In most other countries, similar infrastructures to the ADRN retained data.
  - ii. It was recognised that retaining linked data was a development of the data linkage method recommended in the Administrative Data Taskforce Report
  - iii. Given the issues the Network is currently facing in getting access to data, it is important that any change in the data retention policy helps the ADRN to access data in a more timely fashion.
  - iv. Any change in the data retention policy should be presented to Government Departments as a development that will help them to provide data to the ADRN. It was reported that data custodians would still need the final say on whether or not their data was used in a particular research project.
  - v. The scientific benefits of retaining data were recognised as researchers could challenge and build upon earlier research results by interrogating the data which was analysed to produce earlier results.
  - vi. It was suggested that retained data would need to be reviewed periodically to decide whether or not it should still be retained.
  - vii. The data security implications of any change in the data retention policy would be fully considered.
  - viii. Public attitudes towards retaining data should be further considered.

- ix. A step by step approach to this change in policy could be adopted. A pilot research proposal to explore the methodology of linking and retaining specific data sets across the UK could be put forward for consideration by the Approvals Panel.
- 9.3 The Board was supportive of the general principle of moving in the direction of changing the data retention policy to allow the Network to retain deidentified linked data and suggested that a pilot proposal to explore the methodology of linking and retaining specific data sets across the UK should be put forward to the Approvals Panel. The Board agreed that further work needed to be done before any change to the retention policy could be further considered. In particular, it was suggested that the implications of any change in retention policy for public attitudes, data security and the willingness of Government departments to share data with the ADRN needed to be fully explored. The Directors Group was asked to take this work forward and bring this to a future Board meeting for further discussion.

#### 10. Legislative Issues [ADRN(16)15]

- 10.1 Ms Witherspoon presented a paper on domestic and EU legislative issues. The Board heard that the Cabinet Office consultation on the data sharing proposals was due to close on 22 April. This will be followed by a formal Government response and the preparation of appropriate amendments to the proposals. It was reported that the ADRN Directors Group planned to make a response.
- 10.2 It was suggested that it was important that the wording of the UK derogations for the new General Data Protection Regulation were fit for purpose and that the analytical/research community was involved in those developments.

#### 11. Any other business

11.1 The possibility of holding a future Board meeting at one of the ADRCs was discussed. The ADRC-England and the ADRC-Wales offered to host a future Board meeting.

#### Agenda

# UK STATISTICS AUTHORITY ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

# Agenda

# Monday, 11 April 2016 Board Room, One Drummond Gate, London 11:00am – 3:00pm (coffee from 10:30am)

### Chair: Professor David Hand Apologies: Professor Denise Lievesley, Ms Penny Young 10:30 to 11:00 – Non-executive session

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

1	Minutes and matters arising from previous meeting	Professor David Hand
11:00am		
2	Chair's report	Oral Report
11:10am		Professor David Hand
3	Highlight report	ADRN(16)09
11:20am		Professor Peter Smith
4	Report from the Approvals Panel	ADRN(16)10
11:40am		Dr Andrew Garrett
5	National Statistician's Data Ethics Advisory Committee	ADRN(16)11
12.00pm		Mr Robert Bumpstead
6	A view from ADRC-Wales	Oral Report
12:15pm		Professor David Ford

# Lunch (12:45pm to 1:15pm)

# Part B (1:15pm to 3:00pm)

	Part B (1:15pm to 5:00pm)	
7	Data owner engagement update	ADRN(16)12
1:15pm		Professor Peter Smith
8	ADRN issue mitigation action plan	ADRN(16)13
1.45pm		Ms Sharon Witherspoon
9	Data retention	ADRN(16)14
2.15pm		Professor Peter Smith
10	Legislative issues	ADRN(16)15
2.45pm		Ms Sharon Witherspoon
11	Any other business	
2:55pm		

## Next Meeting: Tuesday 12 July 2016, Drummond Gate, London

## ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

Minute

Monday, 1 February 2016 Boardroom, Drummond Gate, London

#### Present Board Members

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

### **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 minute from the previous meeting held on 1 February 2016 was agreed by correspondence and is published on the <u>UK Statistics Authority Website</u>.

# Chair's Report Professor David Hand

# ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)09

## Highlight Report

## Purpose

1. This paper presents an Administrative Data Research Network (ADRN) highlight report for the period between the 1 January 2016 and the 20 March 2016.

#### 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, UK Statistics Authority, 29 March 2016

#### List of Annexes

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

			Reporting period: Start date: 01 January 2016 End date: 20 March 2015
Overview of progress since the last	report:		
with colleagues from the Secure Anony People Programme using linked adminis study which looked at whether de-ident	mised Information Linkage Databa strative data has been given the g tified linked administrative data co	ank (SAIL) and the Farr institute. F o ahead by the Welsh Governmen ould be used to demonstrate the i	n Government project, also involved collaboration Following this, a study to evaluate the Supporting nt. The announcement follows an initial feasibilit impact of the Welsh Government's Supporting : findings could result from such a study.
The final report for the ADRC-Northern Education' has been submitted to the D		(DEL) led project 'Factors associat	ted with decreased representation in Higher
A new infographic has gone live on the process/application-process/	website showing the journey a res	searcher makes when using the Al	DRN <u>http://www.adrn.ac.uk/application-</u>
ADS have developed a video case study positive results the index of multiple de https://www.youtube.com/watch?v=82	privation has had. 'Jaywick: how	•	JK's most deprived area to make a video about th ives' can be found here
University of Aberdeen hosted a major participants participated in this historic		•	ONF) cohort hosted on 20 January 2016. 300 events/newsitem?newsid=4496.
All Centres have progressed their securi	ty accreditations and all have held	d researcher training sessions to e	ensure safe researchers.
The Moldovan National Bureau of Statis impressed by the facilities and presenta			nd the Secure Lab on 19 Jan 2016 and were
List of current projects			

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 the table below for projects and stages. An overview of the projects and progress is in the summary below the table.

projectid	Title	AP Status
PROJ-		09. Researchers
0001	Combining Survey Data, Paradata and Administrative Data for Nonresponse Investigation	conducting analysis
PROJ-		09. Researchers
0002	Peace Walls in Northern Ireland: developing baseline indicators	conducting analysis
PROJ-	Developing an Analytical Approach for Assessing the Effectiveness of the Flying Start Programme:	08. Data with secure env
0003	Analysis of the Health and Education Impacts of Flying Start.	(ADRC)
		06a. Data supply:
PROJ-	Assessing the health impacts of adults' participation in sports in Wales: investigating the mediating	Negotiating with Data
0004	role of accessibility to sports facilities.	Owners
PROJ-		01. Developing
0005	The Feasibility of Creating an Individual Deprivation Score using Linked Data	Application
PROJ-		
0006	Factors associated with decreased representation in higher education	10. Analysis complete
PROJ-	Sociodemographic characteristics, educational attainment and self-reported health status of farmers	08. Data with secure env
0007	in Northern Ireland	(ADRC)
		06a. Data supply:
PROJ-	Using Data Linkage to obtain accurate population estimates of migrants in Northern Ireland and their	Negotiating with Data
0008	needs for and use of mental health and social care	Owners
		06a. Data supply:
PROJ-	Patterns of error in survey based estimates of consumption and their implications for energy	Negotiating with Data
0009	consumption.	Owners
PROJ-		01. Developing
0010	An Exploratory Analysis of Parental and Child Limiting Long-term Illnesses in Northern Ireland	Application
PROJ-	An Exploratory Analysis of the Socio-demographic Characteristics of Married versus Unmarried	01. Developing
0011	Mothers	Application

PROJ-	Medication use in pregnancy and its risks/consequences in terms of birth outcome and later child	01. Developing
0012	development outcomes	Application
PROJ-		01. Developing
0013	Naming in Contemporary NI	Application
PROJ-		
0014	The completeness and accuracy of the Electoral Register in NI	Project stopped
PROJ-	Evaluating linkage between children's health, education and social care data - pre-term birth sub-	09. Researchers
0015	study.	conducting analysis
PROJ-		09. Researchers
0016	An Investigation into the Impact of Disability on Employment in Wales	conducting analysis
		06a. Data supply:
PROJ-		Negotiating with Data
0017	The Residential Mobility of Mental Health Service Users (MHSUs).	Owners
PROJ-	Social Defeat in Northern Ireland: Assessing the Impact of Social Risk Factors on Serious Psychiatric	01. Developing
0018	Disorders Using Data Linkage	Application
PROJ-		01. Developing
0019	Link between congenital heart diseases early in life and educational outcome in NI	Application
PROJ-		04. Ethical review
0020	Insights from assessing data quality and under-coverage in administrative sources	outstanding
		06a. Data supply:
PROJ-		Negotiating with Data
0021	Understanding participation in post-compulsory education and training in Wales	Owners
PROJ-		09. Researchers
0022	Examining contributory factors in road traffic collision data involving older people in Wales	conducting analysis
		06a. Data supply:
PROJ-	Improving the experience of dementia and enhancing active life: living well with dementia - the IDEAL	Negotiating with Data
0023	study– data linkage extension	Owners
PROJ-		
0024	Refugees, Dispersal and Deprivation	Project stopped
PROJ-	SEED Better Decisions: Uncovering how patients' socioeconomic, educational and demographic	01. Developing
0025	factors impact clinical decision-making	Application
PROJ-	Understanding the determinants of educational achievement and the association with health and	06a. Data supply:

0026	well-being by age 14 in Wales	Negotiating with Data Owners
		06a. Data supply:
PROJ-		Negotiating with Data
0027	Informal care in the last days of life: a data linkage study.	Owners
PROJ-	, , , ,	
0028	Past and Current Same Sex Couples in Northern Ireland: An Exploratory Analysis	05. Approved
PROJ-	Understanding outcomes for children from Scottish Children's Reporter Association (in conjunction	01. Developing
0029	with the British Association for Adoption and Fostering)	Application
PROJ-		01. Developing
0030	Investigating the impact of a sick sibling on family health and educational outcomes	Application
		06a. Data supply:
PROJ-		Negotiating with Data
0031	An investigation of maternal mental health and filial educational attainment in Scotland	Owners
		06a. Data supply:
PROJ-		Negotiating with Data
0032	Placement stability of children in out of home care in Scotland: A sequence analysis	Owners
PROJ-		01. Developing
0033	Does priority need for homeless prison leavers reduce recidivism?	Application
		06a. Data supply:
PROJ-	Extending the opportunities for prevention of suicide: linking dispensing and employment data to the	Negotiating with Data
0034	Suicide Information Database- Wales (SID-Cymru)	Owners
PROJ-		08. Data with secure env
0035	Examining the link between family health events and pupil performance indicators in Wales.	(ADRC)
PROJ-	Me-D-Links: Metformin for diabetes in pregnancy – an analysis of health and educational outcomes	01. Developing
0036	using linked administrative data	Application
PROJ-	Feasibility study exploring the use of data linkage in the evaluation of the Supporting People	
0037	Programme	10. Analysis complete
PROJ-		
0038	Evaluating the use of contextual data in undergraduate admissions	05. Approved
PROJ-	Economic change and internal population dynamics: an innovative study of new residential mobilities	
0039	in Scotland	05. Approved

PROJ-	Methodological innovation in the spatial analysis of educational micro-data: understanding social and	
0040	spatial inequalities	Project stopped
PROJ-	A pilot ADRC-NI project linking Social Security Benefits to understand the health and social needs of	01. Developing
0041	disability benefit claimants	Application
PROJ-		
0042	Improving Migration Statistics by Combining Survey Data	Project stopped
PROJ-	Prevalence and variation in antidepressant prescribing across Northern Ireland: a longitudinal	
0043	administrative data linkage study for targeted support.	05. Approved
PROJ-		
0044	Higher Education: Access, Earnings and Employment	Project stopped
		06a. Data supply:
PROJ-		Negotiating with Data
0045	The kinds of poverty in schools and their impact on student progress	Owners
PROJ-		01. Developing
0046	Assessing the relationship between concessionary bus use and health for older people in Wales	Application
PROJ-		
0047	Leading for Growth: Top Teams and SME Performance.	Project stopped
PROJ-	Use of out-of-home care for children born with drug withdrawal syndrome: longitudinal study of	
0048	mothers and children using linked administrative data.	Project stopped
PROJ-		
0049	Assessing the impact of measures to raise attainment and take-up of STEM subjects	Project stopped
PROJ-		01. Developing
0050	Energy efficiency and household health co-benefits: building the evidence	Application
		06a. Data supply:
PROJ-		Negotiating with Data
0051	Residential mobility and diabetes	Owners
		06a. Data supply:
PROJ-		Negotiating with Data
0052	The wider impacts of benefit sanctions: educational attendance, behaviour and attainment (WP8.1)	Owners
PROJ-		
0053	Technical change, employment and inequality. A spatial analysis of households and plant data.	Project stopped
PROJ-	Examining the effect of relative housing wealth on individuals' Health and Well-Being (H&WB)	Project stopped

0054		
PROJ-	Examining risk factors for Domestic Abuse and Child Sexual Exploitation to inform future policing in	
0055	the Swansea area	Project stopped
PROJ-		
0056	Job quality, well-being and health	Project stopped
PROJ-		
0057	Understanding Educational Disadvantage among Primary School Children in England	Project stopped
PROJ-		01. Developing
0058	Investigating the role of buses in access to hospitals	Application
PROJ-		
0059	Pipeline and Return to Science and Mathematics	Project stopped
		06a. Data supply:
PROJ-	A Longitudinal Examination of Educational Attainment throughout the School Lifecourse in Aberdeen:	Negotiating with Data
0060	Inequality at the Starting Gate and Beyond	Owners
		06a. Data supply:
PROJ-		Negotiating with Data
0061	Evaluating the effects of Community Treatment Orders (CTO) in England	Owners
	Evaluating the impacts of Welsh Government funded schemes designed to improve the energy	
PROJ-	efficiency of the homes of low income households on health outcomes through the use of existing	09. Researchers
0062	data	conducting analysis
PROJ-		01. Developing
0063	The effect of unexpectedly high patient demand in midwife units on educational outcomes.	Application
PROJ-	The Economic Burden Associated with Mental III Health Among Informal Caregivers in Northern	01. Developing
0064	Ireland: an investigation of economic transitions and economic costs.	Application
PROJ-		04. Ethical review
0065	Pilot of the Healthy Ageing in Scotland (HAGIS) study	outstanding
PROJ-		01. Developing
0066	On underlying factors that reduce household energy usages	Application
PROJ-		01. Developing
0068	Effects of the 2011 Local Housing Allowance Reform on the Private Rental Market	Application
PROJ-		
0069	Linking NPD and SWC (to amend)	Project stopped

PROJ-		04. Ethical review
0070	Assessing the Welfare Effects of Jobseeker's Allowance	outstanding
PROJ-		01. Developing
0071	Non-education follow ups of Education Endowment Foundation RCTs	Application
PROJ-	Fluctuations in Community Mental Health and Social Care Services for people diagnosed with a	
0072	mental illness in England	05. Approved
PROJ-		04. Ethical review
0073	Social factors influencing glaucoma treatment persistence in the Northern Ireland population	outstanding
PROJ-		04. Ethical review
0074	Self-rated mental health or medication record? Which best predicts suicide in Northern Ireland	outstanding
PROJ-		04. Ethical review
0075	Social factors influencing uptake of free eye examinations in Northern Ireland	outstanding
PROJ-	Seeing the Whole Picture: A Holistic Analysis of the Profile of Pupils with Special Educational Needs	01. Developing
0076	(SEN) in Northern Ireland.	Application
PROJ-		
0077	Social participation and higher education: exploring variation by elite and other university education	Project stopped
PROJ-		01. Developing
0078	Schooling and Higher Education: Exploring national variation between England and Wales	Application
PROJ-		01. Developing
0079	Confusion and In-Work Benefits: Evidence from UK Welfare Reform	Application
PROJ-		01. Developing
0080	The relationship between benefit sanctions, poverty and deprivation	Application
PROJ-		04. Ethical review
0081	Key Predictors of Educational Attainment in Northern Ireland	outstanding
PROJ-		01. Developing
0082	Understanding the link between urban segregation and inequality	Application
PROJ-		01. Developing
0083	Exploration of influencing factors that inhibit a return to work	Application
PROJ-		04. Ethical review
0084	The Effects of Fiscal Stimulus Programs: The 2009 Vehicle Scrappage Scheme in the UK	outstanding
PROJ-		01. Developing
0085	Longitudinal Study of South Asian Immigrants	Application

PROJ-	Linking Individualised Learner Records (ILR) to business outcome indicators (Employer Data Service	01. Developing
0086	and Inter Departmental Business Register data)	Application
PROJ-		01. Developing
0087	Teaching Across The Divide: Teacher Demography	Application
		06a. Data supply:
PROJ-	Assessing the feasibility of using administrative data to examine risk factors for Domestic Violence	Negotiating with Data
0088	and Child Sexual Exploitation in the Swansea area	Owners
PROJ-		01. Developing
0089	Assessing the Effectiveness of European Social Fund Funded Labour Market Programmes in Wales	Application
PROJ-	Are non-educational facilities a factor in students' choice and attendance of HE institutions?	01. Developing
0090	(tentative)	Application
PROJ-	Evaluating the Quality and Utility of Administrative Records for Non-Response Bias Assessment and	01. Developing
0091	Adjustment in Population-Based Surveys	Application
PROJ-		01. Developing
0092	An investigation into the long-term homicide trends in the UK	Application
PROJ-		
0093	(Draft) An investigation into the incidence of antisocial behaviour by area.	Project stopped
PROJ-	Is exposure to airport noise associated with poor mental health in residents living close to the Belfast	01. Developing
0094	City Airport?	Application
PROJ-	Examining whether competition for college admissions is behind recent trends in parental time with	01. Developing
0095	children. (Draft title)	Application
PROJ-		01. Developing
0096	The effects of BMI feedback on childhood weight loss	Application
PROJ-	An investigation into students' decision-making in choosing academic careers for different social	01. Developing
0097	backgrounds (draft)	Application
PROJ-	Linking Annual Survey of Hours and Earnings to HMRC administrative data to analyse the impact of	01. Developing
0098	(vocational) education investment on earnings	Application
PROJ-	Learning Disability and Northern Ireland: Achieving Proportionate Universalism through	01. Developing
0099	Administrative Data Research	Application
PROJ-		01. Developing
0100	to be confirmed - Melanie Jones - ADRNHELP124	Application
PROJ-	Effects of social inequality on cancer survival	01. Developing

0101		Application
PROJ-		01. Developing
0102	Looked after children and use of unscheduled health care	Application
PROJ-		01. Developing
0103	Socioeconomic effects on travel to work	Application
PROJ-		01. Developing
0104	An evaluation of the 'Recovery through Nature' programme	Application
PROJ-		01. Developing
0105	Investigating controlled deliveries of illegal consignments	Application

To date 17 projects have 'stopped' within the ADRN.

10 of these 'projects' were logged as projects within the Network although full application forms for these projects were not completed. These 'projects' were the initial proposals that were shared with ADS as part of the Secondary Data Analysis Initiative (SDAI) application process. For the SDAI funding call ADS were required to review the eligibility of the applicants to use ADRN and issue a letter of support (the review of eligibility is ordinarily undertaken before a project number is allocated).

For future SDAI funding applicants will be required to gain Approval Panel approval prior to their application to ESRC for funding. Therefore it is possible that, periodically, a number of projects will move from the 'Approved' status to the 'Project stopped' status – as applicants become aware they have not obtained SDAI funding.

Two projects were rejected by the ADRN Approval Panel. One project could not be progressed as the primary dataset requested (microdata for a Home Office survey) no longer exists.



	Leading application development				Grand Total	
Stage	ADRC-England	ADRC-Northern Ireland	ADRC- Scotland	ADRC-Wales	ADS	
Developing Application	0	12	12	7	16	47
Ethical review outstanding	0	5	1	0	2	8
Approved	0	2	1	0	2	5
Data supply: Negotiating with data owners	0	1	5	5	6	17
Data with secure environment (ADRC)	0	1	0	2	0	3
Researchers conducting analysis	2	1	0	3	0	6
Analysis complete	0	1	0	1	0	2
Project stopped	0	1	0	3	13	17
Grand Total	2	24	19	21	39	105

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:

ADRC-Scotland publication of literature review into public perceptions of data, data linkage and data linkage research.

ADRC-Scotland are planning to host in Edinburgh the Director of Strategic Information Division with the Department of Human Services of the Australian Government in summer/autumn 2016 undertaking fieldwork research for the development of an Administrative Data Research Centre in Australia.

The Directors are preparing a response to the consultation on data sharing legislation. <u>https://www.gov.uk/government/consultations/better-use-of-data-in-government</u>. Melanie Wright has prepared a video interview explaining the consultation <u>https://www.youtube.com/watch?v=ltW3aAL5t5c</u>

The second edition of the stakeholder newsletter, *Network*, will be published in April.

## Risks (new):

The Network risk-management strategy is currently under review. A process to identify issues and forward to the issue owner is under development. This process will include recommendations on the options available to the issue owner. Data owner participation remains as an issue for the Network.

A new risk is being added to reflect increased public interest arising from the data sharing legislation consultation.

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

# Workstream Progress Reports and Outlook:

Workstream:	Infrastructure and Network coherence <sup>1</sup>	
Main achievements		
Data owner engag	ement continues, and is the subject of a more in depth report to the Governing Board.	
The Directors met	on 11 January, 19 February and 9 March 2016. Their discussions included: data owner engagement, and options for data retention to	

<sup>&</sup>lt;sup>1</sup> 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.

feed into the paper coming before the Board. The Directors Group have convened a task team to look at what impact may mean for the Network. They have also convened a Public Engagement standing sub-committee to provide advice on the overall public engagement strategy for the Network, and to establish a citizen's panel to capture the public's voice.

The Operations Group met on 28 January and 25 February. They have concentrated on establishing standing sub-committees and task teams to carry out the cross Network activities, looking at the performance of the Network at an operational level and looking forward to the mid-term review.

ADRC-England continue managing the organisation of the ADRN Research Conference on 2-3 June 2016; over 70 colleagues within the Network are booked on the conference; bookings for external attendees opened from 1 Feb 2016 and targeted invitations were also sent out to the individuals in mid Feb; 12 abstracts have been submitted to ADS to present at the conference.

All Centres have the capability to deliver safe researcher training to enable researchers to access the Network. ADRC-England has organised and facilitated Safe Users of Research data Environments 'SURE' (formerly Accreditation) training at Farr Institute in London on 23 Feb; and ADRN SURE training will be run at ADRC-Scotland. At ADRC-Northern Ireland 53 people have undergone accreditation training to date.

In Wales, both the Cardiff and Swansea sites are progressing towards Pan Government Accreditation. The ADRC also operates within an ISO27001 compliant environment. ADRC-Scotland has also progressed its security arrangements. Following the October 2014 move by core staff in Edinburgh into dedicated new facilities, a year of effort to change provider of secure server storage resulted in certification by Evolve (approved by CESG in the first tranche of its Certified Cyber Security Consultancy (CCSC) scheme) who were "pleased to be able to confirm our view, that the National Safe Haven environment [the ADRC-Scotland's data storage, transfer and processing infrastructure] operates with a security profile consistent with what would be expected of a system processing 'OFFICIAL-SENSITIVE' data. There are some areas of operation where security is of a 'very high' standard indeed and in our view is in excess of what would normally be expected for an 'OFFICIAL-SENSITIVE' environment. Most noteworthy of these are the security arrangements at the Advanced Computing Facility and the Researcher Data Entry Booths at BioQuarter No9".

In ADRC-England in January, ONS signed off and issued the 'Safe Settings Assurance Certification' to ADRC-England/University of Southampton Secure Lab and confirmed that the appropriate technical /procedural measures are in place for de-identified ONS data to be held at the ADRC-England/University of Southampton Safe Settings Environment. ONS will assess the ADRC-England/Bloomsbury Secure Lab documentation and arrange a physical assessment of the Lab. BIS representatives have visited the ADRC-England/University of Southampton infrastructure facilities for assurance purposes and have similarly approved the security arrangements.

Formal legal approval was reached by the Scottish Government to link the Scottish Census with other datasets and make this available through the ADRN. This is a major milestone that will permit rapid progress in some high-profile ADRN projects in Scotland that have been approved but unable to progress pending this milestone.

A workshop to anticipate the potential benefits to arise from combining health with administrative data informatics from the co-located efforts of the ADRC-Scotland and the Farr@Scotland was held at the ADRC-Scotland in February. This was hosted by the Principal of the University of Dundee and the Vice Principal of the University of Edinburgh and was attended by senior stakeholders from across Scotland, the Economic and Social Research Council and the Medical Research Council. ADRC-Scotland team members presented at the event and the event was sub-branded as the joint organisations' formal launch. www.adrn.ac.uk/news-events/newsitem?newsid=4497

Additional funding for ESRC associated studentships to commence in October 2016 was secured:

- Professor S Kaye, University of Oxford, Reasonable expectations of use and governance of data for research: What are citizen's expectations and are these reflected in the law in the UK?
- Professor S Kaye, University of Oxford, Analysing the Impact of the new EU Data Protection Regulations on UK Public Bodies Powers to Share Data.
- Professor Mark Elliot, University of Manchester, Synthetic Record Linkage of Administrative Datasets

The associated funded projects between ESRC, ADRC-Wales and Welsh Government on 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. ADRC-Wales was very pleased to have been awarded two ESRC PhD studentships for its Co-Principle Investigators and awaits information on a third.

#### **Training courses**

ADRC-England organised two short courses: "Introduction to Data Linkage" in London on 10 March (fully booked with a long waiting list which has meant that the course will be repeated in Sept/Oct 2015) and "Developing synthetic data for administrative data sources" in Southampton on 21-22 March. Three podcasts of short courses have been successfully produced on the topics: Introduction to data linkage, Introduction to Hospital Episode Statistics and Introduction to Data Visualisation and will be available online shortly.

ADRC-Scotland / the Farr @Scotland hosted a one-day masterclass with Andy Williams (Health and Social Care Information Centre CEO) on 19 January. On 10 March 2016 Jennifer Dixon (Health Foundation CEO) gave the inaugural Innovative Healthcare Delivery Programme (IHDP) guest lecture twitter.com/adrc\_scotland/status/707963594491740160/photo/1?ref\_src=twsrc%5Etfw.

A one day training workshop, "Generating synthetic data in R" – was held at ADRC-Scotland in March. This computer-based training workshop provided a crash course in the R software package, synthpop eventbrite.com/e/generating-synthetic-data-in-r-one-day-workshop-registration-22169058250. Outlook for next reporting period

#### Governance structure

The Directors are preparing a response to the consultation on data sharing legislation. <u>https://www.gov.uk/government/consultations/better-use-of-data-in-government</u>.

The ADRN Directors Group and Operations Group have agreed to collect data across the next work on several key steps of progress within the project journey. This will allow the 'time taken' for various steps of the project journey to be better understood and for any areas where improvement is needed to be better understood and identified. The key points to be measured will be:

- 1 Date of first consideration of a project by the ADRN Approval Panel
- 2- Date of final decision by the ADRN Approval Panel (including those which are 'approved subject to completion of Ethical Review ')
- 3 Date of confirmation of Ethical Review by Panel (if outstanding)
- 4 Date of data being provided by data owners to the Trusted Third Party for linking
- 5- Date of data being made available to the researcher in the ADRC

This will allow for a better understanding of the timescales within which ADRN Approval Panel decisions are made, the timescales of ethical review processes required for ADRN projects, the timescales of negotiating access to data with data owners and the timescale of preparing data for use by researchers in the ADRN safe settings.

ADS have recently implemented a shared, network-wide, database to facilitate project applications and capture the required data to measure the progress, as outlined above, data collection is underway and it is anticipated data on timescales will be available for the next Board meeting.

#### Infrastructure

ADRC-Scotland will follow up, in collaboration with the Urban Big Data Centre (UBDC), the potential for the Scottish Government to use predictive analytics techniques that were initially explored in the joint workshop in Edinburgh in November 2015 adrn.ac.uk/news-events/newsitem?newsid=4292. This is one of several areas of strengthening collaboration between ADRC-Scotland and the UBDC.

## Training courses

ADRC-England has scheduled the following short courses: Introduction to Hospital Episode Statistics (HES), London, 11-12 April; Introduction to the National Pupil Database, London, 4-5 May; Introduction to Data Visualisation, London, 16-17 May; Data Linkage: From Theory to Practice, Southampton, 23-25 May;

16 of 20

ADRC-Scotland is collaborating with University of Stirling's Economics Department to run a "Using Administrative Data for Economic Research" workshop on 12.5.16 and will run its workshop "Re-introduction to Statistical Concepts & Tests for Administrative Data Research" on 16.5.16 in Edinburgh adrn.ac.uk/news-events/upcoming-courses/eventitem?eventid=4453. The ADRC-Scotland will work with the Applied Quantitative Methods Network (AQMeN) and with ADRC-England to run courses on "Stata Programming for Social Surveys & Administrative Data Analysis"

Workstream:	ADRN principles and policies <sup>2</sup>
Main achieveme	nts
The ADRN projec	t Approvals Panel has held two virtual meetings and met face to face in January. The Panel has undertaken a self-assessment exercise,
	fficiency and areas to strengthen. The Panel has made a suggestion that a task team is set up to look at the methodologies of projects.
•	e a separate update from the Approvals Panel.
Outlook for nex	t reporting period
The Approvals Pa	nel will continue to meet once a month to assess project proposals. The task team will be set up to look at the methodologies of projects

Tab 3.1 Highlight report / Annex A

Workstream :	Standards and performance <sup>3</sup>
	please include metrics/indicators, where possible.
Main achievement	· · · · · · · · · · · · · · · · · · ·

Following changes in the internal management structure, information on performance will be collected and reported in a quarterly performance dashboard. This will include the following: logged projects with ADS compared with Approved projects, time between approval and data with the Trusted Third Party set out by project; number of data supplier data sets accessed, number of completed projects and percentage of research summaries available to the

<sup>&</sup>lt;sup>2</sup> 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.

<sup>&</sup>lt;sup>3</sup> Board responsibility (from ToR): iii) Provide oversight of standards and performance of the Network, including reviewing the progress, usage, quality and performance of the infrastructure, the strategic risks to meeting the Network's objectives and the actions to mitigate to these risks.

Workstream:	Public Engagement and Communications <sup>4</sup>
Main achieveme	ents:
A new infograph process/applicat	ic has gone live on the website showing the journey a researcher makes when using the ADRN <u>http://www.adrn.ac.uk/application-</u> ion-process/
	vere visited by First Minister Nicola Sturgeon and her Scottish Government Council of Economic Advisors who held their bi-annual meeting ioquarter on 5 March. <u>adrn.ac.uk/news-events/newsitem?newsid=4464</u>
	e to Trazar Astley-Reid (Communications and Public Engagement Manager) and have welcomed Gemma Hakins (previously at the ESRC's Network Business and Local Government Data Centre) into the role.
topic of 'the Dat	Ireland: formal presentation and Committee discussion was held at the Northern Ireland Privacy Advisory Committee in January on the a Protection Act, Research exemption and linkage of survey and administrate data'. A formal response to the consideration of data linkage using Health and Social Care data was obtained.
organisations to Keith Dugmore N	C-England and the Consumer Data Research Centre (CDRC) communications lead arranged a successful meeting of researchers from both share best practice, contacts and methodologies which was held at CDRC in London on 8 March; Emma White gave a welcome talk and MBE was invited to speak about building positive relationships, creating opportunities for research and networking, alongside his the big data initiative and the challenges that it has been created to address.
-	d Ilse Verwulgen represented the Administrative Data Research Network at the ESRC's Secondary Data Analysis Initiative Showcase, an policy makers, academics and data owners.
	participated in the multinational "Digging into Data Challenge" Conference showcase event, held at the Glasgow School of Art on 27 ught together data projects led by researchers from across the fields of the arts, humanities and social sciences. adrn.ac.uk/news- n?newsid=4451
Staff from the Al	DRC-England have attended many events over the reporting period. Peter Smith was invited to talk about Admin Data at the Kings College

<sup>&</sup>lt;sup>4</sup> Board responsibility (from ToR) iv) Provide oversight of the Network's public engagement and communications strategy.

London (KCL) Maths postgraduate students away day in Cumberland Lodge on 19-20 Feb. Emma White was invited to contribute to: Anonymisation Standard Workshop in Leeds on 29 January, and has given talks at the UK Administrative Data Research Network Seminar in Trinity College Dublin on 2 Feb and the University of Southampton International Women's Day Event on 15 March. Ruth Gilbert was invited to speak about the ADRC-England at the UCL Festival for Digital Health on 1 Mar. Roma Chappell of ADRC-England/ONS attended the BIS Data Labs Workshop on the 8 Feb and promoted the ADRN as part of her presentation. ADRC-England had an exhibition stand at the Big Data event in Southampton St Mary's Stadium on 19 March.

The ADRC-Scotland core team held a Public Involvement training course on 20.1.16. Over 20 participants attended, including from outside ADRC-Scotland and from other ADRCs. adrn.ac.uk/news-events/upcoming-courses/eventitem?eventid=4386

ADRC-Northern Ireland held a one day researchers meeting on January 28. This event was attended by core ADRC-Northern Ireland staff, co investigators from Ulster University and Queen's University, researchers from ADRN projects both approved and in development, representatives of Health and Social Care Research and Development Office and post doctoral students. The day consisted of presentations and discussions on current and proposed projects, data acquisition, funding opportunities, doctoral training initiatives and ethics and legality of data linkage and secondary analysis. As a follow up action the ADRC-Northern Ireland Project Manager has met with investigators from both Universities to discuss opportunities and interest in ADRC-Northern Ireland research and what resources are needed, from the Centre or otherwise to bring these to fruition.

ADRC-Northern Ireland presented at a Public Health Research Event jointly hosted by the Northern Ireland Council for Voluntary Action and Northern Irish Public Health Research Network in February. Attendees included representatives from a number of organisations interested in Public health research, from both academic and community sectors. The presentation was well received and there was a lot of interest in the potential for collaboration with ADRC-Northern Ireland. Tab 3.1 Highlight report / Annex A

The ADRC-Northern Ireland participated in the imagine Belfast festival which is a Civic Conversation called 'Big Data, Big Potential': This event was a round table discussion and debate on the issue research driving administrative data and the potential that this has to impact positively on society in Northern Ireland. The event started with an overview of ADRC-Northern Ireland by Dermot O'Reilly, and introductions by all of the participants. The participants consisted of ADRC staff, representatives from the public and from academia. 19 participants presented and 56 participated via the live stream online. https://imaginebelfast.com/events/better-knowledge-better-society/

ADRC-Northern Ireland has been actively working on building our social media profile through engagement with stakeholders on our twitter account. We are currently sitting at 662 followers, an increase of over 450 since January. We have also enabled live streaming of events by linking a periscope account to our twitter handle.

ADRC-Wales has been actively disseminating their brochure and multi-audience leaflets alongside bi-lingual website materials. They are developing video testimonials for the website.

#### Outlook for next reporting period:

The second edition of the stakeholder newsletter, *Network*, will be published in April.

A video interview to show how ADRC-England/ONS are working collaboratively to benefit society (Lisa Then to interview Emma White and Lucy Vickers) is being arranged on 27 April which will be available on both organisations' web sites and twitter.

ADRC-Scotland are hosting the Natural Environment Research Council "Improving health with environmental data call" Announcement of Opportunity event on 10 May (nerc.ac.uk/innovation/activities/environmentaldata/health-call/ao/) which aims to identify and fill knowledge gaps about the scope and potential utilisation of environmental data in support of improved health outcomes in the UK. This call will focus specifically on research utilisation of environmental data collected on air pollution and/or environmental hazards together with health and biomedical data.

In Northern Ireland, the 15 of June has been confirmed for the launch event for the Access Research Knowledge (ARK) data module on public attitudes to data sharing, part of the Northern Ireland Life and Times Survey.

#### Other comments:

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

The Director of ADRC-Northern Ireland, Dr Dermot O'Reilly has been invited to represent ADRC-Northern Ireland at the launch of the Republic of Ireland Health Research Board administrative data linkage strategy.
## **UK STATISTICS AUTHORITY**

## ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)10

## 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 Approval Panel has met twice, with meetings on the 9th February and 7th March 2016.
- 7. The Panel has further considered the feedback gathered in the self-assessment process to date, and the self-assessment is ongoing. The stakeholder feedback was varied, with both positive and negative feedback from researchers who had used the service, and a variety of perspectives from members themselves regarding the functioning and perception of the Panel. The broad issues that have been identified are:
  - i. perceived delays in the system (which requires clear data to establish whether this is factually correct, or a perception issue);
  - ii. duplication (making sure the Panel processes pays cognisance to other processes that overlap with Panel decision making); and
  - iii. communication (the Panel were surprised by feedback that 'any question raised was viewed as a rejection' by applicants, and consider this to be an issue which was attributable to the way the Panel role was communicated to applicants).
- 8. In order to address some of the issues raised the Panel has:
  - adopted an amended way of capturing its decision when considering each project (to more clearly demonstrate how the decision relates to the criteria against which the Panel judge projects); and
  - initiated the production of specific guidance to clearly demonstrate to applicants what level of information on methodology should be included within project applications. It is anticipated that this guidance will reduce the number of instances where Panel members have to request further information before they can make a final decision.
- 9. The Panel has also requested clearer information be produced to describe the timescales of Panel decisions, and the timescales that apply to wider Network operations (e.g. the time taken to negotiate access to data).

#### Update of any changes to Panel membership

10. There have been no changes to Panel membership. Work is ongoing to recruit one member to fill the remaining vacant position on the Panel (to bring a data owner/government data analyst perspective).

#### Update on any changes to operating procedures

- 11. Since the last Board meeting the Approval Panel has not made any substantive changes to its Operating Procedures, although administrative changes have been made to the recording of Panel decisions to enable clearer communication of the Panel decision.
- 12. The ADRN Directors are supportive of the proposal to produce guidance on methodology description within project applications, and have nominated Dr Chris Dibben (Director of the ADRC Scotland) to contribute to the production of this guidance.
- 13. The Administrative Data Service (ADS) are continuing to pursue feedback on the usefulness and usability of the ethics guidance note that was produced in Summer 2015, with the intention of revising the guidance once sufficient feedback has been received.

#### Calendar of future Panel meeting dates

14. Approval Panel meeting dates for 2016 are:

i. 26 April (face-to-face in Southampton);

- ii. 16th May;
- iii. 20th June;
- iv. 18th July;
- v. 25th August;
- vi. 14th September (face-to-face in Edinburgh);
- vii. 11th October;
- viii. 14th November; and
- ix. 12th December.

15. Titles of projects approved since previous Board meeting:

- i. PROJ-039: Economic change and internal population dynamics: an innovative study of new residential mobilities in Scotland;
- ii. PROJ-028: Past and Current Same Sex Couples in Northern Ireland: An Exploratory Analysis;
- iii. PROJ-038: Evaluating the use of contextual data in undergraduate admissions;
- iv. PROJ-088: Assessing the feasibility of using administrative data to examine risk factors for Domestic Violence and Child Sexual Exploitation in the Swansea area; and
- v. PROJ-072: Fluctuations in Community Mental Health and Social Care Services for people diagnosed with a mental illness in England.
- 16. 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.
- 17. ADS is continuing to work with 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.

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

- 18. The Panel has not rejected any projects since the last Board meeting.
- 19. There have been no appeals of Approval Panel decisions.

John Sanderson, Approvals Panel Secretariat, Administrative Data Service, 29 March 2016.

## **UK STATISTICS AUTHORITY**

## ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)11

## National Statistician's Data Ethics Advisory Committee: Arrangements for ADRN Projects

#### Purpose

 This paper provides an overview of progress made in establishing the National Statisticians Data Ethics Advisory Committee (NSDEC) and details accommodations made for the assessment of ADRN projects within the National Statistician's Data Ethics Advisory Committee (NSDEC).

#### Recommendations

- 2. Members of the Board are invited to:
  - i. note progress made in establishing NSDEC;
  - ii. consider current provisions for the assessment of ADRN projects within NSDEC; and
  - iii. agree the mechanism proposed by which ADRN researchers may appeal against NSDEC decisions.

#### Background

- 3. The UK Statistics Authority Board agreed to the establishment of NSDEC at its meeting on 6 November 2014. The Board agreed that a data ethics committee should be established which would be advisory to the National Statistician, contain independent members and be guided by a set of principles.
- 4. NSDEC has now been established and met three times. Membership (Annex A) includes a representative of the National Statistician as Chair, four members from government, and six independent members. Membership will be reviewed on an annual basis.
- 5. At present NSDEC is scheduled to meet four times a year, although the number of meetings and the structure of the Committee may change depending on demand.
- 6. The overarching aim of NSDEC is to advise the National Statistician that the access, use, and sharing of public data for statistical and research purposes is ethical and for the public good.
- 7. Since establishment the Committee has developed a set of ethical principles (Annex B), agreed a terms of reference (Annex C), developed operational policies and processes and approved an application form and guidance for those wishing to apply to NSDEC for advice.
- 8. NSDEC also has its own web presence within the <u>UK Statistics Authority's website</u>, where the public and prospective applicants can view previous minutes, agendas and papers and download an application form to apply for formal advice.

- 9. NSDEC has a UK-wide remit. Whilst projects received thus far have originated predominantly from the Office for National Statistics, the Secretariat is working with colleagues across the Government Statistical Service, Devolved Administrations and the ADRN to raise awareness of the Committee, and outline how it could benefit relevant parties.
- 10. To date NSDEC has deliberated on a number of projects. This has included a collaborative project between ONS and University College London, assessing the quality of, and further developing, a tool which estimates ethnicities from names. The proposal would make use of Census data to understand the tool's quality and to further develop it to improve its quality.
- 11. Whilst NSDEC saw the benefits of such a tool, they suggested revisions be made to the application to further clarify ownership of intellectual property rights and the ongoing use of the tool following development. ONS are now considering how to administer the tool to ensure that it is only accessed and used by those whose work demonstrates clear public benefit.
- 12. Other projects deliberated on by the committee include the use of geo-located twitter data in the production of population estimates and the appropriateness of using births and deaths registration data as a sampling frame for contentious surveys, such as the National Survey of Bereaved people.

#### Discussion

- 13. At the invitation of the Chair of the ADRN Board, NSDEC agreed to include ADRN projects from government and third sector researchers within its remit. As the ADRN is not within the remit of the National Statistician's functions, NSDEC's advice on ADRN project proposals will be directed to the ADRN Approvals Panel.
- 14. There are four possible outcomes from an NSDEC ethical review. These include advising the approvals panel to:
  - i. approve the research and allow it to proceed;
  - ii. approve the research subject to minor revisions. Here the NSDEC secretariat works with applicants to ensure that recommendations have been implemented;
  - iii. advise major revisions. This requires applicants to reconsider and amend their application in light of comments and resubmit to NSDEC; and
  - iv. advise that the research is blocked and stopped from proceeding.
- 15. NSDEC has suggested appeals against its advice on ADRN projects could be directed to the ADRN Appeals Panel. It has been suggested that Appeals would be relevant if an applicant has reason to believe due process has not been followed.

#### Adil Deedat, ADRN and NSDEC Secretariat, Central Policy Secretariat, 12 March 2016

#### Annex A NSDEC Membership

#### Annex B NSDEC Ethical Principles

## Annex C NSDEC Terms of Reference

#### Annex A- NSDEC membership

Ian Cope (Chair) – Director of Census, Office for National Statistics

Robert Bumpstead (Deputy Chair) - Chief of Staff, UK Statistics Authority

Mr Neil McIvor – Deputy Director of Statistical Services Division and Deputy Head of Profession, Department for Work and Pensions

Mr Osama Rahman – Director of Analytical Services and Chief Economist, Ministry of Justice

Professor Martin Severs- Caldicott guardian and Lead Clinician, Health and Social Care Information Centre

Ms Marion Oswald – Senior Lecturer at University of Winchester and head of the Department's Centre for Information Rights

Mr Colin Godbold – Formerly a partner in IBM's consultancy and services practice senior and lay member of the ADRN Board

Ms Annie Hitchman- Serves on a number of Fitness to practice panels and formerly held public appointments as a non executive director on Health trusts.

Dr Dean Machin – Political Philosopher at University College London

Ms Isabel Nisbet – former Chief Executive of the Office of Qualifications and Examinations Regulations and member of the Home Office's National DNA Database Ethics Advisory Group

Mr Hetan Shah - Chief executive of the Royal Statistical Society

#### Annex B NSDEC Ethical Principles

In reviewing proposals relating to the access use and sharing of data, NSDEC will provide advice to the National Statistician on the basis of the following principles;

- i. The use of data has clear benefits for users and serves the public good.
- ii. The data subject's identity (whether person or organisation) is protected, information is kept confidential and secure, and the issue of consent is considered appropriately.
- iii. The risks and limits of new technologies are considered and there is sufficient human oversight so that methods employed are consistent with recognised standards of integrity and quality.
- iv. Data used and methods employed are consistent with legal requirements such as the Data Protection Act, the Human Rights Act, the Statistics and Registration Service Act and the common law duty of confidence.
- v. The views of the public are considered in light of the data used and the perceived benefits of the research.
- vi. The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public.

NSDEC will review the ethical principles annually to ensure they remain pertinent.

## **UK Statistics Authority**

## National Statistician's Data Ethics Advisory Committee

## Terms of reference

#### Introduction

1. At the UK Statistics Authority Board meeting on 6 November 2014, the Authority Board agreed to establish the National Statistician's Data Ethics Advisory Committee (NSDEC), which would be advisory to the National Statistician.

#### Role and responsibilities

- 2. The role of the National Statistician's Data Ethics Advisory Committee (NSDEC) is to advise the National Statistician on ethical considerations concerning the use of data.
- 3. Specific responsibilities of the NSDEC include to:
  - i. provide ethical consideration of proposals to access, share and use data;
  - ii. advise on individual policies and projects against NSDEC's ethical principles;
  - iii. develop a consistent ethical framework for relevant projects related to official statistics;
  - iv. promote transparency around data shares; and
- v. provide ethical advice on other data issues within the National Statistician's remit, which includes his role as head of the Government Statistical Service.
- At the invitation of the Chair of the Administrative Data Research Network Board, NSDEC will also provide ethical consideration for government and third sector researchers wishing to access the ADRN.
- 5. In reviewing proposals NSDEC will provide advice by consensus.

#### Meetings

6. NSDEC will meet at least four times a year. The Chair of NSDEC may convene additional meetings as deemed necessary.

#### Reporting

- 7. NSDEC will provide reports following each of its meetings to the National Statistician.
- 8. At least seven days prior to its meetings, NSDEC will receive reports on:
  - i. proposed new data shares;
  - ii. relevant projects and programmes and other information as it requires; and
  - iii. reports from any sub-committees.

#### Membership and role of members

- 9. The members of NSDEC will include:
  - i. an representative of the National Statistician (Chair);
  - ii. at least five independent external members, including lay members; and
  - iii. no more than four members from government.

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### Quorum

- 10. NSDEC meetings will be considered quorate when four or more members are present including at least two independent external members as well as the Chair or the Chair's delegated nominee.
- 11. Substitutes will not be permitted to attend meetings, unless with the invitation of the Chair.
- 12. Secretariat for the NSDEC will be provided by the staff from the Central Policy Secretariat.
- 13. NSDEC will review the effectiveness of its meetings and its terms of reference annually.
- 14. The Chair may invite other relevant experts as appropriate to advise the committee.

# Professor David Ford

## A view from the Administrative Data Research Centre Wales

Oral report

## **UK STATISTICS AUTHORITY**

## ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)12

#### Data owner engagement update

#### Purpose

- This paper provides an update for the Board on the Administrative Data Research Network's (ADRN) data owner engagement. The paper outlines progress made in negotiating for data resources to support research undertaken within the ADRN secure infrastructure. The report covers:
  - i. the background to the negotiation;
  - ii. the progress that has been made to date;
  - iii. what the next steps are;
  - iv. the key challenges; and
  - v. if the ADS would like to request support from the Board in establishing access to data from a particular government department.

#### 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 Annex B);
  - ii. discuss how the Board may assist the Network when strategically engaging with data owners; and
  - iii. provide feedback on the suitability of this report structure.

#### Background

- 3. The Administrative Data Service (ADS) lead on data owner engagement. A summary of progress with this work is presented in Annex A. 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. A summary of progress with this work is presented in Annex B.
- 4. At the Board meeting in February 2016 it was felt that access to data was becoming a real risk to the success of the ADRN. The Board felt that the Network would be mostly judged on whether it could generate a significant number of research projects that produced research with real public and policy benefits. To try to achieve this there was agreement that the Board 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 the Board need to receive precise information on the specific issues that are causing the blockages.
- 5. Key challenges that are common to all negotiations relate to:
  - i. the availability of resources within government departments to investigate and prepare data resources;
  - ii. the need to establish the ADRN as a secure network that meets the needs of the data custodians; and
  - iii. the legal and contractual requirements around both releasing and receiving data for linking and research.

6. Annex A notes key challenges that are specific to a department.

Tanvi Desai, Co-director, Administrative Data Service, and Simon Whitworth, ADRN Board Secretariat, UK Statistics Authority, 29 March 2016.

#### **List of Annexes**

- Annex A Data Custodian Engagement Report: Administrative Data Service Engagement, Tanvi Desai, Administrative Data Service
- Annex B Data Custodian Engagement Report: Report from the Administrative Data Research Centres in the Devolved Administrations, Jo Webb, Administrative Data Service

## Annex A - Data Custodian Engagement Report: ADS Engagement

## Department of Energy and Climate Change (DECC)

## Background:

DECC have been very helpful in supporting the Administrative Data Service (ADS) attempts to secure access to energy meter data.

The data are held by DECC but are owned by the energy companies. Energy companies covering 60% of the population are part of a network that is represented by National Grid. The other companies act independently.

The energy companies have been approached in the past with a request to provide data for an academic research project. The independent companies did not object, but the network of companies was not satisfied with the proposed information assurance measures.

DECC has since re-approached the energy companies to request that they release data via the ADRN due to the ADRN's high level information assurance.

## Progress to date:

A meeting has taken place between ADS, DECC, the Network (represented by National Grid) and ExoServe (a company providing data services to the energy sector).

All parties seemed open to the idea of data access via the ADRN. ADS and DECC have drafted a letter to send to all the energy companies outlining the proposal. ADS, DECC and National Grid are currently looking at the legal and contractual arrangements, once we have a form for these National Grid will approach the other companies in the Network. DECC and National Grid are aiming to secure a decision before the end of April.

## Next steps:

- i. letter to be circulated to all energy companies;
- ii. ADS and DECC to work with National Grid to develop legal agreement for data access;
- iii. DECC to send metadata to ADS to assist with researcher support; and
- iv. ADS and DECC to assess whether the energy companies send data products to other sections within DECC that should also be in scope.

## Key Challenges:

- securing support of energy companies; and
- establishing which of DECC's data holdings would be covered by the agreement outlined above and which would not.

## Board assistance requested:

Board assistance is not required at this time.

## Driver and Vehicle Licensing Agency (DVLA)

## Background:

DVLA were originally approached in December 2015. Following significant work trying to locate the correct contact and present the ADRN to DVLA, ADS was told in June 2015 that DVLA were in the process of 'reviewing and developing [DVLA's] future data sharing strategy' and that they expected to have completed this work by the end of 2015.

ADS offered to contribute to the development of their data sharing strategy particularly as we were told that the strategy would cover 'the type of request your organisation has made', and asked if we could use existing gateways while the strategy was under development but we received no response.

ADS approached DVLA again early in 2016, and submitted a DVLA data access request form. After more than a month of chasing up we were informed that DVLA is not currently considering any requests for data access for research purposes and that the issue is under consideration by the DVLA Chief Executive Board. ADS again offered to contribute and had no response.

## Progress to date:

None

### Next steps:

The ADS have received reports that the Secure Anonymised Information Linkage Databank (SAIL) has requested data from DVLA. ADS will investigate further and see if SAIL have a process that can be transferred to ADRN.

#### Key challenges:

DVLA have so far been unwilling to engage with ADRN.

#### Board assistance requested:

Yes.

#### Department for Work and Pensions (DWP)

#### **Background:**

DWP have been broadly supportive of ADRN data requests and a lot of resource has been put in on both sides to try to establish pathways. The ADS User Support team has been having regular meetings with the DWP EDSAC team every two weeks, backed up by meetings between the DWP lead and the ADS Co-Director.

#### Progress to date:

DWP are internally assessing the proposed methodology of the proposed project 052 "The wider impacts of benefit sanctions: educational attendance, behaviour and attainment" to establish feasibility. The next step is expected to be discussion between the researcher and DWP on data specification.

The initial project submitted has been challenging both in terms of the data requested and the project. It has been useful to use this project to uncover issues that may not have been discovered with more straightforward proposals however additional strategies are needed to secure access to DWP data quicker than may be possible with this project. Therefore DWP and ADS have agreed additional projects to progress that are less challenging. In addition DWP are taking forward discussions at director level to secure support for individual projects to add to the support DWP is giving via the External Data Sharing Advice Centre team

#### Next steps:

DWP and the ADS will look at lessons learnt from non-ADRN projects that have recently been achieved between DWP and academia to understand how ADRN projects can also be achieved.

ADS and DWP are working on verifying that the Information Assurance standards across the Network are appropriate to the data that DWP will make available for research. DWP and ADS are investigating if there are ways in which DWP can approve ADRN's Information Assurance as a whole rather than having to audit and approve each individual safe setting. In particular, DWP are looking into whether the planned Network-wide audit being carried out by ADS will provide the reassurance needed.

ADS and DWP are discussing legal and contractual arrangements to enable DWP data to be delivered to ADRN and the Trusted Third Parties.

Due to DWP's challenge in finding resources to uncover information around the suitability of administrative data that has not been previously used for research, on ADS' suggestion DWP has identified 22 data sources that it would be more straightforward for them to deliver. ADS will now work with DWP on collecting the appropriate metadata and making researchers aware that these resources exist. This could enable pathways to be established for the less resource intensive data sources while we work on understanding and addressing access to the more challenging sources.

ADS has highlighted the DWP/HMRC/MoJ linked dataset, as a key linked administrative data resource that we would like to make available.

#### Key Challenges:

Significant resource on both sides has been assigned to securing research access to DWP data. While progress has been made in identifying processes and pathways to access little progress has been made in securing data resources and ADS is finding it hard to identify the precise reasons for this.

#### Board assistance requested:

Yes.

#### Higher Education Statistics Agency (HESA)

#### Background:

HESA has been very supportive in helping ADS establish access to their data for research.

HESA already has extensive mechanisms in place to support use of its data for research purposes so some of the resource challenges ADRN has experienced with other government departments have not been an issue with HESA.

#### **Progress:**

The first project using HESA data is on the verge of being completed in Northern Ireland. Following a request from Northern Ireland via ADS and a direct request from the Welsh Government, ADS has been asked by HESA to coordinate an investigation into the possibility of HESA passing responsibility for data sharing for ADRN projects to the devolved nations (and BIS for the UK). All existing contracts with devolved nations (and BIS) include a clause allowing the data to be shared where those departments have a direct policy interest. HESA is willing to consider amending the contract to also allow 'research within the ADRN framework'.

#### Next steps:

A meeting with key contacts for each devolved nation will take place on 13 April to hold preliminary discussions around legal requirements and processes.

#### Key Challenges:

So far working with HESA has proved very straightforward, however their standard practice of charging for data processing will probably mean that there are some costs that ADRN has to pass on to researchers as the Network does not have resources to pay for data.

#### **Board assistance requested:**

Board assistance is not required at this time.

#### HM Revenue and Customs (HMRC)

#### Background:

HMRC is very restricted in its ability to share data due to its legal status that places more restrictions on its capacity to share data than is the case for other government departments.

#### Progress to date:

No progress since last report. Discussions been HMRC and ADS have taken place and there are plans to meet on a twice-yearly basis, however ADRN has not yet had any request for HMRC data that falls closely enough within HMRC's areas of policy interest to enable them to release the data.

#### Next steps:

ADS will continue to investigate the possibility of securing access to the DWP/HMRC/MoJ linked dataset. Otherwise, nothing further will be done until a request for HMRC data is submitted to the Network. When this happens, ADS is confident that they have the right contacts at HMRC to be able to discuss data access.

#### Key Challenges:

- HMRC legal restrictions on data access;
- lack of projects requesting access to HMRC data means that pathways cannot yet be tested.

#### **Board assistance requested:**

Board assistance is not required at this time.

#### Health and Social Care Information Centre (HSCIC)

#### **Background:**

ADRN has been working closely with HSCIC to try to establish effective, streamlined processes for data access applications and processing. The main aims of the strategic engagement has been to try to find a mechanism to enable ADRN projects to be dealt with in a more efficient manner than standard HSCIC data applications that 'join the queue'. With large support teams at both ADS and HSCIC we are keen to minimise duplication of effort and to expedite the processing of ADRN projects. There has been relatively slow progress in this area due to ADRN and HSCIC setting up new processes, however progress is being made.

#### Progress to date:

In common with many Economic and Social Research Council and Medical Research Council investments ADRN are attempting to arrange a 'sub-licensing' contract with HSCIC similar to the arrangement they have with the Clinical Practice Research Datalink (CPRD).

Tanvi Desai and David Ford presented to the HSCIC Data Access Advisory Group (DAAG) in early February with the aim of familiarising the Group with ADRN standards and processes, and are meeting with Garry Coleman, Head of Data Management Services, to try to finalise the contract.

In the meantime the ADS User Services team are meeting regularly with their HSCIC equivalents to prepare project applications. We are currently awaiting DAAG dates for two projects.

#### Next steps:

Work will continue to progress the projects that are already in the system. Once the first projects are accepted the plan is to use all projects that are submitted to establish the various components of ADRN as appropriate to hold and process HSCIC data and to widen the scope of data that can be linked. Therefore with subsequent applications we will try to vary one component of the application at a time i.e. a similar data request but a different ADRC, or an ADRC we have already established as a suitable safe setting with a data link from a department that has not yet been requested.

In order to make it easier for ADRN staff to understand the data available from HSCIC, ADS will coordinate a visit for User Support staff where analysts who understand each of the data sources in detail will present some of the key issues surrounding each resource.

#### Key challenges:

- i. HSCIC are undergoing a lot of internal changes which can lead to a lack of clarity around some processes and procedures;
- ii. it can be very time consuming to access the information necessary to establish whether a data source is suitable for a proposed research project; and

iii. even if negotiations for data access for the first projects are successfully concluded, ADRN cannot currently grant access to researchers as the ADRN Approval Panel will not approve projects using HSCIC data until there is clarity around how they are going to uphold objections (opt outs).

#### **Board assistance requested:**

Board assistance is not required at this time.

#### Ministry of Justine (MoJ)

#### **Background:**

ADS supported MoJ in a project to develop a metadata schema for two key MoJ data resources. The schema are currently being assessed by MoJ for suitability, after which ADS and MoJ will decide whether there is further work that should be done.

#### Progress to date:

While meetings have taken place with MoJ and contacts are good, there have been no research requests for MoJ data.

#### Next steps:

- assess success of metadata project; and
- investigate the possibility of securing access to the DWP/HMRC/MoJ linked dataset.

#### Key Challenges:

A lack of projects requesting access to MoJ data means that pathways cannot yet be tested.

#### Board assistance requested:

Board assistance is not required at this time.

#### **Office for National Statistics (ONS)**

#### Background:

ONS is a key component of ADRN being a partner in ADRC-England, a Trusted Third Party (TTP) linker and a potential data provider.

#### Progress to date:

ONS have agreed that the ADRC-England safe setting at the University of Southampton is a suitable place for ONS data to be stored, processed and analysed.

To date, the ONS data resource that has been most requested is the census. ADRN has not been successful in securing access to census data at a more detailed level than is currently available via other services.

ADS requested metadata on key ONS data sources that are likely to be of interest to researchers. ONS have said that they are unable to produce metadata around the requested sources. ONS have therefore been asked to share a list of sources for which they can provide metadata. ADS have so far had no response to this request.

#### Next steps:

The following next steps have been identified:

- i. ONS to provide ADS with metadata on data sources that can be made available for linking;
- ADS to request information on the legal gateways allowing the TTP to ingest and link data by government department or data subject, so that information is available during negotiations with data custodians to strengthen the case for ONS being a TTP; and
- iii. ONS to approve other safe settings in the ADRN as suitable to hold ONS data.

#### Board assistance requested:

Yes.

#### Universities and Colleges Admissions Service (UCAS)

#### **Background:**

The ADRN Directors Group rejected UCAS initial proposal to provide a consented dataset three years after the data are collected, with no historical data. This would have required significant additional resources, compared with ADRN standard processes, and delivered a data source with little research utility.

#### Progress to date:

Following a meeting between the UCAS Chief Executive and Melanie Wright and Tanvi Desai of ADS, brokered and attended by Ian Diamond (member of UCAS Board and ADRN Approvals Panel Chair) it was agreed that ADRN and UCAS would continue to work together to try to make linked UCAS data available for research.

ADRN are waiting to receive details of a revised proposal from UCAS, but are progressing information assurance, legal and contractual issues in the meantime.

ADS would like to thank Ian Diamond for his help and support in these negotiations.

#### Next steps:

The key next steps that have been identified are as follows:

- ADRN awaiting clarity from UCAS as to what data can be made available; and
- ADS and UCAS to meet with UK Data Archive (UKDA) to examine information assurance and contractual issues around holding data for the ADRN in April.

#### Key Challenges:

The key challenges that have been identified are as follows:

- a lack of clarity around data being offered; and
- the need to develop processes outside of the standard ADRN procedures.

#### Board assistance requested:

Board assistance is not required at this time.

#### Valuation Office Agency

#### Background:

ADS has held meetings with VOA which have indicated that though they are in principle open to the idea of their data being used for research within the ADRN framework. However, due to their legal status restricting what VOA data can be used for it is unlikely that they will be able to provide ADRN with data. In addition they have concerns over their ability to release data via ADRN and think it likely that any initial release would be through the HMRC data lab.

#### Progress to date:

There has been little progress to date with securing access to VOA data and ADS has been unsuccessful in negotiating access for one project.

#### Next steps:

The ESRC has made housing a key research priority. Consequently there is likely to be an increase in demand for VOA data. ADS will re-approach VOA in light of changing ESRC priorities.

#### **Key Challenges:**

The key challenge is the restricted legal framework available to VOA for data release.

#### Board assistance requested:

Yes.

#### Non-governmental data sources

#### **Centre for Longitudinal Studies (CLS)**

#### **Background:**

CLS initially told the ADRN that they were unable to provide access to data for ADRN as they do not have the resources to undertake regular bespoke extracts. Also as their grant conditions require them to make any data products available for reuse, the requirement on ADRN to destroy data would mean that they could not fulfil these requirements meaning that they could not provide data to ADRN even if they did have resources.

#### Progress to date:

ADS approached CLS with a proposal to work together to secure access to data in a way that would benefit both services. In particular, ADS proposed that when negotiating with a government department to link an administrative data source to a CLS dataset the proposal would include a full link to CLS data that can then provide:

 an anonymised 'end user license' and/or 'secure' linked dataset to be made available by CLS via the UKDA; and  a bespoke subset tailored to the ADRN researcher's needs to be accessed and analysed via ADRN.

CLS have agreed to discuss this proposal with senior staff.

#### Next steps:

ADS is awaiting CLS' response.

#### Key Challenges:

- how to ensure that various ESRC investments that are negotiating for access to government data can act in a coordinated way; and
- consents for reuse of cohort data for research do not cover all topics and all years, so there are restrictions on the data that can be linked.

#### Board assistance requested:

Board assistance is not required at this time.

#### Institute for Social and Economic Research (ISER)

#### Background:

ADS approached ISER for access to Understanding Society to link for a research project. Unfortunately ISER are unable to resource anything other than the standing dataset that is available via the UKDA.

#### Progress to date:

No progress to date.

#### Next steps:

To make a similar proposal to ISER as has been made to CLS.

#### Key Challenges:

- ISER not resourced to provide the type of extract ADRN needs; and
- ensuring that the various ESRC investments that are negotiating for access to government data can act in a coordinated way.

#### Board assistance requested:

Board assistance is not required at this time.

# Annex B –Data Custodian Engagement Report: ADRC Engagement in the Devolved Administrations

#### **ADRC-Northern Ireland**

Since the last Board report ADRC-Northern Ireland have been liaising with Business Services Organisation to negotiate the provision of a personnel resource to work on key data sets requested for Network approved projects and the development of metadata as a resource for researchers.

Table 1 presents a summary of the ADRC-Northern Ireland's data custodian engagement.

Data owner	Further information
Department for Finance and Personal	Agreement in principle has been received for the Census, Vital Events Statistics and Valuation lists. These data sets have been used in a number of projects to date with the Census due to be used in all projects that have currently been approved through the ADRC-NI.
Department for Social Development (DSD)	There is agreement in principle from DSD for benefits data. An application is currently being developed using the data.
Department of Agriculture and Rural Development (DARD)	There is agreement in principle from DARD for the Farm Census and data has been received in the ADRC-NI.
Department of Education (DE)	There is agreement in principle from DE for two datasets - the School Census and the School Leavers Survey. There are currently two projects at different ADS stages which will use this data.
Department of Employment and Learning (DEL)	DEL are nearing completion of one project using HESA data and there is another project requiring HESA data with ADS currently leading on this.
Department of Health, Social Services and Public Safety (DHSSPS)	There is agreement in principle for four datasets in DHSSPS's Business Services Organisation. A large number of projects in the ADRC-NI have requested the data and these projects are being progressed.
Department of the Environment (DOE)	There is agreement in principle for two datasets from DOE.
Northern Ireland Office	There is agreement in principle for the Electoral Register.

Table 1: Summary of the ADRC-Northern Ireland's data custodian engagement.

## **ADRC- Scotland**

Table 2 presents a summary of the ADRC-Scotland's data custodian engagement.

Table 2: Summar	y of the ADRC-Scotland's	data custodian engagement
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Data owner	Update
Aberdeen Birth Cohorts	In progress.
Aberdeen City Council	In contact with data controller. Looks very positive.
Care Inspectorate	Good relationship. Anticipating buy in from the Care
	Inspectorate board.
Cash for Kids	In progress.
Dept for Transport	In progress.
Driver and Vehicle Licensing	In progress.
Agency	
Department for Work and	Positive discussions across three projects.
Pensions	
Edinburgh City Council	Positive engagement with data controller.
Energy Saving Trust (Scotland)	Good engagement. Unrelated issues with project
	funding have delayed negotiations.
Healthy Ageing in Scotland	No problems.
Justice Directorate	In progress.
National Crime Agency	In progress.
National Records Scotland	Access to census now agreed. Other datasets already
	available subject to Information Governance
	conditions.
NHS National Services	Data readily available subject to governance scrutiny.
Scotland	
Phoenix Futures	Data controller keen to share. Proposed project has
	benefits for organisation.
Police Scotland	In progress.
Scotland local authorities	No issues except that there are 32 data controllers
	with whom to engage for national data.
Scottish Childrens Reporter	Positive engagement. Awaiting agreement on suitable
Association	data sharing arrangements.
Scottish Government	Data readily accessible subject to Information
	Governance approval.
Scottish Qualifications Authority	No issues.
ScotXed	No issues.

## ADRC-Wales

Table 3 presents a summary of the ADRC-Wales' data custodian engagement.

## Table 3: Summary of the ADRC-Wales' data custodian engagement

Data owner	Further information
Welsh Government (WG)	Education data (NPD and LLWR) have been made available by WG for ADRC-Wales use
Data Sets: National Pupil Database (NPD) Lifelong Learning Wales Record (LLWR)	Access to HEED, Arbed and NEST data – home improvement data – has been granted.
Health Economic Evaluations Database (HEED) Arbed – Strategic energy performance investment programme Welsh Government Warm Homes Nest Scheme (NEST) Active Adults Flying Start	Access granted to Active Adults survey, which is now available.
South Wales Police	Data ready for transfer subject to data sharing agreement being signed off
Local Authorities in Wales Data Sets: Supporting People	Supporting People data from 3 LAs were successfully negotiated for, access was granted and analysis is being conducted.
PARIS Social Care	Discussion ongoing to obtain PARIS and Social Care Data.
Office for National Statistics (ONS)	ADS acting in relation to Census project. Project outline sent to ADS for dissemination to ONS.
Public Health Wales (Project data funded by Welsh Government)	Negotiations ongoing for access to National Exercise Referral Scheme data
Data Set: Public Health Wales	
Academic data holder	Discussion are being had with data owner in order to obtain Skills and Employment Survey data (SES)
Department for Work Pensions (DWP)	ADS acting in relation to obtaining Work and Pensions Longitudinal Study (WPLS) and other DWP data.
HM Revenue and Customs (HMRC) HMRC data	ADS acting in relation to obtaining HMRC data i.e. council tax banding data.
Valuation Office Agency (VOA) data	

Welsh European Finance Office (Part of Welsh Government)	European Social Fund data ready for transfer subject to data sharing agreement being signed off
Rhondda Cynon Taff Homes	Discussion ongoing for use of property improvement data
Driver and Vehicle Licensing Agency	ADS to act in relation to obtaining car registration data
Institute of Education, University College London	Negotiations via ADS in order to obtain access to Millennium Cohort Study data

## **UK STATISTICS AUTHORITY**

## ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN16(13)

## ADRN Issue Mitigation Action Plan

#### Purpose

 This paper presents a draft ADRN Issue Mitigation Action Plan which aims to set out the mitigations planned and already in place to address the core issues of access to data and demand.

#### Recommendations

- 2. Members of the Administrative Data Research Network (ADRN) Board are invited to:
  - discuss the purpose and aims of the Action Plan; and
  - **consider** any additions or amendments to be made to the Action Plan before it is taken forward.

#### Background

- As members are aware, a key issue that has emerged with the ADRN is the lack of progress with securing data from key UK government departments and the effect this is having on the progress with individual approved ADRN projects reliant on the availability of those data.
- 4. A number of mitigations have been suggested and put in place by the ADRN Directors Group, ADRN Board and ESRC to attempt to address these core issues, including the suggested change in approach around data retention and the development of 'core ADRN resources' (see ADRN 16(14)). However, there has currently been no mechanism to pull together current and planned mitigations and put a framework in place to manage and monitor them.
- 5. A draft Action Plan has therefore been drafted as that mechanism to offer the Board and the ESRC governance bodies a picture of what we are doing collectively to tackle the issues that have emerged with the ADRN and highlight the plans that are in place to progress things over the vital next 12 months. This mechanism will also then allow the ADRN Directors, ADRN Board and ESRC to track the progress of these activities and their success in tackling the recognised issues.

#### Action Plan

- 6. The Action Plan has been constructed around two core issues: access to data and researcher demand. It then attempts to set out for each suggested issue, mitigation activities, intended outcomes of the activity if successful and some provisional suggestions for timescales and responsibilities.
- 7. Those actions deemed vital to the success of the Network have been highlighted in red and this principally focuses on the first three suggested actions which aim to understand and then tackle the reluctance of key government departments to share data through the ADRN. Actions 4-6 and 8 are then aimed as further activities that will support the achievement of actions 1-3, and action 7 is aimed to enable the Board and ESRC to monitor progress against them all. Category B then sets out further actions aimed to keep the research community engaged and up to date with the progress of the ADRN.

and enable them to support the case being made for the value of investing in this infrastructure.

- 8. Ultimately, if successful, the implementation of these actions will ensure that key data owners are willing to share data through the ADRN and more projects using the ADRN infrastructure are submitted and progress to the data analysis stage.
- 9. In order to guide discussion, the Board is asked to focus attention on the following questions:
  - i. Are all actions and activities captured here and are there any listed that should not be on the Action Plan?
  - ii. How can we best monitor progress against the Action Plan and know what success looks like?
  - iii. Given the limits of resources within the ADRN, is there a core set of government departments that this Plan should focus attention on for instance, in terms of the strength of established relationships, value of data held by those departments to researchers, or potential for leverage?

#### **Next Steps**

- 10. The Plan is currently a first draft and needs input from both the ADRN Board and the ADRN Directors Group in terms of both its scope and details around timescales and responsibilities for delivery.
- 11. If Board members agree with the principle and content of the Action Plan, subject to any suggested amendments, it is proposed that it is adopted and the details developed by the ADRN Directors Group at the meeting on 14 April. An update on progress will then be brought to the ADRN Board meeting in July 2016.
- 12. This Action Plan and progress with the individual actions will also then feed into the Mid-Term Review in terms of the ways in which issues are already being mitigated and new approaches being trialled.

#### Paul Meller, ADRN lead at the Economic and Social Research Council, 1 April

## **UK STATISTICS AUTHORITY**

## ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(16)14

#### Data Retention

#### Purpose

- 1. This item discusses the implications and opportunities for the ADRN of changing the Administrative Data Research Network's (ADRN) data retention policy.
- 2. The discussion will focus on data retention policies internationally, some of the implications of a change of policy for the ADRN and what a change of policy could enable for the ADRN.
- 3. The models being considered will be described along with their cost, benefits and risks. In the mid to long term, these models aim to reduce the time and resources required by both data owners and researchers, thereby:
  - i. increasing the speed and volume of projects through the ADRN;
  - ii. increasing data owner participation; and
  - iii. overcoming researcher scepticism and reticence.

#### Recommendations

- 4. Members of the ADRN Board are invited to provide strategic guidance to the Directors Group first on the proposed change of retention policy in line with international practice, and secondly on which models to adapt and/or prioritise, and any other information or support which they can offer to implement one or more of the models. In particular, advice is needed regarding:
  - i. the data owners' perspective of the desirability of a policy change and the likelihood of success in establishing standing linked dataset;
  - ii. how best to manage public perception (e.g. formal consultation, dialogue with activists, quiet change); and
  - iii. the business model for creating the data resources

#### Background

- 5. As was discussed at the ADRN Board meeting on 1 February 2016 there are some concerns being expressed about the ADRN's progress to date in terms of access to data and therefore projects underway (though absolutely recognising the wider contributions and progress of the ADRN). Consequently, at the ADRN Board meeting on 1 February 2016 some consideration was given to whether some key linked de-identified datasets should be retained by the ADRN and used for multiple research projects in a way which the public and data custodians find acceptable.
- 6. Following the Board meeting in February 2016 the ESRC (Jane Elliott and Paul Meller) and the UK Statistics Authority (Andrew Dilnot, John Pullinger and Rob Bumpstead) had a meeting about a range of ESRC/ONS activities, but the main focus was on the ADRN and its progress. This discussion reflected the discussion at the Board but in particular focused on the model of operation in terms of 'bottom up' project-driven data requirements. The group felt that this model had not worked as well or smoothly as hoped and that there therefore needed to be work undertaken to supplement the model with a more 'top down' approach.

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- 7. Specifically, the group felt that there needs to be identification of some key variables/datasets that can be linked to provide a resource for researchers, and the ADRN would then have a role in promoting the use of the data in a safe setting. As was discussed at the Board meeting in February 2016, the benefits of this would mean that the ADRN would hold data resources that it could quickly make available for approved projects that apply to use the data (including for PhD students). It would also enable the ADRN to provide an answer to the question of 'what data does the Network have', hopefully encouraging further researcher demand. This is very much intended as a model alongside the original ADRN model of 'bottom up' project driven data requirements, but the group felt that it could not wait for the mid-term review to report in nearly a year to try new approaches and thereby help support the case to continue funding for the Network.
- 8. The idea then is to start by collating a list of key departments, datasets and variables (perhaps starting by being led by enquiries to the ADRN) and then looking at who is best placed to support the negotiation to get them (the UK Statistics Authority, ESRC and colleagues at BIS have all offered support in this, including reconvening the Departmental Directors of Analysis group once there are clearer asks in terms of these linked data and clearer messages about the Unique Selling Point of the Network). The end result could be something along the lines of a prospectus that the ADRC-Northern Ireland have created outlining data that is available now, data that is likely to be available, and data potentially accessible following some negotiation. This can be found here <a href="http://www.adrn.ac.uk/media/1248/adrcni018-adrc-ni-data-prospectus-v30.pdf">http://www.adrn.ac.uk/media/1248/adrcni018-adrc-ni-data-prospectus-v30.pdf</a>

Professor Peter Smith, Director of ADRC-England, and Melanie Wright, Director of Administrative Data Service, 29 March 2016.

## **UK STATISTICS AUTHORITY**

## ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN16(15)

## Legislative Issues

#### Purpose

1. This paper presents updates on:

- i. UK data sharing legislation; and
- ii. EU data protection regulation.

#### 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 Economic and Social Research Council (ESRC) in its discussions with partners.

#### Background

3. At the February 2016 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 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.
- 5. On 29 February the Minister for Cabinet Office launched a formal consultation on policy proposals based on these discussions entitled *Better Use of Data in Government*. The consultation document was published alongside draft illustrative clauses and supporting impact assessments for the three strands of the policy, namely:
  - i. improving the delivery of public services
  - ii. tackling fraud and debt; and
  - iii. allowing the use of data for research and official statistics.

These documents are available through the Government's <u>policy consultation portal</u>. The Cabinet Office has continued to engage with the organisations and groups that took part in the OPM process. Updates on Cabinet Office's engagement with civil society and other groups continue to be available at <u>http://datasharing.org.uk/</u>.

6. The illustrative clauses related to the research and official statistics strand make provision for new powers as outlined in previous updates to the Board. Namely for the creation of a permissive power to share and link de-identified data for the purposes of research and statistics in the public interest using a trusted third-party sharing model, and for additional powers for ONS to access data from public and private sector organisations for the purpose of producing national and official statistics. The proposed legislation also reaffirms rigorous penalties for the misuse of identifiable data as set out

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in the Statistics and Registration Service Act 2007. It also includes an obligation for data owners whose data is accessed through these powers to consult the National Statistician before making changes to the way this data is collected, stored or retrieved in order to protect the integrity of official statistics outputs which draw on these data.

- 7. The consultation closes on 22 April, and will be followed by a formal Government response and the preparation of appropriate amendments to the proposals. Following the conclusion of the consultation it is expected that those strands of the policy which have an impact on business will be submitted to the Regulatory Policy Committee for scrutiny, before a decision is taken whether to put the package of measures to Parliament. Work continues within and across Government and the research community to refine procedural and legal details of the research and statistics strand of the policy, to identify indirect and direct costs and benefits, and to evaluate the feedback from the ongoing public consultation.
- 8. Cabinet Office, working with policy owners across Government, are continuing to engage with stakeholders including the ESRC, alongside parallel work to build awareness of the proposals:
  - i. On 1 March, the UK Statistics Authority published a policy paper outlining the case for legislative changes, entitled <u>Delivery better statistics for better decisions:</u> <u>Why we need new legislation for better access to data</u>. The paper includes case studies highlighting a number of the tangible improvements the Authority anticipates would be delivered through new legislation, together with comparative international research which shows the relatively weak position of the UK compared to other national statistical systems.
  - ii. On 17 March the Royal Statistical Society held a joint event with the Nuffield Foundation, ESRC and CLOSER to raise awareness of the proposals and encourage consultation responses. The audience were supportive of the proposals around statistics and research, although some stakeholders emphasised the need for addressing clear definition of, for example, 'public good' which will be a criterion for researcher access to de-identified linked data. The audience also acknowledged the significant and expanded role given to the UK Statistics Authority as the accreditation body for indexers and the provider of accredited secure access facilities.
  - iii. Cabinet Office has organised two additional workshops with policy owners, civil society, privacy and academic groups in March and April to elicit additional views and opinions around the policy proposals, focusing specifically on constraints around the proposed powers, consistency between the three strands and frameworks for the anticipated codes of practice and principles governing the policy's implementation.
  - iv. In the spirit of the OPM process the Cabinet Office has also decided to open up the government's analysis of the consultation responses for external scrutiny by a specially formed Quality Assurance Group. The group will publish its report alongside the government's analysis.

#### EU Data Protection Regulation

9. As reported at the previous meeting of the Board, in the last days of the Luxembourg Presidency of the EU (December 2015), an agreement was finally reached in trilogue discussions on the <u>text</u> for a new Data Protection Regulation. The final text of the new regulation is expected in April 2016, following a vote by the European Parliament plenary. It is anticipated that the regulation will then be enacted by the European Commission in June 2016.

- 10. European officials were receptive to the research community's concerns, led by the Wellcome Trust and the European Data in Health Research Alliance, about the impact on research. Concerns raised included the requirement for specific consent from data subjects, and this concern has been reflected in the final compromise text agreed. The Department for Culture Media and Sport (DCMS) is dealing with implementation of the Regulation at UK level. It will be essential that the UK introduces derogation for scientific research from the consent provision, and there may also be a need for a derogation for the processing of personal data for the purpose of journalism and the purposes of academic, artistic or literary expression. Discussions about the status of pseudonomysed data are ongoing with the Information Commissioners Office.
- 11. A number of research funders, led by the Wellcome Trust and including the ESRC, are now preparing a summary document to highlight areas that need to be addressed through derogation or further discussions and to set the tone for implementation discussions. The research community is also drafting a statement stressing the need for Member States to take action to implement the Regulation. Both documents will be sent to policy makers in Member States (research, health and justice ministries) and the European Data Protection Board, and will be published at the same time as an official announcement is made on the final text.

Richard Reed, UK Statistics Authority, and Vanessa Cuthill, Economic and Social Research Council, 29 March 2016

Tab 11 Any other business

Any other business

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