

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

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**Minute, Agenda and Papers**

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Monday 3 April 2017

11:30 – 14:15

Board Room, UK Statistics Authority  
Drummond Gate, London



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

**Minute**

**Monday, 3 April 2017**  
**Boardroom, Drummond Gate, London**

**Present**

**Board Members**

Professor David Hand (Chair)  
Ms Sharon Witherspoon  
Mr Jonathan Athrow  
Ms Orla Bateson for Ms Siobhan Carey  
Mr Peter Benton  
Dr Andrew Garrett  
Mr Colin Godbold  
Mr Roger Halliday  
Mr Glyn Jones  
Professor Denise Lievesley  
Dr Lucy Martin  
Ms Frances Pottier  
Mr Luke Sibieta  
Professor Peter Smith  
Mr Nicky Tarry  
Mr Darren Warren  
Ms Penny Young

**UK Statistics Authority**

Dr Simon Whitworth  
Mr Robert Bumpstead

**Economic and Social Research Council (ESRC)**

Ms Ruth Gibson

**Administrative Data Research Centre – England**

Professor Ruth Gilbert

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

- 1.1 The meeting reviewed progress with actions from the previous meeting held on 7 November 2016.

**2. Chair's Report**

- 2.1 The Chair reported that in February the Non-Executive Directors (NEDs) met to discuss progress with the ADRN. This resulted in a note being sent to the ESRC on behalf of the non-executives expressing the following concerns of the non-executives:
- i. the Administrative Data Service (ADS) does not have the appropriate skills, networks or experience to influence and enable Whitehall government departments to share data with the Network in a timely manner;
  - ii. the Network urgently needs a dedicated overall Director to lead and manage it with clear lines being put in place so that the individual components of the

ADRN are accountable to the Network Director. This would enable the Network Director to provide much needed leadership and direction to the Network executive. This appointment needs to be made urgently; and

iii. that left in its current form they do not believe the ADRN will make sufficient progress towards achieving its objectives in the short or medium term.

2.2 The Chair reported that the ESRC Council had met in February. Following discussion with the Authority, the ESRC Chief Executive Officer made a proposal to Council for a two year extension to the ADRN and the appointment of a Network Director. Ms Lucy Martin reported that the ESRC Council recognised the leadership issues within the ADRN, as identified by the ADRN Board, needed resolution. However, they did not feel that the ADRN had made enough progress to support an extension of funding at this point in time. It was unclear what the response was to the ADRN Board's consistent arguments for a Network Director. The Board were told that the ESRC are currently working on future options and plans for the ADRN. The Chair noted that the ADRN Board had not received a written reply to the Board's recommendations and requested that Ms Lucy Martin makes sure that the ESRC provide the ADRN Board with a written response as soon as possible.

2.3 The Board were informed that the Chair and the Deputy Chair met with Professor Peter Smith, the Network Director for data acquisition, to share the concerns of the NEDs about the slow rate of progress across the ADRN. Professor Smith confirmed that he had shared these concerns with the other Directors in the ADRN and the Pro Vice Chancellor at the University of Essex.

2.4 The Chair reported that he had informed the UK Statistics Authority Board of the NED's concerns.

### **3. Highlight Report [ADRN(17)01]**

3.1 Professor Peter Smith introduced the highlight report for the period between 14 January and 13 March 2017.

3.2 There was some discussion about the progress that had been made on data acquisition. The following points were made in the discussion:

- i. The Board welcomed the news that the ADRN researchers had successfully accessed both Census and Department for Work and Pensions (DWP) data since the last Board meeting.
- ii. It was suggested that these projects had acted as pathfinder projects. A lot had been learned during the process of extracting the data for these projects about the departments' internal processes and the amount of resource required within each department to produce bespoke linked data sets for research purposes. It was stressed that it was important that these pathfinder projects lead to the speedy extraction of data for other projects in the next couple of months.
- iii. It was reported that there were 16 approved ADRN projects wanting to access DWP data and that DWP and the ADS had prioritised eight of these projects.
- iv. The Board heard that DWP were identifying what linked data would answer the majority of research questions that were being posed more generally by ADRN researchers. This kind of strategic thinking was welcomed by the Board. Professor Smith was asked to make sure the Network Directors and staff fully contributed to this work. It was suggested that there had been a lack of this kind of work within the ADRN in the past.
- v. The Board were informed that nobody within the Administrative Data Service had either noticed that four of the eight potential projects using DWP data required access to HMRC data or had realised the implications of this. It was suggested

that lessons had to be learned from this quickly so that the chances of this happening again were reduced. DWP and ADS had discussed this particular issue at working level and have identified how ADS can address it in future projects. Professor Smith was asked to liaise with the ADS to put in place processes and checks to make sure this does not happen with future projects. It was noted that it is the data with the longest time to access which determines the start date of analysis.

- vi. It was reported that that it was important for researchers to know how long they would be expected to wait for data. It was confirmed that DWP and the ADS are working together to provide feedback to researchers.
- vii. The Board welcomed the revised website which was considered a significant improvement on the previous website.

#### **4. Report from the Approvals Panel [ADRN(17)02]**

4.1 Dr Andrew Garrett presented an update from the Approvals Panel. The Board were informed that the Approvals Panel agreed with the Board that it would be helpful if the Network pursued more efficient ways of arranging data provision for projects, particularly exploring ways to reuse data.

4.2 The Board were informed that Dr Garrett had suggested to the Chair of the Board and Chair of the Approvals Panel that as the Approvals Panel was now working well there was no longer the need for a Board member to sit on the Approvals Panel. This recommendation has been agreed by both the Chair of the ADRN Board and the Chair of the Approvals Panel. In the future, the Chair of the Approvals Panel will provide regular updates to the Board on the work of the Approvals Panel.

#### **5. Progress on Data Acquisition [ADRN(17)03]**

5.1 Professor Smith presented an update on the progress made with data acquisition. This included an update on the progress that had been made against the data acquisition milestones, the progress with those departments that are not included in the milestones and the progress in the devolved administrations. Professor Smith also presented the data acquisition plan for 2017 which has been developed by the strategic data negotiator.

5.2 The following points were made in the discussion:

- i. The Board noted that only one out of the five data acquisition January milestones had been fully met. Serious concerns were expressed at this lack of progress. The lack of progress would be reported to the UK Statistics Authority Board in April.
- ii. The data acquisition plan for 2017 that has been developed by the strategic data negotiator was welcomed. It was suggested that some of the steps in the plan should have been put in place much earlier by the Administrative Data Service. Concern was expressed at the large number of actions within the plan for the strategic data negotiator. Professor Smith was asked to make sure that the Directors' Group provided the necessary support for the speedy realisation of the plan and that the Directors' Group made a significant contribution to taking forward the strategic elements of the plan.
- iii. The importance of quickly meeting the January milestones and successfully putting in place the data acquisition plan for 2017 was stressed. It was recognised that the data acquisition plan for 2017 would not lead to many projects in the next couple of months. However, it was suggested that the resources existed across the Network to make faster progress towards meeting the milestones and to implement the data acquisition plan. Professor Smith, as Network Director for data acquisition, was asked to work with the Directors Group

to manage the Network's resources to ensure that faster progress with the January milestones was made and that the strategic data negotiator had the resources and support of the Directors to successfully implement the strategic plan quickly.

- iv. Concern was expressed at the vagueness of the July milestones and that they seemed to bear little relation to the data acquisition plan for 2017. Professor Smith was asked to make sure the July milestones were more specific and to link the milestones to the data acquisition plan for 2017.

## **6. Data Reuse [ADRN(17)04]**

- 6.1 Professor Smith reported on the progress that has been made with the development of a data reuse policy. It was reported that further work to review the ADRN policies which will need changing to enable the reuse of data had been completed but was not reflected in the paper.
- 6.2 The Board reiterated that moves towards enabling the reuse of data for research purposes need to happen quickly if the ADRN is going to realise its full potential. It was noted that there are departments that want to deposit data in the ADRN to be reused for a range of policy relevant research but they are currently unable to do this because of the current restrictive ADRN reuse policy. It was recognised that the ADRN would only reuse data if the data owner was happy for their data to be reused.
- 6.3 Given the Board has been urging a policy for reuse of data for the last year, it was felt that not enough progress had been made by the Directors Group on taking forward the practical steps to enable the policy to happen. It was suggested that future work in this area should focus on urgently taking forward the practical steps required to put this policy in place rather than focusing on the theory of a change of policy. Professor Smith was asked to communicate to all components of the Network the importance of quickly developing the data reuse policy, of taking operational steps needed to ensure it could be put into place, and to bring the policy to the next Board meeting. The Board agreed that the impediments were not to the theory or even the legality of reusing 'anonymised' data sets but in taking the practical steps to ensure that the policy could be put into place and announced. This included discussions with data owners and the Information Commissioner. The Board expected the practical steps to have been taken in time for its June meeting.

## **7. A view from the ADRC-England (ADRC-E)**

- 7.1 Professor Ruth Gilbert provided an update from the ADRC-E. The Board heard about the work that had been done on a range of methodology and exemplar research projects within the ADRC-E. The Board were informed that these projects were not counted as ADRN projects even though they had received ADRN funding either in part or whole. This was because the data for these projects was held in secure environments that were not currently part of the ADRN.
- 7.2 It was suggested that not counting these projects as ADRN projects, even though they received ADRN funding, meant that the Network appeared less successful in facilitating research projects using administrative data than was actually the case. Professor Peter Smith was asked to work with the Directors Group to ensure that all of the projects that receive some ADRN funding are classified as ADRN projects and are reported at future Board meetings.
- 7.3 It was noted that the independent mid-term review of the ADRN recommended that these projects should be classified as ADRN projects. Ms Martin was asked to share with the Board the ESRC's plans to publish the independent mid-term review.

**8. Legislative Issues [ADRN(17)05]**

- 8.1 Ms Sharon Witherspoon presented an update on the progress of the Digital Economy Bill. Both the House of Common and the House of Lords have been broadly supportive of the aims of the Bill while emphasising the need to consider safeguards carefully.
- 8.2 Officials from the UK Statistics Authority continue to support Ministers and parliamentarians during the Bill's passage, and work with colleagues across Government on the development of the codes of practice and implementation frameworks. The Authority will consult publicly on the codes in due course.

**9. Any other business**

- 9.1 There was no other business.





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

***Agenda***

***Monday, 3 April 2017  
Board Room, One Drummond Gate, London  
11:30am – 2:15pm (coffee from 10:00am)***

**Chair: Professor David Hand**

**Apologies:**

**10:00 to 11:30 – Non-executive session**

**Part A (11:30am to 12:45pm)**

|              |   |                                     |
|--------------|---|-------------------------------------|
| 1<br>11:30am | Minutes and matters arising from previous meeting | Professor David Hand                |
| 2<br>11:40am | Chair's report                                    | Oral Report<br>Professor David Hand |
| 3<br>11:50am | Highlight report                                  | ADRN(17)01<br>Professor Peter Smith |
| 4<br>12:05pm | Report from the Approvals Panel                   | ADRN(17)02<br>Dr Andrew Garrett     |
| 5<br>12:15pm | Progress on Data Acquisition                      | ADRN(17)03<br>Professor Peter Smith |

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

**Part B (1:15pm to 2:15pm)**

|             |                              |  |
|-------------|------------------------------|--|
| 6<br>1:15pm | A view from the ADRC-England | Presentation<br>Professor Ruth Gilbert |
| 7<br>1:45pm | Data retention               | ADRN(17)04<br>Professor Peter Smith    |
| 8<br>2:00pm | Legislative issues           | Oral Report<br>Ms Sharon Witherspoon   |
| 9<br>2:10pm | Any other business           |  |

**Next Meeting: Monday 5 June 2017, Drummond Gate, London**



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| 1. Minutes     |
| 2. Chair's     |
| 3. Highlight   |
| 4. Approvals   |
| 5. Acquisition |
| 6. ADRC-E      |
| 7. Data reuse  |
| 8. Legislation |
| 9. AOB         |

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

Minute

Monday, 7 November 2016

Boardroom, Drummond Gate, London

Present

Board Members

Professor David Hand (Chair)

Ms Sharon Witherspoon

Dr Fiona Armstrong

Mr Jonathan Athrow

Mr Peter Benton

Ms Siobhan Carey

Dr Andrew Garrett

Mr Colin Godbold

Mr Roger Halliday

Mr Glyn Jones

Professor Denise Lievesley

Ms Frances Pottier

Mr Luke Sibieta (for items 7 to 11)

Professor Peter Smith

Mr Nicky Tarry

Mr Darren Warren

Ms Penny Young

UK Statistics Authority

Dr Simon Whitworth

Economic and Social Research Council (ESRC)

Dr Lucy Martin

Administrative Data Research Centre – Northern Ireland

Dr Dermot O'Reilly

1. Minutes and matters arising from previous meeting
- 1.1 The minute from the previous meeting held on 7 November 2016 was agreed by correspondence and is published on the [UK Statistics Authority Website](#).

|            |            |              |              |                |           |               |                |        |
|------------|------------|--------------|--------------|----------------|-----------|---------------|----------------|--------|
| 1. Minutes | 2. Chair's | 3. Highlight | 4. Approvals | 5. Acquisition | 6. ADRC-E | 7. Data reuse | 8. Legislation | 9. AOB |
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|------------|------------|--------------|--------------|----------------|-----------|---------------|----------------|--------|
| 1. Minutes | 2. Chair's | 3. Highlight | 4. Approvals | 5. Acquisition | 6. ADRC-E | 7. Data reuse | 8. Legislation | 9. AOB |
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Chair's Report  
Professor David Hand

|            |            |              |              |                |           |               |                |        |
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**HiUK STATISTICS AUTHORITY**  
**ADMINISTRATIVE DATA RESEARCH NETWORK BOARD**

ADRN(17)01

***Highlight Report***

**Purpose**

1. This paper presents an Administrative Data Research Network (ADRN) highlight report for the period between the 14 January 2017 and 13 March 2017. **Annex A** provides more detail on the activities of the Network over the reporting period.

**Recommendations**

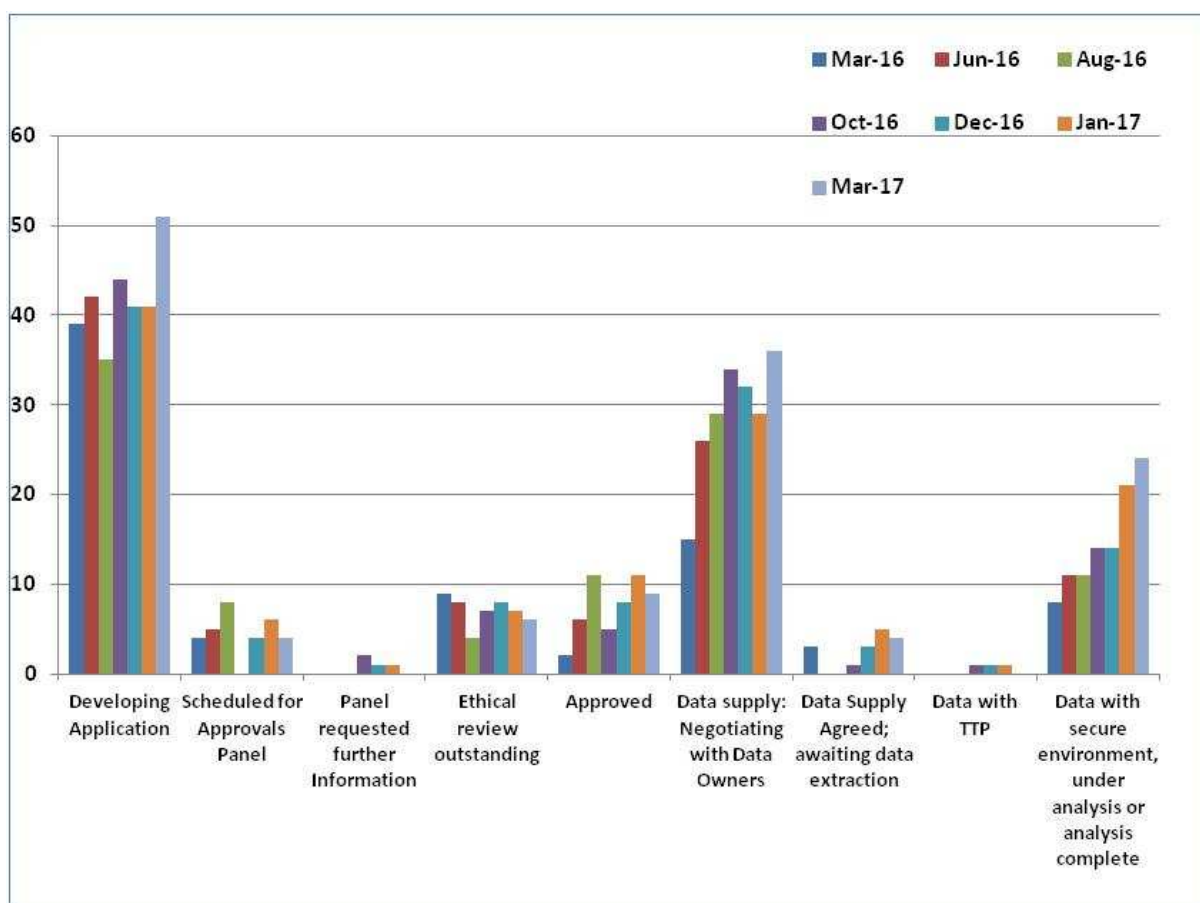
2. Members of the ADRN Board are invited to note and discuss the content of the highlight report.

**Discussion**

Projects at each stage of the ADRN process

3. The graph below presents how many projects are at each stage of the ADRN process. This information is shown in the format suggested by the ADRN mid-term review team. A total of 24 ADRN projects have accessed data. The majority of these projects (21) are from the Administrative Data Research Centres (ADRCs) in the devolved administrations. A comprehensive update on the progress being made accessing data is provided in ADRN(17)03.

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4. The table below presents how many projects from each ADRC are at each stage of the ADRC process.



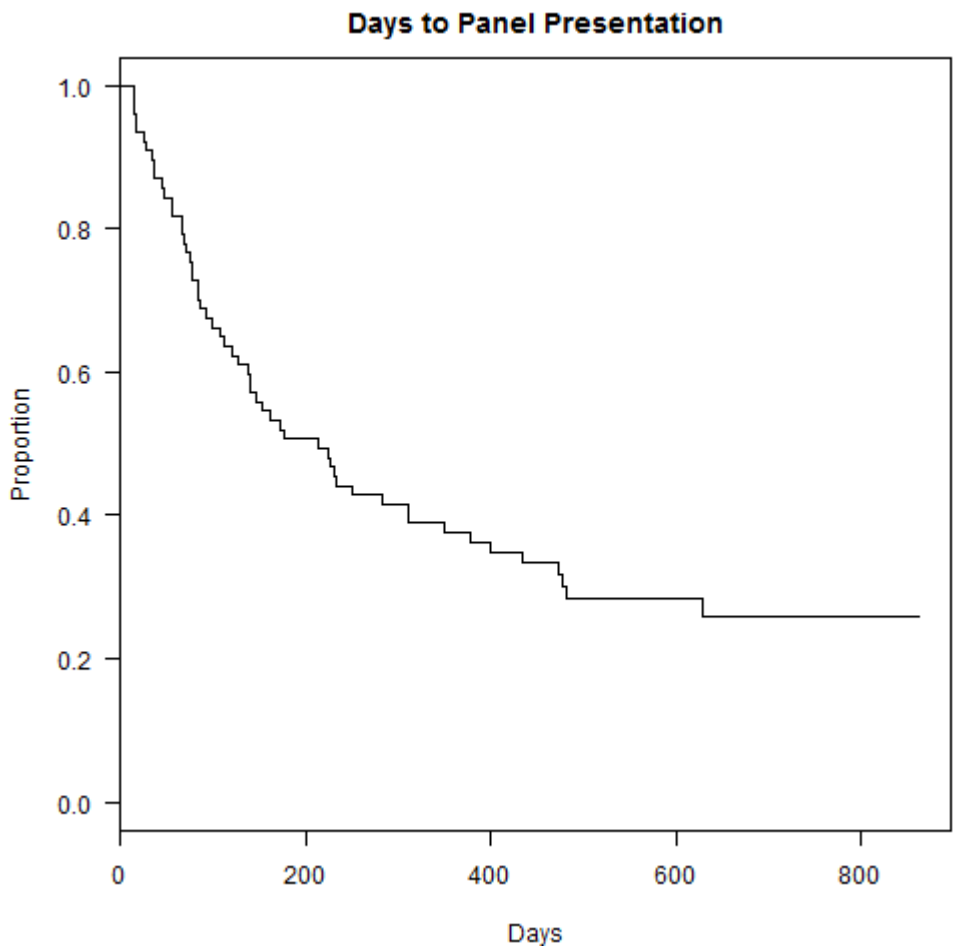
| Projects                                    | ADRC-England | ADRC-Northern Ireland | ADRC-Scotland | ADRC-Wales | Administrative Data Service |
|---|--------------|-----------------------|---------------|------------|-----------------------------|
| Developing Application                      |              | 14                    | 6             | 13         | 18                          |
| Scheduled for Approvals Panel               |              |                       | 3             | 1          |                             |
| Panel requested further information         |              |                       |               |            |                             |
| Ethical review outstanding                  |              |                       |               |            | 6                           |
| Approved                                    |              | 1                     | 2             | 2          | 4                           |
| Data supply: Negotiating with data owners   |              | 6                     | 11            | 4          | 15                          |
| Data supply agreed awaiting data extraction |              | 2                     | 1             |            | 1                           |
| Data with TTP                               |              |                       |               |            |                             |
| Data with secure environment (ADRC)         |              |                       |               | 3          |                             |
| Researchers conducting analysis             | 3            | 5                     | 3             | 7          |                             |
| Analysis complete                           |              | 2                     |               | 1          |                             |

5. The developing application category includes all projects at various stages of development. This represents a pipeline of future projects and includes projects that have been registered with the ADNRN but have not yet been approved. It also includes projects from researchers who have a planned work programme and who are not expecting to progress their project until a point in the future.
6. The reasons why projects are not getting as far as the Approvals Panel are as follows:
  - i. data providers give prognosis for data which makes projects unfeasible
  - ii. researchers pursue other priorities
  - iii. some researchers are managing forward plans by logging projects with clear indications it fits into a programme of work in the future
7. A total of 21 projects have been stopped. The reasons why these have been stopped are listed below:
  - i. 2 projects were rejected by the Approvals Panel;
  - ii. 1 project was stopped as the data the researcher required did not exist;
  - iii. 11 projects were stopped as the researchers did not obtain funding;
  - iv. 2 project were stopped because they were found not to meet ADNRN criteria;
  - v. 1 project was stopped due to insufficient resource; and
  - vi. 4 projects were stopped as the researcher chose not to progress the project.

#### Time it is taking for projects to progress through the ADNRN process

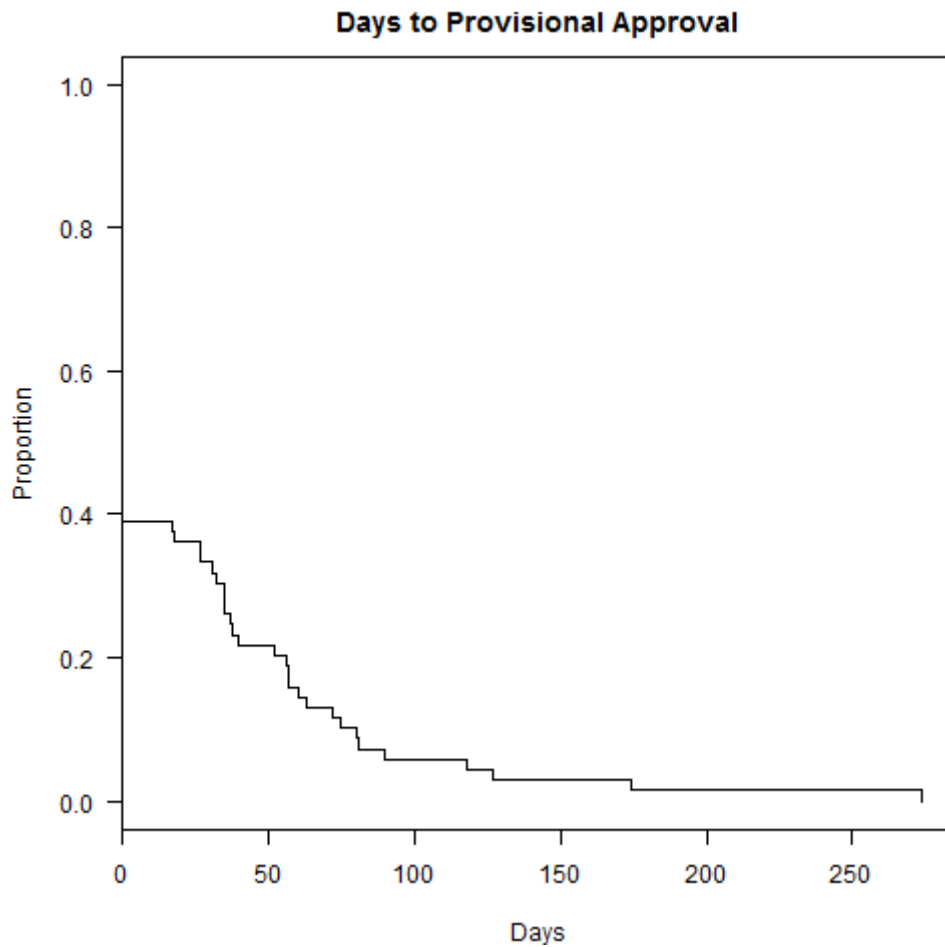
8. The Kaplan-Meier estimate of the distribution of the time taken from a project being assigned a Project Number, the “start date”, to being presented to the Approvals Panels is provided in the figure below. Note that stopped projects are not included when producing this figure. This figure indicates that the increase seen to around 35% of projects being presented to the Approvals Panel within three months of being allocated a Project Number has been maintained and around 60% are presented within a year. The

figure also suggests that if a project has not been presented within a year, currently around 30% of projects, it is unlikely to be forthcoming.

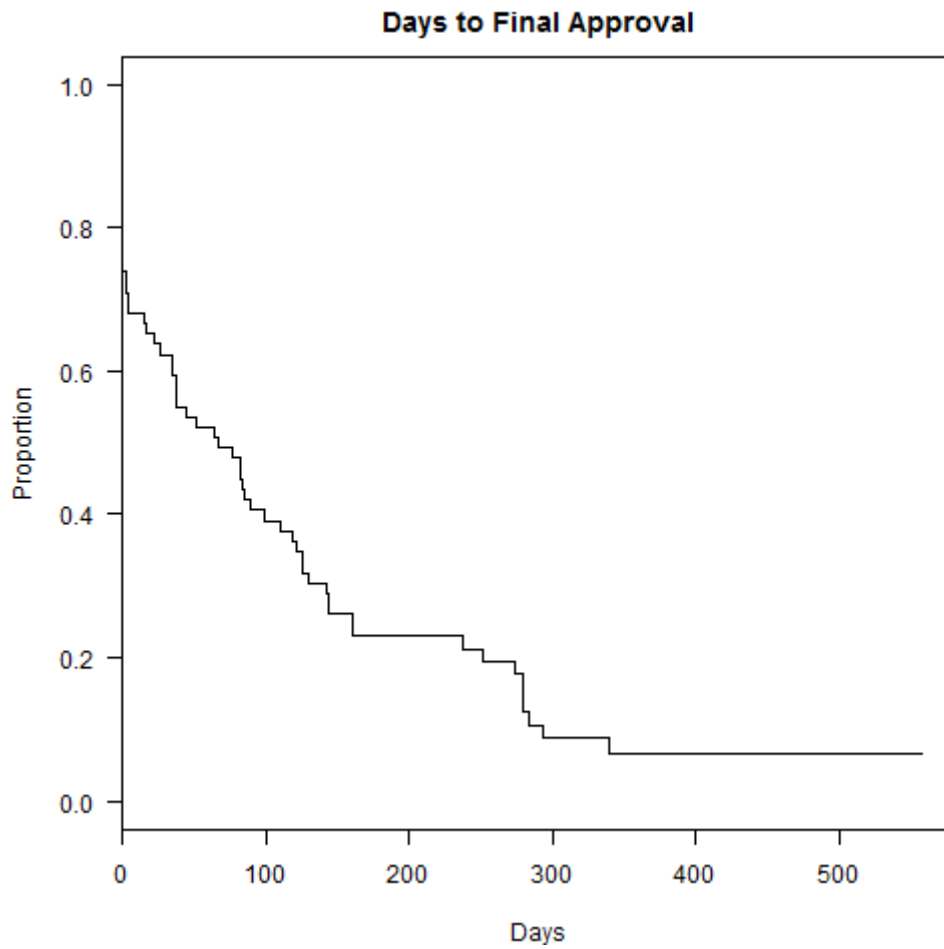


9. The Kaplan-Meier estimate of the distribution of the time taken from a project being presented to the Approvals Panels to it being provisionally approved is provided in the figure below. This figure indicates that over 60% of projects are provisionally approved the first time they are considered by the Approvals Panel and around 85% within two months; fewer than 10% have to wait longer than three months for provisional approval. This has changed little since the last highlight report.

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| 1. Minutes     |
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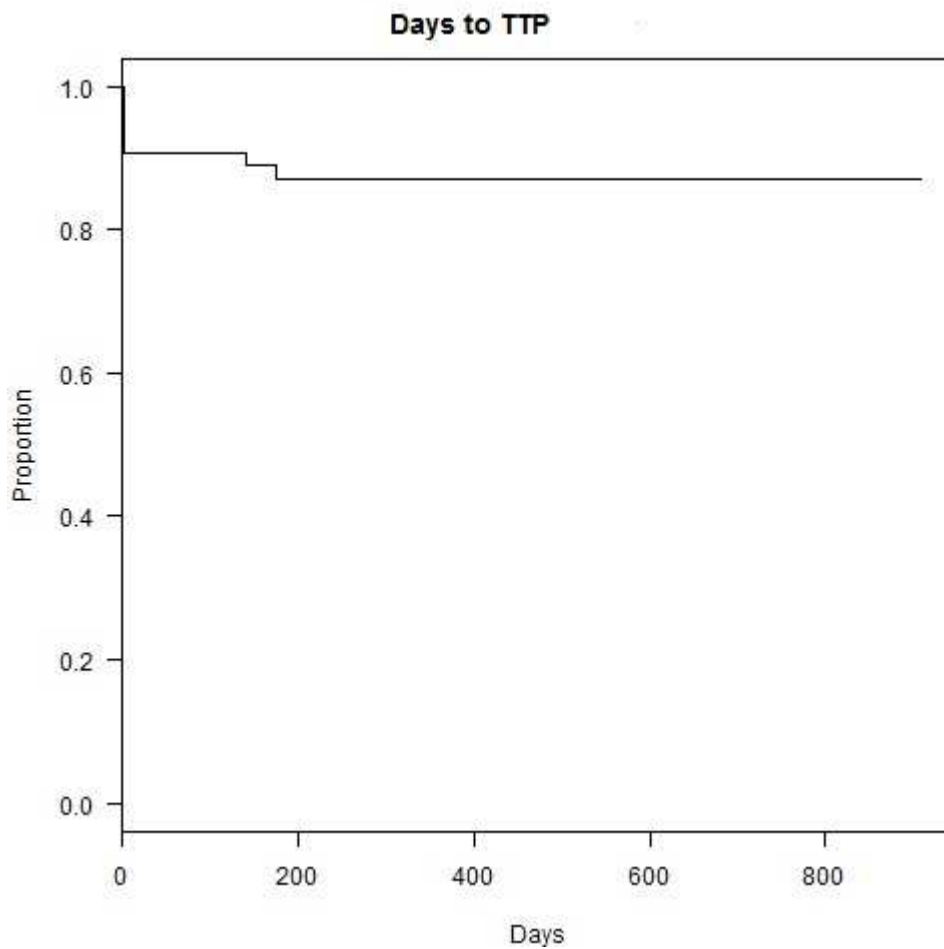
10. The Kaplan-Meier estimate of the distribution of the time taken from a project being presented to the Approvals Panels to it receiving final approval is provided in the figure below. This figure indicates over 20% of projects receive final approval the first time they are considered by the Approvals Panel and an increase to around 50% within two months. Around 40% have to wait longer than three months for final approval. Please note that it was the earlier projects that took a relatively long time to receive final approval.



#### Days to data being provided to the Trusted Third Parties

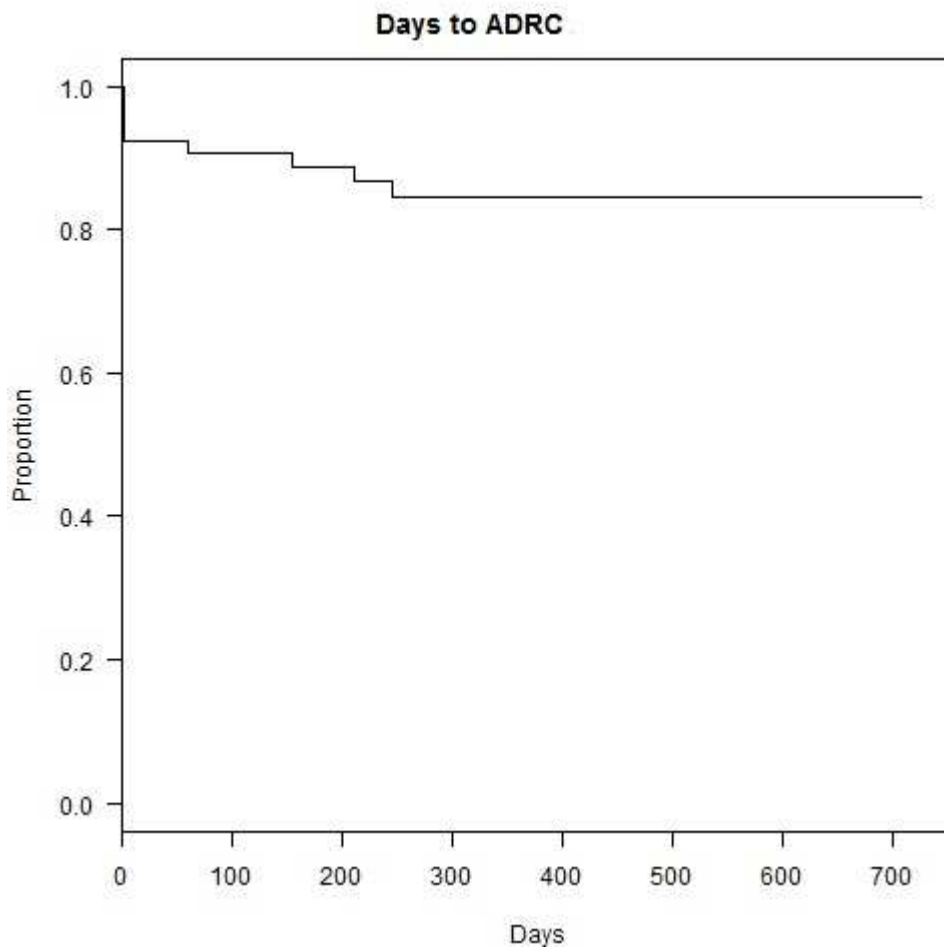
11. At present, most projects with data are using data already available in databanks, therefore 10% of projects with data in the Trusted Third Parties have short timescales.

|            |            |              |              |                |           |               |                |        |
|------------|------------|--------------|--------------|----------------|-----------|---------------|----------------|--------|
| 1. Minutes | 2. Chair's | 3. Highlight | 4. Approvals | 5. Acquisition | 6. ADRC-E | 7. Data reuse | 8. Legislation | 9. AOB |
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Days to data being provided to the Secure Research Environment in the ADRC

12. At present, most projects with data are using data already available in databanks, therefore 10% of projects have short timescales.



### 13. Data Security

There are no data security issues to report.

**Jo Webb, ADRN data acquisition project team, and Peter Smith, Director ADRC-England, 20 March 2017.**

**Annex A      ADRN Activity Report**

|            |            |              |              |                |           |               |                |        |
|------------|------------|--------------|--------------|----------------|-----------|---------------|----------------|--------|
| 1. Minutes | 2. Chair's | 3. Highlight | 4. Approvals | 5. Acquisition | 6. ADRC-E | 7. Data reuse | 8. Legislation | 9. AOB |
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## Annex A      ADRN Activity Report

### Infrastructure/ Network developments

Administrative Data Research Centre-Wales (ADRC-W) has attracted over £1.3 million in external funding and has a strong pipeline of projects that cover many subject areas from health, police and crime, social policy, housing, education, childrens services and more.

### Micro Safe Settings Network

Regional Safe Settings have been reviewed and approved by CLAS consultant. A prototype SafeDesk has been set up at the University of Dundee

(<https://www.dundee.ac.uk/hic/news/2017/the-administrative-data-research-centre--hic.php>)

The establishment of the Regional Safe Settings will reduce the burden on researcher time and costs and incentivise the development of new projects with the increased flexibility of access to project data, with researcher interest already received.

Regional Safe Setting and prototype SafeDesk for the Universities of Glasgow and Aberdeen will be set up by the end of April / early May.

### Events

ADRC-W has undertaken a range of events from an Alcohol seminar in December to a security and Information Assurance event along with a range of Public Engagement events. In early February they hosted a visit by Finnish government and HEI staff who were interested in the ADRC-W model on utilising admin data.

### Communications

Over 50 people a month are visiting the ADRN blog <https://www.adrn.ac.uk/understand-data/blog/> with articles from across the ADRN on a range of subjects.

The Network communications and public engagement teams met in Belfast in February to plan communications activities to support working with data owners. An initial stakeholder mapping was undertaken to identify key figures for the Network. The main focus was on data owners and data acquisition.

ADRC- England (ADRC-E) PhD student Louise McGrath-Lone published a blog article on The Conversation entitled 'Why some children are more likely to go back into care than others'. The article was promoted through Twitter and in the ADRC-E internal mailing list.

### Training offered

Training sessions offered by the Centres included:

- ADRC-E's Introduction to Data Linkage, London, 6 Feb
- Introduction to Spatial Data & Using R as a GIS, London, 14 Feb 2017 (joint course with Consumer Data Research Centre (CDRC))
- Confident Spatial Analysis, London, 15 Feb 2017 (joint course with CDRC)
- ADRC-S's research seminar "Jupyter Notebooks a Quick-Step Towards Literate Computing and Reproducible Research" was held 26.1.17 [tinyurl.com/zj64u9h](https://tinyurl.com/zj64u9h)
- "Introduction to the Jupyter Notebook for Social Survey and Administrative Social Science Data Analysis 26.1.17 [tinyurl.com/zf5h6aw](https://tinyurl.com/zf5h6aw) at the Edinburgh Q-Step Centre.

The researcher training (SURE) continues to be well attended, with more sessions planned across the centres.

## Researcher Engagement

ADRC-E/University of Southampton (UoS) Research Fellow, Corine Driessens, has successfully obtained £250,000 funding from Nuffield Foundation; she along with Peter Smith and colleagues from Southampton and the Mental Health Foundation will carry out research on evaluating the effect of community mental health services during the times of economic insecurity;

UoS ADRC-E contributed to successful bid for Horizon 2020 funding to launch DataPitch, a competition whereby data entrepreneurs will bid for funding to carry out an innovative piece of research on a dataset.

During International Womens Day ADRC-E repurposed pieces of their ADRC-E Research 2016 brochure on Twitter. Five targeted tweets generated a pick up of 5,323 organic impressions on 8 March.

ADRC-E have been engaging with ONS to raise awareness amongst potential ONS researchers in January and spoke to the ONS Social Survey Division (SSD) to raise awareness amongst potential government researchers in March.

In February, ADRC-Northern Ireland (ADRC-NI) and the Northern Ireland Council for Voluntary Action (NICVA) held a data workshop for the Voluntary Community Sector Enterprise focusing on researchers into carer's and caring. Over 20 people from across the voluntary sector, statutory agencies, academia and media took part in this event. Feedback surveys collated by NICVA following the event were overwhelmingly positive. The next ADRC-NI / NICVA data workshop is planned for May 2017 with the theme of 'mental health'.

In February the ADRC-NI held a Department of Education Data Workshop on the School Census and School Leavers Survey datasets that are potentially available from the Department. Over 40 people attend this event with representation from academia, government, voluntary, community and social enterprises and the media.

ADRC-Scotland (ADRC-S) hosted a joint workshop with the [Scottish Civil Society Data Partnership project](#) (S-CSDP) in February to help develop use of their databases as research resources.

The ADRC-S synthetic data team presented to Scotland's Public Benefit and Privacy Panel on the benefits of releasing an entirely synthetic non-disclosive versions of health and social care individual-level datasets.

## Presentations

ADRC-E and ADRN Director Peter Smith was invited to attend the UN World Data Forum in Cape Town, South Africa on 16-18 Jan 2017, He gave a presentation about the ADRN, the ADRC-E and other collaborations with the Office for National Statistics and introduced the audience to the work of the ADRC-E and the ADRN.

The ADRC-S legal team were invited to deliver training at the Urban Big Data Centre in Manchester in February on "Legal myth-busting" for researchers. Leslie Stevens' presentation is available at [youtube.com/watch?v=jyXe\\_Y6-Ilo](https://www.youtube.com/watch?v=jyXe_Y6-Ilo), along with a video of a presentation on Data Access Applications and Safe Hsvens at the same event by Amy Tilbrook from the ADRC-S User Services Team [youtube.com/watch?v=pl72cSG2eBl](https://www.youtube.com/watch?v=pl72cSG2eBl). Leslie also was been invited to attend the British Academy / Royal Society roundtable on Data Governance along with key organisations to a roundtable at the British Academy on January that includes engagement with the legal sector in the Data Governance project.

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| 1. Minutes     |
| 2. Chair's     |
| 3. Highlight   |
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## Publications

The second Network Guide has been published and is available on the website. Written by Jessica Bell and Heather Gowans of Administrative Data Service (ADS), this guide is aimed at academic researchers who have an association with the ADRN as well as at a general audience interested in the subject matter. For Network researchers, the document will serve as useful background for the legal aspects of the certification training they receive before they can access the service. Wider audiences might be interested in how the Network's secure environment ensures the data access we allow is fair and lawful.

The guide sets out the legal background to data protection laws in the UK, and offers a broad explanation of the current law relating to data sharing and linkage, as well as a consideration of the implications of the impending EU General Data Protection Regulation 2016. There is also consideration of some non-legal issues surrounding the topic. Readers can refer to the Network's website for further information, and should consult professional legal advice on any specific legal points. A copy can be accessed at [http://www.adrn.ac.uk/media/174205/legal\\_guide\\_final.pdf](http://www.adrn.ac.uk/media/174205/legal_guide_final.pdf)

Other publications include:

- McGrath-Lone L, Dearden L, Harron K, Nasim B, Gilbert R. (2017). Factors associated with re-entry to out-of-home care among children in England. *Child Abuse and Neglect*, pp. 73-83;
- Downs J, Gilbert R, Hayes R, Hotopf M, Ford T. (2017). Linking health and education data to plan and evaluate services for children. *Archives of Disease in Childhood*, pp. archdischild-2016-311656;
- Harron K, Hagger-Johnson G, Gilbert R, Goldstein H. (2017). Utilising identifier error variation in linkage of large administrative data sources. *BMC Medical Research Methodology*, 17 (1).
- A publication led by the ADRC-S legal team by Springer "Dangers from Within? Looking Inwards at the Role of Maladministration as the Leading Cause of Health Data Breaches in the UK" was published 8.2.17 [http://link.springer.com/chapter/10.1007%2F978-3-319-50796-5\\_8](http://link.springer.com/chapter/10.1007%2F978-3-319-50796-5_8).
- G.Laurie and L.Stevens contributed to the January 2017 publication "The other side of the coin: Harm due to the non-use of health-related data)" in co-authorship with ADRC-W in *International Journal of Medical Informatics* <http://dx.doi.org/10.1016/j.ijmedinf.2016.09.010>
- ADRN blog articles by [Prof. S. McVie](#) "It's a criminal waste: How using administrative data about crime could better inform public policy" and [Alasdair Gray](#) on "the Digitising Scotland Project Colloquium on the Isle of Raasay"
- [Publication](#) "Practical data synthesis for large samples by G. Raab, B. Nowok C. Dibben
- [Publication](#) Revised version of "synthpop: Bespoke Creation of Synthetic Data in R"

## Forward outlook

### Training

The following training is taking place:

- SURE training is planned at all four centres;
- Introduction to Hospital Episode Statistics (HES), Southampton, 27-28 Mar 2017;
- Generating Synthetic Data for Statistical Disclosure Control, Birkbeck, University of London, 2-3 May 2017;
- Introduction to Data Linkage, London School of Hygiene and Tropical Medicine, London, 16 May 2017;
- Combining data from multiple administrative and survey sources for statistical purposes, Southampton, 8-9 Jun 2017;
- SQL Database management software, Farr Institute, London, 28 Jun 2017;
- A Master Class with Paul Lambert on “Generalized Linear Mixed Models” (ADRC-S); and
- Workshops on “Longitudinal Data Analysis for Administrative and Social Survey Data” and on SynthPop, (ADRC-S).

### Researcher Engagement

#### ADRN research conference in Edinburgh 01 and 02 June 2017:

- Three international keynote speakers, Roundtable led by EU Joint Research Centre, 105 talks, 20 posters confirmed. Conference website [ADRN2017.net](http://ADRN2017.net) designed and operated by ADRC-S on behalf of the network receiving many visits. Outline programme has been developed and calendar will be published early in April on the website with a companion mobile app. The next meeting of the ADRN Expert Group on Information Assurance has been set for 2 June at the Conference venue to enable group members to attend most of the conference.
- The external profile has been significant: 1 in 11 of the accepted abstracts have been submitted by overseas presenters; 11% of abstracts are co-authored from overseas; 61% of the accepted abstracts are from researchers unaffiliated to the ADRN.
- The special conference roundtable plus posters organised by five senior officers at the European Commission's Joint Research Centre's 'Competence Centre on Micro Evaluation' should further stimulate Scottish-government focused effort in developing regional capability in using predictive analytics tools to improve policy outcomes in Scotland with research contributions from ADRC-S. This is an effort which has been building since ADRC-S, with the Urban Big Data Centre, began work with Scottish and New Zealand Government in November 2015.

#### ADRN Research Conference 2018

The Network have requested that ADRC-NI host the conference for 2018, this will be the Centre’s second hosting of the flag ship annual event.

#### Other researcher engagement

ADRC-S researchers are planning to present at a [workshop](#) on linking historical records at the University of Guelph, Social Policy Association Annual [Conference](#), ESPAnet’s 2017 [conference](#) in Lisbon on new horizons of European social policy.

A paper has been accepted from Gayle and Connelly on “An investigation of the consistency of parental occupational information in UK birth records and a national social survey” by the European Sociological Review.

ADRC-E has organised the following meetings engaging with researchers and stakeholders:

- Scoping meeting held with Family Justice Service, MoJ, DfE;
- Frontiers meeting on pollution, education and health data – funded by Farr and forward programme of research agreed across ADRN/UK Farr;
- ADRC-E work featured in symposium on using data to improve services for vulnerable adolescents (addressed by Dame Sally Davies);
- Ruth Gilbert speaking to University College London meeting on UK Biobank, cohorts and big data on 22 Mar 2017.

ADRC-NI are holding their second researcher awayday in March. 39 ADRC-NI funded Project Investigators, Post-Doctoral researchers and Ph.D. students have confirmed their attendance. In addition to presentations on their research, the day will consist of discussions on initiatives and methodological developments in specific research areas. Mr Jon Smart, Project Manager from ADRC- Wales will present on the Welsh Centre's work and data. The ADRC-NI User Forum have been engaged in preparations to ensure this researcher focused event meets the information and developmental needs of researchers from both local institutions.

ADRC-NI are presenting to the NI Human Rights Consortium in March.

### **Research partnership development**

ADRC-NI has been working closely with ADRC-NI/Queens University Belfast PhD student Erin Early to develop a public engagement approach to her PhD project using ADRC-NI education data, specifically looking at educational attainment. Meetings have been held with representatives from the East Belfast Partnership (EBP), which delivers the 'EastSide' Learning Project. This positive meeting resulted in plans being made between the researcher and the EBP for ongoing engagement and partnership.

### **Public Engagement**

A new public engagement activity has been designed and developed to enable the public to understand data linkage to benefit society (ie Better Candies Benefit Society). The first run of the activity will take place at the Southampton Science and Engineering Festival 2017 at the University of Southampton and is expected to have over 6,000 attendees. ADRC-E will engage members of the public (300+ people estimated at the stand) with two hands-on data science activities. A follow up blog and communications activities are planned.

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UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(17)02

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

Purpose

- 1. This paper provides an update for the 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. Is the project feasible?
  - ii. Are any relevant privacy implications sufficiently mitigated?
  - iii. Has the project successfully completed a formal ethical review?
  - iv. Is there potential public benefit?
  - v. Is there demonstrable scientific merit?
- 4. The Approvals 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. Steve Rose (Birmingham City Council);
  - v. Professor Richard Harris (University of Durham);
  - vi. Dr John Power (Northern Ireland Assembly);
  - vii. Professor Robert T Woods (University of Bangor);
  - viii. Lynn Wyeth (Leicester City Council);
  - ix. Dr Andrew Garrett (ADRN Board member);
  - x. William Mehaffy (lay member); and
  - xi. Jen Persson (lay member).

Discussion

- 5. Since the last report to the Board the Approvals Panel has met twice, with meetings on 13 February and 14 March.
- 6. During the February meeting the Panel discussed the challenges the Network face regarding the supply of data by government departments. The Panel agreed that it would be helpful if the Network pursued more efficient ways of arranging data provision for projects, particularly exploring ways to retain data in some form. The Panel also noted the importance of effective public engagement to inform any proposed policy change in this area. The Panel chair wrote directly to the ADRN Board chair with this feedback.

#### Update of any changes to Panel membership

7. The two-year term of Jen Persson as a lay-member within the Panel will come to an end in April 2017. A recruitment process was undertaken for a new lay-member during January and February with interviews held in late February. A new lay-member, Denise Kazmierczak, has been appointed to the Panel and her term will commence at the next Panel meeting (27<sup>th</sup> April, in Belfast).
8. Dr Andrew Garrett recently asked the Panel chair and secretariat to consider the relationship between the ADRN Board and the Approval Panel and determine the requirement for this relationship for the future. As a result, a proposal to maintain a link to the Board without direct Board representation in the Panel membership has been submitted to the Board chair for consideration.

#### Update of any changes to Operating Procedures

9. There have been no changes to the Operating Procedures of the Panel since the last report.

#### Calendar of future Panel meeting dates

10. Approvals Panel meeting dates for the remainder of 2017 are:
  - I. 27 April (face-to-face in Belfast);
  - II. 22 May;
  - III. 22 June;
  - IV. 25 July;
  - V. 31 August (face-to-face in Essex);
  - VI. 26 September;
  - VII. 1 November;
  - VIII. 28 November; and
  - IX. 19 December.

#### Titles of projects approved since previous Board meeting (as at 17<sup>th</sup> March)

11. The following projects have been approved:

|          |   |
|----------|---|
| PROJ-080 | The relationship between benefit sanctions, poverty and deprivation.  |
| PROJ-098 | Linking Annual Survey of Hours and Earnings to HMRC administrative data to analyse the impact of (vocational) education investment on earnings.   |
| PROJ-129 | Healthcare utilisation and educational outcomes among children exposed to adverse childhood experiences, children who receive social care and the general population: longitudinal analysis of routinely collected data in Wales. |
| PROJ-131 | Use of administrative data in developing direct measures of social capital: an exploratory study.   |
| PROJ-143 | Selective schooling and long-term health.   |
| PROJ-148 | Childhood cognitive function and later life economic activity: linking the Scottish Mental Survey 1947 to administrative data.  |
| PROJ-152 | What factors influence the transitions and trajectories of school leavers in  |

|          |  |
|----------|--|
|          | Scotland?  |
| PROJ-153 | Childhood cognitive function and later-life recovery: linking the Scottish Mental Survey 1947 to healthcare and administrative data. |
| PROJ-155 | Investigating the impact of supplementing income through charitable cash grants on educational outcomes in West Central Scotland.    |

12. 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.

13. The Administrative Data Service is continuing to work with the Administrative Data Research Centres (ADRCs) to provide 'public benefit summaries' for each of the projects Approved by the Panel. For projects where this has been achieved the summaries can be viewed here: <https://www.adrn.ac.uk/research-impact/research/>. These summaries now appear on the ADRN website alongside various other case studies which highlight the value of research using administrative data, some of which were facilitated by services under than the ADRN.

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

14. The Panel has not rejected any projects since the last Board meeting.

**John Sanderson, Approvals Panel Secretariat, Administrative Data Service, 20 March 2017.**

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UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(17)03

Progress on Data Acquisition

Purpose

- 1. This paper provides a summary of progress with data acquisition.

Recommendations

- 2. Members of the Administrative Data Research Network (ADRN) Board are invited to note and discuss the progress made which is detailed in **Annex A** and **Annex B**.

Background

- 3. A combined issue mitigation and data acquisition plan has been developed by the ADRN Directors group with input from the ADRN Board, Economic and Social Research Council and Department for Business, Energy and Industrial Strategy (BEIS). One of the key aims of this plan was to tackle the lack of progress with securing data from key UK government department and the plan focuses on making progress with five key data owners. The progress that has been made against the key data acquisition milestones identified in this plan is reported in **Annex A**.
- 4. Negotiations for access to data have also continued with departments not included in this plan. **Annex B** provides a summary of the progress that has been made with these departments and **Annex C** presents a summary of the progress that has been made in the Devolved Administrations.
- 5. A secondee from the UK Statistics Authority, Paul Jackson, has been appointed to assist ADRN with strategic acquisition of data. In his first couple of months in post Paul has identified the following work that needs to be urgently progressed:
  - i. present a new services prospectus to key departments at meetings with Departmental Director Generals;
  - ii. explain how those services fit with the opportunities and expectations arising from the Digital Economy Bill and the Better Use of Data transformation strategy;
  - iii. agree the pathway to a permanent relationship with ADRN tailored to the needs of the department and known research priorities; and
  - iv. sign “partnership agreements” acting in the manner of a call-off contract with ADRN to provide its services in support of specific projects with the minimum of bureaucratic burden at the project-by-project level.
- 6. Paul has also developed a data acquisition plan for 2017 which analyses current barriers to data acquisition, and sets out a five part strategy to overcome these barriers and embed new practices. This is attached at **Annex D**. This approach was agreed by the ADRN Directors on 9 March 2017. The actions from this approach have been added to the combined issue mitigation and data acquisition plan.

Jo Webb, ADRN data acquisition project team, 21 March 2017.

**Annex A**      **Progress against the key milestones in the combined issue mitigation and data acquisition plan**

|         |   |
|---------|---|
| Annex B | Progress with departments not included in the combined Issue mitigation and data acquisition plan |
| Annex C | Data acquisition in devolved administrations  |
| Annex D | Data acquisition plan for 2017  |

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## Annex A - Progress Against the Key Milestones in the Combined Issue Mitigation and Data Acquisition Plan

| Priority Department                    | Number of Approved Projects that are requesting data | Number of projects with data | How long negotiations have been in progress | Milestones in the combined issue mitigation and data acquisition action plan   | Progress against the milestones   | Further information   |
|--|--|------------------------------|---|--|---|---|
| Department for Work and Pensions (DWP) | 16   | 1                            | 14 months                                   | <u>October 2016</u><br>Result of submission to minister received.  | Met   | Meetings continue between ADS and DWP to discuss individual projects.<br><br>A round table meeting is planned for on 29 March with other data owners looking at a case study of a project with numerous data owners to discuss the linkage process. |
|  |  |                              |   | <u>January 2017</u> <ul style="list-style-type: none"> <li>- Data delivered for 2 projects; and</li> <li>- Data sharing agreement in place for the a third.</li> </ul>   | Partially met <ul style="list-style-type: none"> <li>- Data was delivered to the trusted third party for one project on 14 March 2017.</li> <li>- A further four projects, prioritised by DWP, are being progressed with two being predicted for delivery before July.</li> </ul> |   |
|  |  |                              |   | <u>July 2017</u> <ul style="list-style-type: none"> <li>- Data delivered for six projects in total; and</li> <li>- Metadata on DWP priority datasets developed and available via ADRN website</li> </ul>                               |   |   |
| NHS Digital                            | 8  | 1                            | 18 months                                   | <u>October 2016</u> <ul style="list-style-type: none"> <li>- Data delivered for one project;</li> <li>- Received approval from the Data Access Advisory Group (DAAG) for one project; and</li> <li>- Three more projects in</li> </ul> | Partially met <ul style="list-style-type: none"> <li>- Data delivered for one project.</li> <li>- One project considered by DAAG but not approved.</li> <li>- Five projects in negotiation.</li> </ul>  | A series of meetings have been held with NHS Digital to discuss how the ADRN can be treated with a higher priority than individual researchers.<br><br>A round table meeting with   |

|                                      |   |   |          |   |   |   |
|--------------------------------------|---|---|----------|---|---|---|
|                                      |   |   |          | data negotiation.   |   | NHS Digital and other data owners will take place on 29 March to discuss a case study of a project with numerous data owners and the linkage process.   |
|                                      |   |   |          | <u>January 2017</u> <ul style="list-style-type: none"><li>- Data delivered for project granted DAAG approval in Oct 2016;</li><li>- DAAG approval/data delivered for two more projects; and</li><li>- Metadata on key NHS Digital datasets available via ADRN website</li></ul>     | Not met <ul style="list-style-type: none"><li>- DAAG approval has still not been granted for the project submitted in 2016 (see Oct milestone)</li><li>- Two more projects have been submitted to NHS Digital but the ADRN has received no further information on future dates when DAAG will consider these projects.</li><li>- Metadata on key NHS Digital datasets not yet available via ADRN website.</li></ul> |   |
|                                      |   |   |          | <u>July 2017</u> <ul style="list-style-type: none"><li>- DAAG approval/data delivered for projects requesting data linked to DWP, DfE and ONS;</li><li>- One complex project with data from more than three departments linked; and</li><li>- One cross national project.</li></ul> |   |   |
|                                      |   |   |          |   |   |   |
| Office for National Statistics (ONS) | 5 | 2 | 8 months | <u>October 2016</u> <ul style="list-style-type: none"><li>- Two Welsh Government projects considered by the National Statistician's Data Ethics Advisory Committee (NSDEC).</li></ul>   | Met <ul style="list-style-type: none"><li>- Both projects have been considered by NSDEC. One was approved. The other will be reconsidered in the future once NSDEC's comments have been taken into consideration.</li></ul>   | The Strategic Data Negotiator visited ONS in February 2017 to discuss how to approach data owners for data. The ONS feedback on this has been considered in the development of the new approach to dealing with |
|                                      |   |   |          | <u>January 2017</u>   | Partially met   |   |

|                           |   |   |           |  |   |  |
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|                           |   |   |           | <ul style="list-style-type: none"> <li>- Data delivered for the two Welsh Government projects.</li> </ul>  | <ul style="list-style-type: none"> <li>- The linked data for one project has been delivered to the Administrative Data Research Centre-Wales;</li> <li>- One project is waiting for permission from the Minister for the Department of Health (DoH) to link DoH data to census data.</li> </ul> | data owners.   |
|                           |   |   |           | <u>July 2017</u> <ul style="list-style-type: none"> <li>- Clear pathway which enables ADRN to secure data within 2 months of project being approved.</li> </ul>  |   |  |
| Ministry of Justice (MoJ) | 1 | 0 | 12 months | <u>October 2016</u> <ul style="list-style-type: none"> <li>- Identify key decision makers for enabling ADRN to retain MoJ/DWP/HMRC linked dataset;</li> <li>- Identify any other data source MoJ might be willing to allow ADRN to make available for research; and</li> <li>- Identify requirements for project approval for retained data</li> </ul> | Met   | Discussions with MoJ have suggested that linkage to data held by MoJ must happen within MoJ. This restricts possible linkage to situations where MoJ has access to the data (e.g. some DWP and HMRC data). |
|                           |   |   |           | <u>January 2017</u> <ul style="list-style-type: none"> <li>- ADRN led data extraction for one MoJ data source;</li> <li>- Clear pathway to securing access to linked</li> </ul>  | Met <ul style="list-style-type: none"> <li>- MoJ National Offender Management data has been secured for use in an ADRC-Wales project and variables are being finalised; and</li> <li>- MoJ is aiming to have access</li> </ul>  |  |

|                                |   |   |           |   |   |  |
|--------------------------------|---|---|-----------|---|---|--|
|                                |   |   |           | MoJ/DWP/HMRC dataset (including all necessary steps) identified.  | to the linked MoJ/DWP/HMRC dataset available to researchers external to the MoJ by the end of March 2017. Following a successful pilot project ADNR researchers will be able to access this dataset.  |  |
|                                |   |   |           | <u>July 2017</u> <ul style="list-style-type: none"> <li>- Progression on pathway for obtaining MoJ/DWP/HMRC dataset for research use</li> </ul>   |   |  |
| Department for Education (DfE) | 8 | 0 | 15 months | <u>October 2016</u> <ul style="list-style-type: none"> <li>- Identify which datasets are controlled by DfE; and</li> <li>- Secure access to metadata for datasets in Secondary Data Analysis Initiative (SDAI) call.</li> </ul> | Partially met <ul style="list-style-type: none"> <li>- Datasets which are controlled by Centre for Longitudinal Studies rather than BEIS identified</li> </ul>  | A workshop is being developed with the DfE to explore possible research and processes. |
|                                |   |   |           | <u>January 2017</u> <ul style="list-style-type: none"> <li>- All DfE data delivered for three SDAI projects; and</li> <li>- Data sharing agreements in place with CLS.</li> </ul>   | Not met <ul style="list-style-type: none"> <li>- The CLS will deposit an enhanced version of an existing dataset with the UK Data service for one SDAI projects by mid-2017</li> <li>- A data sharing agreement for an extension to an existing National Pupil Database is being developed in order that the required data can be made available via the ADNR for a second SDAI project.</li> </ul> |  |

|  |  |  |  |   |  |  |
|--|--|--|--|---|--|--|
|  |  |  |  | <u>July 2017</u> <ul style="list-style-type: none"> <li>- Data delivered for four projects;</li> <li>- Data sharing agreements in place for another five projects; and</li> <li>- Clear pathway to access enabling ADNR users to secure access to DfE data within four months of approval.</li> </ul> |  |  |
|--|--|--|--|---|--|--|

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Annex B - Progress with Departments not included in the Combined Issue Mitigation and Data Acquisition Plan

| Department   | Number of Approved Projects that are requesting data | Number of projects with data | How long negotiations have been in progress   | Further information   |
|--|--|------------------------------|---|---|
| Department for Business, Energy and Industrial Strategy (BEIS) | 3  | 0                            | Negotiation have recently started to reflect the change of governance of the datasets | Ownership of datasets has been established as Department for Education.   |
| Department for Energy and Climate Change (DECC)                | 1  | 0                            | 21 months   | Discussions ongoing to establish data controller status   |
| Driver and Vehicle Licensing Agency (DVLA)                     | 2  | 0                            | 20 months   | The ADRN is learning from the Secure Anonymised Information Linkage Databank's (SAIL) ongoing negotiations with DVLA  |
| Higher Education Statistics Agency (HESA)                      | 3  | 1                            | Negotiations complete   | Straightforward pathway to HESA data offered through the ADRN. One project using HESA (Department for Employment and Learning) data has been delivered by the Administrative Data Research Centre-Northern Ireland. |
| HMRC   | 4  | 0                            | 25 months   | Digital economy bill will impact on HMRC's ability to share data. Meetings to discuss how ADRN and HMRC will work together if change happens are taking place.  |
| Universities and Colleges Admissions Service (UCAS)            | 5  | 0                            | Negotiations complete   | The complete UCAS dataset has been deposited with the UK Data Archive. Negotiations are underway for the datasets to be linked for the approved projects.   |
| Valuation Office Agency (VOA)                                  | 1  | 0                            | 14 months   | Digital economy bill will impact on VOA's ability to share data. Meetings to discuss how ADRN and VOA will work together if change happens are taking place.  |

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## Annex C - Data negotiation in devolved administrations

### Scotland

- **National Records Scotland:**
  - linked 2001 and 2011 Census data (linked to health) now being analysed in Safe Haven;
  - 2 pilot projects currently going through new National Records for Scotland process; and
  - 9 more projects in pipeline to request Census data
- **ScotXed:**
  - 2 data extracts (looked after children and pupil census) now being analysed in the safe haven; and
  - 4 projects approved by ScotXed panel and in process of Data Sharing Agreements/Extraction,
- **Phoenix Futures:** Data provision continues to be delayed by discussion about consent model.
- **National Crime Agency:** Data in safe haven ready to be linked/analysed.
- **Police Scotland:** Data access negotiations underway.
- **NHS National Services Scotland:**
  - first data extract now being analysed in the safe haven;
  - approval received for three projects to use health data; and
  - 6 projects to submit applications for approval, including linkage to historical birth cohorts (1936/1950s), linkage of health and crime data and first use of health data to perform spatial analysis,
- **Aberdeen Children of the Nineteen Fifties:** use of cohort agreed for education project about selective schooling; ADRN approval obtained; health data application submitted.
- **Scottish Mental Survey (1932, 1947):** use of cohort agreed for several projects. Signed approval for use from data controller received.

### Northern Ireland

Agreement in principle has been secured with 22 datasets from 12 data providers. Work is progressing with securing agreement in principle with health and justice data. The Administrative Data Research Centre-Northern Ireland (ADRC-NI) Data Prospectus is being reviewed and a new version will be uploaded in late autumn.

Specific departmental updates are as follows:

- **Department of Education:** access to data is still subject to legal issues being resolved.
- **The Department of Health's Business Service Organisation (BSO)** have established their governance arrangements for the ADRC and these have been approved by senior managers. The first extract of data has been received, matched and linked and researcher analysis has commenced. Data is being linked for another project and a number of other projects using BSO data are progressing.
- **Police Service of Northern Ireland Data:** access to data is still subject to legal issues being resolved.
- Access to data currently held in the **Honest Broker Service** is being negotiated and recent progress has been positive. It is hoped a time line for access will be available in the coming month.

### Wales

Administrative Data Research Centre-Wales (ADRC-W) has recently worked with Welsh Government and ONS to secure Census data for a project. This data is now in the centre and the researcher is being booked into the safe setting.

The Ministry of Justice National Offender Management data provision has been approved and discussion is now focussed on the variables to use for the project.

Local authority data is flowing for projects and further publications are expected in the near future.

The centre continues to enjoy an excellent partnership with Welsh Government (WG) and Farr and has an active programme of research. The ADRC has had approval and funding for the use of the National Research Data Appliance data linkage technology to be based in 5 pilot local authorities in Wales to support them using and benefitting from their own data as well as to support Welsh Government activities and research. Currently the pilot is focussing on Flying Start and Supporting People data, both of which are flagship WG programmes to support the people of Wales. This builds on the other funded projects undertaken for WG in collaboration with Farr.

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## Annex D- ADRN Data Acquisition Plan 2017

### Purpose

To make data acquisition a high-performing business practice for Administrative Data Research Network (ADRN) and for public authorities, in partnership.

### Outcomes

- A **trusted personality** for ADRN as a data partner for all public authorities.
- A **prospectus** of ADRN services and standards with respect to data.
- A clear **pathway** from issuing a prospectus to signing a partnership agreement.
- A **data partnership agreement** model, signed agreements for the 5 priority departments, and expressions of interest from the next priority set.
- A data acquisition delivery **plan and process** integrated into all ADRN services.

### Current issues in ADRN Data Acquisition

*Note - These positions are general statements, and apply most pertinently to the situation in England. There are many excellent exceptions to these general statements.*

#### 1) Trusted personality issues

Trust in ADRN as a recipient of data is not established in public authorities. ADRN lacks a personality that can be assigned the status of "trusted partner" in the singular. A public authority will not share risk management with a partner it is not able to trust. Data acquisition is a risk management activity.

#### 2) Prospectus issues

There is a lack of proper recognition by public authorities of ADRN as a new, different, and valuable stakeholder, and this inhibits their willingness to supply data. ADRN is not perceived as a business partner that will improve the services and the efficiency of the public authority. ADRN's project scrutiny, researcher training, data anonymisation, data linking, information assurance, data management, and data access facilities are not presented persuasively to public authorities as trusted nodes of a single coherent service, and are not recognised as being excellent. A lack of desire to benefit from these services means there is no imperative to supply datasets to ADRN. ADRN is not directly and clearly linked in the mind of senior government officials with the Government Transformation Strategy "Better Use of Data" and the Digital Economy Bill, and is not therefore seen as the solution to the challenges of that transformation.

#### 3) Pathways issues

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The route from being first engaged by ADRN to being in an agreement to supply data is not mapped out. The timeliness, cost, predictability and utility of supplied data are thought not to be significantly different to acquisitions achieved by Principle Investigators before the ADRN was established, probably because no new pathway has been formalised. In the absence of an excellent ADRN alternative, departments will tell ADRN what the pathway is to be in each of their cases. The most familiar pathway is the creation and supply of a one-off, stand-alone, unlinked dataset, and this does not establish a permanent pathway for future supplies of data.

**4) Data Partnership Agreement issues**

ADRN data acquisition is currently an exceptional process rather than business as usual and it is not founded upon a single model document set. Acquisition by ADRN is not embedded as a necessary routine within a wider objective in either the public authorities or in the ADRN. Further, new ADRN procedures are sometimes adding additional steps to the acquisition process, rather than simplifying the process for everyone. The key advantage of ADRN - a suite of joined-up and accredited services offering overarching governance and end-to-end management control of all risks in better use of data for research – is not presented to departments as something they should seek and benefit from through a Partnership Agreement.

**5) Delivery Plan and Process issues**

Excellent work has created a proved concept and a prototype for ADRN, but a production model has not been built from the working prototype and presented as the finished article. Without a production model, evaluation of what works and what needs improvement in data acquisition and project supply is difficult. ADRN partners can not schedule their contributions to data acquisition and other project support tasks. Resources are not being moved around ADRN from where they are (currently) in surplus to where they are (currently) most needed. The information system used for data acquisition is good for record keeping, but there is no automation, reminders, triggers, or routing in it, nor is it integrated with related ADRN functions and services.

**A 5 part Strategy to achieve high-performing business practices in data acquisition in 2017.**

*Note - All parts of the Strategy must take account of the role and functions of the UK Statistics Authority under the Digital Economy Bill / Act, in particular compliance with the Code of Practice, the accreditation standards, as well as any functions delegated to the ADRN. The pressure to acquire data means that this strategic relationship with the UK Statistics Authority under the Digital Economy Bill / Act is critical to data acquisition through 2017/18.*

**1) Personality for Trust.**

Identify the attributes of a **trusted partner** as a recipient of data, based on the 'circle of trust' model recommended by OECD. Evaluate and make changes within ADRN accordingly, and use this work to help shape the *prospectus*. This will involve the following actions:

- 1.1 Paul Jackson to work with Administrative Data Service (ADS) and in consultation with the Network to identify the trust attributes of ADRN in a manner that can be presented persuasively to Departments.
- 1.2 Paper with recommendations and actions to ADRN Directors for approval in correspondence by end of February.
- 1.3 The ADRN trust model to be adopted across ADRN and built into communications, services, correspondence, etc., as new business as usual at least for data acquisition purposes by end of March.

**2) Prospectus**

Prepare a ADRN Data Partner Prospectus that will present all ADRN services in terms of their benefits to the public authority. This will involve the following actions:

- 2.1 Paul Jackson to work with ADS and in consultation with the Network on a ADRN Prospectus, structured in accordance with the trust model.
- 2.2 Paper with the Prospectus, including recommendations, to ADRN Directors for approval in correspondence as soon as possible and before the end of March.
- 2.3 The ADRN Prospectus to be issued to all relevant public authorities as soon as it is approved, where possible delivered by hand by the ADRN leads for each department, and/or Paul Jackson.

**3) Pathway**

The prospectus should include the pathway to an agreement to use ADRN as a partner in research data access, including a description of the agreements that are to be made and documented. This will involve the following actions:

- 3.1 Paul Jackson to work with ADS and in consultation with the Network on a pathway for building the Partnership with departments.
- 3.2 Paper with the Pathway, including recommendations, to ADRN Directors for approval in correspondence by end of March.

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3.3 ADS with Paul Jackson to use the Pathway in meetings with departments from March.

**4) Data Partnership Agreement.**

Agree and present a Data Partnership Agreement for the 5 priority government departments, and publish a Model Data Partnership Agreement. A Data Partnership Agreement is a document set that is headed by a high level agreement of principle ("heads of agreement"), and subsequently addresses all matters of risk management, ownership of decisions, the process flow for data supply, evidence of management controls and information assurance certification, and the undertaking made by both parties with respect to levels of service and delivery.

The outcome should be an Agreement that operates in the manner of a "call-off contract", which allows the department to supply data into ADRN services as required, in accordance with known and pre-agreed criteria, procedures, standards, methods, and decisions, and according to a predictable schedule.

The undertakings made by ADRN in the Agreement require delivery assurance in order to maintain trust. This will involve the following actions:

- 4.1 Paul Jackson to work with ADS and in consultation with the Network on a model Data Partnership Agreement.
- 4.2 Paper with the proposed model Data Partnership Agreement and with recommendations to ADRN Directors for approval in correspondence by end of March.
- 4.3 Paul Jackson and ADS to complete Data Partnership Agreements, following the Pathway, with the 5 priority departments as soon as possible after Royal Assent of the Digital Economy Bill.
- 4.4 ADS with assistance from Paul Jackson to issue model Data Partnership Agreements to departments from end of April, with the aim of securing signatures for "heads of agreement" within a Data Partnership Agreement between the priority set of departments and ADRN according to an agreed schedule following Royal Assent of the Digital Economy Bill.

**5) Delivery Plan and dashboard**

Build and implement a 2017/18 ADRN Data Acquisition Delivery Plan, assigning roles and resources to each scheduled action in each signed Data Partnership Agreement, and assigning roles and resources to each of the prospectus pathways initiated for future acquisitions. Use the ADRN Data Acquisition Business Plan as the core and definitive management information hub on data acquisition for all the ADRN partners, ensuring all ADRN partners are driven by



the same coherent schedule of work. Include a management information dashboard for real-time reporting and evaluation of the expected levels of service and delivery, and for the identification and correction of any failures. This will involve the following actions:

5.1 Paul Jackson to work with ADS and in consultation with the Network on a Data Acquisition Business Plan, including to identify and account for the interdependencies between the Data Acquisition Business Plan and all other ADRN services.

5.2 Paul Jackson and ADS to prepare a real-time dashboard of data acquisition progress in the context of all other related ADRN services, on a project basis.

5.3 Approval of the business plan and dashboard by the ADS Director by end of April.

5.4 Paul Jackson and ADS to explore the availability and use of suitable open source resource management systems for integration of ADRN, using CFC Finland's REMS<sup>1</sup> as the default option.

5.5 Options paper to ADRN Directors by end of April.

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<sup>1</sup> <https://www.csc.fi/-/rems>

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Professor Ruth Gilbert

A view from the Administrative Data Research Centre England

Oral report

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## UK STATISTICS AUTHORITY

### ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(17)04

#### *Progress on data reuse for research purposes*

#### **Purpose**

1. This paper provides a summary of progress on ‘data reuse’.

#### **Recommendations**

2. Members of the Administrative Data Research Network (ADRN) Board are invited to note and discuss the progress detailed in this report and the paper discussing the principles for assessing models of data reuse which is attached at **Annex A**.

#### **Background**

3. The issue of data retention was discussed by the ADRN Board in April 2016. 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.
4. Data retention was further discussed by the ADRN Board in November 2017. The following points were made in the discussion:
  - i. Care would have to be taken in communicating this change in policy given that the ADRN was set up with a different retention model.
  - ii. It was suggested that this policy should continue to be referred to as the data retention policy as the meaning of this was widely understood by the public.
  - iii. The ADRN should be flexible to the particular wishes of the individual data owners when putting this policy into practice.

#### **Progressing data reuse in the Network**

5. A task team has been convened to carry out strategic planning to develop data reuse for research purposes for the Network.
6. The task team took note of some concerns in the Network concerning public engagement, the legal basis for reuse and whether the reuse of data would support the original ADRN principles.
7. Initial public engagement with the Scottish Public Engagement Panel has suggested that there is support for moving away from the ‘create and destroy’ model currently progressed by the ADRN. The advice from the panel was that further public engagement should wait until a data reuse model was firmed up which could be considered by the public rather than carrying out further engagement on the principles. The ADRN Approvals Panel have also given their initial support for reuse, however the

lay members were concerned about any move towards 'large linked 'Big Brother' datasets' and emphasized the need for public engagement.

8. The attached paper at **Annex A** looks at the principles of the ADNR and considers whether data reuse supports or impinges on these principles. It suggests that the current 'create and destroy' model hinders the delivery of the following ADNR principles: *providing value for money and enabling excellence and innovation in research*. The paper then suggests a process to consider data reuse against the Scottish Informatics Programme principles. This consideration is underway and will be completed by the end of March 2017. This action is about completing groundwork rather than acting as a hurdle to data reuse.
9. The task team met with the Strategic Data Negotiator to discuss the background work to the project and what could be the offer to data owners. The Strategic Data Negotiator, Paul Jackson, has worked up a proposal for an approach to data owners which is attached as **Annex D** to the update on data acquisition (ADNR(17)03). As part of this approach, it is proposed that projects will be brigaded into programmes. A linked data set will be negotiated and reused to support the whole programme. This fulfils requirements under the current Data Protection legislation and the forthcoming Digital Economy Bill. Therefore, the data retention task team will align itself to support this approach.
10. The work to review the policies of ADNR and communications to identify those which will need changing to enable the reuse of data is complete.
11. Discussions with Administrative Data Research Centres on implementing the practicalities of this model have started. There will be practical issues around holding and accessing the data along with setting up a structure to ensure obligations around access permissions are agreed with data owners.

#### **The way forward**

12. The task team have completed their work laying the groundwork of the change. Public engagement, focusing on the proposed model, and stakeholder engagement, including with funders and data owners, now needs to be done. It is proposed that the Directors Group is tasked with considering the most effective structure to take this forward.

**Chris Dibben, Director of the Administrative Data Research Centre-Scotland, 23 March 2017.**

#### **Annex A Principles for Assessing Models of Data Reuse**

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## Annex A – Principles for Assessing Models of Data Reuse

# Principles for Assessing Models of Data Reuse

## 1. Introduction

On 12 December 2016, the Task Team (TT) on models for data reuse for research purposes met and agreed an action plan for assessing the rationale for the current model of ‘create-and-destroy’, identifying reasons for moving away from this model and gathering information on the legal, ethical and practical implications of alternative models for data reuse. As part of this plan, the TT agreed to draft a set of principles that could be used to assess any model of data reuse under future consideration by the ADRN.

These principles have been developed in light of the ten overarching principles which govern the ADRN and that ‘must guide all ADRN practice across all ADRNs and the ADS’.<sup>1</sup> We have also considered principles-based approaches in cognate areas, including from the Scottish Informatics Programme (‘SHIP’) and its Guiding Principles and Best Practices which was later incorporated into the Scottish Government’s Guiding Principles for Data Linkage.<sup>2</sup> Finally, we take into account the principles of the ESRC’s Framework for Research Excellence (‘FRE’), as part of the ADRN’s commitment to its funder.

The principles presented in this document do not presuppose the ‘benefit’, or advise the adoption of, any model of data reuse. Rather, this document represents a draft of suggested principles to govern assessment of models of data reuse in the ADRN and is intended to facilitate discussion between the relevant stakeholders on their appropriateness. The document is structured as follows:

- To provide an overview of the principles already adopted within the ADRN and suggest which principles are of relevance to our consideration of models of data reuse;
- To explore principles from relevant, cognate areas including SHIP’s Good Governance Framework (‘GGF’) and the ESRC’s FRE and consider their application to the context of administrative data and the ADRN;
- On this basis, to propose a set of principles for assessing models of data reuse within the ADRN.

<sup>1</sup> ‘Summary of decisions of the Network’ ADRN900 v. 4.

<sup>2</sup> Information Governance Working Group The Scottish Health Informatics Programme, ‘SHIP Guiding Principles and Best Practices’ (2010) <[http://www.scotship.ac.uk/sites/default/files/Reports/Guiding\\_Principles\\_and\\_Best\\_Practices\\_221010.pdf](http://www.scotship.ac.uk/sites/default/files/Reports/Guiding_Principles_and_Best_Practices_221010.pdf)>; The Scottish Government, ‘Joined-Up Data For Better Decisions: Guiding Principles For Data Linkage’ (2012) <<http://www.scotland.gov.uk/Resource/0040/00407739.pdf>>.



## 2. ADRN's Guiding Principles

On 3 June 2014, the ADRN Board agreed that all ADRN, ADRC and ADS activities would be governed by the following ten principles<sup>3</sup>:

- ADRN will always operate to protect the privacy and confidentiality of data subjects.
- ADRN will operate as transparently as possible.
- ADRN will only support research with potential public benefit.
- ADRN will ensure data are accessed safely and securely.
- ADRN will be accountable and operate under appropriate governance.
- ADRN will be independent.
- ADRN will support and enable excellence and innovation in research.
- ADRN will operate ethically.
- ADRN will provide good value for money.
- These overarching principles must guide all ADRN practice across all ADRCs and the ADS, and key policy documents will also be network-wide. Where implementation of policies must vary, due to differences in local infrastructures or different legal frameworks among the devolved administrations, these will be fully documented in local procedural documentation, and will at all times adhere to these overarching principles.

Accordingly, any principles proposed for assessing models of data reuse must abide by these overarching principles.

The current model of create-or-destroy, which does not permit data obtained for one research project 'A' to be used for another research project 'B', already poses tensions with the principles of 1) supporting and enabling excellence and innovation in research and 2) that the ADRN will provide good value for money in its operation. This tension does not in itself support the adoption of another model of data reuse, but suggests that the original model should be kept under consideration in terms of its ability to adhere to *all* the overarching principles, including value for money and supporting research in the widest sense. Where a policy or course of action taken by the ADRN departs from one of these principles, specific and justifiable reasons should be given that explains the need for such a departure. What reasons can the ADRN provide to support the current model of create-and-destroy and thus the departure from these two principles?

### 2.1 Create-and-destroy: providing value for money?

It could be argued that the adoption of the create-and-destroy model was to secure public trust over the safety of the ADRN's operations and potentially also to put at ease any concerns of data controllers over potential, future misuse of data shared with the ADRN. Nevertheless, the create and destroy model could be seen as resource intensive and thus a misuse of public money if acceptable alternatives are available. The costs of this model have been questioned by public panel members in ADRC-Scotland. While exact economic costs might be difficult to assess based on the





current model of create-and-destroy, the process of negotiation with data controllers for access to data and the governance processes researchers must undertake are already lengthy, involving staff time and infrastructure resource in particular. It is possible that in certain circumstances, models that allow further and future reuse of data made available to the ADRN, would provide more economic efficiency to the ADRN (and data controllers) and thus good value for the public money spent to facilitate the operation of the Network. At least two questions and related work streams are necessary: 1) What is the evidence that the costs of operating a create-and-destroy model are considerable and burdensome; 2) What efficiencies might come from alternative models of data reuse? Currently the Network is without sufficient information to answer either question.

## 2.2 Create-and-destroy: enabling excellence and innovation in research?

Reproducibility and verifiability of research results is the gold standard for the undertaking of research. Research which requires the use of administrative data is also subject to this standard. The current model of create-and-destroy poses tensions with the ADRN principle that requires the Network to support and enable excellence and innovation in research. It does so because the current model does not allow for independent verification and reproduction of research studies, beyond the original research team.<sup>4</sup> Alternative models to data reuse may allow limited and specific access to data made available to the ADRN for the purposes of verification and reproduction of previously conducted studies using the Network's resources. This would promote excellence in research, the work of the ADRN and increase the usage of the Network's facilities. Furthermore, alternative models may allow further, related research questions to be answered with the same data resources.

## 2.3 A case for moving away from create-and-destroy: new tensions?

The foregoing analysis has focused on the tensions posed by the current model of create-and-destroy. However, in moving away from create-and-destroy, there is the possibility that any longer-term retention of data may pose different tensions with different principles. For example, any model of data reuse which maintains a dataset over a longer period might pose tensions with the principle of protecting the privacy and confidentiality of data subjects. Furthermore, the longer-term retention of data for unspecified and future research purposes might pose tensions with ADRN's ethical principle.

Below we will consider how principles in operation in cognate areas of research could apply to the ADRN's consideration of models of data reuse considering the tensions posed by the current model of create-and-destroy as well as any new tensions posed by alternative models.

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<sup>4</sup> In the biomedical context, a recent study has revealed that as much as 2/3 of research experiment are *not* reproducible creating a 'reproducibility crisis'. Without access to the same data and variables, under the current model of create-and-destroy, any research produced by ADRN affiliated researchers would not be independently reproducible. Tom Feilden, 'Most Scientists "Can't Replicate Studies by Their Peers"' (*BBC News*, 22 February 2017) <<http://www.bbc.co.uk/news/science-environment-39054778>>.



### 3. SHIP's Guiding Principles and Best Practices

As part of the ADRC Scotland's legal work package and initial scoping work, Laurie and Stevens assessed the suitability of the SHIP Guiding Principles and Best Practices for the administrative data context.<sup>5</sup> Here we extract the key insights gained from this analysis and consider how the SHIP principles might apply to the specific task of assessing models for data reuse. Within SHIP, the team identified the following key areas of concern regarding the reuse of health data for research purposes which were accompanied by relevant principles and associated best practices:

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| <ul style="list-style-type: none"><li>• Public interest</li><li>• Privacy</li><li>• Consent</li><li>• Anonymisation</li><li>• Authorising/advisory bodies</li><li>• Governance</li><li>• Access</li><li>• Trusted third parties</li></ul> | <ul style="list-style-type: none"><li>• Data controllers and data processors</li><li>• Clinical trials</li><li>• Cross-sectoral data sharing</li><li>• Data sharing agreements</li><li>• Public and stakeholder engagement</li><li>• Sanctions</li><li>• Benefit Sharing</li></ul> |
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Clearly, some areas of concern are specific to the health research sphere and thus not directly relevant to the administrative data context (i.e. clinical trials). Other areas are also less relevant for the ADRN including 'consent' and 'access' (at least in terms of 'subject access') given that 1) data which are provided to the ADRN for research are done so based on alternative legal grounds under the Data Protection Act 1998 ('DPA 1998'), 2) and/or they are considered 'anonymous' for the purposes of the DPA 1998, 3) and finally per Section 33 of the DPA 1998, research use of data is exempt from subject access requirements. Most of the other areas identified are of clear relevance to the ADRN and are already incorporated within ADRN's overarching principles. Below we will provide a brief consideration of each area and specific principles that might be relevant to the assessment of models of data reuse for the ADRN.

#### 3.1 Public interest

SHIP's principles on the public interest include:

- Scientifically sound and ethically robust research is in the interest of protecting the health of the public.
- The objective of SHIP is to facilitate scientifically sound and ethically robust research through the appropriate use of health data.

<sup>5</sup> Graeme Laurie and Leslie Stevens, 'The Administrative Data Research Centre Scotland: A Scoping Report on the Legal & Ethical Issues Arising from Access & Linkage of Administrative Data' [2014] Edinburgh School of Law Research Paper No. 2014/35.



- The rights of individuals should be respected with adequate privacy protection, while at the same time the benefits for all in the appropriate use of health data for research purposes should be recognised.
- Data sharing and use should be carried out under transparent controls and security processes, and the purposes and protection mechanisms should be communicated publicly and to oversight bodies/individuals with responsibility for data processing.
- The responsible use of health data should be a stated objective of all organisations adhering to this instrument.

Adapted to the context of ADRN, Laurie and Stevens suggested the following restatement of the public interest principles:

- Scientifically sound and ethically robust research based on the linkage and reuse of administrative data is in the interest of promoting and improving economic growth, personal and social well-being, and maximising the interests of current and future generations of citizens in the UK.
- The objective of the ADRN is to facilitate publicly beneficial research through the safe and efficient reuse of administrative data.
- The rights of individuals' privacy should be safeguarded by robust and proportionate safeguards, in recognition of the public interests served by protecting individual privacy and in the promotion of publicly beneficial research.
- Administrative data linkages should be carried out under a common approach of transparent controls, regularly communicated with the public and agreed upon by relevant oversight bodies and individuals with responsibility over the data.
- The ethical and safe use of administrative data should be a stated objective of all organisations and individuals accessing data via the ADRN.<sup>6</sup>

Applied to the specific context to assessing models of data reuse, the principle of the public interest would require the ADRN to consider:

- *Does the model of create-and-destroy secure the safety of data linkage and reuse by the ADRN?*
- *How efficient is the model of create-and-destroy in relation to the current costs of operating the model, any benefits conferred or deferred by its adoption?*
- *Is the model of create-and-destroy a robust and proportionate means of safeguarding the public interest in privacy and the public interest in research?*
- *How does the alternative model of data reuse contribute to these acknowledged public interests?*

<sup>6</sup> Laurie and Stevens (n 4) 39–41.



### 3.2 Privacy

SHIP's principles on privacy are:

- Data controllers should demonstrate their commitment to privacy protection through the development and implementation of appropriate and transparent policies.
- Every effort should be made to consider and minimise risks of identification (or re-identification) to data subjects and their families arising from all aspects of data handling.

Applied to the specific context to assessing models of data reuse, the principle of privacy would require the ADRN to consider:

- *How does a particular model of data reuse demonstrate the ADRN's commitment to privacy protection?*
- *What additional measures might be required to ensure that the commitment to privacy was maintained robustly with the creation, retention and use of new datasets over time?*
- *How does the technical processes required by a model of data reuse account for and minimise any risks, including the re-identification of data subjects?*

### 3.3 Anonymisation

SHIP's principles on anonymisation are:

- Researchers should normally only have access to anonymised data and be subject to an obligation not to attempt to re-identify individual data subjects.
- Where possible and practicable, data should be anonymised before linkage and use so as to minimise risk of re-identification of individuals.
- Where researchers cannot or do not intend to anonymise data and where consent for use of personal data has not been obtained, approval from an oversight body, e.g. Privacy Advisory Committee, must be obtained.
- Where data have been anonymised, authorisation should be obtained where there is a risk of re-identification; anonymisation does not remove the need for authorisation.
- Risk of re-identification must be assessed by a body/individual with the relevant expertise to make such judgments.
- Data controllers should determine and agree upon the appropriate level of anonymisation to be applied to any given dataset or linkage exercise.

Applied to the specific context to assessing models of data reuse, the principle of anonymisation would require the ADRN to consider:

- *Does the model of data reuse under consideration preserve the safety and security of the data linkage and research access process, including that only de-identified data are made available for research in secure settings?*
- *How far, if at all, could ADRN be assured that adequate anonymity would be maintained with the creation, retention, and use of new datasets?*



### 3.4 Authorising/advisory bodies

SHIP's principles on authorising and advisory bodies are:

- In all circumstances of data use where consent has not been obtained, and for all uses of data which are beyond those specified when consent was obtained, then (a) approval from an independent oversight body/research ethics committee should be obtained and/or (b) anonymisation of data should occur as soon as is reasonably practicable.
- Where neither anonymisation nor consent is possible or where obtaining new consent from patients is not reasonably practical, data controllers and Caldicott Guardians should obtain approval from an independent oversight body/research ethics committee before authorising use of the data.
- In order to uphold the principle of transparency, authorising bodies, such as data controllers and Caldicott Guardians, and advisory bodies, such as PAC and research ethics committees, should clearly articulate and make readily available the criteria and procedures by which they decide whether or not to sanction data use.
- In order to uphold the principles of transparency and good decision-making, all data use/access requests to authorising bodies should include (i) clear information on reasons for access, (ii) purposes of the analyses and (iii) measures to be put in place to ensure privacy risks are minimised.

Applied to the specific context to assessing models of data reuse, the principle of authorising/advisory bodies would require the ADRN to consider:

- *What authorising and/or advisory body should be consulted before a model of data reuse is adopted?*
- *What criteria and procedures should govern the ADRN's decision (and/or an authorising/advisory body's decision/recommendation) to adopt a particular model of data reuse?*
- *What on-going authority might be required for future uses of retained data sets?*

### 3.5 Governance

SHIP's principles on governance are:

- All aspects of data handling must be carried out in accordance with applicable legal frameworks and ethical principles. Where applicable, NHS policy documents and directives must be upheld.
- All practices, including all data linkages, shall be appropriately monitored and regulated by a relevant individual, organisation or governance body as appropriate. It is possible that these activities will be monitored at an individual and organisational level simultaneously. Data controllers are primarily responsible for ensuring such governance policies and procedures are in place and for making these policies and procedures available to research users and the public alike.
- There should be a clear distinction in roles between those carrying out linkages, analyses and those policing governance and enforcing sanctions.



Applied to the specific context to assessing models of data reuse, the principle of governance would require the ADRN to consider:

- *Is the model of data reuse under consideration capable of satisfying all relevant legal requirements including but not limited to data protection law, administrative law, human rights law and common law duties of confidentiality?*
- *Is the model of data reuse under consideration capable of adhering to the ADRN's overarching principles and the ESRC's FRE?*
- *What procedures and policies will be in place to ensure effective monitoring of the model of data reuse?*

### 3.6 Access

SHIP's principles for access are:

- Provided appropriated oversight mechanisms are in place, data controllers and research users should participate in appropriate sharing of data resources within the health and non- health contexts.
- Access policies should be developed in a transparent and open manner; these should also be subject to public scrutiny and review.
- Data should be held and used in a secure manner and should only be accessible to authorised personnel. All access to health data for research purposes should be documented and monitored appropriately.
- All data recipients should be appropriately vetted to ensure they have adequate training. Vetting procedures should be robust and transparent and proportionate to the requests made and the sensitivity of the data requested.

Applied to the specific context to assessing models of data reuse, the principle of access would require the ADRN to consider:

- *Does the model of data reuse under consideration allow for future research uses of data consistent with ADRN's overarching principles and the applicable legal/ethical framework? How would this be verified after access was granted?*
- *Will the model of data reuse be publicised on ADRN's website and through other relevant means?*
- *Will relevant publics and stakeholders have an opportunity to scrutinise and review models of data reuse prior to and after adoption?*

### 3.7 Trusted third parties

SHIP's principles on the use of trusted third parties are:

- There should be a clear distinction as to function between the linker, indexer and the data controller/data custodian/recipient; linkers should be seen as clear intermediaries responsible only for linking data.





- Linkages may only be performed by a party other than a trusted third party in instances where all data subjects have given consent for this (see clinical trials guidance below).
- Trusted third parties should satisfy necessary vetting and training requirements and should be recognised as being free from any conflict of interest.

Applied to the specific context to assessing models of data reuse, the principles on using trusted third parties would require the ADRN to consider:

- *Is the model of data reuse under consideration consistent with the ADRN's policy of linking and making data available via a trusted third party?*
- *More particularly, are there any specific ways in which safe havens might address any concerns or challenges that would arise from this new policy?*

### 3.8 Data controllers and data processors

SHIP's principles on data controllers and data processors are:

- Data controllers and data processors and their respective roles and responsibilities should be identified clearly from the outset and this should be articulated.
- All personnel involved in a role as data controllers or data processors should be fully aware of their roles and responsibilities, including those contained in this document.
- These roles and responsibilities should be subject to robust governance mechanisms designed to ensure that these roles are being carried out appropriately and to the standards legally and ethically required.

Applied to the specific context to assessing models of data reuse, the principles on data controllers and data processors would require the ADRN to consider:

- *How does the model of data reuse impact pre-existing roles and responsibilities as to data being shared? e.g. who are the data controllers and processors under the model of data reuse?*
- *How would ADRN monitor and support the appearance of new data controllers that might occur with the creation and retention of new datasets?*

### 3.9 Cross-sectoral data sharing

SHIP's principles on cross-sectoral data sharing are:

- Where ethical and legal standards are met, data should be made accessible to trusted researchers across disciplines. The value of such cross-sector sharing should be recognised.
- Along with the potential benefits of cross-sector sharing, risks should also be identified and appropriately addressed. In particular, assurance of reciprocal privacy standards across sectors is necessary.



- The unnecessary duplication of approval procedure(s) and governance mechanisms should be avoided. Mutual recognition of equivalent standard and procedures should be sought.
- Where data are to leave the European Economic Area (EEA), data controllers should ensure that equivalent data protection standards apply in the recipient country.

Applied to the specific context to assessing models of data reuse, the principles on cross-sectoral data sharing would require the ADRN to consider:

- *Does the model of data reuse under consideration make data available to researchers across sectors?*
- *What policies and procedures need to be in place to ensure robust governance and oversight across and between sectors?*
- *What policies and procedures need to be in place to minimise the duplication of approvals and governance mechanisms when data are made available for future research under this model of reuse?*

### 3.10 Data sharing agreements

SHIP's principles on data sharing agreements are:

- Roles and responsibilities of parties to data uses and linkages should be identified from the outset, terms and conditions for data sharing should also be agreed upon in the form of a memorandum of understanding (MoU).
- Where researchers wish to deviate from/modify the terms of the data use/sharing agreement at any time, new terms must be agreed upon by all parties concerned and such changes should be monitored by the relevant oversight body/mechanisms

Applied to the specific context to assessing models of data reuse, the principles on data sharing agreements would require the ADRN to consider:

- *Considering the roles and responsibilities created by a model of data reuse, will there be appropriate agreements in place to outline the terms and conditions of data reuse?*
- *How does ADRN envision its role in the creation and support of these agreements?*

### 3.11 Public and stakeholder engagement

SHIP's principles on public and stakeholder engagement are:

- Public and stakeholder engagement is an integral part of good governance. As far as possible, account should be taken of the full range of stakeholder positions in the development and implementation of governance arrangements.
- The interests of one (or a few) stakeholder(s) should not dominate use/linkages or the conditions of the same, especially where this might be at the expense of other stakeholder interests. Robust justifications must be given for any departure from this principle.





Applied to the specific context to assessing models of data reuse, the principles on public and stakeholder engagement would require the ADRN to consider:

- *Will relevant publics (e.g. those who the data in question specifically relate to, public panels etc.) and stakeholders (e.g. data controllers, funding bodies, regulators, researchers, technical experts) be consulted prior to the adoption of a model of data reuse?*
- *If relevant publics and stakeholders are to be consulted, how will these views be incorporated into decisions taken on adopting particular models of data reuse?*

### 3.12 Sanctions

SHIP's principles on sanctions are:

- Sanctions for failure to respect terms and conditions should be clearly stipulated in all data use/sharing documentation.
- Sanctions should be enforced by a body/individual independent to those granting permissions for access to data sets (i.e. data controllers) e.g. an independent body set up for monitoring/governing or the Information Commissioner's Office.

Applied to the specific context to assessing models of data reuse, the principles on sanctions would require the ADRN to consider:

- *Will the model of data reuse in question require changes to ADRN's current sanctions policy? e.g. will new parties need to be obligated by it?*
- *Given the roles and responsibilities created by a particular model of data reuse, which parties will be subject to ADRN's sanctions policy?*
- *How will ADRN support new parties who might become subject to its sanctions policy by participating in this reuse policy?*

### 3.13 Benefit sharing

SHIP's principles on benefit sharing are:

- Benefits arising from data use/sharing using health data are public goods and should be shared as widely as possible.
- The sharing of outputs and benefits arising from research under SHIP should be the norm and associated commitments should form part of data sharing agreements.
- Where linkages resulting in commercial gain are envisaged, this should be clearly articulated and widely communicated.

Applied to the specific context to assessing models of data reuse, the principles on benefit sharing would require the ADRN to consider:

- *How will the model of data reuse comply with the ESRC's requirements on open access?*



- *What policies and procedures will be in place under the model of data reuse in question to ensure outputs and benefits from research are shared as widely and securely as possible?*
- *How will the reuse policy be monitored and evaluated to generate robust data of its added value, including the acceptability of any cost/benefit analysis?*

#### 4. ESRC's FRE

As an ESRC funded project, the ADRN must also adhere to its FRE and its six key principles for conducting ethical research:

- 1. Research should aim to maximise benefit for individuals and society and minimise risk and harm**
- 2. The rights and dignity of individuals and groups should be respected**
- 3. Wherever possible, participation should be voluntary and appropriately informed**
- 4. Research should be conducted with integrity and transparency**
- 5. Lines of responsibility and accountability should be clearly defined**
- 6. Independence of research should be maintained and where conflicts of interest cannot be avoided they should be made explicit.**

While many of these principles overlap with those from ADRN and SHIP, the FRE further raises the following considerations for ADRN when assessing models of data reuse:

- *Does the model of data reuse under consideration maximise the opportunities for undertaking research which serves the public interest?*
- *What are the specific risks of harm and impact posed to individuals, relevant publics, stakeholders and/or society under this model of data reuse?*
- *How will these risks be minimised under this model of data reuse?*
- *Does this model of data reuse pose conflicts of interests between stakeholders?*
- *How will the obligation to conduct research with integrity and transparency be discharged, especially with the potential or creation of multiple new datasets by a range of new parties?*

Immediately below we combine the foregoing analysis into a draft set of principles to govern the ADRN's assessment of models of data reuse.

#### 5. Draft Principles for Assessing Models of Data Reuse

The following principles are intended to be initial points of consideration when the ADRN considers the potential adoption of a model of data reuse. These principles are consistent with ADRN's overarching principles and with the ESRC's FRE principles.

##### Public interest

Scientifically sound and ethically robust research based on the linkage and reuse of administrative data is in the interest of promoting and improving economic growth, personal



and social well-being, and maximising the interests of current and future generations of citizens in the UK.

It is in the public interest that the ADRN operate efficiently and provide good value for the public funds invested in the Network.

The rights and interests of individuals' privacy should be safeguarded by robust and proportionate safeguards, in recognition of the public interests served by protecting privacy and in the undertaking of publicly beneficial research.

### Key questions:

- *Does this model of data reuse maximise the possibilities to undertake research in the public interest?*
- *What is the evidence that the costs of operating a create-and-destroy model are considerable and burdensome?*
- *What efficiencies might come from alternative models of data reuse?*
- *What are the specific risks and harms posed by this model of data reuse (to individuals, relevant publics, stakeholders and society) and how will they be minimised?*
- *How will concerns about demonstrating trustworthiness and securing public social licence be addressed?*

### Context-sensitivity: one size does not fit all

The rights, interests, technicalities and practicalities at stake for particular data sets must be considered prior to the adoption of a model of data reuse.

### Key questions:

- *What are the specific legal considerations that apply to this dataset?*
- *Is it practically and technically feasible to apply this model of data reuse to this particular data set? (e.g. what do the technical experts say?)*
- *What are the reasonable expectations of the individuals as to the reuse of the particular data set in question?*
- *How will relevant publics and stakeholders (especially data controllers) be consulted as to the model of data reuse under consideration?*
- *How will the results of public and stakeholder engagement be incorporated into decision-making?*

### Meaningful public and stakeholder engagement

Decisions to adopt a model of data reuse must be informed by meaningful public engagement. Consideration must be given to the multiplicity of publics and views, therefore public engagement should include awareness raising, consultation and most importantly ongoing deliberative dialogue with diverse publics.

Once a model of data reuse is adopted, this must be plainly communicated to relevant publics, with provision made for regular review.



**Key questions:**

- *When, where and how will relevant publics and stakeholders be consulted as to the model of data reuse under consideration?*
- *How will the outcome of public and stakeholder engagements be incorporated into decision-making?*

**Roles and responsibilities**

The roles and responsibilities of the ADRN and its affiliated bodies (e.g. universities) vis-à-vis data controllers must be transparently outlined and agreed prior to the sharing of data under a new model of data reuse

**Key questions:**

- *What are the roles and responsibilities of the ADRN and its affiliated bodies (e.g. universities) as to data shared under this model of data reuse?*
- *If data are not considered to be 'anonymous' for the purposes of the DPA 1998 (or under the forthcoming General Data Protection Regulation) which legal entity will carry the responsibility of data controller or processor under this model of data reuse?*
- *How will these obligations be monitored?*
- *What sanctions will apply and who will be obligated under this model of data reuse?*
- *How can transparency and clear lines of accountability be maintained in a new, potentially highly-complex set of overlapping environments?*

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Ms Sharon Witherspoon

Legislative Issues

Oral report

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Any other business